

**The lived experiences of caregivers of stroke survivors in a rural Western
Cape Setting**

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in Human Rehabilitation Studies**

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Declaration

By submitting this research assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the author/owner thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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December 2022

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Abstract

Introduction: Caregivers play a pivotal role in the community re-integration of stroke survivors. However, they face challenges that they are not always prepared for. This might leave them feeling anxious and uncertain about fulfilling the caregiving role. Caregivers' emotional, physical, and mental well-being might be affected by the caregiving duties. Few studies have explored caregiver lived experiences specifically and none could be identified that was done in a rural South African setting. Purpose: The aim of the study was to explore the lived experiences of caregivers of stroke survivors discharged from Ceres Hospital, in the Witzenberg sub-district.

Methods: A qualitative descriptive phenomenological design underpinned by constructivism was adopted. A pilot study was conducted to practice my interview skills, test the appropriateness of the data collection tool as well as the logistics of the interview. Data was collected by means of face to face, individual interviews with a sample of 5 participants. The interviews were recorded and transcribed verbatim. Inductive thematic analysis guidelines were used.

Main findings: Four themes were identified; 1) "It is my duty". Participants felt obligated to care because of the relationship they had with the stroke survivor. 2) "I don't make things difficult for him". Participants neglected their own needs and interests and prioritized their caregiving duties and the needs of the stroke survivor. 3) "God gave me the strength". Participants found their faith to be a foundation from which they drew strength and 4) "They showed me nothing". Participants reported anxiety in the initial stages of caring and did not utilize or acknowledge the information provided by healthcare workers.

Conclusions: Caregivers find it difficult to adapt to caring for a loved one and are not always equipped with coping strategies. Relationship-specific changes should be considered during stroke rehabilitation and the necessary support should be provided by healthcare workers

Key words

Lived experiences, informal caregiver, stroke survivor, rural, relationship shifts, duty, spouse, parent, South Africa

Abstrak

Inleiding: Versorgers speel 'n deurslaggewende rol in die gemeenskapsherintegrasië van beroerte-oorlewendes. Hulle kom egter voor uitdaginge te staan waarvoor hulle nie altyd voorbereid is nie. Dit kan hulle angstig en onseker laat voel oor die vervulling van die versorgingsrol. Versorgers se emosionele, fisiese en geestelike welstand kan deur die versorgingspligte beïnvloed word. Min studies het spesifiek versorger-ervarings ondersoek en geeneen kon geïdentifiseer word wat in 'n landelike Suid-Afrikaanse omgewing gedoen is nie. Daarom was die doel van die studie om die geleefde ervarings van versorgers van beroerte-oorlewendes wat uit die Ceres-hospitaal in die Witzenberg-subdistrik ontslaan is, te verken.

Metodes: 'n Kwalitatiewe beskrywende fenomenologiese ontwerp onderlê deur konstruktivisme was gebruik. 'n Loodsstudie is uitgevoer om my onderhoudvaardighede te oefen, die toepaslikheid van die data-insamelingsinstrument asook die logistiek van die onderhoud te toets. Data is ingesamel deur middel van persoonlike onderhoude met 'n steekproef van 5 deelnemers. Die onderhoude is opgeneem en woordeliks getranskribeer. Induktiewe tematiese ontledingsriglyne is gebruik.

Resultate: Vier temas is geïdentifiseer; 1) "Dit is my plig". Deelnemers het verplig gevoel om te sorg vanweë die verhouding wat hulle met die beroerte-oorlewende gehad het. 2) "Ek maak dinge nie vir hom moeilik nie". Deelnemers het hul eie behoeftes en belange verwaarloos en hul versorgingspligte en die behoeftes van die beroerte-oorlewende geprioritiseer. 3) "God het my die krag gegee". Deelnemers het gevind dat hul geloof 'n fondament was waaruit hulle krag put en 4) "Hulle het my niks gewys nie". Deelnemers het angs gerapporteer in die aanvanklike stadiums van omgee en het nie die inligting wat deur gesondheidsorgwerkers verskaf is, gebruik of erken nie.

Gevolgtrekkings: Versorgers vind dit moeilik om aan te pas by die versorging van 'n geliefde en is nie altyd toegerus met hanteringsstrategieë nie. Verhoudingspesifieke veranderinge moet tydens beroerte-rehabilitasie oorweeg word en die nodige ondersteuning moet deur gesondheidsorgwerkers verskaf word.

Sleutel woorde

Geleefde ervarings, informele versorger, beroerte-oorlewende, plattelands, verhoudingsverskuiwings, plig, eggenoot, ouer, Suid-Afrika

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Acronyms

| | |
|------|--------------------------------|
| ADLs | Activities of Daily Living |
| CVA | Cerebrovascular accident |
| CHWs | Community healthcare workers |
| HCWs | Healthcare workers |
| NGOs | Non-Governmental Organisations |

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Introduction

Stroke is amongst the top ten causes of disability in South Africa; leaving 66% of stroke survivors requiring assistance with at least one activity of daily living (ADLs) (Connor et al., 2004; Maredza & Chola, 2016). Yet few studies exist that explore the impact of cerebrovascular accident (CVA) on the stroke survivor as well as their families (Maredza et al., 2015). Due to the high burden of disease of CVA and the increased risk factors that people in rural areas face such as poverty, decreased access running water and sanitation as well as healthcare services (Maredza et al., 2015), it is important to understand the impact of stroke in rural areas.

Due to financial and social pressures, stroke survivors are most likely to be cared for by an informal caregiver who is often a family member (Masuku et al., 2018; Scheffler & Mash, 2020). Informal caregivers do not always have the training and knowledge to provide care; and are thus unprepared for the physical and emotional demands of caregiving (Cameron et al., 2006; Olivier et al., 2018; Jacobs-Nzuzi Khuabi et al., 2020). They might not feel competent or be able to cope with all the responsibilities and can experience strain that can impact their physical and mental health negatively (Jacobs-Nzuzi Khuabi et al., 2020).

In South African low-resourced rural settings, caregivers might not be aware of how to access support services, or these services might sadly not be available. Adult day care, respite care and/or counselling and support groups are not commonly found in rural South Africa (Kalra et al., 2004; Schure et al., 2006).

Problem statement

In the Witzenberg sub-district where I am employed as a speech therapist, I was concerned that the needs of caregivers were not being actively discussed during discharge planning. I felt that as a team we do not consider the needs and lived experiences of the informal caregivers of our patients sufficiently. This omission can be detrimental to the wellbeing of the stroke survivor and the caregiver. Few studies have explored caregiver lived experiences specifically and none could be identified that was done in a rural South African setting. Currently in the Witzenberg, healthcare workers (HCW) and employees at other support structures such as Non-Governmental Organisations (NGOs) have little information on the challenges that informal caregivers of stroke survivors face and might be unaware of their specific needs. Thus, the study was undertaken with the aim to explore the lived experiences of informal caregivers of stroke survivors discharged from Ceres Hospital.

It is hoped that the findings of this study will assist HCWs and community stakeholders in developing focused interventions and establishing community-based support to assist caregivers in the Witzenberg and other rural areas.

Literature review

Post stroke care needs

Stroke survivors often experience residual impairments and require support once discharged (Rhoda et al., 2015). This support may include physical support to complete activities of daily living (ADLs), psychosocial support to adapt to their new norm, cognitive support and lifestyle support to avoid secondary complications (Connor et al., 2004; Kleineibst, 2007; Hassan et al., 2011; Pendleton & Schultz-Krohn, 2017; Scheffler & Mash, 2020). Challenges and requiring support with these tasks make it difficult for stroke survivors to resume their pre-morbid lives and gain some independence (Govender et al., 2019). In a study conducted by Govender et al. (2019) stroke survivors reported that neither they nor their caregivers were prepared for the return home.

They had no information about their condition or coping strategies that would help them once they returned home. Caregivers and stroke survivors require support from HCWs to support the transition home.

The informal caregiver

The role of the informal caregiver is important in providing social and emotional support for the stroke survivor once discharged from the healthcare facility (Antle et al., 2008). These caregivers must manage many responsibilities such as assisting stroke survivors with their ADLs and taking medication (Broodryk, 2014). As caregivers spend much of their time on caregiving-related duties, they often neglect other ADLs such as sleep and eating healthy. This can affect their well-being (Serfontein, 2018). Therefore, it is important to include the caregivers in rehabilitation and to provide them with support to confront the diversity of tasks they are faced with (Kerr et al., 2001).

Lived experiences of informal caregivers of stroke survivors

Various aspects of the lived experiences of caregivers of stroke survivors have been researched in South Africa (Thomas & Greenop, 2008; Mthembu et al., 2016; Masuku et al., 2018; Scheffler & Mash, 2020; Jacobs-Nzuzi Khuabi et al., 2020;), as well as the broader continent (Gertrude et al., 2019) and the following areas emerged; effect of caring on the caregiver, support needs of

caregivers, and training of informal caregivers (Mthembu, 2016; Masuku et al., 2018; Jacobs-Nzuzi Khuabi et al., 2020; Scheffler & Mash, 2020). A systematic review conducted by Lou et al. (2017) included studies that investigated the experiences of caregivers in Europe and North America. Commonalities are observed between high income countries and Africa as caregivers experience similar challenges such as wanting time for themselves and having to develop their own strategies to cope with their new norm.

Though the above studies explored lived experiences of informal caregivers, the emphasis of the studies are on improving information access and with this equipping caregiver with skills that can reduce the strain of caregiving and improve their overall well-being (Mthembu et al., 2016; Jacobs-Nzuzi Khuabi et al., 2020). Some studies were conducted where stroke survivors and caregivers were interviewed together (Scheffler & Mash, 2020) and caregivers were possibly afraid to provide a true account of their experiences as to not offend the stroke survivor. Due to the unique and challenging circumstances caregivers in rural South Africa face such as poverty, poor access transport and inconsistent healthcare services (Maredza et al 2015), it is necessary for stakeholders involved in stroke management to look beyond the traditional approach to caregiver training and investigate the needs of the individual caregiver and so develop support strategies that can best serve them.

Effect of caring on the caregiver

Caring for a stroke survivor is a sudden event. For family caregivers this comes with additional responsibilities and tasks. As informal caregivers are not always equipped with information and skills, they find it difficult to juggle many activities (Gertrude et al., 2019). Upon assuming the caregiving role, caregivers find it difficult to balance the demands of caring with their other responsibilities such as household chores, caring for children, and their careers (Kleineibst, 2007; Khondowe et al., 2007; Gertrude et al., 2019). Caregivers must restructure their daily routines to accommodate the demands of caring (Jacobs-Nzuzi Khuabi et al., 2020). These caregivers are left with little flexibility to tend to their own needs (Masuku et al., 2018; Denham et al., 2019). Their caregiving duties take priority over everything, which affects external relationships and can negatively impact their mental and physical health (Jacobs-Nzuzi Khuabi et al., 2020). This results in stress and can presents as physical fatigue, poor sleep, and body pain, especially among elderly caregivers that have their own health challenges (Masuku et al., 2018). The stressors affect their ability to provide high quality care (Mthembu et al., 2016; Jacobs-Nzuzi Khuabi, 2020; Scheffler & Mash, 2020).

The caregiving role also brings about changes in the dynamic of the relationship between the caregiver and the stroke survivor (Jacobs-Nzuzi Khuabi et al., 2020). This new relationship is characterized by dependence and can affect the intimacy in marital relationships (Jacobs-Nzuzi Khuabi et al., 2020). Despite the challenges faced when caring for a loved one, many caregivers reported a renewed sense of purpose of their own lives through caring and acknowledged the value of deepened connection with the stroke survivor (Gertrude et al., 2019).

Support needs of caregivers

Jacobs-Nzuzi Khuabi et al. (2020) found that the caregiving experience can be positive if the caregiver's support needs are met. These needs are physical, socio-economic, educational, emotional and psychosocial support (Jacobs Nzuzi Khuabi et al., 2020: 198). Stroke survivors may need support to execute ADLs such as toileting, washing and eating (Kleinebst, 2007). Caregivers indicated the need for more training with regards to the physical skills required for caring (Hassan et al., 2011; Mthembu et al., 2016; Scheffler & Mash, 2020). The level of dependence of the stroke survivor increases physical and emotional demands on the caregiver (Scheffler & Mash, 2020). This goes hand in hand with the need for information with regards to impairments associated with the stroke (Scheffler & Mash, 2020). Lack of information and skills leave caregivers feeling frustrated and humiliated, especially in the study conducted by Masuku et al. (2018), as the caregivers could not communicate with persons with aphasia. These feelings of frustration are reduced when family and friends provide opportunities for respite as well as an ear for the caregiver (Mthembu et al., 2016). The lack of familial support adds to the burden of caring and leaves caregivers feeling lonely and isolated (Masuku et al., 2018). Caregivers may also have to deal with residual cognitive-behavioral impairments (Kleineibst, 2007). Stroke survivors also experience a sense of loss of their premorbid self and require support to adapt to their new norm (Jacobs-Nzuzi Khuabi et al., 2020; Scheffler & Mash, 2020). It is also crucial for stroke survivors to make the necessary changes in their diets and executing exercise programs (Kleineibst, 2007).

Table 1: Summary of studies researching lived experiences of caregivers of stroke survivors in South Africa

| Name of authors | Research Design | Setting | Number of participants | Findings |
|--|-------------------------------------|--|--|--|
| Thomas and Greenop (2008) | Qualitative | Government institution, Johannesburg | 6 | Initial stages of caring are challenging and the caregivers found it difficult to balance their needs with those of the stroke survivors. Support from HCWs was reported as useful |
| Mthembu et al. (2016) | Qualitative exploratory-descriptive | Southern and Northern Suburbs as well as Cape Flats in Cape Town | 6 | Participants were predominantly female from Muslim and Christian religious groups. Findings of this study were characterized by the difficulty of balancing their occupational and caregiving duties, which eventually had financial implications for the household. Participants found strength in their faith and noted it as a foundation for overcoming challenges. |
| Masuku et al. (2018) | Qualitative | Tembisa, Johannesburg | 14 female caregivers | Found that participants had a low level of health literacy, which led to frustrations and feeling overwhelmed as they did not understand the diagnosis of aphasia and were unable to communicate with the person they were caring for. The participant experiences also reflected context-specific challenges such as feminisation of caregiving as well as barriers to healthcare. |
| Scheffler and Mash (2020) | Qualitative exploratory-descriptive | Breede Valley sub-district Western Cape | 41 CHWs, 21 caregivers and 26 stroke survivors | The findings noted that stroke survivors and caregivers had to “figure things out for themselves” due to the lack of support from rehabilitation therapists. The stroke survivors and caregivers indicated the need for emotional support, knowledge, and skill training. CHWs were also underutilised as they felt they were not equipped with the necessary skills to support stroke survivors and their caregivers. |
| Jacobs-Nzuzi Khuabi et al. (2020) | Qualitative phenomenological | Western Cape Metropole | 8 | The findings reiterate those of Thomas and Greenop (2008), Mthembu et al. (2016) and Scheffler and Mash (2020). Due to the high demands of caring, caregivers neglected their own needs. This can negatively impact their well-being in the long run. |

Training of informal caregivers

Informal caregivers usually have no formal training in caregiving. Their caregiving knowledge is often limited to training received at the healthcare facility the stroke survivor is discharged from (Kniepmann & Cupler, 2014; Mthembu et al., 2016). Training programs are not standardized and vary between facilities. Programs vary from structured interventions that include formal sessions and specific requirements provided by a team in some settings to no training in others (Cameron & Gignac, 2008).

The need for training is the highest prior to discharge as caregivers are eager to gain experience to help manage the acute stage of caring (Pierce et al., 2007; Scheffler & Mash, 2020). This includes information on dependence and incontinence (Scheffler & Mash, 2020). The lack of training can cause caregivers to set unrealistic expectations, which can lead to anxiety and having to “figure things out for themselves” (Hassan et al., 2011; Quinn et al., 2014; Jacobs-Nzuzi Khuabi et al., 2020; Scheffler & Mash, 2020). This lack of training leave caregivers feeling afraid that they might injure the stroke survivor and cause further harm (Cawood & Visagie, 2016).

Conclusion

Caregivers play a pivotal role in the participation and re-integration of stroke survivors once discharged into the community. Caregivers, as much as the stroke survivor, face new challenges that they are not always prepared for. This can leave them feeling anxious and uncertain in fulfilling the caregiving role. Caregivers acknowledge that in caring for the stroke survivor, major changes take place in their emotional, physical, and mental well-being. It is for these reasons that it is important to understand the lived experiences of caregivers of stroke survivors discharged from Ceres Hospital to better understand the unique phenomena and experiences in this rural setting and make suitable recommendations.

Methods

Setting

The Witzenberg sub-district where the study was conducted is located about 90-minutes' drive from Cape Town and forms part of the rural Cape Winelands district in the Western Cape Province (Witzenberg Municipality, 2021). The Witzenberg consists of five towns; namely Ceres, Prince Alfred Hamlet, Op die Berg, Tulbagh, and Wolseley.

The Witzenberg has a total of 35 976 formal households, of which 99,3% have access to water within 200m from their dwelling and 34 017 have access to sanitation (Statistics South Africa, 2012; Western Cape Government, 2020). 2 967 of the residents reside in areas as far as 100 kilometers from the nearest hospital and 61% are employed in the agricultural sector (Witzenberg Municipality, 2021). The community has a low socio-economic status, and this affects their ability to access healthcare services and information.

Acute health care is provided by Ceres hospital. This district hospital is an 86-bed facility. A multi-disciplinary team provides rehabilitation services to the hospital, nine surrounding PHC facilities and an intermediate care facility (Western Cape Government, 2020). Due to bed pressures as well as lack of human resources, stroke survivors are discharged from the hospital into the care of a family member as soon as they are medically stable.

Research Design

A qualitative descriptive phenomenological design underpinned by a constructivism paradigm was used to explore the lived experiences of informal caregivers of stroke survivors. A constructivism paradigm will contribute to understanding the process through which people attach meaning to their experiences (Lee, 2012; Charmaz, 2006).

Population, sampling and recruitment

The study population comprised caregivers of stroke survivors who received speech therapy at Ceres Hospital and the surrounding primary healthcare facilities between September 2018 and August 2021. Stroke survivors that present with speech, language and feeding difficulties usually require support to complete their ADLs. Ninety-four stroke survivors received speech therapy during the study period. Only nine of the 94 files contained information about the caregiver. The nine stroke survivors' files were reviewed, and rehabilitation professionals from other disciplines were consulted to gain additional information such as correct contact details and addresses and to determine the level of physical dependence of the stroke survivor. Two caregivers were excluded as the stroke survivor had demised, and one was excluded as result of incorrect contact details. This yielded a group of six caregivers. Due to the small number, no sampling was done.

All 6 prospective participants were contacted telephonically to explain the study, confirm demographical information and obtain provisional verbal consent. Participants had to be 18 years and older, able to sign informed consent and caring for a stroke survivor discharged from Ceres

Hospital displaying a level of physical dependence and requiring assistance with self-care tasks for a minimum of 6 months.

A date and time at the convenience of the participant was scheduled to obtain written consent (Addendum A) and conduct the interview. On the day, in the convenience of the participant's home, I explained the study as well as the consent form and provided an opportunity for questions. One participant agreed to do the study, but on the scheduled day I was not able to reach her. The number of participants included was therefore five.



Figure 1: Witzenberg sub-district map (Source: https://visitwittenberg.co.za/wp-content/uploads/2019/05/Witzenberg_Menader_2019_Voorkant.pdf)

Methods of data collection and analysis

Primary narrative data was collected by me by means of face-to-face semi-structured interviews over a 5-month period (July to October 2022). The interviews lasted 50 to 70 minutes and were audio recorded by means of a mobile phone. All interviews were conducted in Afrikaans, the language preferred by participants, and was supported by an interview guide with prompts (Addendum C). Conducting face-to-face semi-structured interviews in the participants' homes meant they incurred no transportation costs, and I was able to observe them in their natural environment and it allowed me to build rapport (O'Leary, 2021). It also allowed me to observe body language and facial expressions, which added a deeper understanding of their experiences and richness to my field

notes. Interviews were not conducted in the presence of the stroke survivor and a conscious effort was made for privacy to ensure that the caregiver felt comfortable to speak freely and openly.

The interview started with reviewing the demographic information obtained telephonically as well as building rapport with the participants. Participant experiences were then explored by using the semi-structured interview guide. The following questions were included:

- What is it like caring for the stroke survivor?
- What has been the most rewarding caring for the stroke survivor?
- What has been the most challenging caring for the stroke survivor?
- How has your relationship changed with the stroke survivor since caring for him/her?
- What skills have helped in caring?

A pilot study was conducted with one caregiver to practice my interview skills and test the appropriateness of the data collection tool, and the logistics of the interview process (O'Leary, 2021). The pilot study was transcribed and discussed with my supervisor. The findings showed that the interview guide allowed me to collect information that addressed my aims and was included in the main analysis, as no changes were made.

Interviews were transcribed verbatim by me and stored on a password-protected computer. Provisional analysis was done after each interview to determine whether further probing was necessary to develop a deeper understanding of the data. There were certain answers that I wanted to explore further and therefore I conducted follow-up telephonic interviews with two participants.

I made use of the inductive thematic analysis guidelines for phenomenology as proposed by Sundler et al. (2019). These guidelines emphasise openness, questioning pre-understanding, and adopting a reflective attitude (Sundler et al., 2019). This method allowed me to identify, analyse and report themes from the data and in the process describe the lived experiences of participants.

Transcriptions were printed and I familiarised myself by reading the transcription in its entirety whilst listening to the recording and making notes. The Afrikaans transcripts were analysed. This was done in conjunction with reviewing my field notes. Additional descriptions such as body language or tone of voice were added in the margins to support initial notes made. Through this process I highlighted meanings and made notes. I moved between the isolated meanings, the text as a whole and the notes that I had made in the margins. These meanings were then compared to identify differences and similarities across all transcripts. This assisted in developing provisional themes and sub-themes (Figure 2). These themes and sub-themes were supported by isolated meanings as well

as quotes from the transcriptions. The quotes were then translated from Afrikaans to English. This provisional information was tabulated and discussed and reviewed with my supervisor to determine whether it did justice to the described lived experiences of the participants (Addendum E).

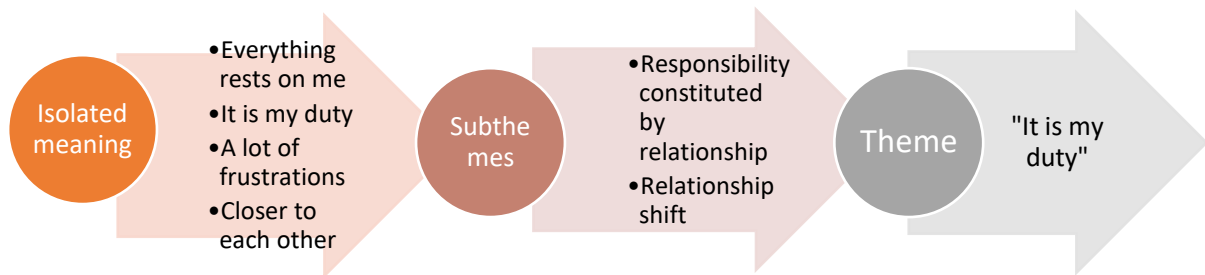


Figure 2: Process of inductive thematic analysis

Trustworthiness

Trustworthiness was enhanced through strategies of credibility, dependability, transferability, and confirmability (Anney 2014; Mabuza et al. 2014). Credibility was ensured through prolonged engagement with the caregivers during the interviews which lasted 50-70 minutes and follow-up interviews with two. The interviews were supported by an interview guide, which was reviewed by my supervisor to determine its appropriateness. Member checking was done by telephonically contacting three participants to check if the analysed data correctly summarized their experiences. This assisted to ensure that the analysis was a true reflection of the caregivers' lived experiences. Transferability was achieved by providing a detailed description of the participants' demographics, the research setting as well as the methods used in the study (Bless et al. 2013). This also supported dependability, which was further strengthened using a reflective journal, which I made use of after every interview. Being a service provider and a member of the rehabilitation team, it was important to reflect on my own values, interests, and perceptions to ensure that during data analysis I present the views of the participants and not my own opinions and biases (Nowell et al 2017). Maintaining an audit trail also supported dependability and confirmability.

Ethical considerations

Ethical clearance was obtained from the University of Stellenbosch Health Research Ethics Committee (reference number S21/10/219) (Addendum B). Permission to access medical records of stroke survivors was obtained from the Western Cape Department of Health and the medical manager of Ceres Hospital (Addendum D).

Participants were made aware of the possible psychological/ emotional discomfort through sharing their experiences and, if counselling services were needed, they could be referred. However, none of the participants requested these services. Participation in the study was voluntary and all participants were informed of the aim of the study and their role and provided with an opportunity to ask questions. The participants also signed an informed consent form and interviews were conducted in a language of the participants' choosing. This included consent to use a tape recorder. All data will be kept confidential and stored on a password-protected computer and back-up in cloud storage for 5 years (DOH, 2015; O'Leary, 2021). Hard copies of the transcriptions will be stored in my office in a locked cabinet at Ceres Hospital (O'Leary, 2021). Confidentiality was maintained by removing all names and identifying information from transcripts and digital spreadsheets.

Findings

The aim of the study was to explore the lived experiences of informal caregivers of stroke survivors discharged from Ceres Hospital. The demographic information of the five participants is presented in Table 2.

Table 2: Demographic profile of participants

| Participant Pseudonym | Age | Gender | Level of education | Duration of caregiving | Relation to stroke survivor |
|-----------------------|-----|--------|---------------------|------------------------|-----------------------------|
| Stoffel | 59 | Male | Grade 8 | 2 years and 9 months | Husband |
| Betrus | 58 | Female | Grade 6 | 2 years and 6 months | Mother |
| Johanna | 68 | Female | Grade 5 | 2 years and 1 month | Wife |
| Karen | 35 | Female | Grade 12 +Diploma | 3 years | Wife |
| Trudy | 78 | Female | No formal schooling | 2 years and 10 months | Wife |

Four themes emerged during data analysis: "It is my duty," "I don't make things difficult for him", "God gave me the strength", and "They told me nothing" (Table 2).

Table 3: Themes, subthemes and supporting quotes

| Theme 1 | | Theme 2 | | Theme 3 | Theme 4 |
|---|--|---|--------------------------------------|-----------------------------------|--|
| "It is my duty" | | "I don't make things difficult for him" | | "God gave me the strength" | "They showed me nothing" |
| Sub-themes | | | | | |
| Caregiver Responsibility | Relationship shifts | Adjustments made to lifestyle to accommodate stroke survivor | Repressing feelings and needs | Foundations in faith | Knowledge and training with regards to stroke |
| <i>I did not have a choice (Stoffel)</i> | <i>I am more attached to my child (Betrus)</i> | <i>Must stay at home for him (Johanna)</i> | <i>I must be strong (Johanna)</i> | <i>Stayed on my knees (Trudy)</i> | <i>We did not understand (Johanna)</i> |
| <i>I have to tend to my wifely duties (Trudy)</i> | <i>Suddenly there is just one (Johanna)</i> | <i>Like a child (Karen)</i> | <i>Why am I talking? (Trudy)</i> | <i>She prays for me (Karen)</i> | <i>Nothing (Trudy)</i> |

Theme 1: "It is my duty"

Caregiver responsibility

Participants expressed that it was their duty to care for the stroke survivor. They felt that this responsibility was not something they could ignore or from which they could run.

It is my duty; it is my husband. I must be content...I do not even go to church on Sundays. I cannot go. I must take care of him. I must make sure he gets his pills and things. (Johanna)

I did not think of anyone else. I decided it is my child. I will look after him myself. (Betrus)

They felt this responsibility rested solely with them.

But the fact that I see it now in my case that it is my wife, and I can't shift my responsibility onto someone else (Stoffel)

Their caregiving role became their priority and, despite challenging conditions, they pledged to support the stroke survivor. Taking on this responsibility often meant having to give up their own interests, employment, and dreams.

Then the rugby is also still there, but I decided no, rugby is not more important than my wife. Understand? So sometimes one does not feel good because you do not have that time for your activities, those activities that you would like to do to do them. But I do not have a choice, so I must let it go. (Stoffel)

Today I could have been someone important but looking after him I could not. I have certificates from the police. I really want to continue with that and then I have the childcare that I want to do at the schools and things, but I had to stop. I could not go further just because I had to look after him. (Karen)

Regardless of the challenges and the sacrifices, caregivers felt honoured caring for a loved one.

But just the fact that I have the privilege as her husband to care for her. (Stoffel)

One caregiver was also motivated to care for his mother as his father did not support her.

I will say that many times there are many things that contribute to that responsibility that you take yourself. To say when I look back now that I have seen many times growing up that my father wasn't always there for my mother, understand? So I also had the privilege to be with the wife of mine (Stoffel)

Relationship shifts

The caregivers caring for a spouse reported changes in their marital relationship. It is as if the stroke and its aftermath robbed the stroke survivor of the ability to still take on spousal and parental roles. Spouses used to be a team, but after the stroke one was left with all the responsibilities.

He was a man; we did things together and suddenly there is only one...There is no one else, I must be the mother and the father. (Johanna)

Caregivers reported a loss of emotional and physical intimacy from their partner.

I prayed sometimes and said, Lord I want my husband back, my husband was not like this. I am still praying today to get my husband back. I want the father of my children back. That is what I want. I do not know my husband like this. [Participant very emotional and starts crying. Continues after she composed herself]. You know there was a time that I said to him. I am going to speak direct now. Then I tell him come, can we not be affectionate? Can we do something? Then he says no. No ha ah (Karen)

He does not want to talk. It is always with him, "no leave it". He also does not want to open up about what really bothers him. (Karen)

A shift in relationship between mother and child was seen in the lives of Betrus and her son. Where there was previously independence, the relationship is now characterized by overprotectiveness and it is stifling. The parent granted the stroke survivor little freedom.

I am more attached to my child now. I feel like I will not just let him go away from me now. Then it will be very difficult for me. He and I are with each other every day and he is my baby. He is only twenty-five now. He is my baby, my only son. (Betrus)

The circumstances around the stroke left this mother feeling anxious not only for the stroke survivor but also for other loved ones.

My biggest fear is my child could get hurt again. Look, he was not at home when this thing happened. He was at his residence. Because when it happened then he was there, and we were here. Then he was alone. Then we had to pick him up from there and get him to the doctors ourselves. Now my biggest fear is with all my children, the one who also works in town, my grandson, I am just as afraid he could get hurt. After this happened, I have that fear if my children are gone, something could happen to them, but then I just pray. I just keep on praying. (Betrus)

Anxiety that something might happen was seen in other participants' narratives too.

I was always careful, went to see what he is doing when he stays too long outside, of he goes to the toilet. I knock on the door, "Are you OK?" (Trudy)

Others felt that caring brought closeness and helped to resolve long-standing conflicts.

It brought us closer together. The crooked spot came right. (Trudy)

Theme 2: "I don't make things difficult for him"

Adjustments made to lifestyle to accommodate stroke survivor

Caregivers acknowledged the demanding nature of caring and explained that they had to make changes to include the role of carer in their lives. Their lives and activities became focussed on the stroke survivor and his/her needs.

It actually makes it difficult for me because now I must do everything...It is a rushed business. I must rush to finish; I must rush with that. So if he wakes up everything is ready so that I can feed him and give his medication and everything. I must do everything for him. It is actually a bit uncomfortable for me because I must run in the house to get everything right. (Johanna)

Stroke survivors' demands did not make things easier.

Because then he's sitting there then I have to bring it to him. Then he tells me, but he didn't want this. Then I say you said you wanted this. No, I want that now or bring me some water. If I bring the water, then he asks me if the water was in the fridge. Then I say no, man, I poured it from my bottle... I want cold water. Oh Lord, now I have to give him the cold water. So, he made me walk up and down like that. (Trudy)

Time for themselves was a luxury caregivers did not have.

So sometimes one does not feel well because you do not have time for your own activities, those activities that you really want to do. (Stoffel)

An increased load of responsibilities was taxing for caregivers and added to their own physical health challenges.

I struggle with my back, and I have to bend every time to put on her shoes. (Stoffel)

It was paining all the way from my neck, but I'm used to it. (Johanna)

For some, adjustments meant quitting their jobs as they feared that leaving the stroke survivor alone could cause further harm.

So I went to work and saw the time that I am away from him makes him weaker. He does not improve. So I decided I am going to leave my work that is why I am looking after him now. (Karen)

They also pushed their interests and social lives to the bottom of their lists of priorities.

For example I sing in the men's church choir, and I am not there because my responsibility is here. (Stoffel)

The adjustments had repercussions for themselves as well as their households. Quitting their jobs meant that they no longer had an income to cover their day-to-day expenses as well as the additional needs of the stroke survivor.

But I said if they can just give me a bit extra with my grant; that will be enough. Because I must pay our funeral policies, I must pay everything from the grant AND I asked, and one man said I must go to SASSA because some days I do not have money and then the nappies are finished. (Johanna)

Nonetheless, most participants made the choice without much torment.

It was easy for me. I did not have any doubts...it was not difficult for me. I love my child too much. (Betrus)

They were caring for someone they loved.

Mm uh I do not have any regret. I am looking after my husband. I am looking after my love.
(Karen)

Despite the selfless nature of the caregiver, stroke survivors did not help with household duties.

I try to help him walk short distances from the room to the living room, they say it will help. Every day so five minutes, it will help Daddo. Now I do that because he does not want to by himself. On his own he does nothing; I must do everything. (Johanna)

Now [stroke survivor] comes here with a sweet, he shows the child. Oooh and the child goes on, it is mine not yours. Give my thing and [stroke survivor] says no it is mine. Oooh and the child screams. I must put out fires (Karen)

They were seemingly inconsiderate and oblivious to the efforts of the caregiver.

I followed him. Then I walk quietly because I cannot be with him then he pushes me away. Then he walks to the neighbouring farm in the night and then I follow him. He must not see me. (Karen).

Even though caregivers were upset that stroke survivors were not appreciative of their efforts, they did not openly speak about being upset:

I was really incredibly angry because God, can you not see? I still want to help you but you are just on to something else? I was very angry but what can I do? I must swallow my mood and do my thing. (Karen)

Familial support helped to accommodate the demands of caring. Participants found family support valuable. It gave them comfort knowing that there were people that cared and could provide them with an ear to listen.

Yes, then I just went on like this, but they never will, they also told me, my mother, you should talk. You don't have to struggle like that. Then I always say it is okay; don't worry. I am okay. (Trudy)

Neglect and repress needs and feelings

The aftermath of the stroke impacted the caregiver as much as the stroke survivor. It was unfamiliar territory and challenges were inevitable but for the sake of the stroke survivor, the caregiver chose not to voice their emotions.

Because there is no help for me...I must do all this, it was just too much pressure for me. Really. A lot of pressure. I have to cook; I have to struggle with him, but then I say oh Father help me so that I don't have an outburst towards him and what will I do then. Then I break him. So, I don't do this to him but I'm honest it was a difficult time for me (Trudy)

Caregivers also felt that if they openly spoke about their frustrations, they would be judged by their communities because caring for a loved was expected.

I am simply scared for the stones that will be thrown; it is your husband why are you talking? I have heard this a lot. (Trudy)

For some, repressing their feelings caused stress to such an extent that they could not label their emotions anymore.

I am happy but then I am not happy. I am not right. I do not feel right, and I have always gone on like that. (Trudy)

The caregivers acknowledged that repressing their feelings might cause physical ailments and loss of sleep, but this was their only coping strategy.

Sometimes I cannot sleep. I am overly tired that cause the sleeplessness. (Long pause] But I have to be content. (Johanna)

Participants acknowledged the benefit of being interviewed about their caregiving experiences as that gave them the opportunity to speak about themselves and what bothered them. Voicing their feelings brought a bit of relief.

Do you know what? You have taken a bit of the load off. My mother is on the farm. Sometimes I tell her something so and so, but I must speak so fast. Daddy will hear or sometimes the children sit with us because they want to hear what we are speaking about. (Karen)

Theme 3: “God gave me the strength”

Foundation in faith

Participants’ faith in God gave them the strength to persevere. They also turned to prayer when they were unsure or sad.

I stayed calm, and always talked to the Lord and then we carry on. I talk a lot to the Lord when I feel unsure or a little heartbroken” (Betrus)

It was very difficult, but I stayed on my knees so that God can take that away and give me the strength to look after him. (Trudy)

They found the prayers from family members to be important and beneficial.

My mother (participant giggles) and she pray for us. She prays for me and all the things. Sometimes I just let her sleep here so that she prays over the house. She is a prophet. Then I let her pray over my house. So that we can just be right again. (Karen)

Theme 4: “They showed me nothing”

Knowledge and training with regards to stroke

Participants reported receiving no information with regards to stroke or training on how to provide care.

They did not tell me anything. Nothing. Only told me that morning he can go home [from the hospital], he is all right. (Trudy)

This led to anxiety and fear of harming the stroke survivor.

They showed me nothing. We did not understand when he came out of the hospital. It was very difficult. I was incredibly stressed. I was so scared I could do something wrong and then he gets hurt. So it was stressful for me in the beginning. (Betrus)

There were difficulties and frustration in negotiating stroke-related impairments.

But they did not explain to me how to communicate with him using gestures. He was very stressed in the beginning but later he relaxed because then I understood most of the things he was showing. (Johanna)

Stoffel reported the benefits of respite services but knew it was not available in his area.

Because if there were facilities where you could have a break to where you could send someone ... but there are not such facilities. (Stoffel)

Discussion

The findings of the study indicated that caregivers had three different motivations to care for loved ones. Firstly, caregivers felt responsible to care for their spouses because of the vows they took before God; secondly, reassuming caring for a child and thirdly, caring relationships seen in previous generations. This correlates with existing literature that indicates that informal caregivers' decision to care are influenced by religious beliefs and reciprocity seen in previous generations (Jacobs-Nzuzi Khuabi et al., 2020) as well as family members feeling obligated to care (Hankey, 2004; Van den Berg et al., 2005). With this responsibility came a change in dynamics of the relationship between the caregiver and the stroke survivor.

Literature highlights the adjustments caregivers of spouses have to make from a mutually supportive and romantic relationship to a relationship where one person shoulders all the responsibility (Quinn et al., 2014). This places strain on the caregiver and can lead to separation (Kerr & Smith, 2001). Caregivers in the current study felt alone and longed for physical and emotional intimacy from the stroke survivor as also described by Jacobs-Nzuzi Khuabi et al. (2020). Traditional caregiver training programs do not prepare caregivers for these emotional experiences which eventually can negatively impact their overall well-being (Jacobs-Nzuzi Khuabi et al., 2020). It is important to evaluate caregiver training programs and allow space for caregivers to speak about their challenges. However, therapists are often overwhelmed with high caseloads and transport challenges makes it difficult for caregivers to return for further intervention. In addition, psychological support services are often not available (Scheffler & Mash 2020). Peer support groups for caregivers might allow a safe space for caregivers to share their emotional experiences.

One of the participants, a mother, experienced a shift in her relationship with her adult son. The mother was overprotective and held her son back from living his life. This is in line with the findings of Jones and Morris, (2013) who explored the relationship between adult stroke survivors and their parents. The adult survivors experienced shame as their parents treated them like children. Since a

positive self-concept and maintenance of identity is important, infantilizing an adult is detrimental to the overall well-being of the stroke survivor (Jones & Morris, 2013).

Caregivers struggled to balance their caring duties with their own needs, and they gave up their interests, dreams, and occupations. Ross & Deveral (2010) reported that giving up on personal dreams can lead to anger and depression. The focus might be on the stroke survivor in the acute phase as the family finds ways to adapt, but caregivers should be encouraged to pay attention to their own well-being as stroke care has a chronic trajectory (Quinn et al 2014). Jacobs-Nzuzi Khuabi et al (2020) emphasise the importance of caregivers being provided with an opportunity to pursue their own interests. This is observed as being crucial in reducing the emotional and social strain of caregiving (Jacobs-Nzuzi Khuabi et al., 2020).

Caregivers also reported anxiety about leaving the stroke survivor alone as they were afraid, they would harm themselves. Because of this anxiety and the caregiving duties, caregivers gave up their jobs. The loss of income places strain on the caregiver (Kleinebst, 2007; Wasserman et al., 2009; Hassan et al., 2011). Unfortunately, in rural South Africa, few specialized rehabilitation facilities as well as respite opportunities exist for caregivers (Hassan et al., 2011). Hence it is important for HCWs should support caregivers in normalizing these feelings of anxiety and highlighting the benefits of spending time away from the stroke survivor as well as the benefits of respite care.

In the study, caregivers reported feeling overwhelmed and frustrated about the caring experience. They did not voice these feelings because they were afraid that it might cause the stroke survivor to have a setback. The participants also feared that they would be judged by their communities because caring for a loved one meant they could not complain. They acknowledged that repressing their feelings was not a healthy coping strategy, but they did not know what else to do. The stress of repressing their feelings manifested as physical ailments and disturbed sleep. This is similar to the findings of Quin et al. (2014) where spousal caregivers chose to suffer in silence and put on a brave face, so others don't see them as complaining. None of the participants expressed a need to seek professional help but thanked me for the opportunity to speak freely about their challenges. They described it as taking a bit of the burden off their shoulders. The negative effects of these coping strategies influenced the psychological wellbeing of caregivers, and caregivers should be allowed to express their emotions and couples, and peer support groups are recommended (Quinn et al., 2014; Masuku et al., 2018)

Despite the sacrifices the caregivers made, stroke survivors acted entitled and inconsiderate. They neglected their responsibilities and placed additional pressure on the caregivers. One participant

reported that her husband would call her to parent the children as he was afraid that the children would not take him seriously because of his speech impairment. On the other hand, he would tease his children and his wife would be left to diffuse the situation. This added to the stress she was already experiencing.

Like the findings of Mthembu et al. (2016) participants in the current study depended on their faith as a way to cope with the demands of caring. Being grounded in their faith, participants found the strength to persevere despite the challenges that came with caring. They reported that the challenges placed on one's road are not without reason and were placed there to strengthen their faith. Great value was placed on spiritual support from family and the broader community. Findings by Mthembu and Knipemann (2022) highlight the value religious leaders play in supporting HCWs, stroke survivors and their caregivers in developing community support programmes.

Many of the stroke survivors in the current study had a short stay in the hospital, which left the caregiver little time to prepare for the caring role. The caregivers initially experienced anxiety as they were afraid of harming the stroke survivor and worsening their condition. This was noted with tasks where the stroke survivor needed physical assistance or had swallowing difficulties. Current literature highlights the importance of caregiver education and training prior to discharge to reduce caregiver anxiety (Scheffler & Mash, 2020). Caregiver training is included in the rehabilitation guidelines as outlined by Bryer et al. (2011) but in low-resourced settings similar to the study done by Scheffler & Mash (2020), where rehabilitation services are provided by one multidisciplinary team roaming a sub-district, standardised guidelines are scarcely implemented. Four participants were seen by rehabilitation professionals, but the information provided was not acknowledged nor utilized.

Limitations

- Speech therapy statistics did not include information about all caregivers of stroke survivors. This meant that only nine possible participants could be identified, no sampling could be done, and only five people participated in the study.
- While phenomenological studies can be done with five and fewer participants, I would have liked to include more as data was not as rich and nuanced as I would have liked, and additional participants might have increased the depth of the data.

Conclusion and recommendations

The study findings reflected that caregivers were not prepared for the impact that caring for a stroke survivor had on their everyday lives. They employed unhealthy coping strategies which impacted their overall wellbeing. Despite numerous studies on the negative emotional and psychological impact of caring on informal caregivers of stroke survivors, few caregiver training programs provide caregivers with adequate support strategies. In rural areas where rehabilitation professionals are faced with overwhelming caseloads, it is necessary to reevaluate the traditional caregiver training programs and tailor them to allow space for the emotional and psychological impact of caring. Many caregivers in the current study found their faith as a foundation from which they drew strength. The collaboration with religious leaders could assist in developing community stroke support programs. Couples and peer support groups are recommended, although they may be hampered by distance and transport challenges. Community based support groups for informal caregivers of stroke survivors with the involvement of religious bodies can be explored in further studies.

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Addenda

Addendum A: Informed Consent

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

| | |
|--|---|
| Title of Research Project: | |
| The lived experiences of caregivers of stroke survivors in a rural Western Cape setting | |
| DETAILS OF PRINCIPAL INVESTIGATOR (PI): | |
| Title, first name, surname: Mrs Mylcka Fisher | Ethics reference number: |
| Full postal address: 4 Ausone, Verdeau Lifestyle Estate Wellington, 7655 | PI Contact number: 082 948 9120/ 023 348 9600 Mylcka.Fisher@westerncape.gov.za |

I would like to invite you to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask me any questions about any part of this project that you do not fully understand. It is very important that you are completely satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary**, and you are free to decline to participate. In other words, you may choose to take part, or you may choose not to take part. Nothing bad will come of it if you say no: it will not affect you negatively in any way whatsoever. Refusal to participate will involve no penalty or loss of benefits or reduction in the level of care to which you are otherwise entitled. You are also free to withdraw from the study at any point, even if you do agree to take part initially. The Health Research Ethics Committee at Stellenbosch University has approved this study. The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice (2006), the Medical Research Council (MRC) Ethical Guidelines for Research (2002), and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).

What is this research study all about?

- Many caregivers of stroke survivors have noted the uniqueness of caring for a stroke survivor. Little information is available about the experiences of caregivers of stroke survivors in the Witzenberg. I therefore want to collect information on your experiences of caring.
- The aim of my study is to explore the lived experiences of caregivers of stroke survivors discharged from Ceres Hospital.
- Telephonic or face to face interviews will be conducted with 6-8 participants. The interviews will be 50-70 minutes long and will be audio-recorded to help me with the

write up. The interview will be at a time and place that is chosen by you. I might want to ask you some follow up questions. If this is the case, I will inform you well in advance and schedule a second interview at your convenience.

Why do we invite you to participate?

- My study focuses on caregivers of stroke survivors. Your experience as a caregiver is thus important to me.
-

What will your responsibilities be?

- To participate in a telephonic or face to face interview at a time that is convenient for you.
- To share your experiences of caring for a stroke survivor as honestly as possible.

Will you benefit from taking part in this research?

- There will be no immediate benefits from participating in the study.

Are there any risks involved in your taking part in this research?

- The research should not put you at any risk. However, if you experience any emotional pain, you will be referred with your consent to an appropriate healthcare worker.

Who will have access to your medical records?

- I will have access to the stroke survivor’s medical record. This will only be used to obtain your contact information. This will not be shared with anyone

Will you be paid to take part in this study and are there any costs involved?

- There are no costs linked to you participating in the study

Is there anything else that you should know or do?

- You can phone Mrs. Surona Visagie (principal investigator) on **021 938 9649** if you have any further queries or encounter any problems.
- You can phone the Health Research Ethics Committee at 021 938 9677/9819 if there still is something that your study doctor has not explained to you, or if you have a complaint.
- You will receive a copy of this information and consent form for you to keep safe.

Declaration by participant

By signing below, I agree to take part in a research study entitled the lived experiences of caregivers of stroke survivors in a rural Western Cape setting.

I declare that:

- I have read this information and consent form, or it was read to me, and it is written in a language in which I am fluent and with which I am comfortable.
- I have had a chance to ask questions and I am satisfied that all my questions have been answered.
- I understand that taking part in this study is **voluntary**, and I have not been pressurised to take part.

- I may choose to leave the study at any time and nothing bad will come of it – I will not be penalised or prejudiced in any way.

Signed at (*place*) on (*date*) 2019.

Signature of participant Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document in a simple and clear manner to
- I encouraged him/her to ask questions and took enough time to answer them.
- I am satisfied that he/she completely understands all aspects of the research, as discussed above.
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) on (*date*) 2019.

.....
Signature of investigator

.....
Signature of witness

Declaration by interpreter

I (*name*) declare that:

- I assisted the investigator (*name*) to explain the information in this document to (*name of participant*) using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) on (*date*)

.....
Signature of interpreter

.....
Signature of witness

Permission to have all anonymous data shared with journals:

Please carefully read the statements below (or have them read to you) and think about your choice. No matter what you decide, it will not affect whether you can be in the research study, or your routine health care

When this study is finished, we would like to publish results of the study in journals. Most journals require us to share your anonymous data with them before they publish the results.

Therefore, we would like to obtain your permission to have your anonymous data shared with journals.

Tick the Option you choose for anonymous data sharing with journals:

I agree to have my anonymous data shared with journals during publication of results of this study

Signature_____

OR

I do not agree to have my anonymous data shared with journals during publication of results of this study

Signature_____

Signature_____

b. Draft letters requesting permission from other Country Committees, DoH, institutions etc

c. Interview guide

Addendum B: Ethics approval



Approval Notice

New Application

14/04/2022

Project ID :24064

HREC Reference No: S21/10/219

Project Title: The lived experiences of caregivers of stroke survivors in a rural Western Cape setting

Dear Mrs MJ Fisher

The Response received on 30/03/2022 was reviewed by members of Health Research Ethics Committee via expedited review procedures on 14/04/2022 and full approval was granted.

Please note the following information about your approved research protocol:

Approval date: 23 March 2022

Expiry date: 22 March 2023

Please remember to use your Project ID 24064 and Ethics Reference Number S21/10/219 on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC 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.

After Ethical Review

Translation of the informed consent document(s) to the language(s) applicable to your study participants should now be submitted to the HREC.

Please note you can submit your progress report through the online ethics application process, available at: [Links Application Form Direct Link](#) and the application should be submitted to the HREC before the year has expired. Please see [Forms and Instructions](#) on our HREC website (www.sun.ac.za/healthresearchethics) for guidance on how to submit a progress report.

The HREC will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Please note that for studies involving the use of questionnaires, the final copy should be uploaded on Infonetica.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: <https://www.westerncape.gov.za/general-publication/health-research-approval-process>. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: [Forms and Instructions](#) on our HREC website <https://applyethics.sun.ac.za/Project/view/Index/24064>

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Melody Shana

Coordinator: Health Research Ethics Committee 1

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1)*REC-230208-010 (HREC2)

| Addendum C: Interview Guide | | | |
|--|---|--|---|
| Introduction and Key Components: | <p>My name is Mylcka and as I have explained on the phone, I would like to talk to you about how it is caring for ... (Stroke survivor's name). Thank you for taking the time from your busy schedule to speak to me. As explained when seeking your permission, the interview will be recorded therefore would it be possible to speak loud and clear so that I do not miss any information. All comments and responses will be kept confidential. I will not share your name with anyone. If I share things from what you have said nobody will know that you have said that. Therefore, anything in the study will not include anything that could identify you as the participant. The interview will take 50-70 minutes and you can stop me at any time if you feel tired or do not want to speak about the topic at hand.</p> <p>Do you have any further questions?</p> | | |
| Demographic information | Reviewing information obtained from folder review. | | |
| Open ended Questions: | <table border="1"> <tr> <td> <ol style="list-style-type: none"> 1) How did you come about caring for ... (stroke survivor name)? 2) What is it like caring for ... (Stroke survivor name)? 3) What changes have you experienced since caring for ... (Stroke survivor name)? 4) What has been challenging since caring for ... (Stroke survivor name)? 5) What has been rewarding since caring for ... (Stroke survivor name)? 6) Which skills have helped you in caring for ... (stroke survivor name)? 7) How has your relationship with ... (stroke survivor) changed since caring for him/her? </td> <td> <p>Probes:</p> <ul style="list-style-type: none"> • How has this affected your life? • How does it make you feel? • Are there specific things that influence your decision/feelings? • Did you have to “figure things out yourself” (Scheffler& Mash,2020: 4) or did someone help you? • How does the rest of the family support you? • What do you think influences the changes and/challenges encountered since caring? • What services have been helpful if available and known? </td> </tr> </table> | <ol style="list-style-type: none"> 1) How did you come about caring for ... (stroke survivor name)? 2) What is it like caring for ... (Stroke survivor name)? 3) What changes have you experienced since caring for ... (Stroke survivor name)? 4) What has been challenging since caring for ... (Stroke survivor name)? 5) What has been rewarding since caring for ... (Stroke survivor name)? 6) Which skills have helped you in caring for ... (stroke survivor name)? 7) How has your relationship with ... (stroke survivor) changed since caring for him/her? | <p>Probes:</p> <ul style="list-style-type: none"> • How has this affected your life? • How does it make you feel? • Are there specific things that influence your decision/feelings? • Did you have to “figure things out yourself” (Scheffler& Mash,2020: 4) or did someone help you? • How does the rest of the family support you? • What do you think influences the changes and/challenges encountered since caring? • What services have been helpful if available and known? |
| <ol style="list-style-type: none"> 1) How did you come about caring for ... (stroke survivor name)? 2) What is it like caring for ... (Stroke survivor name)? 3) What changes have you experienced since caring for ... (Stroke survivor name)? 4) What has been challenging since caring for ... (Stroke survivor name)? 5) What has been rewarding since caring for ... (Stroke survivor name)? 6) Which skills have helped you in caring for ... (stroke survivor name)? 7) How has your relationship with ... (stroke survivor) changed since caring for him/her? | <p>Probes:</p> <ul style="list-style-type: none"> • How has this affected your life? • How does it make you feel? • Are there specific things that influence your decision/feelings? • Did you have to “figure things out yourself” (Scheffler& Mash,2020: 4) or did someone help you? • How does the rest of the family support you? • What do you think influences the changes and/challenges encountered since caring? • What services have been helpful if available and known? | | |
| Summarizing | <p>Is there anything that you would like to add?</p> <p>Thank you for taking the time out for the interview.</p> | | |

| | |
|--|---------------------------------------|
| | Explain purpose of a second interview |
|--|---------------------------------------|

Addendum D: Department of Health Approval



STRATEGY & HEALTH SUPPORT
Health.Research@westerncape.gov.za
tel: +27 21 483 0866: fax: +27 21 483 6058
5th Floor, Norton Rose House,, 8 Riebeeck Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: WC_202204_040
ENQUIRIES: Dr Sabela Petros

Francie van Zijl Drive
Tygerberg
7505
Cape Town
South Africa

For attention: Mrs Mylcka Fisher, Dr Surona Visagie

Re: The lived experiences of caregivers of stroke survivors in a rural Western Cape Setting

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:

| | | |
|----------------|----------------|--------------|
| Ceres Hospital | Dr Elton Titus | 023 316 9603 |
|----------------|----------------|--------------|

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 and the constraints caused by the Covid-19 epidemic above are respected and adhered to.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**Annexure 9**) within six months of completion of research. 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**) and an updated ethics clearance letter 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

A handwritten signature in black ink, appearing to read 'V. Zweigenthal'.

PROF. V ZWEIFENTHAL
DIRECTORATE: HEALTH INTELLIGENCE
DATE: 9 June 2022
CC

| Addendum E: Data analysis: coding and themes | | | | | | | | |
|--|--|--|---|--|----------------------------|--|---|---|
| Themes | "It is my duty" | | "I don't make things difficult for him" | | "God gave me the strength" | | Experience of caring | |
| Participants | Responsibility constituted by relationship | Relationship shifts | Adjustments made to lifestyle to accommodate stroke survivor | Neglect and repress needs and feelings - | Initial anxiety and fear | Foundation in faith | State of stroke survivor (level of dependence, additional challenges) | Support needs (family, financial, healthcare workers) |
| Pilot: Husband of stroke survivor | <p><i>"I didn't have a choice"</i></p> <p><i>"The privilege to look after her"</i></p> <p><i>"Everything rests with me"</i></p> <p><i>"My responsibility is here"</i></p> <p><i>"My wife is my first priority"</i></p> | <p><i>"We fight a lot"</i></p> <p><i>"There are a lot of frustrations"</i></p> <p><i>"Become closer to each other"</i></p> <p><i>"It is not always sunshine and moonlight"</i></p> | <p><i>"I must adjust to the circumstance"</i></p> <p><i>"Will push my activities to the back"</i></p> <p><i>"Sometimes I can't provide the right food"</i></p> <p><i>"We don't have a choice"</i></p> | <p><i>"No time for myself"</i></p> <p><i>"Only when she sleeps"</i></p> <p><i>"I am also not healthy"</i></p> <p><i>"I will look after her as long as I can"</i></p> | | <p><i>"Where you get your strength from"</i></p> <p><i>"The answer I get from above"</i></p> | <p><i>"She gives her cooperation"</i></p> | <p><i>"She has her own responsibilities"</i></p> <p><i>"She would help if she could"</i></p> <p><i>"I have walked this road already"</i></p> <p><i>"There aren't such facilities"</i></p> <p><i>"Actually a very big impact"</i></p> <p><i>"My father wasn't there for my mother"</i></p> |

| | | | | | | | | |
|------------------------------|---|---|---|--|---|--|--|---|
| | <p><i>"You must accept everything"</i></p> <p><i>"I can't ignore my responsibility"</i></p> | | | | | | | <p><i>"Her sister is here"</i></p> <p><i>"There are people that care"</i></p> |
| P1 Mother of stroke survivor | <p><i>"I did not think of anyone else. I decided it is my child. I will look after him myself."</i></p> <p><i>"I do it with love"</i></p> | <p><i>"I am more attached to my child. I feel I won't let him be away from me"</i></p> <p><i>"I am just concerned"</i></p> <p><i>"Boeta you won't be able to go away from mommy now"</i></p> <p><i>Worried when stroke survivor is away; "I was very worried about him"</i></p> | <p><i>"I don't make things difficult for him"</i></p> <p><i>"I became very quiet/rustig"</i></p> | <p><i>"They must pain, I look after my child. I do what I must"</i></p> | <p><i>"In the beginning it was very stressful to look after him"</i></p> <p><i>"I was very tense"</i></p> <p><i>"I just felt a bit anxious, is this right?"</i></p> | <p><i>"Always spoke to God"</i></p> <p><i>"I speak to God a lot when I feel unsure and sad"</i></p> <p><i>"I just keep on praying"</i></p> | <p><i>"But he told me what I could not give him to eat"</i></p> <p><i>"He is very positive from the beginning"</i></p> | <p><i>"If we go out for a bit, she will stay with him"</i></p> <p><i>"They always say if mommy needs anything, mommy must just ask"</i></p> |
| P2: Wife of stroke survivor | <p><i>"It is my duty; it is my husband".</i></p> <p><i>"I must probably be satisfied because it is</i></p> | <p><i>"It was an adjustment" "I have never looked after someone"</i></p> <p><i>"we did things together and</i></p> | <p><i>"I don't even go to church on Sundays"</i></p> <p><i>"I must stay at home for him "</i></p> | <p><i>"Sitting with arms that pain but I endure"</i></p> <p><i>"I don't rest ever"</i></p> | | <p><i>"My prayers that help me stand strong"</i></p> <p><i>"The faith is strong"</i></p> | <p><i>"I can't leave him by himself because he can't help himself"</i></p> | <p><i>"In the beginning, we struggled"</i></p> <p><i>"There isn't money left"</i></p> |

| | | | | | | | | |
|------------------------------------|---|---|--|--|--|---|---|--|
| | <i>my husband" "I had no one else that could take care of him"</i> | <i>suddenly there is only one"</i> | <i>"I had to leave my work"</i> | <i>"I must be the strong one now"</i> <i>"I look after myself in my own way, but my focus is on him"</i> | | | <i>"I must do everything for him"</i> <i>"On his own, he does nothing"</i> <i>"He sits and does nothing"</i> <i>"It makes it difficult for me because I must do everything"</i> <i>"But the nappies are a story"problem</i> | <i>"I must pay everything from the grant"</i> <i>"They showed me nothing"</i> <i>" We didn't even understand when he came out of the hospital"</i> |
| <i>P3: Wife of stroke survivor</i> | <i>"I don't have regret"</i> <i>"I'm looking after my love"</i> <i>"I have to attend to my wifely duties"</i> | <i>"Then he says no"</i> <i>"A lot closer, really"</i> <i>"Also reignited our love"</i> | <i>"Again to the toilet like you would do with a child"</i> <i>"I could not leave him alone"</i> <i>"I had to make sure he didn't get hurt"</i> <i>"I could not go further"</i> | <i>"Show everything is okay but here inside"</i> <i>"I must just repress my mood and do my thing"</i> <i>"I have heavy stress"</i> <i>"I have to swallow it"</i> <i>"Taken off a load"</i> | <i>"It was a bit stressful"</i> <i>"Had to be put on a point"</i> <i>"Scared he gets hurt"</i> | <i>"God gives me strength"</i> <i>"She prays for me"</i> | <i>"Sometimes his mind setting"</i> | <i>"We don't have a relationship"</i> <i>"She is my role model"</i> <i>"We have financial struggles"</i> <i>"Mmm uh they did nothing"</i> |

| | | | | | | | | |
|-----------------------------|---|--|---|--|--|---|--|---|
| | | | <p><i>because I looked after him</i></p> <p><i>"When I'm away from him, he gets weaker"</i></p> | | | | | |
| P4: Wife of stroke survivor | <p><i>"I must not be impatient; it is my partner"</i></p> <p><i>"It isn't right towards God"</i></p> <p><i>"I'm in it, I can't run away"</i></p> <p><i>"You must stand by him no matter what"</i></p> | <p><i>"I learnt a lot"</i></p> <p><i>"It brought us closer together"</i></p> <p><i>"The crooked spot came right"</i></p> | | <p><i>"I was very tired"</i></p> <p><i>"I have never spoken about it till today"</i></p> <p><i>"Why am I talking"</i></p> <p><i>"I will say I'm alright and then I'm not"</i></p> <p><i>"I always hide my things"</i></p> <p><i>"I'm very happy but I'm not"</i></p> <p><i>"I am not okay"</i></p> <p><i>"I'm scared something happens to him"</i></p> | <p><i>"I was just a bit careful"</i></p> <p><i>"It was a very difficult time"</i></p> <p><i>"I'm scared he falls"</i></p> <p><i>"I always walk with him"</i></p> | <p><i>"Ai Father please help me"</i></p> <p><i>"Stayed on my knees"</i></p> <p><i>"My faith is important"</i></p> | <p><i>"He just ordered too much"</i></p> | <p><i>"I didn't worry with them"</i></p> <p><i>"Then I say no you have your house"</i></p> <p><i>"Stood by me with him"</i></p> <p><i>"No they explained nothing to me"</i></p> |

| | | | | | | | | |
|--|--|--|--|--|--|--|--|--|
| | | | | <i>"I don't know girl"</i> | | | | |
| | | | | <i>"I'm scared for the stones that will be thrown"</i> | | | | |

