Experiences regarding formal and informal support for significant others of Individuals living with traumatic brain injury during the COVID-19 pandemic

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Submitted in fulfilment of the requirements for the degree MA Speech-Language Pathology in the Department of Speech-Language Pathology and Audiology

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Declaration of Originality

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Declaration

1. I understand what plagiarism is and are aware of the University's policy in this regard.

2. I declare that this research is my own original work. Where other people's work has been used (either from a printed source, Internet, or any other source), this has been properly acknowledged and referenced in accordance with departmental requirements.

3. I have not used work previously produced by another student or any other person with a view to handing it in as my own.

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SIGNATURE

Acknowledgments

I would like to dedicate this dissertation to individuals living with traumatic brain injury, and to those who love and support them.

To my supervisors, Mrs Pillay and Dr Krüger, thank you for your constant support and insight. Thank you for inspiring me to aim high through your knowledge of, and passion for, our profession. I am immensely grateful for the role you played in this journey.

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Title:	Experiences regarding formal and informal support for significant others of individuals living with traumatic brain injury during the COVID-19 pandemic

Abstract

Background: The COVID-19 pandemic prompted a disruption in rehabilitation and loss of support systems for significant others of individuals with traumatic brain injury. This study explored experiences regarding support that significant others encountered during the 2020-2021 period of the COVID-19 pandemic.

Aim: To describe the experiences and views of SOs of individuals with TBI regarding formal and informal support during the COVID-19 pandemic.

Method: Seven significant others of individuals with a traumatic brain injury participated in an online semi-structured interview. Interviews were transcribed verbatim and analysed using Computer Assisted Qualitative Data Analysis Software.

Results: Support structures for significant others of individuals with a traumatic brain injury were shown to have declined during the pandemic, resulting in increased caregiver burden, stress, financial strain, emotional distress, and breakdowns in relationships. The emerging role of technology as a support was identified as a promising feature to counter these negative effects.

Conclusion: Both access to, and continuity of, support structures and services were found to be vital to the well-being not only for individuals with a traumatic brain injury, but also their significant others, particularly during times of crises such as the global COVID-19 pandemic.

Keywords: COVID-19 pandemic; rehabilitation; significant others; support; traumatic brain injury; semi- structured interview; qualitative thematic analysis

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List of abbreviations

The following abbreviations are used in this dissertation:

ADL	activities of daily living
ASHA	American Speech-Language-Hearing Association
COVID-19	coronavirus of 2019
HPCSA	Health Professionals Council of South Africa
PLWD	people living with disabilities
POPI	Protection of Personal Information
PPE	personal protective equipment
TBI	traumatic brain injury
SASLHA	South African Speech-Language-Hearing Association
SOs	significant others
SLT	speech-language therapist
WHO	World Health Organisation

CHAPTER 1: INTRODUCTION

The purpose of this first chapter is to provide a comprehensive review of recent literature to explore the background and relevance of the current study. Experiences regarding support of significant others of individuals who have sustained a traumatic brain injury before the COVID-19 pandemic are discussed, including how the pandemic may have altered or intensified these experiences. The problem statement and rationale for this study is outlined and the research question stated. Terminology is discussed as used in this dissertation. The delimitations adhered to in this study concludes the chapter.

1.1. Introduction

The COVID-19 (SARS-CoV2) outbreak was declared by the World Health Organisation (WHO) as a "Public Health Emergency of International Concern", on 30 January 2020 (WHO, 2020a). On 11 March 2020, the WHO declared this outbreak as a global pandemic (WHO 2020b). In response to this pandemic, an unprecedented national state of disaster in the form of a nationwide lockdown was declared in South Africa on 15 March 2020 (SA Corona Virus, 2020). The pandemic resulting from this disease has greatly impacted all domains of South Africa's healthcare system, including rehabilitation services of people living with disabilities (PLWD). Investigation of how this pandemic may have affected PLWD and their families or significant others (SOs) due to factors such as social distancing, lockdown and the reduced access to resources is therefore warranted. Globally, there are over 1 billion PLWD (Kuper & Heydt, 2019). In South Africa, it is reported that over 3 million people live with a disability (Arnold-Day et al., 2020). On average, South Africa presents with 89 000 cases of new traumatic brain injuries (TBIs) annually (Maluleke, 2018). It is therefore evident that TBI is of serious concern in South Africa.

1.1.1. Support for significant others

With increasing advances in health and medicine, more individuals that sustain a TBI are surviving, and will require care and support from SOs (Klemen & Grmec, 2006; Marehbian et al., 2017). In South Africa, there are rehabilitation centres and programmes serving individuals with a TBI and

their SOs. However, disparities exist in accessing such services between the public and the private sector where services are more readily available in the latter (Morris et al., 2019). Not only are individuals with TBI positively affected by rehabilitation programmes, but research has shown that caregivers or SOs of these individuals also benefit; both directly and indirectly (Fortune et al., 2016). A TBI has a considerable impact on the life of the individual with a TBI, as well as that of the caregivers and family (Bermejo-Toro et al., 2020). Family members often become or act as primary caregivers of individuals with a TBI and spend hours with, and around, their loved ones with TBI throughout the rehabilitation process, which is often a life-long process (Oyesanya, 2016). Becoming a primary caregiver means that SOs might have increased roles with the individual with TBI such as caring for the individual, grooming, driving, and providing other such supports to assist with activities of daily living [ADL] (Cheklin et al., 2020). This can result in a variety of different emotions not previously experienced. Feelings of loss and uncertainty may arise as the SOs of individuals with a TBI navigate through their new role and search for support (Checklin et al., 2018). SOs rely on support through formal mechanisms such as rehabilitation centres, as well as through informal support structures found within the community (Bermejo-Toro et al., 2020; Cheklin et al., 2020).

1.1.2. Rehabilitation services for individuals with TBI and their SO

Formal mechanisms such as rehabilitative care involve physical social interactions with an individual with a TBI, the rehabilitative team, as well as SOs such as family and caregivers (Boldrini et al., 2020). Rehabilitative care involves support of SOs of people living with TBI. (Holloway & Tasker, 2019). Generally, rehabilitation centres or teams provide a variety of services from speech-language therapy to psychosocial support. In South Africa, limited resources result in day-facilities being popular in targeting all facets that come with having a TBI (Brainlife, 2019). There is a lack of longer-term facilities such as those with assisted living environments, in South Africa (Ned et al., 2017). Furthermore, the majority of care facilities in South Africa are targeted at the aged population, which might not always be suitable for a young individual who has sustained a TBI (Ned et al., 2017). Such care centres, such as day centres, focus on individual therapy, skills development, and training in areas of cognition, creativity and functional ADL as recommended by speech-language therapists

(SLTs) and other allied healthcare professionals (Ned et al., 2017). These often take place in a group setting, allowing for socialisation and development of these skills; as well as providing families with support and counselling through the rehabilitative process (Brainlife, 2019; Oberholzer & Müri, 2019).

Healthcare providers and other allied professions can be a vital source of support to SOs at the beginning post-TBI, as well as throughout the rehabilitative process. SOs try to navigate changes in their loved ones as well as their own new roles and responsibilities (Cheklin et al., 2020). Healthcare providers and other allied professions can be a vital source of support to SOs at the beginning post-TBI, as well as throughout the rehabilitative process (Cheklin et al., 2020). During the nationwide lockdown in 2020, the South African population was confined to their houses for months and could only leave if they were performing an essential service or needed acute care (SA Corona Virus, 2020). Although South Africa is an upper middle-income setting, with lower middle-income areas, rehabilitative care was not deemed to be an essential service and was not considered a priority (Berry et al., 2013). The COVID-19 pandemic and the associated restrictive measures have possibly altered these support structures and access thereof, necessitating further investigation.

Globally, preparation for the continuation of effective rehabilitation during the COVID-19 pandemic was inadequate, as preference was placed on acute emergency services (Boldrini et al., 2020). Research such as that of Leocani et al. (2020) showed that there is no time to place neuro-rehabilitation on pause. Rather, during the pandemic, rehabilitation centres should have offered larger spaces that are shared, extended operating hours allowing for fewer clients in the facility at once, and centres should have sanitised all equipment multiple times a day (Leocani et al., 2020). SOs rely on informal support such as family, friends, support groups and other outings or activities headed by a rehabilitative care team (Biester et al., 2016). This, however, could not have occurred due to the strict lockdown rules put in place by the local Government from March to June 2020 (SA Corona Virus, 2020).

A suggestion for continuation of rehabilitative services was to provide all people - staff, individuals with TBI, as well as their SOs – with adequate personal protective equipment (PPE) (Leocani et al., 2020). Numerous incidents occurred throughout the pandemic, where South Africans did not have access to sufficient PPE (Maphanga, 2020). Limited PPE had also been provided to health care workers, particularly to those working in acute settings, where preference was given (Singh & Moodley, 2020). The lack of PPE to vulnerable populations such as people with TBI and their SOs, would make active rehabilitation as conducted before the onset of the pandemic, unsafe. It was, therefore, a safety risk to not place neuro-rehabilitation on pause in South Africa. The extent to which the effects of the pandemic have affected SOs, needs to be explored to understand the importance of both formal and informal support structures during the various levels of restricted measures to combat the spread of the virus in South Africa.

1.1.3. Significant others as caregivers

Numerous studies have explored caregivers' views, experiences, and perceptions of living with a person with a brain injury before the COVID-19 outbreak, in which trauma, change, grief, loss, uncertainty, depression, stress, and strain were all shared emotions and themes generally experienced by SOs (Biester et al., 2016; Cheklin et al., 2018; Degeneffe & Lynch, 2006; Fortune et al., 2016; Pielmaier et al., 2012; Wongvatunyu & Porter, 2005). Through support, whether formal or informal, SOs experienced increased positive thoughts regarding themselves and their SO such as relief, collaboration in the journey, interaction, and hope (Cheklin et al., 2018). SOs were also better able to cope with caring for, or living with, an individual with a TBI when having access to support services (Broodryk, 2014). Research has also shown that SOs, regardless of their relation to the individual presenting with a TBI, experienced similar emotions and views on support services (Biester et al., 2016; Cheklin et al., 2018; Degeneffe & Lynch, 2006; Fortune et al., 2016; Pielmaier et al., 2012; Wongvatunyu & Porter, 2005).

Following a TBI, the individual's relationship with the SO changes (Holloway & Tasker, 2019). Negative emotions that may arise can adversely impact the relationship between an individual with

a TBI and their SO, which can potentially lead to isolation from the individual with a TBI (Holloway et al., 2019; Tramonti et al., 2017). Isolation is a common theme experienced by caregivers, resulting in grief, resentment and other negative emotions previously not held towards the individual with a TBI (Tramonti et al., 2017). The impact of a TBI on SOs are complex and enduring due to the permanent symptoms that accompany a TBI (Ponsford, 2013). SOs reveal that the perceived invisible effects of TBI, such as loss of insight and cognitive difficulties, make their role even more demanding (Holloway & Tasker, 2019). This saddens, confuses, and frustrates SOs (Holloway et al., 2019). SOs prioritise the well-being and safety of the individual with a TBI rather than their own, often leading to burn-out and other fatigue-like symptoms (Holloway et al., 2019). Research has found that up to 50% of SOs lose friendships, a much-needed form of informal support, when they take on the caregiver role (Holloway & Tasker, 2019). The same study reported that the individual with a TBI also experiences a drastic decline in the number of friends (Holloway & Tasker, 2019). The COVID-19 pandemic may have placed further strain on friendships and on caregivers' support networks (Singh & Moodley, 2020). Furthermore, because of COVID-19 pandemic-related actions, the support and relief that SOs typically receive from rehabilitative centres may be unavailable.

Family members have been recorded to be the largest group of caregivers for individuals with TBI (Elliott & Parker, 2012). Individuals that take care of their partners who have a TBI have reported multiple reasons for the toll it has taken on their relationship. These SOs play a key part in their partners' road to recovery and rehabilitation (Pielmaier et al., 2012). Partners cannot always effectively fulfil this role, due to their own personal experiences in dealing with their new role, responsibility, and drastic and unexpected changes that are lifelong (van der Meer et al., 2020). Tramonti et al. (2015) reports that this distress can negatively affect the individual with a TBI's healing process. SOs have been found to experience chronic depressive, anxious and post-traumatic stress disorders, often debilitating to their daily life (Pielmaier et al., 2012; Ponsford & Schonberger, 2010). Lower partner satisfaction, in terms of relationships, is a common theme in partners who have become carers (Fortune et al., 2016). Research has revealed that caregivers' emotions also affect the recovery and life satisfaction of the individual that they are caring for,

reiterating how imperative it is to provide SOs with the support they need (Bermejo-Toro et al., 2020). This is further maintained by the fact that carers of individuals with TBI experience higher levels of distress when compared to carers of persons with intellectual disabilities, cancer, and spinal cord injuries (Fortune et al., 2016).

Similar experiences are reported by siblings of individuals with TBI. High levels or stress, intense grief, as well as the burden of caring for the individual with a TBI, cause depression in SOs, including siblings (Holloway & Tasker, 2019; Ownsworth & Karlsson, 2020). Parents of the children, with and without TBI, often assume that the non-injured sibling will take on the role of caregiver when the parents pass or become unfit to do so (Degeneffe & Lynch, 2006). This creates feelings of resentment and depression, in the context of a relationship that may previously have been described as being good friends (Headway, 2021). Other family members also report feelings of confusion and isolation due to insufficient knowledge of brain injury and the care thereof (Biester et al., 2016).

Family members, particularly parents, experience an intense need to help, accompanied by feelings of grief, helplessness, and failure (Wongvatunyu & Porter, 2005). Parents feel pressure to make life as normal and as safe as possible, advocating for the individual all while dealing with grief and associated emotions (Wongvatunyu & Porter, 2005). Parents often feel criticised, that they have failed their child, causing psychological distress, lack of motivation and burnout (Fortune et al., 2016).

Lack of support services affect SOs ability to cope with the demands of caring for an individual who has sustained a brain injury (Bermejo-Toro et al., 2020). Quality of life, carer burden and diminished mental health are more common for TBI carers than those that care for other individuals that require long-term care, thus reiterating the importance of support for SOs of TBI survivors (Bermejo-Toro et al., 2020). Supporting SOs with effective coping strategies and support systems may lead not only to better outcomes in the individual with TBI, but also provide more positive experiences and adaptations in the lives of SO caring for the individual with TBI (Wongvatunyu & Porter, 2008), even more so in stressful situations such as the COVID-19 pandemic.

1.1.4. The effect of the COVID-19 pandemic

It is reported that most individuals who have sustained a TBI have difficulty coping with routine changes (Persel & Ashley, 2020). Support groups, networks, and structures for both the individual living with a TBI, as well as their SO, help establish coping mechanisms to overcome this challenge (Brain Injury Alliance of Arizona, 2020). Support structures also serve SOs needs to determine if their feelings and emotions are valid and experienced by others in the same circumstances (Bermejo-Toro et al., 2020). Families and SOs that cope best with living with and caring for an individual with a TBI, have a channel of communication and support with others; as well as SOs that are receiving attention, guidance, and education (Bermejo-Toro et al., 2020). However, due to lockdown regulations, accessibility of these support structures changed due to the various levels of restrictions. Coping strategies for the individual with TBI may now fall on that of the SO, adding further stress and anxiety (Headway, 2021; Persel & Ashley 2020).

The COVID-19 pandemic has generally intensified negative experiences and minimised possible positive experiences (Thelwall & Levitt, 2020). The negative perceptions and views already experienced by SOs of individuals with a TBI may be exacerbated due to the adverse effects of this global pandemic such as the loss of normality; potential additional financial or social stress; a new added level of uncertainty; as well as further strain, depression, and anxiety (Cullen et al., 2020). Additionally, lack of support or physical interaction for SOs due to a nationwide lockdown and restrictive measures may have contributed to minimising possible positive experiences warranting the current study.

The WHO released a document summarising disability-related considerations during the COVID-19 pandemic (WHO 2020c). This included guidelines for governments and institutions that incorporated protective steps to be taken for persons living with a disability (PLWD), such as planning for the effects of measures taken for social distancing; as well as the need to plan to ensure the continuation of services for PLWD (WHO, 2020b). The aim was to ensure continuation of rehabilitation services, so that families and SOs could safely support PLWD to meet their ADLs, health, transport,

educational and employment needs (Lancet, 2020). Strict lockdown regulations imposed by the local government made it imperatively difficult for rehabilitation, community, and other support programmes to continue - including those for individuals with TBI (SA Corona Virus, 2020).

Tele-intervention or rehabilitation was a platform that many health professionals utilised to continue rendering their much-needed services. Tele-intervention or tele-therapy has been used intermittently in the last decade (Waska, 2015). The COVID-19 pandemic and its associated social distancing rules and regulations has brought tele-intervention into the foreground (Armitage & Nellums, 2020). The benefits include the continuation of rehabilitative care from an individual's place of residence (SA Corona Virus, 2020). Due to the ongoing COVID-19 pandemic, local health regulatory bodies such as the Health Professions Council of South Africa (HPCSA) and South African Speech-Language-Hearing Association (SASLHA) have introduced tele-intervention or tele-therapy guidelines – guidelines that are still new in implementation (Kwinda 2020; SASLHA Executive Council, 2020). Tele-intervention requires a working computer or laptop and a relatively strong connection to the internet as a minimum. As of 2019, only 61,6% of the South African population had access to the internet, and 24% had access to computers (Clement, 2020; Harrison, 2019). It can be assumed that this number has remained similar or decreased due to South Africa's already collapsing economy and the economic effects of COVID-19 (Renzaho, 2020). Tele-rehabilitation was therefore not a viable option for all PLWD in South Africa meaning individuals with TBI as well as their SOs were left with possibly minimal to no formal source of support.

1.2. Problem statement and rationale

It is possible to evaluate whether SOs can be more effectively assisted during times of crisis. This is done by determining whether common negative experiences of SOs, such as fatigue and resentment, were further exacerbated by the pandemic. This is further explored by determining how and to what extent these negative experiences influenced or impacted their daily lives. The adverse effects of this global pandemic may exacerbate the negative perceptions and views already held by SOs of individuals with a TBI. These include caregiver fatigue; guilt; depression; anxiety; and

emotional, social or financial stress. Due to the lack of support and physical interaction that may have occurred as a result of lockdown and restrictive measures, a SO's established positive experiences may have been minimised.

The research question that therefore arose, was 'What are the experiences and views of SOs of individuals with TBI regarding formal and informal support during the COVID-19 pandemic?'. This study hoped to highlight possible pertinent factors deemed important to SOs when caring for and living with individuals with TBI and the main needs for support. This is to ensure that people living with a TBI and other groups of PLWD, as well as caregiver or SO support programmes, will be prioritised in future planning efforts to ensure inclusivity of this vulnerable population (Leocani et al., 2020).

1.3. Terminology as used in the dissertation

Significant others

Significant others (SOs) can refer to a wide variety of people in the life of an individual who has sustained a TBI (Biester et al., 2016). SO is used in this study to refer to a family member, a partner, a spouse, a child, a friend, or another individual. The participants of this study must be the SO of individuals specifically with a TBI, and not another acquired brain injury such as a tumour or meningitis, psychological disorder, or dementia.

Neurorehabilitation

A multifaceted medical process aimed to recover from, to minimise, or compensate for, changes in function as a result of injury to the nervous system (Krucoff et al., 2016).

People living with disabilities (PLWD)

People who experience long-term intellectual, sensory, physical, neurological and/or psychosocial impairment that substantially limits their opportunity to enter into or advance in employment (Nkonyane, 2020).

Rehabilitative care

A set of interventions needed when an individual experiences limitation in ADL due to a health condition (WHO, 2019).

1.4. Outline of chapters

The dissertation consists of five chapters, as described as follows:

Chapter 1: A comprehensive introduction to the current state of the research, the problem statement and the rationale, the research question, as well as the terminology used in the dissertation. The chapter concludes with an outline of chapters contained in the dissertation.

Chapter 2: An in-depth discussion outlining the method used in the study including the aim; objectives; research design; ethical considerations; setting; sample; participants; material and apparatus; procedures and data analysis; as well as the trustworthiness of the study.

Chapter 3: The article that was submitted on 20 August for reviews to an international journal entitles *Health and Social Care in the Community*.

Chapter 4: A concluding chapter discussing the theoretical and clinical results of the study. It outlines the strengths, limitations and recommendations for future research.

CHAPTER 2: METHOD

This chapter discusses the aims and objectives of the research study. The design, setting and study population, sample, and participants are outlined. Material, apparatus, and procedures to collect and analyse the data are discussed thereafter. Additionally, this chapter explores the ethical considerations in this study. The trustworthiness of the study concludes this chapter.

2.1. Research aims

2.1.1. Aim

The aim of the study is to describe the experiences and views of SOs of individuals with TBI regarding formal and informal support during the COVID-19 pandemic.

2.1.2. Research design

The study was conducted using a descriptive, qualitative research design. This qualitative type of design is used when there is little known about a certain phenomenon, or when what is known is poorly defined (Brink et al., 2018). A qualitative research design allows for researchers to describe and provide an in-depth understanding of human emotions and experiences. This research design is aimed to gain a better understanding of a phenomenon or problem, without providing definitive solutions (Braun & Clarke, 2016). Descriptive research designs intend to shed light on an existing phenomenon, such as the support offered to SO during the COVID-19 pandemic, where there had previously been little or insufficient knowledge (Brink et al., 2018). The study is phenomenological in nature as it describes what people were experiencing during the COVID-19 pandemic as well as how those experiences are interpreted (Brink et al., 2018) by means of a semi-structured interview. Thus, the researcher was able to describe what people experience in relation to particular phenomena, as well as their interpretations of these experiences (Brink et al., 2018).

2.2. Ethical considerations

2.2.1. Ethical clearance

This study obtained ethical clearance from The Research Ethics Committee of the Faculty of Humanities at the University of Pretoria (Appendix A). It was of the utmost importance that all ethical principles were considered and adhered to throughout the research process. The following considerations were reflected throughout this research study:

2.2.2. Informed consent

Written informed consent (Appendix B) was requested from each potential participant prior to data collection. A clear, simple explanation of the study was provided in lay terms to participants in an information leaflet and informed consent document. Ethical principles of voluntary participation were explicitly outlined in this document: information regarding the protection of participants from harm was stated; the researcher would not coerce participants in the study and state that participants are free to decide whether they wish to participate; as well as an explanation informing participants that withdrawal from the study at any given time was possible with no consequences thereof (du Plooy-Cilliers et al., 2018).

2.2.3. Confidentiality

Interviews took place over the videoconferencing platform, Zoom. Such a platform has end-to-end encryption, and this data is protected from the public (Zoom Help Centre, 2021). Data obtained from participants during the study was kept confidential. Names were not recorded during the data collection process; but rather, each participant was assigned an alphanumeric code, which was used in all recording and processing of data as well as reporting of results. All electronic data, such as the recordings of the interview, is stored on a password-protected computer and documents stored in a lockable office, Room 2-12, at the Department of Speech-Language Pathology and Audiology at the University of Pretoria. Data will be stored for 15 years on a password protected computer as per the university's policy. The data are only accessible to the researcher and the supervisors.

2.2.4. Beneficence

Beauchamp and Childress (2019) describe the principle of beneficence as a research study that offers a two-way benefit. In other words, when an individual participates in a research study, it should not only be the researchers who benefit from their contribution, but the research should also benefit the participant themselves. In this study, participants were given an opportunity to provide their experiences regarding living with a loved one with a TBI, particularly during the COVID-19 pandemic and perceived support during this time. This study highlights possible pertinent factors deemed important to SOs as well as their main needs for support during the unprecedented lockdown period in South Africa.

Participants were each gifted data to the value of R50 to reimburse any data costs of utilising the video-conferencing platform, by electronically loading it onto participants' phones. Participants may have also experienced other benefits from this study. Sharing experiences can facilitate emotional release, which can be beneficial or therapeutic, with the potential to aid in the healing process and bring about positive change (Rossetto, 2014). Findings from this study can be used to advocate for appropriate action to be taken to ensure equal opportunities for support and rehabilitation for individuals with TBI as well as their SO during times of crises. This study therefore aims to highlight essential factors for support of SOs that may be taken into consideration in times of crises or other global emergencies (Leocani et al., 2020).

2.2.5. Respect and non-maleficence

Non-maleficence is based on four principles: avoid inflicting harm; to prevent harm; to remove harm; and to do or promote good (Motloba, 2019). The principle of respect for persons states that individuals have the right to self-determination and are therefore autonomous (Brink et al., 2018). Both of these principles were ensured throughout this study by respecting the participants answers, or decision not to answer certain questions as is their right. This was clearly stated in the informed consent document. Non-maleficence was made a priority throughout the study as the researcher only presented factual information, ensured participants felt comfortable, and they knew their rights. In the event that participants became emotional as they related events and experiences, they were

referred for counselling if they indicated a need for it (Appendix C). Participants received the referral letter via email after the conclusion of the interview. Such an action ensured that the principal of non-maleficence was abided by.

2.2.6. Justice

According to the principle of respect for persons, individuals have the right to self-determination, and as a result, remain autonomous (Brink et al., 2018). This principle was respected by ensuring that participants were fully informed that they were able to discontinue with the study at any time during the interview process, that they may withdraw their participation, and that this will not affect any potential relations with the University of Pretoria or their SO's therapy service provider.

2.2.7. Procedural integrity

Procedural integrity, also known as fidelity, is described as the extent to which the research is implemented with accuracy and as per the protocol (Braun & Clarke, 2016). The dependent variable in this study was the experiences that SOs of individuals with a TBI hold regarding formal and informal support during the COVID-19 pandemic, which was determined by responses and experiences provided during the semi-structured interview. To ensure that this variable was implemented with precision, a topic guide formulated with extensive research, based on two prior studies that explored perspectives and experiences of SOs of individuals with a TBI (Broodryk, 2014; Holloway, 2017), was used during the semi-structured interview. During these interviews, the researcher provided standard prompts where necessary during the open-ended interactions to increase interview quality, as well as to alert participants that the interviewer is actively listening, putting participants at ease (Sigstad & Garrels, 2017).

2.2.8. Plagiarism

All consulted sources have been acknowledged using the guidelines set out in The Publication Manual of the American Psychological Association (APA), Seventh Edition. The author does not claim the work of other authors as her own and has referenced and cited such work in the APA 7th edition referencing style.

2.3. Setting and population

A group of SOs of individuals with TBI were asked to participate in this study, following a referral by rehabilitation teams. Potential participants were sourced from rehabilitation facilities, non-profit organisations (NPOs) and private practices in Gauteng, South Africa, remaining mindful of maintaining confidentiality and adhering to the Protection of Personal Information (POPI) act. South Africa is an upper middle-income country, with lower middle-income settings, reflected by the participants selected (Berry et al., 2013).

2.4. Sample

2.4.1. Sample size

The selection of a sample size is imperative for guaranteeing the credibility and trustworthiness of a study (Elo et al., 2014). A sample of seven SOs participated in this study. Authors such as Braun and Clarke (2016), as well as Fugard and Potts (2015), recommend a sample size of six to 10 participants in a qualitative study to obtain a commendable level of trustworthiness.

2.4.2. Sampling method

Purposive sampling, a type of non-probability sampling, was used in identifying participants (Holloway, 2005). This sampling method is appropriate to a qualitative research design, where participants are selected from the population, which best suits the purpose of the study (Brink, et al., 2018). Potential participants were referred, via a predetermined checklist (Appendix D), by SLTs working in rehabilitation facilities, NPOs and private practices in Gauteng.

2.5. Participants

2.5.1. Inclusion criteria

To be eligible to participate, participants needed to meet the following inclusion criteria as set out in Table 1.

Table 1

Selection criteria and justification thereof

Criteria for selection	Justification
The SO must have spent a minimum of four times per week or 20 hours with the individual who has sustained a TBI to attend to their ADL and offer support.	The SO needed to spend a substantial amount of time with the individual with a TBI and have played an active part in his/her life (Biester et al., 2016).
The SO must have been 18-years or older.	The age of legal capacity is 18-years-old. A significant other that was 18 years or older could therefore legally consent to this study (McQuoid-Mason, 2007).
The SO must have had adequate hearing abilities through self-report.	This ensured that the SO heard and understood all questions posed, so as to have ensured the accuracy of the results and potential comparisons thereof (Bolderston, 2012).
The SO must have been proficient in English through self-report.	The individual must have had a basic or foundational ability to read, speak, write, or understand the English language (Stephen & Zoucha, 2020). This was the primary language of the interview, as well as of all appendices such as the informed consent document.
The SO must have had access to a video or telephonic platform, through a phone, tablet, laptop, or other similar devices; as well as sufficient data to participate in the interview.	Due to the restrictions of the COVID-19 pandemic, it was advisable to conduct interviews through platforms such as Zoom, WhatsApp or telephonically to reduce the spread of the virus (Dhawan, 2020).

2.5.2. Recruitment of participants

The researcher telephonically contacted SLTs in Gauteng, South Africa. These SLTs provided prospective participants' information once clients provided consent (Appendix E) for their contact details to be shared with the researcher. The inclusion criteria were emailed to the SLT in the form of a checklist (Appendix D), where the SLTs were asked to email the contact details of prospective participants. The potential participants were then contacted telephonically by the researcher and invited to participate in this study. Informed consent to participate in the study was then requested. Participants were limited to SOs of individuals who sustained a TBI, where the TBI had been

sustained prior to the year 2020. This was in order to ensure that a comparison could be made between formal and informal support prior to the COVID-19 outbreak and after the lockdown period.

2.5.3. Description of participants

Participants included females who were either wives or mothers of their loved one with a TBI, ranging from 40-68 years of age (Table 2).

Table 2

Participant characteristics (n=7)

Assigned code	Age	Gender	Home language	English proficient	Occupation	Relationship to SO with a TBI	Primary caregiver	Years since SO sustained a TBI
P1	40	Female	Xitsonga	✓	Senior Accountant	Wife	✓	7
P2	58	Female	Northern Sotho	✓	Retired	Mother	✓	30
P3	68	Female	Afrikaans	✓	Pensioner	Mother	✓	3
P4	49	Female	English, German, Afrikaans	✓	Boarded Accountant	Wife	✓	7
P5	59	Female	Afrikaans	✓	Insurer	Mother	✓	16
P6	56	Female	English	✓	General Manager	Mother	✓	1
P7	54	Female	Afrikaans	✓	Teacher	Married	✓	10

2.6. Material and apparatus

2.6.1. Structured interview schedule: Interview schedule and topic guide

Data collection took place through a semi-structured interview via video-conferencing platforms. Semi-structured interviews allow for the participant to take the lead, enabling the researcher to obtain

data reflecting participants' feelings, beliefs, and thoughts (Nelson & Gilbert, 2020). Data collection through video-conferencing has been found to produce rich data in a convenient manner (Hai-Jew, 2015). During a semi-structured interview, the interviewer asks a specified number of questions but is free to pose additional questions (Brink et al., 2018). Throughout the interview, open-ended questions were used to elicit rich, diverse data for explanatory purposes (Brink et al., 2018). The interview instrument used to elicit this information was an interview schedule (Appendix F), which is beneficial for qualitative research studies such as this study (Braun & Clarke, 2016; Brink et al., 2018).

The interview schedule, topics, and questions therein, were adapted from two previous studies exploring experiences of SOs of individuals with TBI in different contexts (Broodryk, 2014; Holloway, 2017). The interview schedule consisted of a questionnaire with 20 closed-ended questions to obtain biographical information and a topic guide consisting of open-ended probing questions (Appendix F), formulated, and administered in English. An evidence-based justification of questions used in the topic guide was imperative for scientific rigour (Appendix H). Making use of an interview schedule allows for structure to be added to the interview, to ensure scientific rigour, but is constructed in such a way that still allows for a conversational setting resulting in an in-depth reflection of the participant's experiences (Brink et al., 2018).

2.6.2. Apparatus

The semi-structured online interviews were recorded on the voice recorder application of an Apple iPhone 11, 2019 model to be transcribed on an Apple MacBook Pro laptop 2020 model for data analysis. In the case that a problem arose with regard to recording of the interview, a back-up Samsung Galaxy phone was used.

2.7. Procedures

2.7.1. Data collection

Each potential participant was emailed the informed consent document (Appendix B) in PDF format and asked to send back a signed version. Clear instructions on how to add a signature to a PDF document was provided (Appendix B). Prior to the interview and once informed consent had been obtained, participants were telephonically contacted to schedule a once-off interview at a time suitable for the participant; as well has to clarify which video-conferencing platform will be utilised as per the participant's request. Participants were advised to limit background noise, position themselves in good lighting as well as an optimal position to ensure the effectiveness of the interview via the video-conferencing platform (Nehls, 2015). Due to the ongoing COVID-19 pandemic, it was determined that no face-to-face interviews would be conducted to ensure the researcher and participants' safety. While difficulties with internet connectivity were possible, the researcher ensured that effective troubleshooting procedures were in place such as ensuring a backup phone was fully charged and loaded with airtime to call the participant should the need arise, such as in one case where the participant had an unstable internet connection.

The interview schedule was emailed to participants prior to the interview. By doing so, participants did not become nervous and flustered when answering questions. This allowed for bias to be removed, objectivity to increase, as well as to increase the accuracy of the study (Brink et al., 2018). Once informed consent was gained, participants were provided with closed sets of questions for biographical information in the form of a short questionnaire asked by the researcher during the video interview (Appendix F). The interview was conducted in a video-conferencing session on average, one hour and four minutes. Open-ended questions were presented through a semi-structured interview that served as a guide for broader qualitative information, where opinions could be provided more openly and not constricted to a list of potential answers (Christensen et al., 2015). Clarification of questions was provided as requested by participants (du Plooy-Cilliers et al., 2019). Participants were prompted for further elaboration on their perspectives and guided the researcher's questions using prompts such as "In what ways did that affect you?", "How did that make you feel?",

as well as periods of silence as an indication for the participant to elaborate further (Murphy & Boar, 2012). Interviews were audio recorded and later transcribed by the researcher. Rabionet (2014) states that audio recording is the recommended method of recording data during an interview above written notes. This recording method also allowed for the researcher to be more actively engaged in the interview, putting the participant at ease (Rabionet, 2014).

Following the interview, participants were offered a reimbursive voucher for the data utilised for the interview, to the monetary value of R50 each. The data voucher was electronically loaded onto participants phones after the interview, once their cell phone providers and contact details had been confirmed.

2.7.2. Data analysis and management

Participants' responses and experiences were safely stored on a password protected phone on which the recordings took place as an interim measure before recordings were transferred, onto a password protected Google Drive. These recordings were transcribed verbatim (Appendix G) by hand, facilitating analysis by bringing the researcher closer to the data (Campion et al., 2020). The data was then analysed in an organised, controlled manner.

Thematic analysis was conducted for the interpretation of data obtained from open-ended questions. Thematic analysis involves coding and categorisation of data obtained in a systematic way to discover if patterns, trends, or relationships exist therein, resulting in solid, meaningful findings (Bondas et al., 2013; Saldaña, 2016). Thus, thematic analysis involves preparation by immersing oneself in the data; organising data by using open coding to create categories and subcategories to form a general description of the research; and finally reporting of findings that are presented through conceptual systems, in categories, or in the form of a story (Elo & Kyng, 2008).

Open, inductive coding of data (Table 3) was completed with the aid of ATLAS.ti 9 (Soratto et al., 2020), which is a software programme used for qualitative data analysis. In utilising a Computer Assisted Qualitative Data Analysis Software, data management security was increased and the risk for human error was eliminated (Soratto et al., 2020).

Table 3

An example of coding used in data analysis

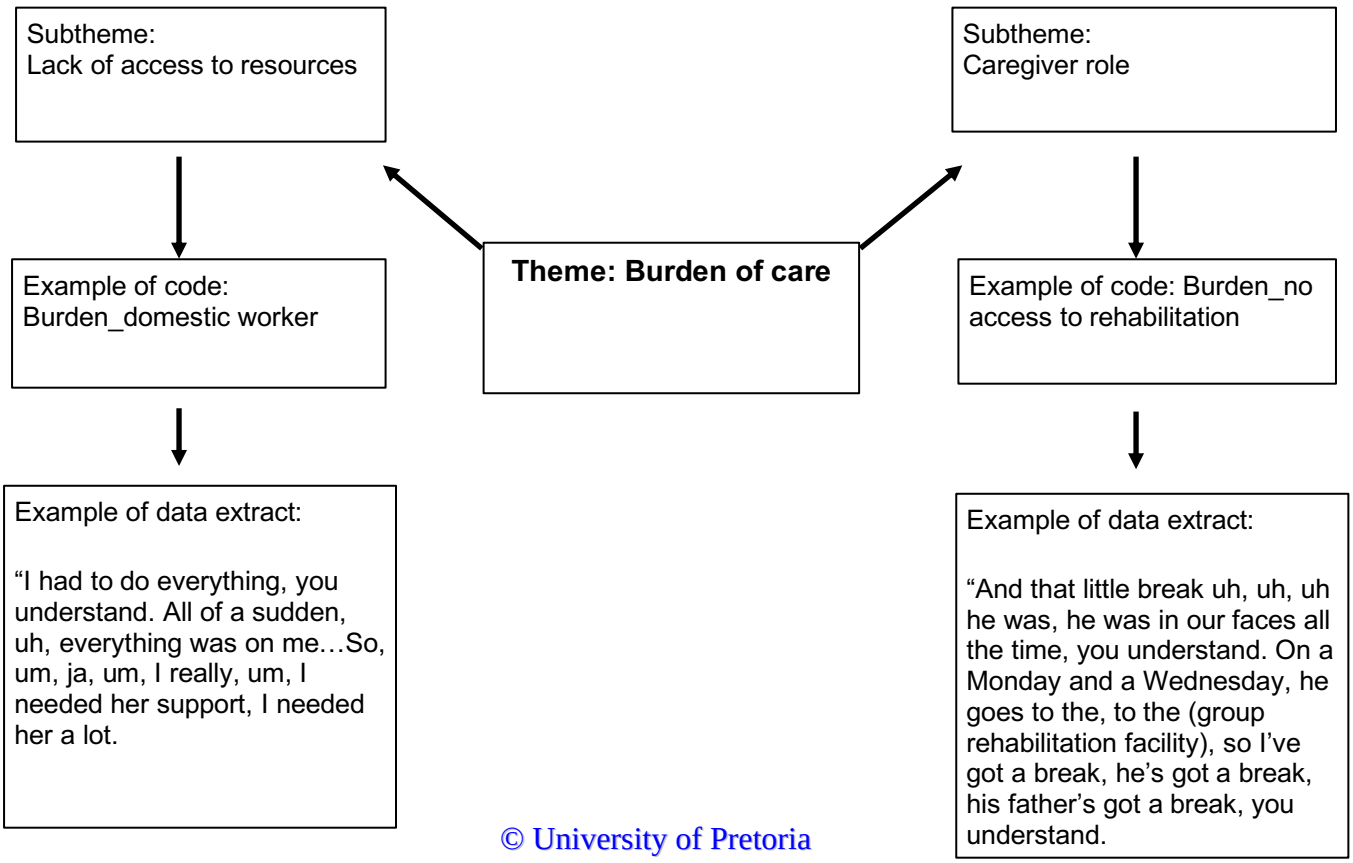
Code	Example of data extract
Burden_family	"…Not be able to go to my family and, uh, just kuier you know, be functional…That was, that very bad. It's not the same when you phone somebody" (P3)
IC support_social media platforms	"OK with church we decided um we're doing online but with our church because there are a lot of old people it was only the recordings on WhatsApp…" (P1) It,it,it's only the psychiatrist that we, um, we was able to do Skype. (P3)

Key: IC - In COVID-19

Codes were organised to develop a thematic framework using thematic networks in the form of mind maps (Figure 1).

Figure 1

An example of thematic network used in data analysis



In conjunction with the researcher, another qualified SLT perused the data to ensure the utmost accuracy and appropriate coding, thus adding to the trustworthiness of the data (Brink et al., 2018). A second rater, a qualified SLT, listened to 20% of the interviews and confirmed the accuracy, clarity and consistency of the way questions were posed across interviews.

2.8. Trustworthiness

Trustworthiness involves reliability of a qualitative scientific study, and attributes to the accuracy of the study's results (Brink et al., 2018). To ensure quality control and trustworthiness, the measurement tool was adapted from two previous studies that explored perspectives and experiences of SOs of individuals with a TBI (Broodryk, 2014; Holloway, 2017). The first study by Broodryk (2014) was conducted in South Africa, ensuring its relevance to the local population. The second study by Holloway (2017) has been published and therefore contributes to the trustworthiness of the study. In order for in-depth knowledge on the phenomenon to be acquired, extensive research needs to continually take place (Cresswell, 2013). Trustworthiness was ensured by following five criteria: credibility, dependability, confirmability, transferability, and authenticity, in all phases of the research study (Brink et al., 2018; Beck & Polit 2017; Elo et al., 2014).

2.8.1. Credibility

Confidence in the accuracy and truth of data are established to determine the credibility of the study (Brink et al., 2018). Peer debriefing was a strategy employed where expert supervisors were consulted. Credibility in the data collection, organisation and reporting phase of this research study was ensured through persistent observation, prolonged engagement, as well as member checks (Brink et al., 2018).

2.8.2. Dependability

This criterion signifies data stability both under varying conditions, as well as over time (Elo et al., 2014). In other words, the findings reported should match those if the study were to be repeated in similar circumstances i.e., a pandemic (Brink et al., 2018). Credibility can only be obtained if dependability exists (Brink et al., 2018). Therefore, the above strategies and criteria that affect credibility can be applied to optimise dependability. In addition, inquiry audits in which the data,

results, interpretations, and recommendations were thoroughly examined. Thus, both dependability as well as confirmability were established (Brink et al., 2018).

2.8.3. Confirmability

Confirmability explores the objectiveness of the data in order to achieve congruence of data in its relevance, meaning and accuracy (Brink et al., 2018; Elo et al., 2014). The researcher aimed to exclude bias so as to suit the preconceived ideas of the study's results through inquiry audits (Brink et al., 2018). However, it is know that the qualitative researcher may influence the research process due to prior experiences, beliefs and assumptions (Braun & Clarke, 2016). Field notes and verbatim transcriptions were used to contribute to reflexivity (Braun & Clarke, 2016).

2.8.4. Transferability

This refers to the reasoning that the results of the data can be transferred or generalised into alternative participants or contexts (Elo et al., 2014). Purposive sampling, as used in this study, is a method to encourage transferability (Brink et al., 2018) by being deliberate in participation selection, context, setting and topic under investigation. Therefore, clinically valuable conclusions were made even though the sample was not representative.

2.8.5. Authenticity

Beck and Polit (2017) describe authenticity as reporting a range of realities that are just, truthful, and fair in nature. In order to achieve this, reporting of results were not tampered with to suit the agenda of the researcher, but rather sensitivity was built to gain an in-depth understanding to the issues pertinent in this study (Brink et al., 2018).

In addition to the above-mentioned criteria, to improve the trustworthiness of the measurement tool as per guidelines outlined by Christensen et al. (2015), questions were arranged in a logical order, so as to not lead responses on. In addition, technical jargon was avoided so as to reduce the possibility of misunderstanding. In addition, control questions were implemented in the measurement tool so as to indicate the reliability of the responses provided by the participants (Christensen et al., 2015). Through collecting data via an interview as opposed to a questionnaire, it allowed for

clarification of questions if needed thereby improving the quality of the results obtained (Brink et al., 2018). Both the researcher and the supervisors followed the guidelines set out by Braun and Clarke (2016) in terms of exploring and finalising themes from coded data. By following scientific guidelines, validity and reliability of the results were ensured.

CHAPTER 3: ARTICLE

This article was admitted to the international journal entitled *Health and Social Care in the Community*. The style and format are in line with the author guidelines and journal specifications and thus differ from that of the rest of the dissertation. Proof of submission can be found in Appendix I.

Experiences of significant others of individuals with traumatic brain injury during the COVID-19 pandemic in South Africa

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Conflict of interest

No potential conflict of interest was reported by the authors.

Experiences of significant others of individuals with traumatic brain injury during the COVID-19 pandemic in South Africa

Abstract

The COVID-19 pandemic prompted a disruption and loss of support systems for significant others of individuals with traumatic brain injury. This study explored experiences regarding support that significant others encountered during the 2020-2021 period of the COVID-19 pandemic. Seven significant others of individuals with a traumatic brain injury participated in an online semi-structured interview. Interviews were transcribed verbatim and analysed using Computer Assisted Qualitative Data Analysis Software. Support structures for significant others of individuals with a traumatic brain injury were shown to have declined during the pandemic, resulting in increased caregiver burden, stress, financial strain, emotional distress, and breakdowns in relationships. The emerging role of technology as a support was identified as a promising feature to counter these negative effects. Both access to, and continuity of, support structures and services were found to be vital to the well-being of significant others of individuals with a traumatic brain injury, particularly during times of crises such as the global COVID-19 pandemic.

What is known about this topic

- Rehabilitation programmes benefit both an individual with traumatic brain injury (TBI), as well as their significant others (SOs).
- SOs experience many negative emotions when their loved ones sustain a TBI, which are mitigated through support structures including friends and family.
- During the COVID-19 pandemic, many countries worldwide imposed a strict lockdown which resulted in limited access to rehabilitation and support structures.

What this paper adds

- The pandemic exacerbated the ongoing burden of care and stressors already experienced by SOs.
- The emerging role of technology is a promising tool to counter restricted in-person support structures.
- Further research is necessary for a comprehensive representation of SOs' views on support systems and structures in low- and middle-income settings.

Keywords: COVID-19 pandemic; significant others; support, traumatic brain injury; structured interview schedule; qualitative thematic analysis

1. Introduction

The COVID-19 (SARS-CoV-2 virus) outbreak was declared by the World Health Organisation (WHO) as a "Public Health Emergency of International Concern" on 30 January 2020 (WHO, 2020). In response to this pandemic, an unprecedented national state of disaster in the form of a nationwide lockdown was declared in South Africa on 26 March 2020 (Koh, 2020). People were confined to their homes for months, leaving only to perform essential services or receive acute care during level 5 lockdown (Madia, 2020). As South Africa vacillated between lockdown levels 1-4, restrictions eased or tightened accordingly. The lockdown had a significant impact on all domains of the healthcare system. Rehabilitative care was not deemed to be an essential service, with a deleterious effect on access to support structures and services for individuals with traumatic brain injury (TBI) requiring rehabilitative therapy (Stasolla et al., 2021).

Rehabilitation for people living with disabilities such as TBI, and the support for their significant others (SOs), was one such casualty of the pandemic. On average, South Africa presents with 89 000 cases of TBIs reported annually (Arnold-Day et al., 2020). It is therefore important to investigate how individuals with TBI and their SOs were impacted during the pandemic through lockdown restrictions, including social distancing and reduced access to resources.

Rehabilitation centres and programmes in South Africa often cater for individuals with a TBI as well as for their SOs. SOs are caregivers, or someone frequently associated with an individual with a TBI, such as parents, siblings, spouses or partners, children, friends or others who play an essential role in the life of an individual with TBI (Biester et al., 2016). TBI has a considerable impact on the life of the individual with the injury, as well as that of the caregivers and family (Cheklin et al., 2018). Family members often become primary caregivers of individuals with a TBI and spend hours with, and around, these individuals throughout rehabilitation - often a life-long process (Oyesanya, 2016). Not only are individuals with TBI positively supported by rehabilitation programmes, but their SOs also benefit directly and indirectly (Fortune et al., 2016).

Formal rehabilitative care involves physical and social interactions with an individual with TBI, the rehabilitative team, as well as offering substantial support for SOs (Boldrini et al., 2020; Holloway & Tasker, 2019). Trauma, change, grief, loss, uncertainty, depression, stress, and strain are all shared themes experienced by SOs (Biester et al., 2016; Cheklin et al., 2018; Degeneffe & Lynvh, 2006; Fortune et al., 2016). Healthcare providers and allied health professionals are a vital source of support to SOs throughout the rehabilitative process (Cheklin et al., 2020). Informal structures such as family, friends, support groups and other outings or activities headed by a rehabilitative care team also play an important role in supporting SOs (Biester et al., 2016; Cheklin et al., 2020).

Through support, whether formal or informal, SOs experience increased positive thoughts such as relief, collaboration in the journey, interaction, and hope with their loved-ones that they care for (Cheklin et al., 2018). SOs are better able to cope with caring for, or living with, the individual with TBI when having access to support services (Broodryk, 2014; Pielmaier et al., 2012). The strict lockdown regulations in 2020 curtailed these rehabilitative services. Although easing of lockdown restrictions occurred in phases throughout 2020 and 2021, the Government-mandated regulations such as social distancing and curfews may have made attaining support difficult.

Preparation for continuation of effective rehabilitation during the COVID-19 pandemic was inadequate, as preference was placed on acute emergency services (Boldrini et al., 2020). Interrupting rehabilitation of individuals with TBI is detrimental to an individual's progress in therapy (Leocani et al., 2020; SAHİN, 2020). Additionally, caregivers' emotions affect the recovery and life satisfaction of the individual that they care for. Consequently, the extent to which the effects of the pandemic have affected their SOs also requires investigation, and could further inform the impact of access to formal and informal support structures during the various levels of restrictions imposed to combat the spread of the virus.

The current study aimed to explore the experiences and views of SOs of individuals with TBI regarding the support received during the pandemic, as well as experiences of participation in daily life with the individual with a TBI during the lockdown period. Understanding SOs views may prompt long-term positive healthcare considerations that could counteract consequences of future outbreaks or other global emergencies (Leocani et al., 2020). Individuals living with TBI or other disabilities, as well as caregivers or SOs, need to be prioritised in future planning efforts to ensure inclusivity of this vulnerable population.

2. Materials and Methods

2.1. Study design

A descriptive, qualitative research design was used (Braun & Clarke, 2016; Brink et al., 2018). The study is phenomenological in nature as it describes SOs' experiences during the COVID-19 pandemic, as well as how those experiences are interpreted (Brink et al., 2018) by means of a semi-structured interview.

2.2. Setting

South Africa is an upper middle-income country, with lower-income settings, reflected by the participants selected (Berry et al., 2013). Participants were recruited from the private sector, where access to devices and internet were more common (Watkins et al., 2018).

2.3. Participants

Purposive non-probability sampling was used to recruit seven participants (Braun & Clarke, 2016). Eligible participants had to meet the following criteria: The SO needed to play an active role, spending a minimum of 20 hours a week with the individual with a TBI (Biester et al., 2016); the SO must have been 18 years or older to legally consent to participate in the study (South Africa, 2006); and be English proficient. Adequate hearing ability through self-report was a pre-requisite to ensure accurate results during the interview (Bolderston, 2021). Interviews were conducted through video-conferencing platforms (Zoom) through an electronic device. Participants were offered a reimbursive data voucher. Participants were all females who identified as either wives or mothers of individuals

with a TBI, ranging from 40-68 years of age. Participants were a diverse group and came from a cross-section of socio-economic statuses, with a variety of home languages. All participants identified as the primary caregiver and lived with their SO with a TBI.

Table 1: Participant information

Assigned code	Age	Gender	Home language	English proficient	Occupation	Relationship to SO with a TBI	Primary caregiver	Years since SO sustained a TBI
P1	40	Female	Tsonga	✓	Senior Accountant	Wife	✓	7
P2	58	Female	Northern Sotho	✓	Retired	Mother	✓	30
P3	68	Female	Afrikaans	✓	Pensioner	Mother	✓	3
P4	49	Female	English, German, Afrikaans	✓	Boarded Accountant	Wife	✓	7
P5	59	Female	Afrikaans	✓	Insurer	Mother	✓	16
P6	56	Female	English	✓	General Manager	Mother	✓	1
P7	54	Female	Afrikaans	✓	Teacher	Married	✓	10

2.4. Study instrument and apparatus

A custom-designed questionnaire and topic guide were used during a semi-structured interview. The questionnaire comprised of 20 questions to obtain biographical information, and a topic guide consisting of open-ended probing questions. The topic guide was adapted from two previous studies exploring SOs of individuals with TBI's experiences in different contexts (Broodryk, 2014; Holloway, 2017).

Interviews were recorded with the voice recorder application of an Apple iPhone 11, (2019), and orthographically transcribed on an Apple MacBook Pro Laptop (2020), with a back-up Samsung Galaxy Phone (2016) in case technical issues arose.

2.5. Procedures

Participants were interviewed once informed consent was obtained. The interview questions were emailed prior to the interview, which placed participants at ease when answering questions, increasing the objectivity and accuracy of the data obtained (Brink et al., 2018). Each interview was conducted in one video-conferencing session and interviews lasted on average one hour and 4 minutes.

Participants who became emotional as they related experiences were referred for counselling if they indicated a need for it. Participants were reimbursed for the data used during the interview by electronically loading the voucher to participants' phones thereafter.

2.6. Data analysis

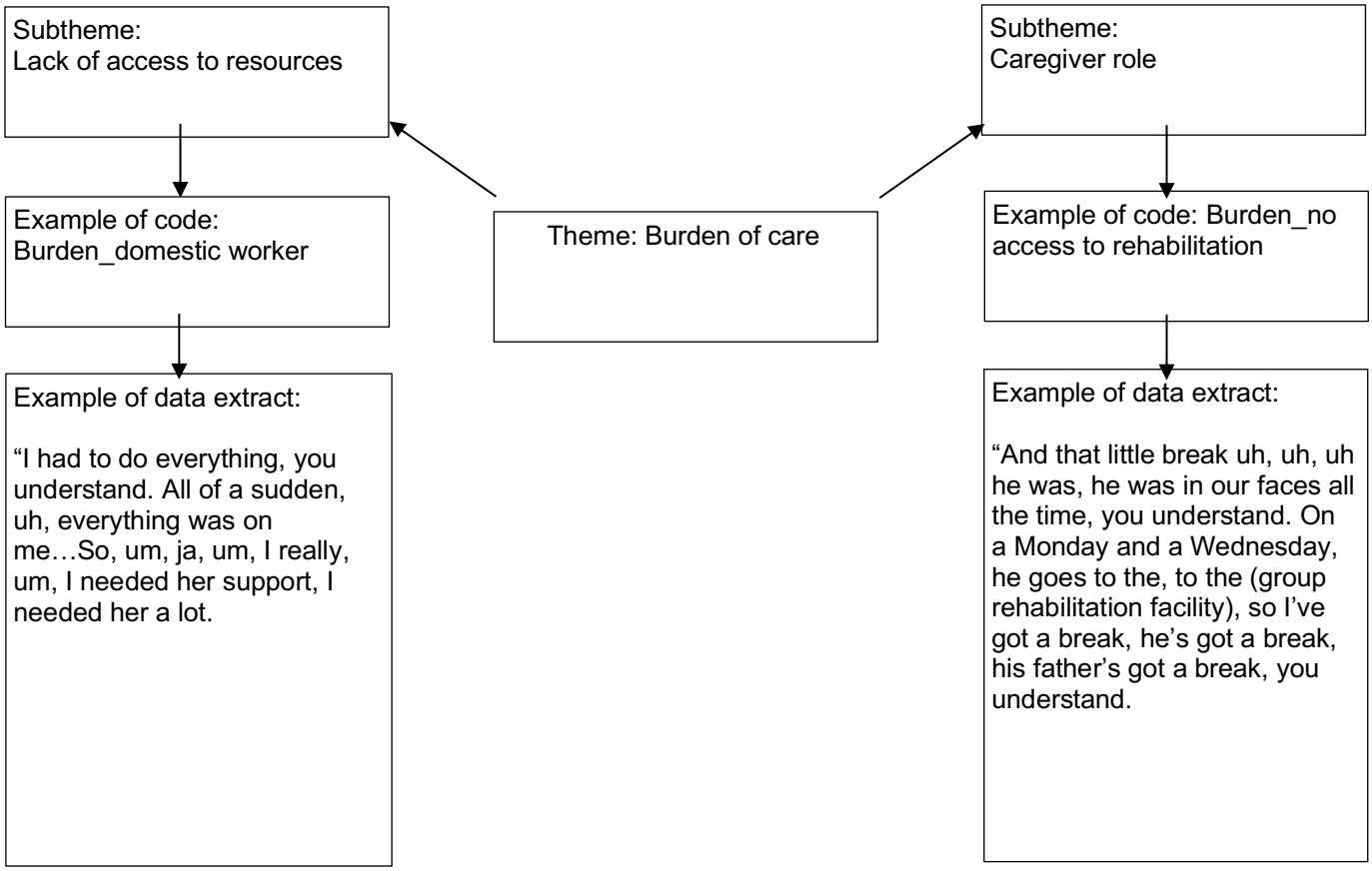
Recordings of participants' responses were transcribed verbatim and safely stored on a password protected laptop (2020). Thematic analysis, per the guidelines outlined by Braun and Clarke (2016), was conducted. Open, inductive coding of data was completed with the aid of ATLAS.ti 9 (Soratto et al., 2020) as outlined in Table 2. In utilising Computer Assisted Qualitative Data Analysis Software (CAQDAS), data management security was increased and the risk for human error was eliminated (Soratto et al., 2020). Codes were organised to develop a theme framework using thematic networks in the form of mind maps as per Figure 1 (Attride-Stirling, 2001). In conjunction with the researcher, another qualified speech-language therapist (SLT) perused 20% of the data to confirm accuracy and appropriate coding, thus ensuring the trustworthiness of the data (Brink et al., 2018).

Table 2: An example of coding used in data analysis

Code	**Example of data extract**
Burden_family	"…Not be able to go to my family and, uh, just kuier you know, be functional…That was, that very bad. It's not the same when you phone somebody" (P3)
IC support_social media platforms	"OK with church we decided um we're doing online but with our church because there are a lot of old people it was only the recordings on WhatsApp…" (P1) It,it,it's only the psychiatrist that we, um, we was able to do Skype. (P3)

Key:
IC - In COVID-19

Figure 1: An example of thematic network used in data analysis



2.7. Ethical considerations

Institutional ethical clearance was obtained (number: HUM035/0121) prior to commencing with data-collection. Signed informed consent was requested from all participants prior to data collection and participants' identities were kept confidential.

3. Findings

Four main themes and 10 sub-themes emerged according to the aim of this study (Table 3) and reflected participants' experiences regarding their role, day-to-day life and views regarding support throughout the varying levels of lockdown during the COVID-19 pandemic.

Table 3: Themes and sub-themes

Theme	**Sub-theme**
Burden of care	Emotional and financial strain
	Increased role as caregiver
Day-to-day living	Lack of face-to-face interaction
	"No escape"/outlets
The emerging role of technology and support	Platforms
	Source of support in COVID
Positive outcomes, feelings and attitudes	Improved role
	Relationships
	Emotions as restrictions eased
	Needs in future times of crisis

3.1. Burden of care

All participants (n=7) experienced additional physical, financial, emotional, and/or social difficulties in acting as a caregiver during the ongoing COVID-19 pandemic – more so than before the pandemic. The following sub-themes arose:

3.1.1. Emotional and financial strain

Prior to the COVID-19 outbreak, all participants relied on support structures which comprised rehabilitation services (n=7), group rehabilitation services (n=6), and/or domestic workers (n=2). All

participants indicated that a lack of access to both formal and informal rehabilitation services for their loved ones during the lockdown put strain on their emotional well-being, as these services were also a source of support. Six participants stated that these services had previously helped with the regulation of their loved one's emotions and behaviour, while fulfilling their social needs as described by the following statements:

"…he gets irritated very fast… you don't know what to do" (P7)

"I felt very sorry for him…Um, the people described (son) at (group rehabilitation facility) completely different person…This (son) at my house, it's a different (son)." (P5)

The remaining participant (n=1) reported that the closure of group rehabilitation services did not further exacerbate the burden of care. Although this SO expressed that she is "…so happy taking (daughter) to (group rehabilitation facility) …" (P2).

Three out of seven participants indicated that when their loved one with a TBI attended rehabilitation activities, they had time to focus on their own day-to-day activities and needs, as supported by the following statements:

"I mean I could, um, keep (son) busy on Monday and Wednesday (days of group rehabilitation) …So he was around 24/7 and that was frustrating…His father picked a fight with him and irritate each other cause [because] it was frustrating…" (P3)

"Well, I suppose I sleep while he's there. Because with MS [multiple sclerosis] you get very tired…So I do the things that I need to do for myself…It gives me a chance to rest…" (P4)

"And that little break uh he was, he was in our faces all the time, you understand. On a Monday and a Wednesday, he goes to the (group rehabilitation facility), so I've got a break, he's got a break, his

father's got a break. Now …we were in each other's faces all the time. And I must say the sparks sometimes flew" (P5).

Lockdown affected two participants' financial support systems as businesses were forced to shut down. One participant stated "…it actually affected us financially because that money that I receive once in a while it brings so much change in the house..." (P1).

As restrictions eased, all participants were relieved to have their support networks return again, with one participant expressing that "at least everything's easier." (P2)

3.1.2. Increased role as caregiver

Restricted access to rehabilitation services caused most participants (n=6) to experience additional stress in respect of their loved one's functioning, as well as their treatment goals and progress. Participants were unable to access services such as physiotherapy, optometry, and/or speech-language therapy services, resulting in a decline in their loved ones' behaviour, concentration, memory and problem-solving abilities. A decline in loved ones' speech abilities was noted by two participants. One participant expressed "the speech was a little bit affected than before [COVID-19 pandemic] (P1)" and another participant said her loved one's speech "het lui geraak" [Afrikaans phrase – local language, meaning "became lazy"] and he began to "mompel" [meaning "mumble"] again (p3).

Prior to lockdown, two participants felt supported through permanently employed domestic workers who also acted as an additional caregiver for their loved one with a TBI. Government-mandated restrictions during the initial level 5 lockdown prevented access to domestic workers. For one participant (P6), restrictions did not allow for the hiring of a home care nurse, as interprovincial travel was banned at this time. Participant 5 felt her domestic worker's absence by the following statements:

“I was not in a really good space in that period of time. I felt I was just working the whole day…I was just busy cleaning, …It was just a continuous role of being busy…I needed her [domestic worker] support, I needed her a lot.” (P5)

Participant 5 additionally stated that her domestic worker’s absence had an effect on the participant’s husband with a TBI who thrives on routine, as is attested to in the following:

“… (domestic worker) comes in at a certain time every day and, um, and she leaves at a certain time going back home… So, the big challenge for us was actually because we were also out of a daily routine, it also affected him (SO)…So that was basically the big thing.” (P5)

Participant 5 indicated that, she experienced an overwhelming sense of “relief” once care workers for people with disabilities became an essential service..

Four out of seven participants reported an exacerbated role as caregiver during the lockdown period. P3 and P5 had to take extra care of their loved one’s emotional, psycho-social and physical well-being; as well as having to constantly keep their loved one occupied. P4 indicated that although her physical role did not change, she worried more about her loved one with TBI than before. P7 reported that her loved one had short-term memory difficulties, as well as a disordered concept of time, requiring constant reassurance and attention. Her role in assisting with these difficulties placed additional strain on her, as seen in the following quote:

“It's still becomes quite frustrating to answer the same questions…many times um in a day. But, um, during the lockdown, I, I think it was worse...” (P7)

Three out of seven participants experienced additional health complications during the period of the COVID-19 pandemic, adding to their stress and emotional well-being. Two participants indicated that their loved one with a TBI acted as their caregiver during their illnesses, reducing the burden of care

at that time. P4, however, reported that her own health condition caused fatigue. The remaining participant indicated that her loved one with a TBI did not require specific care, before or during the pandemic.

3.2. Day-to-day living

Six out of seven participants experienced a negative change in their activities of daily living (ADLs) as a result of the varying lockdown levels in 2020/ 2021.

3.2.1. Lack of face-to-face interaction

Most participants reported that face-to-face interaction comprised the major element of their support system. Being unable to access this support during the lockdown had negative effects on five participants.

"…there were times where I would feel so lonely… there were those times where I feel like I just need to cry a little bit then I will feel better…" (P1)

Four participants indicated that family was a source of support and it was difficult to not see them during the lockdown, as described below:

"…not be able to go to my family…and uh just *kuier* [Afrikaans phrase – local language, meaning "visit"] you know, be functional…. That was, that very bad. It's not the same when you phone somebody." (P3)

Three participants were unable to rely on their friends as a support structure. As restrictions eased, these participants were able to be supported again:

"I think because divorced and I'm alone. Um, it's nice to have somebody just give you a hug… and then I have that." (P6)

One participant reported that she felt sufficiently supported throughout the pandemic, as she lived with family (husband and daughters) whom she described as giving her “much support” (P2).

Most participants indicated a change in their loved one’s functioning or behaviour during the lockdown. This affected either their social (n=4), work (n=3), relaxation (n=3), and/or community life (n=3), as well as their emotional well-being (n=3), as seen in the following quotes:

“How did affect your relaxation, your community life…?” (Interviewer)
“A lot because…. my friends would come and say ag on the spur of the moment, let’s go to the Kruger National Park for the weekend. If it wasn’t for (son), I can do it…There must always be somebody to take care of (son), I must always ask my domestic worker, will you be here the weekend for me…it definitely affects my my husband and our social um um way of living. I sometimes get angry.” (P5)

“I actually realised also with lockdown is how draining it can be, um, being around a person with a brain injury, 24/7. …And the frustration of him being…passive the whole time and not doing things…it's frustrating…” (P7)

One participant (P1) revealed that due to the nature of the lockdown restrictions, particularly that of the initial lockdown, she was able to prioritise rest and relaxation, which helped her in her role as a caregiver.

3.2.2. “No escape”/outlets

Six participants reported that when their loved one attended a group rehabilitation facility, they were provided with a break in their role of caregiver. These participants used this time to relax, rest, perform household chores, and other activities that were important to them. During various levels of

the lockdown these facilities were closed, making it difficult to take a break as a caregiver. Participant 4 described this experience as her “freedom was gone”.

Prior to COVID-19, one participant explained that she and her husband went on vacation as an outlet to cope with their caregiver roles. P5 also revealed that she used to go on vacation to support her well-being. Two participants revealed that their occupation was a source of escape, with one participant describing her job as one of her “saving graces” (P6). The lockdown restrictions precluded the typical continuation of these activities.

3.3. Emerging role of technology as a form of support

3.3.1. Platforms

Prior to the start of the pandemic, participants were able to access various social media platforms as a form of support, namely Skype, Zoom, Facebook, WhatsApp, television and telephonic counselling. As the pandemic progressed, all participants reported that social media provided an increased level of either formal or informal support as other support structures waned due to the restrictions.

3.3.2. Sources of support during COVID-19 pandemic

Online family counselling services offered through holistic rehabilitative interventions were described as a support structure by four participants. Counselling with a social worker and SLT were provided in the form of multimedia. P7 emphasised that “it was good to speak to them and to know that they're all still there”. P6 continued with her telephonic trauma counselling sessions. P3 reported that although her family counselling group was unable to meet, Zoom was a platform that was utilised as an alternative. Although this helped “a little”, P3 reported that this was not the same as an in-person session. P2 reported that because of social media, her loved one was able to stay in contact with her group rehabilitation facility, resulting in no decline in function and no concern to the participant regarding extra burden of care or acquiring the virus, as seen in the following:

“Do you think it would have been better for (daughter) to have physically gone into (group rehabilitation facility)?” (Interviewer)

“I think social media was enough for her because going to (group rehabilitation facility). You were afraid of this COVID. We don't know where…to catch it…Using social media is the best because you are in the house.” (P3)

Three participants felt a sense of support from family and friends, via WhatsApp. Two participants relied on Facebook support groups for both information and support, and could continue throughout the pandemic. One participant indicated that social media allowed them to stay updated and informed regarding the COVID-19 pandemic.

Four participants described their faith and faith-based community as pillars of support. In response to the closure of faith-based facilities, two participants turned to online services, television services and social media:

“OK with church…it was only the recordings on WhatsApp so it was just not a normal online service where we will be able to see other people… my husband likes um likes most of the preachers on TV so for him it was church always.” (P1)

3.3.3. Continuing presence of social media in clinical practice

All participants stated that they would have liked to have received support through family counselling and were open to online platforms. One participant effectively received trauma counselling electronically. Participant 2 described that, although her loved one could not physically attend rehabilitation services, social media countered her potential decline in function:

“And do you think that social media will still offer her the services that she needs to help with her difficulties?” (Interviewer)

"Ja [Afrikaans phrase – local language, meaning "yes"] I think so now." (P2)

3.4. Positive outcomes, feelings and attitudes as restrictions eased

3.4.1. Improved role

Two participants reported that through the hard lockdown period, as well as the subsequent varying levels, they were able to improve in their role as a caregiver. One participant described this improvement below:

"…being with him in the in the house for that period it was so amazing because it was only me and him in the house…so many things that I've learned during that that period…from my husband that I was not aware of." (P1)

P4 described that the hard lockdown had allowed her to rest more, resulting in her being able to more effectively fulfil her role as a caregiver.

3.4.2. Relationships

Three participants reported no change in their relationship as the focus of SO was coping during the pandemic. P6 did not comment on their relationship. The remaining three participants reported that the COVID-19 pandemic improved their relationship with their loved ones because of closeness, bonding and support brought about by the lockdown restrictions. "We were playing games. And bonding…Having fun." (P2)

3.4.3. Emotions as restrictions eased

All participants (n=7) expressed positive emotions as restrictions eased and they were able to access their support structures again. Participants described re-accessing this support using words such as: exciting, easier, wonderful, great. One participant cried "happy tears" (P3), while another described how good it felt to be able to hug her friends and family. Another participant stated that

"spirits were lifted and everything's better" (P7). Participant 5 described the return of her domestic worker as "that was the greatest moment when she walked through that door" (P5).

3.3.4. No effect

Two out of seven participants indicated that the pandemic had had little effect on their emotional well-being. They were either retired or medically boarded before the pandemic and spent most of their time at home.

3.3.5. Needs in future times of crisis

Participants' responses to how they, or any loved one of an individual with a TBI, could have been better supported during the pandemic (Table 4).

Table 4: Participant needs in times of crisis

Support needed	**Example**	**Total participants**
Support groups – formal	Family support groups	4
Support groups – informal	Contact with SOs in the same situation	4
Faith services	Church	2
Caregiver	Domestic worker In lockdown level 5	2
Access to group rehabilitation facilities for individuals with a TBI	For SO to have a break in caregiving	2
Access to psychological intervention	Trauma counselling	2
Support from health care professions (social worker and SLT)	Social work SLT	2
Friends and Family	For support and to provide a break in caregiving	2
Facility for SO with a TBI	A group home	1
Rehabilitation services	Physiotherapy	1

Two participants pleaded that in future times of crisis, or global emergencies, it would be important for faith-based activities to be allowed to continue as a source of support. Another two participants

implored that domestic and other home-based help should be included as essential work, to assist in alleviating increased caregiver burden.

4. Discussion

When support structures for SOs of individuals with a TBI are in place, the burden of care is reduced and bearable, in line with previous literature (Broodryk, 2014; Pielmaier et al., 2012). During the ongoing COVID-19 pandemic, many support structures were banned or restricted, with challenging consequences. Although minimal access to formal rehabilitation services was offered to individuals with TBI, support structures were restricted for their SOs. SOs expressed a need for support services to continue during trying times of the pandemic. This finding is consistent with current research, which explored negative consequences experienced by caregivers unable to receive support during the pandemic (Sutter-Leve et al., 2021). These negative effects yield potential to advocate for support services in future times of crises.

The roles of SOs are shared worldwide, but with differing levels of restrictions imposed by different countries. African countries had a poor response to provision of rehabilitative care during initial phases of the pandemic (Lugo Agudelo et al., 2022), impacting the extent to which SOs felt unsupported. Local restrictions increased the burden of care of SOs, and impacted emotional and financial well-being and relationships, which concurs with other research (Gutenbrubber et al., 2020).

By limiting rehabilitation services available to TBI survivors, a decline in functioning was observed by some SOs. Not only does this have a discouraging and emotional toll on SOs, but may contribute to an increased caregiver role as SOs provided additional support in ADLs. Alleviating caregiver burden improves the well-being of both the SO and individual with a TBI (Gallagher & Wetherell, 2020).

Confinement to one's house further exacerbated strain on caregivers. The link between good caregiver support and reduced caregiver burden is well-documented (Hanson et al., 2019; Manskow et al., 2017; Stevens et al., 2015). Some outlets described by SOs, such as vacation and work, were halted due to lockdown regulations, which contributed to fatigue and hindered their ability to emotional, personal and stress-related fallout. Caregivers of individuals with disabilities need breaks for practices such as self-care to rejuvenate and effectively perform their role (Washington et al., 2021).

Personal negative responses to the COVID-19 pandemic, thus, cannot be discounted. Taylor et al. (2022, p. 27) described "pandemic fatigue", which aggravated mental health and, in turn, caregiver fatigue. This study confirms the importance of contingency planning to establish active and ongoing support for SOs, especially during times of crises.

The current study found that external assistance from care workers, specifically domestic workers locally, provides much needed assistance, support and peace of mind for SOs, in line with international research (Hand in Hand, 2021). Lack of such assistance appears to have detracted the primary focus of SOs from offering support to their loved one with a TBI to tending to household chores, responsibilities and overall day-to-day living. As the lockdown progressed, local government allowed caregivers of those with disability to return to their occupational duties (Schoeman Lawn Inc, 2020). Some SOs expressed relief when domestic workers returned following easing of restrictions. It is important to advocate for domestic services to be unrestricted in future times of crisis to reduce caregiver burden.

The overarching restrictions resulted in an increase in social media use and technology, which is commonly used to bridge interpersonal isolation (Whiting & Williams, 2013). This emerged as a standard practice in the world of healthcare (Monaghesh & Hajizadeh, 2020). Support, in the form of telephonic counselling services and social media support groups used prior to the pandemic, was able to continue throughout the pandemic. Face to face support was not able to continue, with

deleterious consequences. Subsequent to the lockdown, telephonic counselling was found to provide effective emotional and psychological support (Barker & Barker, 2020). SOs were likewise unable to take individual time when their loved ones would have been at rehabilitation or therapy. An implication of the study is to consider online rehabilitation service offerings as a support, both for those with TBI, as well as for SOs. Such services are already readily available in higher income countries such as the United States of America [USA] (Suntai et al., 2021). In future, tele-intervention may be considered, in isolation, or as an adjunct to in-person interventions. Online platforms and the use of technology are not accessible to all individuals in settings similar to South Africa's socio-economic circumstances (Monzon, 2022). It is important for SLTs and other healthcare professionals to advocate for access to connectivity in communities of a lower SES in unprecedented crises, as well as for those who cannot access face-to-face services beyond the pandemic.

Caregiver support groups provide an unmatched support system for SOs of individuals with TBI. Online support services may provide a solution to improving the frequency of, and access to, such services. In the USA, online support during the pandemic was well-received by caregivers (Mystic Valley Elder Servives, 2022). This correlates with findings in the present study revealing SO's positive experiences with online platforms. It would be necessary to explore the effectiveness of online platforms within rehabilitation in South Africa before advocating for online services as standard practice, and further research is necessary.

We cannot discount the role SLTs have in counselling (Nash et al., 2021). However, SLTs' collaboration with other mental health professionals may be necessary for the overall success of holistic, family-centered intervention. Taking into account the ever-growing use of counselling services online, telephonically and through other multi- and social media channels, SLTs can, and should, promote the use of technology in intervention (Nash et al., 2021).

The study shows that females mainly assumed the role of primary caregiver to their loved ones with TBI, in line with global literature (Swinkels et al., 2017). Women typically perform the role of

caregiver, with many, additionally, being breadwinners in South Africa (Parry & Segalo, 2017). Acting as caregivers during the pandemic may have also increased financial pressure on households. One study found that women are more vulnerable than men to negative effects and fears of the pandemic (Sandín et al., 2020). Timeous and appropriate psychological and financial referrals should be standard practice for healthcare professionals when working with SOs of people with TBI.

Despite negative consequences experienced by SOs as a result of interruption of support services, the findings of the study show that the pandemic resulted in other needs being fulfilled, as in line with international literature (Sandín et al., 2020; Schmiedeberg & Thönnissen, 2021). Families may have experienced closeness and a reminder of their ongoing resilience. This intimacy delivered a deeper understanding of loved ones with TBI's needs, beyond merely needs relating to their medical conditions. This enabled SOs to reconnect with loved ones on a personal level and to come to appreciate personal, social, and emotional desires beyond the brain injury. Positive outcomes assisted in counteracting negative experiences brought about as a result of the lockdown restrictions and were viewed as beneficial by all SOs during this time (Schmiedeberg & Thönnissen, 2021). The study also revealed that negative effects of the pandemic outweighed these positive outcomes. The current study only explored the perceptions of a limited number of individuals and, therefore, it would be important to research whether similar feelings are experienced by individuals from different SES.

An SLT's scope of practice extends beyond providing rehabilitation services to clients. Evidence continues to emerge that caregivers remain the active agent of change in the progress and prognosis of therapeutic outcomes (ASHA, 2016). Communicative disorders, especially in individuals with TBI, affect the entire family system (Cheklin et al., 2018). Person-centered care, therefore, must extend to the individual's environment and surroundings, including family members. Optimal success and carryover in the rehabilitation journey of an individual with a TBI can be ensured if their SOs feel supported. The physical and psychosocial health and well-being of a SO correlates with their involvement in their loved one's rehabilitative journey (Gallagher &

Wetherell, 2020). Healthcare providers need to consider these emotional and psychosocial changes when individuals with TBI and their SOs re-enter rehabilitative services, and adapt their interventions accordingly (Fama et al., 2021). This is in line with Kolcaba's Comfort Theory, stating that the experience of care for individuals with disability and their SOs lies on relief, ease and transcendence in domains such as their environment (Timothea, 2020). It is vital for healthcare professionals to utilise this model during times of crisis to promote optimal therapeutic outcomes.

As restrictions have eased, some SOs reported an influx of positive emotions related to their caregiver role, such as relief, determination, excitement and care, as a result of a return to previous support services. It is, therefore, vital for healthcare providers to advocate for access and continuity of both formal and informal support structures for overall health of SOs of individuals of a TBI during unprecedented disruptions, such as the COVID-19 pandemic.

5. Limitations

South Africa has 11 official languages. The use of a qualified interpreter may assist in exploring a wider profile of South Africa's diverse population. Another limitation may be that due to lockdown restrictions, no face-to-face interviews were conducted, limiting the diversity of the sample. The sample size only included females and those with digital access, further limiting sample diversity such as excluding those of a lower SES.

6. Conclusion

The lack of support structures for SOs of individuals with a TBI during the pandemic resulted in increased caregiver burden, stress, financial strain, emotional distress, and breakdowns in relationships. The emerging role of technology in support is promising to counter these negative effects – both in terms of support and rehabilitative services. Access to, and continuity of, support structures and services are vital for the well-being of SOs of individuals with a TBI, particularly during times of crisis such as the global COVID-19 pandemic.

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CHAPTER 4: IMPLICATIONS AND CONCLUSIONS

The aim of this final chapter is to provide a summary of the most important results and explain the central findings of this study. Clinical and theoretical implications, strengths and limitations of the study and recommendations for future research are discussed.

4.1. Summary of results

Four main themes and 12 sub-themes emerged according to the aim of this study (Table 4).

Table 4

Themes and sub-themes

Theme	Sub-theme
Burden of care	Emotional and financial strain
	Increased role as caregiver
Day-to-day living	Lack of face-to-face interaction
	"No escape"/outlets
The emerging role of technology and support	Platforms
	Source of support in COVID
	Continuing presence of social media in clinical practice
	Improved role
Positive outcomes, feelings and attitudes	Relationships
	Emotions as restrictions eased
	No effect
	Needs in future times of crisis

These themes and sub-themes reflected participants' experiences regarding their role, day-to-day life and views regarding support throughout the varying levels of lockdown during the COVID-19 pandemic. All aspects explored in the themes related to informal and formal support experienced by SOs.

4.2. Theoretical and clinical implications

When support structures for SOs of individuals with a TBI are in place, the burden of care was reduced and bearable, in line with previous literature (Broodryk, 2014; Pielmaier et al., 2012). During the ongoing COVID-19 pandemic, many support structures were banned or restricted, with challenging consequences. Although minimal access to formal rehabilitation services was offered to individuals with TBI, support structures were restricted for their SOs. SOs expressed a need for support services to continue during trying times of the pandemic. This finding is consistent with current research, which explored negative consequences experienced by caregivers unable to receive support during the pandemic (Sutter-Leve et al., 2021). These negative effects yield potential to advocate for support services in future times of crises.

The roles of SOs are shared worldwide, but with differing levels of restrictions imposed by different countries. African countries had a poor response to provision of rehabilitative care during initial phases of the pandemic (Lugo Agudelo et al., 2022), impacting the extent to which SOs felt unsupported. Local restrictions increased the burden of care of SOs, and impacted emotional and financial well-being and relationships, which concurs with previous research (Gutenbrubber et al., 2020).

By limiting rehabilitation services available to TBI survivors, a decline in functioning was observed by some SOs. Not only does this have a discouraging and emotional toll on SOs, but may contribute to an increased caregiver role as SOs needed to provide additional support in ADLs. Alleviating caregiver burden improves the well-being of both the SOs and person with a TBI (Gallagher & Wetherell, 2020). SLTs and other therapeutic support services therefore need to adapt service provision protocols, aiming to provide more support services online and through social media platforms where available. Therefore, adopting a hybrid approach of face-to-face and online support, as in line with research by Miao et al. (2022), is recommended to ensure caregiver well-being, and in turn, the success of the rehabilitation process.

Confinement to one's house further exacerbated additional strain on caregivers. The link between good caregiver support and reduced caregiver burden is well-documented (Hanson et al., 2019; Manskow et al., 2017; Stevens et al., 2015). SOs described individualised outlets to escape from their day-to-day roles and other caregiver-related responsibilities. Some outlets, such as vacation and work, were halted due to lockdown regulations. Participants described lockdown regulations as a contributor to their fatigue by restricting sources of escape required to restore emotional, personal and stress-related fallout. Caregivers of individuals with disabilities need breaks for practices such as self-care to rejuvenate and effectively perform their role (Washington et al., 2021).

Personal negative responses to the COVID-19 pandemic cannot be discounted. Taylor et al. (2022, p. 27) described "pandemic fatigue", which aggravated mental health and, in turn, caregiver fatigue. This study explored the possibility of fatigue in future pandemics, confirming the importance of contingency planning to establish active and ongoing support for SOs. Such a plan may include supporting caregivers using interdisciplinary approaches with mental health professionals, as well as support groups within communities – physically where available, online or a hybrid of both.

The current study found external assistance offered by caregivers, specifically domestic workers locally, provides much needed assistance, support and peace of mind for SOs, in line with international research (Hand in Hand, 2021). Lack of such assistance appears to have detracted the primary focus of SOs from offering support to their loved one with a TBI to tending to household chores, responsibilities and overall day-to-day living. As the lockdown progressed, the South African Government allowed caregivers of those with disability to return to their occupational duties (Schoeman Lawn Inc, 2020). Some SOs expressed relief when domestic workers returned following easing of restrictions. It is important to advocate for domestic services to be unrestricted in future times of crisis to reduce caregiver burden.

The overarching restrictions resulted in an increase in social media use and technology, which is commonly used to bridge interpersonal isolation (Whiting & Williams, 2013). This emerged as a

standard practice in the world of healthcare during the COVID-19 pandemic (Monaghesh & Hajizadeh, 2020). Support, in the form of telephonic counselling services and social media support groups used prior to the pandemic, was able to continue throughout the pandemic. Face-to-face support was not able to continue, with deleterious consequences. Subsequent to the lockdown, telephonic counselling was found to provide effective emotional and psychological support (Barker & Barker, 2020). SOs were likewise unable to take individual time when their loved ones would have been at rehabilitation or therapy. An implication of the study is to consider online rehabilitation service offerings as a support both for those with TBI as well as SOs. Such services are already available in higher income countries such as the United States of America [USA] (Suntai et al., 2021). In future, tele-intervention may be considered, in isolation or as an adjunct to in-person interventions. Online platforms and the use of technology are not accessible to all individuals in the context of South Africa's socio-economic circumstances (Monzon, 2022). This is important to explore for SLTs and other healthcare professionals to advocate for access to connectivity in communities of a lower SES in unprecedented crisis times, as well as for those who cannot access face-to-face services beyond the pandemic. It is also important to establish and expand upon existing support services within the community, especially those of a lower SES.

Caregiver support groups provide an unmatched support system for SOs of individuals with TBI. Online support services may provide a solution to improving the frequency of, and access to, such services, contributing to an overall feeling of support for SOs in circumstances where movement of people is restricted, such as during a lockdown. In the USA, online support during the pandemic was well-received by caregivers (Mystic Valley Elder Servives, 2022). This correlates with findings in the present study revealing SO's positive experiences with online platforms. It would be necessary to explore the effectiveness of online platforms within rehabilitation in settings like South Africa before advocating for online services as standard practice and further research is thus warranted.

We cannot discount the role SLTs have in counselling for both our clients and their loved ones (Nash et al., 2021), but it is important to remember where SLTs reach the limit of their scope of practice.

Timeous referrals to relevant healthcare professionals are vital for the overall success of holistic, family-centred intervention. Taking into account the ever-growing use of counselling services online, telephonically and through other multi- and social media channels, SLTs can and should promote the use of technology, or a hybrid approach in intervention. Caregiver wellness needed to be integrated into the rehabilitation plan, highlighting the need for interprofessional collaboration with mental health professionals. With emerging research on quantitative scales such as the TBI-CareQOL, healthcare professions can and should conduct regular screening of the significant others of their clients with a TBI (Carlozzi et al., 2022).

The study shows that females mainly assumed the role of primary caregiver to their loved ones with TBI, in line with global literature (Swinkels et al., 2017). Women typically perform the role of caregiver, with many additionally being breadwinners in the local context (Parry & Segalo, 2017). Acting as caregivers during the pandemic may have also increased financial pressure on households. One study found that women are more vulnerable than men to negative effects and fears of the pandemic (Sandín et al., 2020). Timeous and appropriate psychological and financial referrals should be standard practice for healthcare professionals locally when working with SOs of people with TBI.

Despite negative consequences experienced by SOs as a result of interruption of support services, the findings of the study show that the pandemic resulted in other needs being fulfilled, as in line with international literature (Sandín et al., 2020; Schmiedeberg & Thönnissen, 2021). Families may have experienced closeness and a reminder of their ongoing resilience. This intimacy delivered a deeper understanding of loved ones' needs, beyond merely needs relating to their medical conditions. This enabled SOs to reconnect with loved ones on a personal level and come to appreciate personal, social, and emotional desires beyond the brain injury. Positive outcomes assisted in counteracting negative experiences brought about as a result of the lockdown restrictions and were viewed as beneficial by all SOs during this time (Schmiedeberg & Thönnissen, 2021). As healthcare professionals, is important to encourage resilience by identifying positive behaviours in

SOs and communicate this during counselling sessions (Carlozzi et al., 2022). The above-mentioned study also revealed that negative effects of the pandemic outweighed these positive outcomes. The current study only explored the perceptions of a limited number of individuals and therefore it would be important to research whether similar feelings are experienced by individuals from different SES.

An SLT's scope of practice extends beyond providing rehabilitation services to clients. Evidence continues to emerge that caregivers remain the active agent of change in the progress and prognosis of therapeutic outcomes (ASHA, 2016). Communicative disorders, especially in individuals with TBI, affect the entire family system (Cheklin et al., 2018). Person-centred care therefore must extend to the individual's environment and surroundings, including family members. Optimal success and carryover in the rehabilitation journey of an individual with a TBI can be ensured if their SOs feel supported. The physical and psychosocial health and well-being of a SO correlates with their involvement in their loved one's rehabilitative journey (Gallagher & Wetherell, 2020). Healthcare providers need to consider these emotional and psychosocial changes when individuals with TBI and their SOs re-enter rehabilitative services, and adapt their interventions accordingly (Fama et al., 2021). This is in line with Kolcaba's Comfort Theory, stating that the experience of care for individuals with disability and their SOs lies on relief, ease and transcendence in domains such as their environment (Timothea, 2020). It is vital for healthcare professionals to utilise this model during times of crisis to promote optimal therapeutic outcomes.

As restrictions have eased, some SOs reported an influx of positive emotions related to their caregiver role, such as relief, determination, excitement and care, as a result of a return to previous support services. It is therefore vital for healthcare providers to advocate for access and continuity of both formal and informal support structures for overall health of SOs of individuals of a TBI during unprecedented disruptions such as the COVID-19 pandemic.

4.3. Strengths and limitations

South Africa has 11 official languages and findings may have been limited due to the data-collection occurring in English only. The use of a qualified interpreter may assist in exploring a wider profile of South Africa's diverse population. Although research suggests that females are more likely to be caregivers, the lack of male participants reduces the diversity of the sample (Swinkels et al., 2017). Another limitation may be that due to lockdown restrictions, no face-to-face interviews were conducted, only those with access to technology were interviewed. This further limits the diversity of the sample by excluding those of a lower SES who may have access to fewer resources than the individuals interviewed. In utilising a Computer Assisted Qualitative Data Analysis Software, data management security was increased and the risk of human error was reduced. (Soratto et al., 2020). Although subjectivity and bias is always present in qualitative research, using a second rater, particularly that of an SLT, contributed to trustworthiness and reduction in subjectivity (Cheung & Tai, 2021).

4.4. Recommendations for future research

This study provides emerging evidence and a starting point for further research to take place. These findings can be compared to similar studies of other pathologies, such as studies involving SOs of individuals with stroke or neurodegenerative disorders such as Parkinson's, to determine whether the need for support is unique to, or shared across, SOs of individuals with TBI. Future research can focus on males as SOs of individuals with TBI, to compare the similarities or differences relative to the experiences of the females in this study. It would be insightful to explore the thoughts and feelings of SOs of individuals with a TBI abroad, specifically in first world countries, to establish methodologies which could be implemented in South Africa, to provide better support structures in this country.

4.5. Conclusion

The lack of support structures for SOs of individuals with a TBI during the pandemic resulted in increased caregiver burden, stress, financial strain, emotional distress, and breakdowns in relationships. The emerging role of technology in support is promising to counter these negative effects – both in terms of support and rehabilitative services. Collaboration of therapeutic support services and mental health professionals are vital to the success, buy-in and carry over of the rehabilitation progress. Access to and continuity of support structures and services are vital for the well-being of SOs of individuals with a TBI, particularly during times of crisis such as the global COVID-19 pandemic.

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APPENDICES

Appendix A: Ethical clearance letter: Faculty of Humanities Research Ethics Committee

18 May 2021

Dear Miss KE van Coeverden de Groot

Project Title:	Experiences of significant others of people with traumatic brain injury during the COVID-19 pandemic
Researcher:	Miss KE van Coeverden de Groot
Supervisor(s):	Dr E Krüger Mrs SB Pillay
Department:	Speech Language Path and Aud
Reference number:	17092788 (HUM035/0121)
Degree:	Masters

I have pleasure in informing you that the above application was **approved** by the Research Ethics Committee on 18 May 2021. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project.

Sincerely,

Prof Innocent Pikirayi
Deputy Dean: Postgraduate Studies and Research Ethics
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: PGHumanities@up.ac.za

Appendix B: Information leaflet and informed consent document

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Faculty of Humanities
Fakulteit Geesteswetenskappe
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Department of Speech-Language Pathology and Audiology

Information leaflet and informed consent document

Dear Prospective Participant

1) Introduction

You are invited to volunteer for a research study entitled: Experiences of significant others of people with traumatic brain injury during the COVID-19 pandemic. I am doing this research as part of my Master's degree in Speech-Language Pathology, at the University of Pretoria. The information in this document is given to help you to decide if you would like to participate or not. Before you agree to take part in this study, you should fully understand what is involved. If you have any questions, which are not fully explained in this document, you can ask the researcher. You should not agree to take part unless you are completely happy with the kind of questions that will be asked.

2) The nature and purpose of this study

The aim of this study is to find out what significant others of people with traumatic brain injury (TBI) think about the support given during the COVID-19 pandemic and what significant others think is important to consider when caring for and living with individuals with TBI and the main needs for support. The results can be used to improve services for significant others during times of crisis or other future pandemic like situations.

3) Explanation of procedures and what will be expected from participants

This study will ask about your experiences as a significant other of a person with TBI and what you think about the support that you were given during this COVID-19 pandemic in 2020 and 2021 in South Africa. I would like you to please participate in this interview. It will take approximately 60 minutes to complete. If you do not understand any questions or topics during the interview, you may ask me for clarification.

I will keep the notes and recording of the interview in a safe place to make sure that only people working on the study will have access to them. If you use names in the interview, I will provide an

alias or code in the transcribing process as well as when I present the results and answers you gave in the interview.

The interview contains two parts:

Part 1: Personal information which involves answering some questions about yourself and your significant other.

Part 2: A discussion with me about your experience as a significant other of a person with TBI and what you think about the support you were given or had during the COVID-19 pandemic in 2020 and 2021 in South Africa.

4) Risk and discomfort involved

There are no likely physical discomforts or risks involved if you participate in this study. If you experience any discomfort, please let me know. If the information you give brings feelings of distress or other emotions and you would like to speak to a professional, a referral letter will be given to you with a list of possible counsellors. The interview will take an hour of your time, but you may take a break if you become tired. The interview will be on a video-conferencing online platform like Zoom, WhatsApp call, or any other platform that you are happy and comfortable with. You will be given R50, to reimburse the data that the interview will use, by loading the data directly on your phone.

5) Possible benefits of the study

The study aims to learn about positive healthcare effects that may help the consequences of future outbreaks or other global emergencies so that people living with a TBI and other groups of people living with disabilities, as well as their significant others feel supported and included.

6) Ethical approval

This study has been given ethical approval from the Speech-Language Pathology and Audiology Departmental Research Committee, University of Pretoria and written approval will be given by that committee. The study has been submitted for ethical approval at the Faculty of Humanities Research Ethics Committee for their approval.

7) Information

If you have any questions concerning this study, you may contact me (katherinevcdegroot@gmail.com) or my research supervisors: Mrs Pillay (bhavani.pillay@up.ac.za) or Dr Krüger (esedra.kruger@up.ac.za).

8) Confidentiality

No identifying information such as your name will be used as alphanumeric codes (e.g., P01) will be used instead. This code will be used throughout the recording of the interview, the analysis of the data collected and the results. The answers and results will only be accessible to the research team, and safely stored at the University of Pretoria on a password protected Google Drive for 15 years. Results of this study may be used in future research, where strict confidentially will be maintained.

9) Compensation

You will be reimbursed for the data spent sharing your views with me. Data to the value of R50 will be provided to you to compensate for the cost of the interview.

Thank you for your time.

SIGNATURE OF RESEARCHER:

Miss Katherine Van Coeverden de Groot (0848801995)

SIGNATURES OF SUPERVISORS:

.

Mrs Bhavani Pillay

Supervisor

.

Dr Esedra Krüger

Co-supervisor

.

Prof Jeannie Van der Linde

Head of Department: Speech-Language Pathology and Audiology

CONSENT TO PARTICIPATE IN THIS STUDY

I confirm that the person asking for my consent to take part in this study (Experiences of significant others of people with traumatic brain injury during the COVID-19 pandemic) has told me about the nature and process, any risks or discomforts, and the benefits of the study.
I have also received, read, and understood the above written information about the study.

I have had enough time to ask questions and I have no objections to participate in this study.

I am aware that the information obtained in the study, including personal details, will remain confidential in collection data and presenting results.

I understand that I will not be punished in any way if wish to stop the interview and my this will not affect my current or future employment status.

I am participating willingly, and I can stop at any time.

I have been given a signed copy of this informed consent agreement.

I am aware that the information gathered from this study may be used for future research purposes.

Can we use this data in future research? Please make an 'X' over the box you wish to choose.

YES	NO

_____ _____

Participant's name (please print) Date

_____

Participant's signature

_____ _____

Researcher's name (please print) Date

_____

Researcher's signature

VERBAL INFORMED CONSENT

I, the undersigned, _____ have read and have explained fully to the participant, named _____, the participant informed consent document, which describes the nature and purpose of the study (Experiences of significant others of people with traumatic brain injury during the COVID-19 pandemic) in which I have asked the participant to participate. The explanation I have given has mentioned both the possible risks and benefits of the study. The participant indicated that he/she understands that he/she will be free to withdraw from the study at any time for any reason and without jeopardising his/her standard care. I hereby certify that the participant has agreed to participate in this study.

_____ _____

Participant's name (please print) Date

_____

Participant's signature

_____ _____

Researcher's name (please print) Date

_____

Researcher's signature

_____ _____

Name of the witness (please print) Date

_____

Signature of the witness

How to add my signature to a PDF document:

STEP 1:
Open this PDF document in Adobe Acrobat Reader

STEP 2:
Click on the ‘Fill & Sign’ option in the ‘Tools’ tab at the top

STEP 4:
Click on the sign ‘Sign’

STEP 5:
Select ‘Add Signature’

STEP 6:
Select one of the three options:

- ‘Type
- Draw
- Image’

STEP 6:
Click ‘Apply”

STEP 7:
Drag, resize, or move your signature to the correct position

Appendix C: Counsellor referral letter

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REFERRAL LETTER

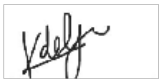
_____ - ____ - 2021

Dear _____,

Thank you for your time in participating in this research study entitled "Experiences of significant others of people with traumatic brain injury during the COVID-19 pandemic". You expressed that you would benefit from further discussing your feelings and experiences with a qualified counsellor. Please see below a list of possible counsellors in the Tshwane area:

Counsellor Name	**Counsellor contact details**	**Description**
Life Line	Telephone counselling - 012-804-3619 Face to face counselling - 012-804-1853	Free services by counsellors both in person as well as via telephone
FAMSA Pretoria	Brooklyn – (012) 460 0733 Mamelodi – 084 617 9980 Soshanguve – 076 310 6484	Free services in the greater Tshwane metro area, with offices in Brooklyn, Mamelodi and Soshanguve

Kind regards,

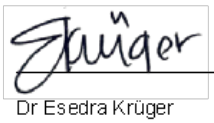


_____

Katherine van Coeverden de Groot
UP MA Speech-Language Pathology student
katherinevcdegroot@gmail.com

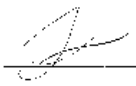
_____

Mrs Bhavani Pillay
Supervisor



_____

Dr Esedra Krüger
Supervisor



_____

Prof Jeannie Van der Linde
Head of Department: Speech-Language Pathology and Audiology

University of Pretoria, Private Bag X20
Hatfield 0028, South Africa

Appendix D: Inclusion criteria checklist

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Department of Speech-Language Pathology and Audiology

Dear _____

(Speech-language therapist at _____),

Thank you for your time and willingness in referring individuals that I can recruit to participate in my study, as per our telephonic conversation.

Title of study: **Experiences of significant others of people with traumatic brain injury during the COVID-19 pandemic**

Please see the following criteria below as to which participants I would like to include in my research:

Criteria	√/x
A significant other of an individual who has sustained a traumatic brain injury before 2020, who spends a minimum of four times or 20 hours per week with the individual who has sustained a brain injury	
The significant other must be 18 years or older	
The significant other must be proficient in English	
The SO must have access to a video or telephonic platform, through a phone, tablet, laptop or other similar device; as well as enough data for the interview to take place.	

If any of your past or current patients meet these criteria, I would greatly appreciate it if you could refer them to me by sending their details to via email at katherinevcdegroot@gmail.com.

This information will remain strictly confidential, as the information will only be available to my research team. Please do not hesitate to contact me if you have any questions on 0848801995.

Thank you again for your time.

Kind regards,

SIGNATURE OF RESEARCHER:

Miss Katherine Van Coeverden de Groot (0848801995)

Mrs Bhavani Pillay
Supervisor

Dr Esedra Krüger
Supervisor

Prof Jeannie Van der Linde
Head of Department: Speech-Language Pathology and Audiology

University of Pretoria, Private Bag X20
Hatfield 0028, South Africa

Appendix E: Client consent for obtaining contact details for research

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Department of Speech-Language Pathology and Audiology

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Client Consent for Obtaining Contact Details for Research

_____ - ____ - 2021

I, (FULL NAME AND SURNAME OF CLIENT)
_____, hereby give my consent for _____(FULL NAME AND SURNAME OF SPEECH-LANGUAGE THERAPIST) at _____(SITE) to provide my contact details to the researcher, Miss Katherine van Coeverden de Groot, under the supervision of Mrs B. Pillay and Dr E. Krüger, for her research study (Experiences of significant others of people with traumatic brain injury during the COVID-19 pandemic).

_____
SIGNATURE OF CLIENT

_____
SIGNATURE OF SPEECH-LANGUAGE THERAPIST

_____	_____
Katherine van Coeverden de Groot	Mrs B Pillay
SIGNATURE OF RESEARCHER	SIGNATURE OF SUPERVISOR
_____	_____
Dr E Krüger	Professor J van der Linde
SIGNATURE OF SUPERVISOR	SIGNATURE HOD

Place Official stamp here

Appendix F: Interview schedule and topic guide

Interview schedule to determine the experiences and views of significant others of individuals with traumatic brain injury regarding support during the COVID-19 pandemic

A semi-structured interview (+/- 60 minutes)

Welcome

Hello! My name is Kate, and I am doing my Master's in Speech-Language Pathology at the University of Pretoria. Thank you so much for agreeing to participate in this study and for taking the time to let me interview you. Before we start, I'd just like you to know a few things. I have asked you to please participate in this study because you have a relationship with someone that has a TBI, or traumatic brain injury and it would therefore be really valuable to interview you. I'd like to hear your views, experiences, thoughts and needs on what it means to you to be such a significant other to a person with a TBI, particularly during the COVID-19 pandemic. South Africans were faced with a sudden lockdown, which cut off contact with others. This meant that many services and support systems you and the person with a TBI had before the virus were halted, and may have affected you as a significant other. This interview will explore how you coped during the pandemic as well as your feelings throughout lockdown, and how things changed after the lock down was lifted. I'd like to thank you in advance for your answers to my questions but would like to remind you that if at any point during this interview you feel uncomfortable, please let me know. If you don't feel comfortable answering a question, please do not feel pressured in any way to answer. This interview will be recorded to allow me to listen again for research purposes. All of your information will remain confidential, so all personal information will not be exposed or given to anyone other than myself and my supervisors. I would like to let you know that there are no wrong or right answers, and I will in no way judge you or any of the answers you give. Do you have any questions at this point? Do you give your consent to participate in this study and for the interview to be recorded?

B) Close-ended demographic questions

To begin, please answer the following questions about background and demographic information about you and the person living with a brain injury.

1. How old are you?

_____

2. What is your gender?

2. What is your home language?

3. What is your highest level of education?

4. What was your occupation before lockdown?

5. What was your occupation during lockdown?

6. What is your current occupation status?

7. What is your marital status?

8. Do you have children? If so, how many?

9. What is your relationship to the person with a TBI?

10. When did this person acquire a TBI?

11. How did this person acquire a TBI?

12. What age did this person sustain a TBI?

13. At what age is this person who sustained a TBI now?

14. Who is the person with a TBI's primary caregiver?

15. How long has this person been the primary caregiver?

16. Did the primary caregiver change because of the COVID-19 pandemic?

17. Does the person with a TBI live with you? If not, where does this person live?

18. Does the person with a TBI work?

20. Did lockdown affect the person with a TBI's work status?

C) Open-ended questions

Topic	Probing Questions
Experiences of being a significant other to someone with a TBI.	How did you feel when your significant other first sustained a brain injury?
	What helped you cope with the news? e.g., family, anyone at the hospital, church, friends
	What information were you given on how to support or care for your significant other with a TBI?
	Thinking back, what new challenges did you face after your significant other sustained a brain injury?
	How did your relationship change after your significant other sustained a brain injury?
2. Support and functioning before the COVID-19 pandemic.	What was/is your role in caring for your significant other with a TBI?
	Describe a typical day for you as a significant other or caregiver?
	How has your day-to-day life changed since the brain injury?
	How did you manage with everyday activities pre-COVID-19?
	What was your level of support before the COVID-19 pandemic to help you to cope with living with someone who has a brain injury?
	What type of support helped you cope, and who are what provided you with this support?
	How did the sudden lockdown change you and your significant other's life?

3. How life changed during lockdown due to the COVID-19 pandemic.	What stressors did you experience during the lockdown period?
	How did the lockdown affect your relationship with your significant other?
	Tell me about ways you coped during the lockdown period.
	What support could you access?
	What types of support did you not have access to?
	Did any form of social media assist as a form of support during lockdown? If yes, in what ways?
	In what ways do you think social media platforms could have been used to offer support during the pandemic?
4. Functioning of the significant other with a brain injury as a result of lack of services all levels of lockdown.	The lockdown didn't allow for services to be provided to the individual with a brain injury. Did your significant other's functioning change at all during the COVID-19 pandemic? Such as (probe each): • Communication Difficulties: how your S/O makes him-/herself understood to others and how your S/O) understands others • Physical Difficulties: moving independently, being able to use the bathroom, walk, dress self, etc. • Behavioural Difficulties: temper, conduct, aggression, shouting, and ability to listen • Occupation Difficulties: significant other's job as well as chores around the house • Social Difficulties: friendships and relationships • Cognitive Difficulties: the ability to multi-task, carry out instructions, procedures, concentration and memory

	• Executive Function Difficulties: the ability to plan, organise, prioritise, carry out a plan, solve problems, make decisions, and flexibility • Emotional Difficulties: depression, anxiety and mood swings • Sensory Difficulties: sight, hearing, sense of touch, taste or smell
	How have these difficulties influenced the following areas of your life (probe each): • social life • work • relaxation • community life • emotions
	How has your role changed or been exacerbated by the lockdown?
	How has the lack of face-to-face interaction affected how you cope with living with your significant other with a brain injury?
5. Decisions after the lift of the various lockdown levels and ease of its restrictions.	Tell me how things changed as the lockdown lifted through the different levels.
	What decisions did you have to make regarding support for yourself?
	What decisions did you make regarding your significant other post-lockdown?
	What factors influenced these decisions?
	How did your support systems change as lockdown eased?
	If yes, how did it feel to have support again?

6. How significant others could have better been supported.	Ideally, what services would you have liked to continue receiving during lockdown for your significant other?
	What support would you, personally, have liked to receive for yourself and from who?
	What would have helped your emotional well-being during lockdown regarding feelings of being a significant other to a person with a TBI?
	Did the COVID-19 pandemic better or worsen your relationship with your significant other with a TBI?
	What support do you think is most important for those living with someone with a TBI, in these unprecedented times of COVID-19?

D) Conclusions

We are reaching the end of our interview. Is there anything else you would like to share about how lockdown and the COVID-19 pandemic affected you and your significant other with a TBI? Is there anything I didn't ask you that you would like to share? Thank you for participating in this study. I will use the information to help advocate for appropriate support during future times of crises. If there is anything else you'd like to add, ask, or comment on, please feel free to contact me. I appreciate your honesty and willingness to take part in this interview

Appendix G: Example of a transcribed interview

Experiences of significant others of people with traumatic brain injury during the COVID-19 pandemic

Interviewer	Katherine van Coeverden de Groot
Participant	P02
Date	11 June 2021
Time	07:00pm
Duration of interview	31m 45s
Context and Setting	Zoom
Audio file name	P02

Key	
Interviewer	**BOLD**
P02	normal

Transcription:

And we can start. So I'm just going to start with some simple, um, about 20 questions, just asking for a bit of background. So I think we're going to direct this to you, miss Anna, but anyone else can talk at any time. Um, but how old are you?

I'm 58, turning 59 this year.

58. And what it's, what gender do you identify as?

own conversation

Sorry. I'm back. Can you hear me.

I didn't hear you.

Oh, okay. I said, um, what gender do you identify as?

Ja, now I can hear you.

Perfect. Oh, no, I think it's my. I think it's my internet. I'm quickly going to connect to another one if that's okay.

Okay.

Thank you. Okay. Is that better? Can you?

Yes.

Great. And I heard you say female.

Yes.

Good. I just have to make sure cause some people identify as other things. Um, what, what is your home language?

Northern Sotho.

Northern Sotho. Okay. And what is your highest level of education?

Uh, grade 12.

Grade 12. And what was your occupation before the lockdown before COVID? Before the lockdown I was not working I was at home.

Okay. And during COVID?

During COVID still at home.

And now after the ease of the lockdown?

Uh, I'm still at home. I stopped uh working ah 2010, uh 2010.

Okay. No problem. And what is your marital status?

I'm married.

And who is the person with the TBI in relation to you?

What, mm, uh my daughter Patricia.

Patricia. Okay. Oh I've made Patricia before.

Yes.

Yes I have.

Yes, I know.

I recognize you, Patricia. Um, do you have, obviously Patricia's your daughter, do you have other children?

Yes. Yes. I've got three.

Three. Oh, wow. Lucky woman. And, um, when did Patricia acquire a TBI?

On, 1991. 1991.

And how old was Patricia at the time?

Oh, she was 7.

Seven years old. Yes. And if I may ask, how, how did it happen?

It was a car accident they were going to school with her sister.

Okay.

I was at work.

You were at work. And what work were you doing at the time?

I was a uh a clerk.

Oh, I see. And perfect. And what age is Patricia now?

She's 37. 37.

Um.

Ja. That means 30 years.

30 years yes, the time goes quickly.

Mmm.

And, um, who is Patricia's primary caregiver?

Uh, me. My mom.

Okay. You. And has it always been that way?

Yes.

Yes. Um, okay. And did so you the caregiver now, you were the caregiver before nothing changed because of COVID?

No nothing changed. **Okay. And does Patricia live with you?**

Yes.

Yes. And do you work?

Who Patricia?

Yes.

Me? I'm not working. Oh Patricia, no. Not working.

Alright. Um, so this interview is mainly directed to you, the primary caregiver. Um, so would that be okay if Patricia is still here or would you like to be on your own or what do you feel comfortable with asking these, answering these questions?

Uh it's no problem she can be here.

Okay, great. We're going to talk a little bit about her, but if you say it's fine that she's there then no problem.

No she's a big girl she's fine.

Okay. Thank you, Patricia. All right, so let's get started. So the first topic I want to talk to you about is just your experiences of being a mom to a person with a traumatic brain injury and the caregiver or the significant other of Patricia. So if you can think back 30 years to 1991, how did you feel when Patricia first sustained her brain injury?

Ooh, it was so terrible. So I can't even explain that feeling eh. Mmm. It was very hard.

Hard. Yes. I can imagine.

But as a mom, I had to be there for her.

Definitely, definitely. And I can see you have a very close relationship.

Too much.

That's wonderful. And so you said, you said that it was quite, um, hard. So what helped you cope with that news? Sorry, come again. Um. What helped you to cope with the news?

Um, we went to therapies, counselling. That helped me to cope about that situation.

And, um, what about family or anyone at the hospital? Maybe church.

Ja, family was giving us the support especially my husband, my other children were giving me much support so, it can, as time goes on can it came easy and easier. **Good, yes.** Now she's a big girl, she can look after me.

Oh.

After herself.

The tables have turned.

Yes.

Um, so when you first found out and you said it was hard and it was difficult, what information was first given to you on how to support and care for Patricia?

Because after an accident Patricia was like a newborn baby.

Mmm.

She couldn't walk, she couldn't speak, she couldn't do any anything. It was just like a newborn baby.

Mmm.

I had to, to deal with that. And. It was very um difficult ja.

Oh, I can just imagine. But look at you. You've done a fantastic job.

Yes.

So what information were you given on now how to look after your child. That's now like a newborn baby, as you say.

You must be patient and you you must have love.

Yes.

You must love your child then you must have patience.So then you must pray God to help you because it's very difficult.

Yes.

Ja.

So I hear that you uh have a relationship with God. Did church support you in all of this?

Yes. Yes. Very much. They did support me.

Good. I'm glad you have that um support structure.

Mmm.

And if you could think back what new challenges were there in your life now that you had to deal with that you didn't have to deal with before the injury.

My new challenges was now she can not do what other children do.

Yes.

Like normal children do. Because now she has, eh, she has to speak slowly. She has to learn speaking, she has to learn walking again. All all all all those certain things.

Yes.

There was new things now and we have to face that and we have to deal with it.

That's exactly it. And how did you deal with it? Did you um rely on anything or anyone for support?

No, I didn't. I reply on God only. Myself and God.

I see. That's fantastic. That's really beautiful. So now we've spoken a bit about the actual, um, incident. So now I'd just like to ask going forward a few years just before COVID and how your life was before all of this hit. Um, how would you describe your role as being a caregiver to Patricia?

Before COVID?

Yes.

Oh, okay. Um, before COVID everything was fine, Patricia will go to brain life.

Yes.

On Wednesday and come back home and then she's always with me at home. It's always me and her at home.

Oh that's lovely.

Yeah. And now she said, I'm getting old now. She's the one who's helping me clean, to wash, to cook, you know.

That's fantastic. I'm glad you can help.

Ja, I'm enjoying that life now, but now I see Patricia as a normal person because she can do anything.

Yes. Wow. That's fantastic. I'm so glad you've made such a wonderful recovery.

Ja, she did. She did.

And so you say that your, a typical day for you as a caregiver before COVID was just normal life.

Yes.

So there wasn't anything special. You didn't, did you have to take her to brain life or what was your role?

No, I have to take her to brain life once a week and then, that's it.

Okay. I see. And how had your day to day life changed because of the brain injury? Was there anything noticeable that changed?

To Patricia?

Yes.

Um, the brain um, life changed very much because she can do so many so beautiful things. They teach them to do um mosaic. Let, let me say they are doing hand work things.

Oh wow. Yes.

Uh um and Patricia, they can do a soak bath soaps, you see. Yes.

No, it's wonderful there.

Ja. Brain life made eh eh made wonder wonders to Patricia. She can do anything and then. Now she's doing a soap with a a the um with a all purpose cleaner.

Oh, are you making it?

Yes she's making all purpose cleaner.

You must start a business. I'll come and be a customer.

It's money to start a business, you know.

Oh yes. That's true. Everything is.

Ja, everything is money to start a business so.

And um, so if we're going back now to COVID, um, you say you had your friends, you had your family. Was this your level of support to, um, just cope with this new life that you now have.

Ja as I said it was a difficult time. But now we are coping with this new life hey.

Yes.

There's nothing we can do.

Yes.

We are coping now.

That's true. I'm glad to hear that.

So everything like it's going back to normal.

Yes, definitely.

It's new life.

Definitely a new normal.

Ja.

Yes. Okay, great. Thank you. So now we just, Um going to talk a little about, about how life changed in lockdown. So we've spoken a little bit about your life before lockdown. And then we were hit with the sudden lockdown where all the supports and all the friends and brain life and everything like that was halted. And we just going to talk about how that affected you as a significant other.

Okay. Everything everything it just stands still now. We can't go out. She can't go to brain life.

Still?

We are just sitting in the.

Still?

Um now they are they started now.

Okay.

But uh after eh after level 1 then they started.

Yes. So let's talk a little bit about that first initial lockdown, where everything, like you said was.

The one everything was so horrible because we had to just to stay in the house.

Yes.

You can't go out.

Yes, that's exactly it.

Everybody was in the house and you know.

Were there more?

Uh.

S**orry, carry on.**

No you can carry on.

So being stuck in the house as you say, we're there more stressor that lockdown gave you?

Actually I didn't see any stress because eh eh the person was not always working at home.

Okay. And you mentioned, um, that you rely on God and you have a good community at church. How did that affect you? Because you couldn't go to church anymore because of lockdown.

Ja it affect but not a lot because you know God is everywhere.

Yes.

Even in the household he is there's I can just kneel down and pray.

Yes.

Pray in the house.

Yes that's true.

Even now we are not going to church now, still closed. Our church is still closed. **Okay.**

But we do pray in the house.

Okay.

So God is everywhere.

So do you still, do you still then feel that support even though you aren't going to?

Yes.

Good.

Yes because we communicate. Yes.

Good. That's fantastic. And how did the lockdown affect your relationship with Patricia?

Ah it didn't. It didn't affect me.

It didn't?

No no.

Good and good. Good. Can you tell me a little bit about how you coped during lockdown?

We were paying games. And bonding. The other children and the father, you know. Yes and my grandchildren so we were singing sometimes. Having fun, eating a lot we are now we gain weight and all cause we are eating the whole day.

I think we all did.

Ja.

That's fantastic. That sounds like a very happy environment.

Ja.

Yes. And you mentioned brain life as a source of support. How does brain life help you as a significant other? So we know how it helps Patricia, but how does brain life support you?

Brain life support me because now I can say, during lockdown now they giving eh a Patricia parcels and then supported me by teaching Patricia lots of things and then she gained a lot of strength.

Mmm. From brain life.

Yes.

Ja and then every week they are giving her um uh food parcels so Brain life is very much supporting me.

Great. That's fantastic.

So I'm so I'm so happy taking Patricia to brain life as a mother.

Yes. Good. I'm just, that's so wonderful. Brain life truly is a wonderful place. Ja, it is.

And how did affect you that Patricia couldn't physically go to brain life anymore?

Oh oh I don't know I didn't know, You know?

Okay. I don't know.

Okay.

Yes.

So it didn't, um, make things a bit more stressful at home for you or it didn't have any effect?

No. No effect.

Okay, good. So I'm glad the lockdown wasn't cruel on you and your family.

No, lockdown was not bad to me actually.

Ah, that's fantastic to hear. A lot of people really suffering.

Ah normal normal normal life.

Oh, good. I'm so glad to hear that.

Ja. Because my my my house is a house of girls. So we always happy, singing, playing you know. Playing games you know.

Yes.

I got all girls in the house. Ja.

That's wonderful. I have three brothers. So I'm the only girl I should come join at your house.

Ja, but you must come. And I've got eh eh eh horrible twins hey. I got twins they they are so horrible.

Oh really? That's funny you say that because I'm a triplet.

Yes. Yes. They keep us busy, laughing you know it's so it's so it's so beautiful.

Yes. That's wonderful. Wonderful. You are very blessed.

Thank you.

And I want to ask a little bit about social media. Are you involved in social media or how do you feel about it?

No, I'm not involved in the social media and I don't want social media.

Okay. And I know you said you don't want social media, but in what ways do you think social media or social media platforms like this, like zoom could have been used to offer you support during the lockdown?

I I didn't think about it, but as I say me and social media we are not friends hey. **Okay.**

Yes.

Well, I'm glad that you could use it today to talk to me.

Yeah. This is the first time.

Really? Hopefully not the last. So we're going to talk a little bit about the functioning, um, Patricia's functioning, um, because of the results of the services that she couldn't access during lockdown anymore. So because of the brain life that she couldn't go to, how would you say her functioning changed at all?

It didn't change.

That's Good. So i.

It didn't change anything. Ja.

So communication, physical, behavior. Did you notice a change in any of these?

No, because they are using a social media. Patricia and then she communicate with brain life stuff, Cindy and eh eh you know?

Okay.

Ja so it was mm.

And do you think, um, this is a question about you Patricia, but I'd like to um ask your mom what she thinks. Do you think it would have been better for Patricia to have physically gone into brain life? Or do you think social media was enough for her during the lockdown?

I think social media was enough for her because going to brain eh eh brain life. You were afraid of this COVID. We don't know where. You know.

Yes.

Where to catch it Ja.

Yes.

Using social media is the best because you are in the house.

Yes.

You are not going out.

And do you think that social media will still offer her the services that she needs to help with her difficulties?

Ja I think so now, as I see now because as I told you me and social media, I'm not that person.

Yes. Well, I'm very glad that it has helped you Patricia. Very glad. So has?

I can see there's a there a effort for to you be on social media Ja. Now as we speak.

Oh, it is shame, sorry, but we're getting there. We're almost done.

Ja okay.

And so when Patricia sustained this brain injury, as you said that she had to learn how to talk again, learn how to walk, all those things I'd like to ask how that affected you in terms of your, your work and your social life.

Uh it affected me a lot because I had to leave the work for a I think for a year. And look after her.

I see, I see.

Ja.

And your community life, how was that affected.

My community life was so affected that I can't even explain, you know, but through um the mercy of God I could coped

I can see that.

I don't know how I I I did cope

Yes. And, um, Anna how has your role changed um by the lockdown, your role as a caregiver or your role as a significant other?

Uh, through lockdown it changed a lot because it made me lazy now. So chilling I'm sitting and I just sitting they doing everything for me. Because they are home now.

Good. And in particular, how you care for Patricia has that changed at all?

Uh, I told you I don't care for Patricia now, Patricia is caring for me, you know. 2 weeks back I had an operation on my knee.

Okay.

So she's always taking care of me.

Oh, I'm so glad you have her there.

She take care of me.

I'm so glad she has you there, Patricia. And so in lockdown, you couldn't have face to face with any of your friends or, um, any of the people that support you. And I know that you said that, thank goodness you had your family with you, but has that affected you at all as a caregiver?

Oh, not really. Not really.

Okay good. Good. And can you tell me?

Im not a a person who has lots of friend. I don't have lots of friends.

Yes.

My friends are the girls in the house here.

Yes. Your family are your friends.

Ja, my family, ja.

Yes, definitely. I like that as well. My family or my best friends. And.

Yes.

Tell me how things changed as the lockdown got easier in terms of you as a significant other and the rehabilitation services offered to you, Patricia.

Um, you asking Patricia now?

Uh, Both of you.

Oh, both of us. Mmm. Repeat again the question.

Um, how, let me ask you Anna, how has things have things changed now that the lockdowns got an easier in terms of how you feel supported?

Mmm. Um, uh, it has changed a lot because now you can visit maybe a friend.

Yes. Ja, easy now. Now you can go out, go to the restaurants. Even ever if you go to the shops now at least it's better than before.

Yes. And then Patricia can go on on Wednesdays she can go to Brain Life.

Exactly.

And um even Fridays they go to go to brain life.

Oh fantastic.

At at least everything's easier.

Yes. Uh, I'm glad for all of us, for the world.

Ja, for the world.

Yes. And we go into our last section now and it's all about how, so this one's all to you and about how significant others could have been better supported during COVID. So ideally what services would you have liked to continue during lockdown?

Services? Like?

Like Brain life?

Yes okay. Ja like continued to going to church, to continue that because of the COVID everything just becomes standstill.

Yes exactly.

So ja it was that that's why I I told you in the beginning that at times it was very, it was difficult, but we had to eh to learn how do we deal with this COVID.

Yes.

Because it's there it's not going anywhere

Yes. So you mentioned that you got to, um, you had a great time in lockdown with your family with Patricia. So how would you say your relationship changed because of lockdown?

Because we were bonding all the time. Yes. We are bonding even now we are bonding a lot. Because every, every time we are together.

Yes. That's so lovely. One of the positive things that came out of lockdown. Yes yes.

And my last question is to you, I know what support do you think is the most important for those living with someone with a traumatic brain injury during these difficult times of COVID?

Um, you know they must, firstly you must pray and get strength. And family, uh family friends you know.

Yes, yes.

Ja.

No, exactly. Exactly.

Mmm.

So that is it. We have reached the end. Is there?

Okay.

Is there anything you'd like to tell me or anything more you'd like to share on being a significant other to someone with the TBI that I have not asked already?

Um no. That would be all for today. I don't know. Maybe eh eh one day.

Okay. Well, please feel, please feel free to contact me whenever, um, you have my details. And did you receive the voucher to your phone? The Vodacom voucher?

Yes thank you very much I forgot to say that thank you very much.

No that's okay. Thank you.

Sorry.

Never mind I said what voucher.

Oh okay.

Between me and you.

Yes ma'am. And then, um, I sent you these two forms, I'm not sure if you received them.

Uh. These girls they just came now. I didn't sign so what must I do.

Um, so On this form over here. I'd like you to please sign where I put an X. So where I put an X there. If you can just add your signature.

Hi

Hi. How are you?

Good. How are you?

Good. Thank you. Can you hear me okay?

Ja I can. Do you want us to, do you want us to print it out and then sign it and then scan it back to you?

Um, if that's easier, otherwise you can just add your electronic signature. Whatever's easier for you.

Okay I'm is tomorrow fine?

Yes Tomorrow's fine. Tomorrow's good.

Oh okay.

Thank you. So it's just, I sent you two, so it's this one and then where the x is and then the second form, the second form looks like this. So if you could just put a cross either at yes or no. It just asks if we can use um data you've given me in further research and then your signature where the X is again.

Okay.

Okay thank you.

Both of us?

Um, just actually both of you please.

Yes. So you're gonna need 4 forms?

Oh no you can just sign next to that's. No problem.

Oh okay.

Yes. Great. Thank you. I really appreciate it. Thank you very much.

It was nice talking to you.

You as well.

Now I like social media.

Oh Good. I'm glad I could do that for you.

Yes.

Thank you. Have a great weekend. Stay warm.

And you too. Thank you.

Bye-bye.

Bye.

Appendix H: Rationale for questions and topics in the interview schedule

The measurement tool was adapted from two previous studies that explored perspectives and experiences of SOs of individuals with a TBI (Holloway, 2017; Broodryk 2014).

Guiding Literature for contents of the semi-structured interview schedule

Guiding literature for content	Contents of the semi-structured interview schedule
The interview schedule derived by Broodryk (2014), a South African study conducted in the Western Cape area, and this relevant to the South African context. It consisted of four main sections, namely, a welcoming, biographical questions, open-ended questions and conclusion. This interview framework is useful in ensuring that all required information is attained in a way that is respectful to all participants (Brink et al., 2018). A schedule allows for the structure to be presented in the same way for each participant. This allows for the same type of information to be gathered, in order to make a fair and accurate comparison of results (Brink et al., 2018)	Interview schedule format followed as in Broodryk (2014) for these sections. A: Welcome: Enabled the researcher provide an overview of the study, explain the logistics surrounding the study, as well as gain consent from the participant that is based on informed knowledge. B: Close-ended biographical information questions: Gained insight on the age of the participant, cause of the TBI, relation as a SO,and other such information. C: Topic guide and probing questions: This was guided by work of Broodryk (2014) as well as that of Holloway (2017), and made relevant to the COVID-19 pandemic. D: Conclusion: To provide the participant and opportunity to ask questions or reveal any additional information, as well as to thank participants for their time.
Broodryk (2014) and Holloway (2017) both acknowledged the importance of probing the experiences of SOs, who play a vital role in the rehabilitative process. Both researches indicate the influence this may have on a SO, and	The questions in the topic guide aimed to determine the experiences of significant others of individuals with traumatic brain injury (TBI) and their views on formal and informal support before, during, and after the time of the COVID-19 pandemic. In addition, to explore whether actions were taken or adaptations were made

how support systems are paramount to SOs wellbeing. The importance of personal factors is also considered, such as avoidance behaviours towards or inability to participate in daily activities or new situations before, during and after the pandemic (ICF, 2018).	regarding access to health care, including rehabilitative care, during the global pandemic in South Africa. Finally, the questions utilised aimed to explore SO experiences of participation in daily life during the period of the COVID-19 pandemic Section C of the interview schedule thus comprised of six topics, each accompanied by four to six probing questions, which sought to provide insight into the above-mentioned aims. These topics, or sections, were namely: • Experiences of being a significant other to someone with a TBI. • Support and functioning before the COVID-19 pandemic. • How life changed during lockdown due to the COVID-19 pandemic. • Functioning of the significant other with a brain injury as a result of lack of services. • Decisions after the lift of the lockdown and ease of its restrictions. • How significant others could have better been supported.
. Initially, support is provided through information counselling by professionals (Broodryk, 2014). SOs often have to search for their own ways to cope that suits them and their family's new experiences. Studies have shown that the relationship of the SO and the individual with a TBI often changes post injury, and important aspect to explore (Broodryk, 2014; Holloway, 2017).	This study aimed to find out what supports and coping mechanisms SOs were exposed to our sought out before the pandemic. How their life changed after the injury in terms of relationships and challenges will be explored. The following are examples of questions used in the interview schedule: • What helped you to cope with the news? • Did your relationship change after your significant other sustained a brain injury? If so, how?

When an individual sustains a brain injury, not only is that individual's life altered, but the lives of their SOs also faces change (Oyesanya, 2016).	This study explores in what ways the lives of individuals with a TBI, as well as that of the SOs has changed because of the injury. Specifically, this question was asked in terms of daily functioning before, after and during the pandemic by the questions presented in the interview schedule. Examples of these questions include: • Before COVID-19: Describe a typical day for you as a significant other or caregiver? • During COVID-19: How did the sudden lockdown change you and your significant other's life? • After COVID-19: How did your support systems change as lockdown eased?
It is widely recognised that a person who sustains a TBI experiences changes or fall-out in many abilities, including difficulties in the following areas: communication, physical, behavioural, occupation, social, cognitive, executive functioning, emotional, and sensory (Holloway, 2017).	To explore SOs experiences with these difficulties during the COVID-19 pandemic the following question will be asked, according to each of the difficulties adjacently mentioned. The lockdown didn't allow for services to be provided to the individual with a brain injury. Did your significant other's functioning change at all during the COVID-19 pandemic? Such as (probe each) : (the adjacent mentioned difficulties) The following questions will determine how the functioning of the person with TBI affects that of the SO: • How have these difficulties influenced the following areas of your life (probe each): 1. social life 2. work 3. relaxation 4. community life 5. emotions

SO rely on support through formal mechanisms such as rehabilitation centres, as well as through informal support structures found within the community (Cheklin et al., 2020). Increasing advances in health and medicine, more individuals that sustain a TBI are surviving, but still require care and support from SOs (Klemen & Grmec, 2006). This reiterates how vital it is that SOs are support throughout the rehabilitation process.	In the present study, the researcher aims to investigate what supports, with formal and informal, would have helped the SO during the pandemic. This will be achieved through the following questions: • What support would you, personally, have liked to receive for yourself and from who? • What support do you think is most important for those living with someone with a TBI, in these unprecedented times of COVID-19?

Appendix I: Proof of submission to journal