THE BARRIERS AND FACILITATORS EXPERIENCED BY PRIMARY CAREGIVERS WHEN IMPLEMENTING OCCUPATIONAL THERAPY HOME PROGRAMMES WITHIN A PRIMARY HEALTHCARE SETTING

By

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Ethics Clearance Certificate Number: M220837

DECLARATION

I declare that the research report, which I hereby submit for the degree Master of Science in Occupational Therapy at the University of the Witwatersrand, is my own work and has not previously been submitted by me for a degree at this or any other tertiary institution.

Name: Ella Topham Date: 09 Oct. 25

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ABSTRACT

Introduction

This study aimed to describe and explore the facilitators and barriers that primary caregivers experience when implementing an occupational therapy home programme.

Methods

An exploratory, descriptive qualitative research design was used. The researcher conducted semi-structured interviews with 12 primary caregivers attending Hillbrow Community Health Centre. Purposive sampling methods were used to gather participants involved in the study and participants were sources largely from outpatient groups for children with Cerebral Palsy and Down syndrome.

Findings

The data gathered from the 12 semi-structured interviews were analysed using thematic analysis. Four themes were generated throughout this process, namely: family dynamics; “sometimes he just doesn’t want to”:-child-centric factors; faith, strength and responsibility and, “it’s hard, it’s complicated”: the broader context. These themes described how factors in the primary caregivers’ immediate household contexts as well as the broader socioeconomic contexts of their communities contributed to their ease or difficulty they experienced when implementing occupational therapy home programmes. While it was found that these themes described the facilitators and barriers that primary caregivers experienced, they were not experienced in isolation and it was an interplay of factors between the primary caregiver, the child and contextual factors that influenced the home programme implementation. It was found that surprisingly few barriers related to the home programme activities themselves and that a consolidated understanding of the home programme activities was important for effective implementation. This study found that the interaction between the primary caregivers, children and household context contributed to the primary caregivers’ opportunity to implement the home programme activities.

Conclusion

This study aimed to describe facilitators and barriers that influenced how primary caregivers implemented occupational therapy home programmes. All primary caregivers interviewed managed to implement the programmes but provided insight into what factors within their immediate and broader environments and contexts made it easier or more difficult to implement the home programme activities. This insight showed how

factors and resources within their household and broader socioeconomic environments were a greater influence on implementation than the home programme activities themselves. This insight is important for occupational therapists to understand when prescribing home programmes and working with children with disabilities and their primary caregivers.

PUBLICATIONS ARISING FROM THIS STUDY

As part of the submission of this research report a journal article has been submitted to the South African Journal of Occupational Therapy for peer review.

TABLE OF CONTENTS

NOMENCLATURE/LIST OF ABBREVIATIONS AND SYMBOLS

CHC: Community health centre

ADLs: Activities of daily living

CP: Cerebral palsy

WHO: World Health Organisation

NHRD: National Health Research Database

HREC: Human Research Ethics Committee

OPERATIONAL DEFINITIONS

Primary healthcare facilities:

Primary healthcare facilities are facilities within the public sector aimed to redress the inequities in the South African public healthcare landscape, where the majority of the South African population can access healthcare services. They include district hospitals, clinics and community health centres where services are provided by general practitioners and nursing staff (Coovadia et al., 2009).

Community health centres:

A primary healthcare facility providing a range of services including maternity care, care for children under the age of six, outpatient services and emergency care. Services can be provided by general practitioners and nursing staff (Coovadia et al., 2009).

Home programmes:

Home programmes are a therapeutic tool used by a variety of healthcare professionals such as occupational therapists, physiotherapists and nurses. Home programmes are a set of activities designed to be used within the home environment. They are used to support therapeutic gain and continue to contribute to progress in between appointments (Novak and Honan, 2019).

Primary caregivers:

Primary caregivers are individuals providing physical and emotional care for children and adults with impairments and/or disabilities. These individuals are the primary source of support for individuals in their care (Trafford, 2023).

Cerebral palsy:

Cerebral palsy is a neurological condition resulting from a lesion. It is characterised by reduced musculoskeletal and neurological functions that influences overall development of motor, cognitive, psychosocial and emotional functions (Donald et al., 2020).

Down syndrome:

Down syndrome is a genetic condition affecting the development of chromosomes, resulting in delays in foetal and child development. Down syndrome contributes to intellectual disability as well as reduced development of motor, cognitive and socioemotional skills (Diamandopoulos and Green, 2018).

LIST OF FIGURES

LIST OF TABLES

APPENDICES

CHAPTER 1.1: INTRODUCTION

1.1.1 Introduction to the problem

The South African public healthcare system faces many challenges, including limited access to physical and human resources, with significantly high numbers of service users to healthcare professionals (Coovadia et al., 2009). As part of the primary healthcare re-engineering policy, primary healthcare services were meant to redress some of these inequalities. However, services at these facilities face similar challenges to those outlined above, especially the limited human resources. In a move towards providing improved access to healthcare for the majority of South Africans, the National Health Insurance aims to provide a greater number of professionals to healthcare facilities (Ned et al., 2020). Occupational therapy services within primary healthcare facilities are influenced by time and resource-limiting factors. These factors as well as the high ratio of service users to professionals mean that services are frequently only accessed monthly and are frequently short and do not offer time for lengthy and in-depth discussions (Richards and Galvaan, 2018). Occupational therapists therefore make use of home programmes as a valuable therapeutic tool to support gains made in therapy and to ensure that service users can still work towards therapeutic goals in the time between monthly appointments. Client populations who benefit from occupational therapy home programmes include primary caregivers caring for children with disabilities. However, primary caregivers encounter various challenges in their environment which influence their ability to effectively implement these home programme activities (Bester, 2020).

1.1.2 Background and setting of the problem

Including primary caregivers as active collaborators in the therapy process is an important aspect of working towards effective practice in the resource-limited environment of the public healthcare sector in South Africa (Richards & Galvaan, 2018). For occupational therapy interventions, and especially home programmes, to be as effective as possible it is vital that primary caregivers are active participants in the process of prescribing therapy interventions that should be done at home. Home programmes are used by occupational therapists treating a variety of client populations, including children. For this population,

the activities or exercises are frequently prescribed to the children's primary caregiver. (Finet, 2016; Novak & Berry, 2014).

There is evidence suggesting that home programmes and home-based interventions have a greater chance of making gains and working towards therapeutic goals when primary caregivers are empowered and actively involved in these interventions (Akamoglu & Meadan 2018).

Caregivers caring for children with difficulties are however faced with many burdens and experience difficulties inherent in the role of caregiving (Reddy et al., 2019). Engaging in all the activities included in caregiving places demand and expectations on the primary caregivers. Understanding the experiences of primary caregivers and the influence of these experiences on their ability to perform their required activities is therefore important for healthcare professionals, like occupational therapists, providing services to the individuals under their care.

1.1.3 Problem statement

Home programmes are a valuable part of occupational therapy practice and are frequently used by occupational therapists to support gains made in therapy (Jansen van Vuuren et al., 2021). Home programmes are especially useful and necessary within the South African healthcare context and notably on a primary healthcare level where there are many service users in relation to the number of occupational therapists available to provide services (Jansen van Vuuren et al., 2021; Richards & Galvaan, 2018).

On an outpatient basis, clients can access occupational therapy services often only once a month. These appointments are also often short and are carried out relatively quickly, which influences the quality of services that are provided by occupational therapists in these environments (Richards & Galvaan, 2018). Home programmes are therefore important to supplement the time between therapy sessions to ensure clients are still receiving some form of therapy services. As described by Richards and Galvaan (2018), it was found that visits made by clients to clinics are fast and there is little time or resources available for lengthy or in-depth discussions. The reduced number of therapists available as well as reduced access to resources are time-limiting factors influencing the length and quality of interaction between occupational therapists and primary caregivers (Richards & Galvaan, 2018). This limited time and other important resources available in these visits

limits the capacity for occupational therapists to actively involve and empower primary caregivers relating to the therapy services for their child.

A client population for whom home programmes are especially useful is children who are receiving occupational therapy services. These home programmes aimed at improving the occupational performance of children are frequently prescribed to the primary caregiver (Bester, 2020). It is understood that for these home programmes to be useful and effective, the children's primary caregivers should be active participants in both the design and implementation of the home programmes (Jansen van Vuuren et al., 2021). Understanding and acknowledging these areas is important for the therapists working together with both the children and the caregivers (Fewster et al., 2020). However, the primary caregivers are frequently not involved in this process, negatively influencing their ability to apply the home programmes in their home environments (Angeli et al., 2019). This lack of involvement in home programme development reduces the ability of the primary caregivers to implement the home programmes effectively. Together with these challenges occurring in the clinic environment, primary caregivers also encounter barriers and facilitators within their own environment that influence their ability to meet all of the demands of caregiving effectively (Fewster et al., 2020).

1.1.4 Research question

What are the barriers and facilitators experienced by primary caregivers of children to implementing a home programme prescribed by an occupational therapist in a public healthcare setting?

1.1.5 Research aims and objectives

1.1.5.1 Aim of the study:

To explore and describe the barriers and facilitators experienced by primary caregivers in the implementation of occupational therapy home programmes in a public health care setting.

1.1.5.2 Objectives of the study:

a. To identify and describe the barriers experienced by caregivers when implementing occupational therapy home programmes in a public healthcare setting.
b. To identify and describe the facilitators experienced by caregivers when implementing occupational therapy home programmes in a public healthcare setting.

1.1.6 Significance of the study

The benefit and importance of home programmes as a supplementary treatment tool within the public healthcare sector is an area that is understood within the field of occupational therapy (Jansen van Vuuren et al., 2021). There is also available literature on the benefit and usefulness of home programmes to support children who are receiving occupational therapy services, however, less of this literature appears to be situated within a South African context. The experiences of caregivers and caregiving as a role have also been explored in existing literature (Fewster et al., 2020). Despite this, there is little existing literature available on how caregivers experience the implementation of occupational therapy home programmes. This study could potentially provide insight into this area and provide information to occupational therapists prescribing home programmes within the public healthcare setting, specifically clinics. By developing an understanding of caregivers' experiences implementing home programmes, this study has potential to inform evidence-based practice specifically relating to the prescription of occupational therapy home programmes. Further contribution and construction of knowledge in this area may serve to be beneficial for healthcare professionals and primary caregivers. This study will therefore contribute to this body of knowledge. As this study is qualitative in nature, it will provide insight into the experiences of primary caregivers when implementing home programmes. The contextual barriers and facilitators influencing their engagement with the home programmes themselves will also be researched. Both areas

have been recommended as further areas of research for occupational therapists to potentially contribute to and improve home programme development and implementation.

1.1.7 Organisation of the thesis

The general outline of the thesis is summarised as follows:

Chapter 1: Introduction, Literature Review, Methodology

Chapter 2: Submissible manuscript in the form of a journal article that has been submitted to the South African Journal of Occupational Therapy for peer review.

Chapter 3: Summary of main findings, strengths and limitations of the study, conclusion and recommendations.

CHAPTER 1.2: LITERATURE REVIEW

1.2.1 Introduction to literature review

This chapter highlights the existing knowledge and available literature about occupational therapy programmes implemented by primary caregivers. The chapter provides insight into occupational therapy as well as the role of occupational therapy in supporting children with disabilities. It explores public healthcare settings and occupational therapy service provision within these healthcare settings in the South African context. This chapter includes a significant focus on occupational therapy services within these settings, such as the use of home programmes. This chapter also describes the importance of home programmes and how they are implemented and used with different populations. There is also insight on the use of home programmes within the South African context. While exploring this there is a focus on barriers and facilitators influencing the implementation of occupational therapy home programmes. The relevant literature that informed this chapter was acquired through accessing several databases. These databases included Google Scholar, EBSCO Host and PubMed. Individual journals were also accessed through the University of the Witwatersrand Library. Grey literature including unpublished Master's, PhD theses and dissertations were accessed through the WireDSpace website (https://wiredspace.wits.ac.za/). The search for literature aimed to include works from the last three to five years, however, seminal and foundational works were also included due to a reduced availability of more recent literature.

1.2.2 What is occupational therapy?

Occupational therapy is a profession that makes use of everyday activities and occupations with individuals, groups and populations to support participation. Occupational therapy services are focused on prevention of ill-health and promoting health and wellness both for people with and without disabilities (Boop et al., 2020). The primary goal of occupational therapy intervention is to facilitate engagement in activities that are meaningful, valuable and important to the individual, group or population receiving services (WFOT, 2018). To be effective, occupational therapy intervention makes use of the interaction between the client's person, environment and activities and utilises this interaction to promote health and wellness. The transactive nature of the interaction of

these three elements is described in the person-environment-occupation model (Law et al., 1996). This model can be used by occupational therapists to effectively understand their clients' needs and effective engagement in valuable, meaningful occupations within their environment and context. This understanding is valuable for all client populations receiving occupational therapy, including children with disabilities (Law et al., 1996).

Children with disabilities encounter difficulties and require support to engage in valuable and developmentally appropriate activities. Occupational therapy services can support the children and their families by addressing their impairments, environments and working to promote optimal participation in meaningful activities (Novak and Honan, 2019). The contextual embeddedness of occupational therapy services allows for intervention focused on environmental adaptations or rehabilitation to support optimal engagement in meaningful activities (Boop et al., 2020).

1.2.2.1 Occupational therapy intervention with children with disabilities

The intervention of occupational therapists working with children with disabilities seeks to improve the children's ability to engage with and participate in different life roles (Novak and Honan, 2019). Due to the physical impairments and environmental barriers that children with disabilities experience, their engagement in developmentally appropriate activities and occupations is reduced (McConnell et al., 2016). Occupational therapy intervention with children with disabilities is therefore focused on improving children's functional performance in various activities, such as activities of daily living (ADLs) as well as their ability to explore and engage with their physical, social and cultural environments (Novak and Cusick, 2006).

As a child is embedded within the family unit and participation in family activities is important, involvement of the family is essential for occupational therapy services to be effective for children with disabilities. Intervention usually seeks to involve primary caregivers throughout the therapy process to support this effective service provision.

1.2.3. Role of primary caregivers

Primary caregivers are the main source of physical, emotional and social support for individuals in their care and this creates a significant responsibility and burden for the

primary caregiver (Kokorelias et al., 2019). Due to the responsibilities and burden experienced by primary caregivers, the caregivers can experience burnout and significant influences on quality of life (Bester, 2020). This understanding is important to work towards collaboration and effective therapy services for the individual the primary caregiver is caring for. Evidence has shown (Novak and Honan, 2019) that the collaboration between the primary caregiver and occupational therapist is essential to ensure effective and meaningful service provision from the occupational therapist.

Empowering primary caregivers throughout the occupational therapy process has been shown to contribute to wellbeing and achievement of health goals. Cloete and Obaigwa (2019) found in a qualitative study conducted with primary caregivers in Kenya, that attending occupational therapy sessions was helpful and supportive to their ability to adjust and work towards accepting the condition the individuals they care for had been diagnosed with. While collaborative relationships with primary caregivers are emphasised as being valuable and important for the occupational therapy process, a significant proportion of the studies in this area have been conducted in Australia and the United Kingdom. In other countries and settings, the healthcare landscape looks different, creating different factors influencing the development of these relationships (Milton et al., 2019; Novak et al., 2013; Novak and Honan, 2019).

Understanding the experiences of primary caregivers and the influence of these experiences on their ability to perform their required activities is therefore important for healthcare professionals, like occupational therapists. To shift occupational therapy intervention towards more family-centred care, practitioners should work to understand the daily routines, contexts and home environments of the children and primary caregivers receiving therapy services. (Beckers et al., 2020; Novak, 2011; Novak and Berry, 2014; Novak and Cusick, 2006; Walker et al., 2020). Delivery of occupational therapy services within the South African healthcare system can be challenging due to the contextual difficulties experienced.

1.2.4 South African context and primary healthcare

1.2.4.1 Primary healthcare in South Africa

The South African healthcare system continues to be affected by historical inequity, and this is a prolonged influence on the service delivery in all healthcare settings (Coovadia et al., 2009). To redress the past inequalities in service provision, the post-1994 government focused on providing services at tertiary, regional and district levels of care (Naidoo et al., 2017). This, together with a focus on prioritising primary healthcare services aimed to work towards improving access to services for under-resourced populations (Jejelaye et al., 2019). Despite this focus and prioritisation from the new democratic government, access to quality healthcare continues to be difficult for the majority of South Africans (Rensburg, 2014). This may in part be due to little re-allocation of resources from the private to the public sector by the government (Maphumulo and Bhengu, 2019). Clinics and community health centres (CHCs) are the primary healthcare facilities accessed by patients in South African communities. While under the primary healthcare re-engineering, these facilities are meant to provide services to the majority of South Africans despite the inequitable division of resources outlined above. The World Health Organisation's (WHO) model of chronic care, used in primary healthcare settings within South Africa, puts forward that involving the client and their family or community members is important (Jansen van Vuuren et al., 2021). An important method to achieve provision of person-centred care is to work closely with the service user's family and community, allowing for the development of more contextually appropriate services that are sustainable and integrated (Dahl-Popolizio et al., 2018). While this may be beneficial and ideal, the significant resource constraints in South African healthcare facilities restricts implementing this in practice.

Maphumulo and Bhengu (2019) indicated that services are therefore often constrained by time-limiting and resource-limiting factors, negatively influencing the quality of interaction between healthcare professionals and service users (Conradie et al., 2022). Despite the significant priority placed on primary healthcare services during primary healthcare re-engineering in post-1994 South Africa, primary healthcare facilities face the same difficulties as other facilities within the public sector (Jejelaye et al., 2019). This disparity

has negatively influenced the ratio of healthcare professionals to service users within primary healthcare facilities, with high numbers of service users to very few professionals.

To combat resource limitations, there is increasing emphasis being placed on ensuring that when services are accessed, they are as effective and impactful as possible within primary healthcare settings (Chinchai and Khamwong, 2017). To work towards effective and impactful service provision, it is acknowledged that within South African primary healthcare settings (as well as other resource-constrained environments) services must move beyond the physical facilities in which they practice (Richards and Galvaan, 2018).

1.2.4.2 Occupational therapy intervention in primary healthcare in South Africa

With the aim for comprehensive service provision in mind, there was significant effort made to include rehabilitation services at primary level within the plan for primary healthcare re-engineering (Ned et al., 2020). Despite evidence that including rehabilitation service at primary level is effective for managing the needs of service users, there is a significant shortage of occupational therapists working at primary healthcare facilities. There is a high ratio of service users to healthcare professionals within the public sector. This shortage of healthcare professionals means that service users frequently attend therapy sessions monthly. These appointments are also often short, influencing the quality of services that are provided by occupational therapists in these environments (Richards & Galvaan, 2018). This limited time and other important resources available in these visits limits the capacity for occupational therapists to actively involve primary caregivers in the appointments and therapy process. To continue providing support to clients and caregivers in between the monthly appointments at clinic facilities, occupational therapists providing services to client populations in public health care settings make use of home programmes that are designed to be used in the home environment and support gains between therapy appointments (Msengana et al., 2019).

1.2.5 Home programmes

1.2.5.1 Description of home programmes

Home programmes are a tool used by a variety of healthcare professionals, including occupational therapists, physiotherapists, speech therapists and nurses to supplement the gains made in therapy in between therapy appointments, especially when access to consistent one-on-one therapy is reduced (Novak et al., 2009). A home programme is defined as therapeutic activities that a client carries out within the home environment to work towards achieving desired health and wellbeing related outcomes (Novak and Berry, 2014). Currently, there is more available literature describing the use of home programmes in the global north. However, many of these studies outlined the need for further research into home programmes, especially related to primary caregivers and contextual factors influencing their use and effectiveness.

When are home programmes used?

Home programmes are used by occupational therapists treating a variety of client populations, including children (Novak and Berry, 2014). An acknowledged benefit of home programmes, especially where children are the clients, is the application within the home environment and daily context of the family. This aligns with working towards providing family-centred care (Novak, 2011; Novak and Berry, 2014; Novak and Honan, 2019). Home programmes prescribed by healthcare professionals can be multimodal. They can be prescribed verbally or as a written description. These written descriptions can be supported by a pictorial or video format to support implementation of the home programme activities (Novak and Cusick, 2006).

Benefits of home programmes

The benefit and clinical usefulness of home programmes in occupational therapy has been well-established in the literature. According to the literature and extensive studies conducted by Novak et al. (Novak, 2011; Novak et al., 2009; Novak and Berry, 2014; Novak and Cusick, 2006; Novak and Honan, 2019). Home programmes have been established as a useful tool to support gains made in occupational therapy sessions and work towards achieving functional goals. However, there is no established consensus on clinical guidelines for the development of home programmes, (Smidt et al., 2020) and are designed specifically for individual clients and that client's specific context. There is

evidence suggesting that home programmes and home-based interventions have a greater chance of making gains and working towards therapeutic goals when primary caregivers are empowered to implement and actively involved in these interventions (Akamoglu and Meadan 2018). Home programmes can be used as a clinical alternative to therapy and to increase the dosage of therapy received by the client, contributing to the achievement of therapeutic goals. This has been described not only in the countries named above but also in Taiwan as demonstrated by Wuang et al. (2013). As well as these benefits, when home programmes are effectively implemented, they can become a form of guidance and support. This can then be used by primary caregivers to build confidence about how to best support their child in reaching their optimal potential (Novak, 2011). As appointments are often short and there is not enough time available for in-depth discussions, home programmes have been found to support the outpatient therapy in achieving gains relating to functional goals even with clients attending outpatient appointments once a month (Msengana et al., 2019). Occupational therapy home programmes are frequently utilised as a support tool for children with disabilities and their families. However, there is little available literature describing the use of these programmes within the South African context (Russell et al., 2016).

Home programme implementation and effectiveness

Novak (2011) described that factors influencing the effective use of home programmes include guidance from the occupational therapist, practice, allowing the home programmes to become a part of life and if caregivers can juggle competing demands to implement the home programmes. A model for optimal home programme development and implementation with primary caregivers were described by Novak and Cusick (2006). These model describes the optimal home programme approach as: developing a collaborative relationship; setting mutually agreed goals; selecting therapeutic activities; supporting implementation and evaluating outcomes. While this model describes an optimal home programme approach, it can be challenging for this optimal approach to be implemented in therapeutic setting (Novak and Cusick, 2006).

For home programmes to be as effective as possible, the client should be involved in the process of designing the home programme together with the therapist to ensure that the activities and exercises put together to be done in the home environment will be appropriate to the individual, their family and context (Bester, 2020). The implementation

of home programmes is very dependent on the primary caregivers as they need to execute the intervention in their home environment. Novak and Berry (2014) found evidence in that shows that the way home programme is implemented influences quality of the effectiveness of the intervention. However, for home programmes to be described as effective, not only do primary caregivers need to be active collaborators throughout the process but they need to become empowered to carry out the programme themselves. Practitioners could support this by ensuring that home programmes are developed with the daily routine and context of the home environment in mind, as well as if the primary caregiver is supported and coached throughout the implementation process (Novak and Berry, 2014). It is also acknowledged that there are specific actions that occupational therapists should focus on to improve the effectiveness of home programmes. These actions include working closely together with clients and, in the case of children receiving occupational therapy services, primary caregivers, to develop person and family-centred activities that are contextually appropriate and address areas of importance (Bester, 2020). However, while home programmes are meant to be designed for individual clients on a client-by-client basis that is frequently not the reality in clinical settings for a variety of reasons, such as reduced human and physical resources and time constraints. The occupational therapist should aim to provide family-centred interventions by working together with the family to ensure interventions are working towards family goals (Smidt et al., 2020).

1.2.5.2 Home programmes in the South African context

It is understood that the challenges and difficulties present in the South African healthcare system are an influence on the accessibility of healthcare services and the quality of services themselves (Jejelaye et al., 2019). Due to these challenges, alternative and supplementary tools and techniques are frequently employed by healthcare professionals within the public sector in South Africa. Home programmes are described as a useful tool to supplement the outpatient therapy being received by an individual and are used to supplement therapy in between outpatient appointments at all levels of healthcare (Jansen van Vuuren et al., 2021).

While home programmes are a widely used tool by occupational therapists and other healthcare professionals working within the public sector, there are no formal guidelines to inform the development, implementation and prescription of home programmes within

this setting (Smidt et al., 2020). The usefulness and potential contribution of home programmes to the ongoing care of clients receiving occupational therapy services is acknowledged within the literature (Jansen van Vuuren et al., 2021; Richards and Galvaan, 2018).

1.2.5.3 The use of home programmes with children with disabilities

Throughout this literature, home programmes are described as being useful, essential and important to support the participation and engagement of children with disabilities (Novak and Berry, 2014;Novak and Honan, 2019).

Studies conducted largely within the United States, United Kingdom and Australia demonstrate how home programmes can facilitate improvements in motor function and engagement in daily activities (Beckers et al., 2020; Milton et al., 2019; Novak, 2011; Novak and Berry, 2014; Novak and Cusick, 2006; Novak and Honan, 2019). A significant proportion of this research is related to the use of home programmes with children with CP. In the research of Novak (2011)

Cerebral palsy

Cerebral palsy (CP) is a neurological disorder affecting a significant number of children across the globe, with approximately 2 per 1000 births affected (Katangwe et al., 2020). CP is defined as a group of disorders that influence movement, postural control and that limits the engagement in various activities. The disorders are caused by non-progressive disturbances of a developing neonatal brain. Together with motor functions, CP can also negatively influence sensation, cognitive function, communication and behaviour (Milton et al., 2019). The needs of children with CP are complex and demanding and as a result, the care provided by their primary caregivers is greater than that provided by caregivers of typically developing children of the same age (Pousada et al., 2013). Contributing to the increased burden places on primary caregivers as previously described. Children with CP are often dependent on their caregivers for engagement in all daily activities. Due to the difficulties children with CP experience engaging in these activities, these children can receive occupational therapy services to support activity participation. As children with CP have difficulty engaging in activities within the home environment, home programmes can be useful tools to support them and their families. Home programmes can support addressing the clinical symptoms associated with CP, including: postural control, sensory stimulation, fine motor skills and cognitive development (Novak and Cusick, 2006). There

is more widely available literature on the use of home programmes specifically with children with CP in Australia, the United Kingdom and the United States. A significant proportion of home programmes used with children with CP are focused on the use of constraint-induced movement therapy with children with hemiplegic CP as well as improving motor functions overall (Milton and Roe, 2017; Novak et al., 2013, 2009). A study conducted in 2019 by Milton surveyed the use of home programmes for children with CP across the United Kingdom. A cross-sectional survey design was used to ascertain the level of best practice conducted by paediatric occupational therapists when prescribing home programmes (Milton et al., 2019). It was described that the most frequently used interventions were activities of daily living, fine motor activities, analysing activities in the home and activities focusing on active range of motion. According to Novak et al. (2013) home programmes focused on improving motor function and self-care should be included in the standard care for children with CP. While it has been documented that home programmes can be an effective alternative or supplement to therapy sessions, the success of these home programmes is dependent on caregiver involvement and collaboration. When caregivers and families are involved in the goal setting and home programme development processes, it is easier for the home programmes to become embedded in daily routine and context, influencing their ease of implementation. The subsequent gains achieved are then more meaningful, functional and generalisable to other contexts and environments (Novak et al., 2009; Novak and Cusick, 2006). However, while there is unanimous agreement that collaborating with and empowering caregivers of children with CP is essential, this is not always satisfactorily performed by therapists (Milton et al., 2019). This was found to be evident in contexts and settings in the United Kingdom. While there is little available literature to confirm whether the same could be said in South African primary healthcare settings, due to the significant challenges encountered by healthcare professionals in these environments a similar conclusion could be drawn. It is agreed within the literature that parents and caregivers' voices must be heard in the process of compiling home programmes. Further research is also recommended to understand best practice, parent experiences and participation in daily activities regarding home programmes for children with CP.

Down syndrome

Down syndrome is the most common genetic disorder that has an influence on foetal and child development. Down syndrome is a contributing cause to intellectual disability. Children with Down syndrome present with delayed development in motor areas as well as in terms of their emotional and social development. There can be associated medical conditions with the diagnosis of Down syndrome, including cardiac and thyroid difficulties as well as leukaemia and gastrointestinal difficulties (Ciucurel and Iconaru, 2012; Diamandopoulos and Green, 2018). The symptoms of Down syndrome include: cognitive and socioemotional impairments; delayed development of both gross and fine motor skills as well as reduced independence engaging in functional activities (Diamandopoulos and Green, 2018). Due to these difficulties influencing their participation in meaningful life activities, children with Down syndrome are frequently recipients of occupational therapy interventions. As well as supporting intervention in functional activities in the home environment, home programmes can address the symptoms described above. Walker et al. (2020) described that it is important for occupational therapists to support the parents, caregivers and families of children with Down syndrome with home programmes. However, despite the importance of home programmes for this population being acknowledged, there is limited research available proving insight into the use of home programmes with children with Down syndrome (Walker et al., 2020). It has been reported that specific programmes that have been previously designed have not necessarily targeted children with intellectual disability or Down syndrome (Wuang et al., 2013). As described above, primary caregivers are important collaborators. For home programmes to be effective for children with Down syndrome, practitioners need to understand the strengths and needs of each child and each family. It would be valuable for occupational therapists therefore to conduct more research to gain further insight into the design and implementation of home programmes and their use with children with Down syndrome (Walker et al., 2020).

For children receiving occupational therapy services in the public sector, literature promotes that for occupational therapy home programmes to be most effective, primary caregivers need to be active participants in the design and implementation of home programmes (Bester, 2020). These home programmes aimed at improving the occupational performance of children are frequently prescribed to the primary caregiver (Bester, 2020). However, caregivers are frequently not involved in these processes

(Jansen van Vuuren et al., 2021). This negatively influences their ability to apply the home programmes in their home environments (Angeli et al., 2019). This reduced collaboration may be the case throughout the public sector and will be most observable in primary care facilities. Occupational therapists working in these facilities face significant barriers to effective service delivery and insufficient support from existing systems and structures to work towards providing accessible services to those requiring them (Ned et al., 2017). Understanding and acknowledging these areas is important for the therapists working together with both the children and the caregivers to improve upon home programme development and prescription within these settings (Fewster et al., 2020). The uniqueness of the South African healthcare landscape needs to be considered and further researched to inform guidelines and best practice regarding home programme development for occupational therapists. Together with the lack of collaboration occurring in the clinic environment, primary caregivers also encounter barriers and facilitators within their environment that influence their ability to meet all the demands of caregiving effectively (Fewster et al., 2020). While the importance of the use of home programmes within the public healthcare setting in South Africa is well-documented (Jansen van Vuuren et al., 2021), there is less available information relating specifically to challenges, facilitators, and barriers to the implementation of home programmes and the experiences of primary caregivers (Bester, 2020; Mthembu et al., 2016; Reddy et al., 2019).

1.2.6 Barriers and facilitators when implementing home programmes

Barriers

Caregivers caring for children with difficulties are faced with many burdens and experience difficulties inherent in the role of caregiving, which may be unique to the role of caring for a child (Reddy et al., 2019). These burdens and difficulties significantly impact the quality of life of primary caregivers and could be said to contribute to these individuals experiencing burnout. This negatively influences their ability to effectively meet the demands of caregiving demands and activities expected of them (Bester, 2020).

While the children for whom they are caring present with different difficulties, there are common shared experiences and difficulties inherent in fulfilling the caregiving role (Bester, 2020). A barrier influencing the experience of implementing home programmes

may be related to the **formulation** of the home programme itself. While the usefulness and potential contribution of home programmes is acknowledged, there is little literature supporting **clinical guidelines** to support professionals' ability to formulate and prescribe effective home programmes (Davies, 2016). Novak and Cusick (2006) identified a need for this and formulated a model for the development of ideal home programmes, emphasising the importance of collaborative relationships and mutually agreed goals between the occupational therapist and the caregiver. Following the ideal model is not always feasible in clinical settings and **the lack of collaboration** influences the individuality and family-centredness of the home programme (Davies, 2016). This is a barrier to effective and easy **implementation** of prescribed home programmes by primary caregivers as the lack of inclusion of the family unit in its development may not always facilitate easy implementation in the family's routine. It has been outlined in other literature that the nature of caring for a child with a disability is a barrier to the caregiver being able to engage in full-time employment (Bester, 2020). This, together with the all-encompassing **demands of caregiving** and contextual barriers within the environment can negatively influence the caregivers' sense of self and identity (Reddy et al., 2019).

The significant **demands inherent within the role of caregiving** itself may serve as barriers to the implementation of home programmes (Davies, 2016). Primary caregivers face significant emotional, social and physical difficulties within their environments that reduce their capacity to engage in additional activities outside of their complex and demanding caregiving activities. Together with these demands and difficulties, caregivers can face reduced access to support structures, further influencing their emotional difficulties and burnout they may experience (Bester, 2020). This was found to be a commonality amongst caregivers in a variety of settings, contexts and environments. While there is literature available describing the demands and barriers influencing caregivers' engagement in caregiving activities, more research should be conducted into the barriers experienced by primary caregivers when implementing occupational therapy home programmes (Bester, 2020; Reddy et al., 2019).

Caregivers face **demands on their time** due to the demands inherent in caring for a child with disabilities (Bester, 2020). **Time-restrictions** together with demands placed on the physical environment of the home leave little availability within the daily routine of primary caregivers to implement and perform home programme activities (Angeli et al., 2019). The

unique factors and presentation of their child's disability contributed to the experiences and ability to meet the demands inherent in the role of caregiving. Primary caregivers describe the difficult behaviours, developmental delay and physical impairments present in their children's disability and the effect that managing these has on their quality of life (Woodgate et al., 2015). As well as managing the physical or emotional difficulties inherent in the disability, the ability to accept their child's diagnoses influenced the well-being of the caregivers and their ability to perform their caregiving duties (Nor et al., 2018). Understandably, when there is a lack of community and family support for primary caregivers caring for children with disabilities, it creates a consequential difficulty for the caregiver and adds to the emotional burden they experience in this role (Bester, 2020; Pretorius and Steadman, 2018). This lack of support may be due to traditional beliefs surrounding the cause of the child's disability and blame sometimes being attributed to child's parents or primary caregivers. This can lead to a lack of understanding and support from community and sometimes family members and subsequent reluctance to provide support to the child and the caregiver (Khan et al., 2020). This lack of support adds to the numerous challenges and difficulties primary caregivers face when caring for children with a disability (Bester, 2020). As has been outlined in the above paragraphs, meeting the demands of caregiving is emotionally taxing and creates a significant burden for the primary caregivers themselves. This burden is amplified by contextual barriers such as decreased access to crucial services and poor social support. Trafford (2023) outlines in a qualitative, descriptive study how reduced financial support available for caregivers caring for a child with a disability in South Africa often creates reliance among caregivers on a government grant.

It is widely acknowledged that caring for any individual with a disability or difficulty is demanding and creates a specific set of burdens and responsibilities.

Facilitators

Novak and Cusick (2006) outlined that any of the five components described in their model for development a home programme can be considered as a facilitator to home programme implementation. These include developing a collaborative relationship; setting mutually agreed goals; selecting therapeutic activities; supporting implementation; and evaluating outcomes.

Other supportive factors included resources in the community related to healthcare and education for the children in their care (Pretorius and Steadman, 2018). Primary caregivers caring for children with disabilities, further, described social support in the form of family care and collaboration, can reduce the burden primary caregivers experience (Davies, 2016). In a study conducted by Cloete and Obaigwa, (2019), it was found that the common experiences shared by primary caregivers, especially those caring for children with disabilities was a significant support and facilitator for them. It was found that when caregivers learn from people who have experienced similar challenges and difficulties, they are able to cope better with the difficulties they experience daily when caring for the child in their care (Cloete and Obaigwa, 2019). Another study by (den Besten et al., 2016) supported the view that along with shared experiences and commonality, support from other family members, members of the multidisciplinary team as well as the community at large was important. The theme of community support positively influencing the ability to care for a child with a disability was common among different sources of African and South African literature (Cloete and Obaigwa, 2019; den Besten et al., 2016; Pretorius and Steadman, 2018).

Any factor in the environment that reduces demand placed on primary caregivers may facilitate more available time and emotional capacity to implement occupational therapy home programmes. These factors could include reduced financial resources, time constraints due to employment and reduced access to physical and healthcare resources. The facilitators for implementing home programmes are largely described theoretically, with little available literature from the perspective of primary caregivers. Therefore, gaining insight into these facilitators from the perspective of primary caregivers could be valuable and contribute to develop formulating effective occupational therapy home programmes. It was found in a study by Woodgate et al. (2015) that the child's difficult behaviours, developmental delay and physical impairments present in their children's disability may play a role in the barriers and facilitators when implementing a home programme.

1.2.7 Conclusion

Occupational therapy aims to promote health and wellbeing through supporting engagement in meaningful and valuable life activities for people experiencing illness,

injury and disabilities. A significant client population that receives occupational therapy services is children with disabilities, their primary caregivers and their families. These occupational therapy services are aimed at facilitating improved engagement in meaningful and developmentally appropriate activities. Home programmes designed and prescribed by occupational therapists can be a useful therapeutic tool that can be a supplement to in-person therapy, especially in resource-constrained environments. Home programmes for children with disabilities can be effective, although this requires collaboration with primary caregivers throughout the design and implementation of home programmes. As well as involving primary caregivers in the design and implementation of home programmes, occupational therapists should understand the complex demands and burdens inherent within the role of caregiving.

Owing to the unique healthcare landscape of South Africa and the difficulties primary caregivers experience as a result, occupational therapy home programmes can be a valuable therapeutic tool to supplement the gains made in between infrequent therapy appointments. In the resource constrained environments that are South African primary healthcare settings, primary caregivers gain unique experiences through accessing occupational therapy services together with their experiences of completing caregiving activities.

CHAPTER 1.3: METHODOLOGY

1.3.1 Introduction

This chapter details the research design and specific steps followed by the researcher to conduct the study and collect and analyse the data. This insight aims to provide steps that can be replicated by subsequent researchers.

1.3.2 Study design

This study uses a descriptive qualitative study design, using a inductive research strategy. Descriptive qualitative research designs can be used to identify, describe and understand problems and experiences of populations or groups (Creswell and Creswell, 2018). Qualitative research methods not only provide insight into experiences of populations or groups but also allow the researcher to understand and describe the reasons and issues underlying these problems and experiences. These reasons and issues may be complex. Using qualitative research methods can provide insight into the complexity of these issues and what is currently happening for the research participants. Within a healthcare context, descriptive methods can be useful to determine issues or difficulties with a clinical practice or environment (Siedlecki, 2020). This study aims to explore facilitators and barriers influencing occupational therapy home programme implementation. To do this and to best use the data obtained to contribute to home programme development, it was thought most appropriate to gain an in-depth understanding of a small number of primary caregivers' experiences. Depth rather than breadth of information, as might have been achieved by quantitative methods, was felt to be most appropriate for this study (Siedlecki, 2020). Narrative, semi-structured interviews were used by the researcher to gain rich, in-depth and detailed information relating to the barriers and facilitators experienced by primary caregivers regarding occupational therapy home programmes (Creswell & Creswell, 2018; Denzin & Lincoln, 2018). Semi-structured interviews was chosen to be used in this study as this tool provides opportunities for flexibility during the interview process while also maintaining a level of consistency. Using a set of key questions that formed the main structured of the interview allowed the researcher opportunity to explore any information shared by the research participants that may have come up in answering one of these questions that would have seemed

particularly relevant or unexpected. The semi-structured nature of the interviews facilitated flexibility and the opportunity to explore other aspects in an empathetic way where participants felt comfortable. This may not be possible in a large-scale quantitative survey approach.

A thematic analysis approach was used to code and analyse the interviews. Thematic analysis is a specific method in which patterns, particularly within rich and in-depth data are identified, investigated and presented (Clarke and Braun, 2017). As this study was concerned with understanding the experiences of a limited number of primary caregivers implementing occupational therapy home programmes, using thematic analysis allowed the researcher to focus on developing a complex and nuanced understanding of the data and providing in-depth insights into the experiences of the research participants (Braun and Clarke, 2021). Using an alternative analytical approach, such as content analysis, would have put a greater emphasis on how experiences were described and the language used by the research participants, rather than what experiences were being described (Jaspal, 2020). For this study, it was decided by the researcher that it was most important and valuable to explore what the primary caregivers' experiences were and the reasons for these experiences.

1.3.3 Study setting

Specifically, the research was conducted at a public healthcare facility the Hillbrow Community Health Centre (CHC) in the Johannesburg Metro area. Initially, the researcher had proposed conducting research at more than one clinic, however despite attempting to the researcher was unsuccessful in gaining permission to do so. Through the National Health Research Database (NHRD) and Professor Shabir Moosa from the Research Committee of the Johannesburg Health District *(Appendix J)*, permission was gained for the researcher to conduct research solely at Hillbrow CHC. The researcher contacted the occupational therapist working at Hillbrow CHC to establish communication and subsequently met with the clinic manager. After the necessary documentation was sent to the clinic manager, an in-person meeting was set up to explain the study in detail and to ensure full understanding prior to participation. The clinic manager facilitated an introduction to the head of the rehabilitation department and all of the occupational therapists working within the

department. The head of department gave subsequent permission for the occupational therapist to be the researcher's first point of contact in the department, to communicate regarding the data collection procedure and research population. Clients attending occupational therapy services at Hillbrow CHC attend clinic for follow up appointments on a monthly or bi-monthly basis, which occurs at most South African primary healthcare facilities. This client population therefore makes use of home programmes to support therapeutic gains made in therapy. The frequent use of home programmes by primary caregivers made Hillbrow CHC a suitable site for conduction of this research study.

1.3.4 Participants

1.3.4.1 Population

The research population consisted of primary caregivers caring for children between the ages of zero to eight currently attending monthly outpatient occupational therapy services at a public healthcare facility, namely Hillbrow CHC.

1.3.4.2 Sample

The participants were sourced largely from primary caregivers of children receiving outpatient occupational therapy services, either individually or by attending therapy groups for cerebral palsy and Down syndrome. One of the primary caregivers described her child's condition as a spinal cord injury, however, the formal diagnosis was cerebral palsy as they attended the cerebral palsy clinic. The therapy groups at Hillbrow CHC took the form both of support groups for primary caregivers as well as therapy groups to provide activities to support functional engagement for the children with cerebral palsy and Down syndrome.

1.3.4.2.1 Sample selection

Eligibility criteria

Primary caregivers that met the following criteria were eligible for inclusion in the research sample:

a. Primary caregivers caring for children attending outpatient occupational therapy services at Hillbrow CHC.

b. Primary caregivers of children with mild to moderate physical, cognitive, psychosocial and/or emotional disabilities attending outpatient occupational therapy services at Hillbrow CHC were included (Reid et al., 2011).
c. Primary caregivers that were comfortable being interviewed in English or comfortable with being interviewed with the support of a translator and answering in-depth and qualitative questions.
d. Primary caregivers caring for children between the ages of six months to eight years old. Children with disabilities above six years old are eligible for continued support from the National Department of Health.
e. Caregivers who received and implemented an occupational therapy home programme over the time period of six months to a year were included.
f. Caregivers who received a home programme that was prescribed by the occupational therapist working at Hillbrow CHC that was verbal, handwritten or printed.

Exclusion criteria

a. Individuals involved in the care of children attending occupational therapy services who brought them to outpatient appointments but were not involved in direct implementation of occupational therapy home programmes were not eligible for inclusion in this study.

1.3.4.2.2 Sampling method

The researcher used purposive sampling methods to select the research sample. Purposive sampling methods allow the researcher to select specific participants to be included. This works to develop depth of understanding of the rich and nuanced experiences of the research participants (Campbell et al., 2020). The researcher utilised support from one of the occupational therapists working at Hillbrow CHC to identify potential participants from patients attending outpatient occupational therapy. The occupational therapist was made aware of the eligibility criteria for inclusion in the study and the participant information sheet was sent to the clinic.

1.3.4.2.3 Sample size

The sample was made up of 12 primary caregivers of children receiving occupational therapy services. The study aimed to recruit a homogenous sample of participants and

12 participants is enough to achieve data saturation, according to my understanding of Guest, Bunce and Johnson (Guest et al., 2006). By using 12 participants the researcher was able to achieve coding saturation (Neuman, 2014).

1.3.5 Procedure of data collection

1.3.5.1 Instrumentation

The data collection tool of the interview questions was developed from the existing literature and was circulated, for feedback and comments, amongst a group of occupational therapists with knowledge relating to home programmes and primary caregivers.

Prior to the start of the data collection process, the researcher obtained permission and consent from the following organisations and individuals:

1. The Ethics Committee of Wits University and the Occupational Therapy Department of Wits University. *(Appendix A: ethical clearance certificate)*
2. Faculty of health science assessor's committee seen in research protocol. *(Appendix B)*
3. The National Health Research Database: Research Committee of Johannesburg Health District. *(Appendix J: NHRD letter of approval)*
4. The primary caregivers, research participants, being interviewed. *(Appendix F: interview consent form)*
5. Permission for audio recording of interviews *(Appendix G: Example of consent sheet for audio recordings)*

1.3.5.2 Data collection process

Pilot study

Before starting data collection, the researcher conducted an exploratory study to ensure the quality and appropriateness of the questions to be used in the semi-structured interviews. A colleague and fellow classmate conducting qualitative interviews was interviewed as part of the pilot study to assess the appropriateness of the questions to be used in the interviews with participants. Two primary caregivers caring for children attending occupational therapy services at Hillbrow CHC were also included. Exploratory, or pilot, studies are a useful and important way to make sure that the data collection tools, in particular, are appropriate for the study and gather the

desired information in the most appropriate way possible. Pilot studies allow the opportunity to establish that the questions are understood by research participants and are sensitively worded. This means the interview questions will provide the important data and information from research participants in a comfortable and empathetic manner. This is particularly important when sensitive subjects are being discussed (Shakir and Rahman, 2022). Doing some preliminary analysis of the pilot study data also helps to ensure validity and rigour of research (Shakir and Rahman, 2022).

1.3.5.2.1 Data collection

The data was collected by the researcher over December 2023, January and March 2024 at Hillbrow CHC. In some interviews, the researcher had to rephrase or shorten some of the questions to facilitate ease of understanding and answering the questions, especially for participants who were not completely fluent in English. Rephrasing and shortening the questions supported and allowed the participants to answer the researcher's questions more easily. This rephrasing and shortening of questions was found to be a successful manner to support understanding in the pilot study. The pilot study provided useful insight into how the researcher's previously worded interview questions were not easily understood by the research participants. By thoroughly evaluating responses from the pilot study, it was found that by shortening and rephrasing some of the research questions, as was done with the second primary caregiver, the research participants were able to easily understand the questions and speak more freely in a more natural and comfortable manner.

The researcher conducted semi-structured interviews and used an audio recorder to record the interviews. Throughout the data collection process, the voice and audio recordings of the interviews were recorded onto a password-protected device that was only accessed by the researcher and the researcher's supervisor. An audio recorder and the researcher's laptop were used to record the audio of the interviews. The audio files from the audio recorder were transferred onto the researcher's laptop once the interview concluded and the original recordings were removed off the audio recorder. The interviews were then transcribed for coding and analysis by the interviewer. The interviews were then transcribed for coding and analysis by the interviewer, utilising a free transcription software. After the audio files were transcribed by the software, the researcher checked the transcriptions and removed all identifying data from the transcriptions.

1.3.5.3 Data management

The POPI act and the HPCSA General Ethical Guidelines for Health Researchers guided the management of data (Health Professions Council of South Africa, 2016; South Africa, 2013). This ensured that participants' information and rights were protected.

Interviews were recorded on the researcher's laptop and voice recorder. A consent form for recording can be found in Appendix G. Caregivers did not use their name but received a number e.g., participant 1 to ensure confidentiality. All the interview transcriptions were anonymised by ensuring the number assigned to each participant was applied throughout the interview.

Managing and storing data

Voice files were transcribed into text files for analysis of the data. The researcher transcribed the audio files of the interviews. The researcher used a basic software to transcribe the audio file to text and following this, the researcher listened to the interviews while refining and checking the transcriptions. Self-transcription as well ensuring opportunities to check the transcriptions supports the researcher's opportunity to immerse themselves in the data and the analysis process (Point and Baruch, 2023). A second reader was used to check that the transcription of the voice recordings was correct.

Data security and confidentiality

The researcher ensured that each participant was randomly allocated a numerical identifier that ensured anonymity. Confidentiality was also achieved by the removal of any identifying information from the interview transcriptions and audio recordings. As the primary caregivers who participated in the research care for children with difficulties, which would be considered a vulnerable population, extra care was taken to ensure that this vulnerable population is protected through anonymity of data.

Data sharing and access

The researcher transcribed the data from the audio recordings of the interviews. This was also saved on a password protected computer for controlled and restricted access, with only the researcher and her supervisor. Data was only shared by the researcher to the supervisor through the analysis of the transcriptions.

1.3.5 Data analysis

The researcher made use of a qualitative thematic analysis method to analyse and interpret the data (Braun and Clarke, 2021a). Atlas.ti software was used to assist with coding and thematic analysis. Version 23.3.0 (28730) of Atlas.ti was used by the researcher. Atlas.ti has been found to be a useful software to conduct data analysis as well as managing and storing the data. It is a well-established software package that has been specifically designed for analysing qualitative data. The benefits of storing and managing the data using software allows the researcher more time to effectively code and engage with the data (Soratto et al., 2020). Thematic analysis facilitated comprehensive insight into the data collected. A further benefit of thematic analysis is that it allowed for multiple different perspectives to be investigated for similarities and differences (Nowell et al., 2017). The researcher applied the six different phases of thematic analysis, including:

1) familiarising with the data by reading the interview transcripts;
2) generating initial codes through the use of manual means and Atlas.ti;
3) identifying themes in the data through the use of manual and paper-based means;
4) reviewing themes by evaluating their central organising concepts;
5) naming and defining themes; and
6) production of a report of the data.

By following the specific phases, the researcher was striving towards and reinforcing trustworthiness (Nowell et al., 2017). The analysis and interpretation of the data was conducted from December 2023 to April 2024. Checking of the thematic analysis was done throughout the process between the researcher and the researcher's supervisor. Similarities and differences in the researcher and supervisor's findings were discussed in depth. The analysis and interpretation of the data occurred at the researcher's home, and the University of the Witwatersrand.

1.3.6 Ethical considerations

Ethical clearance was obtained from the University of the Witwatersrand Human Research Ethics Committee (HREC) (Clearance number: M220837), found in Appendix A. The ethical principles outlined by the HPCSA were adhered to during the research process (Health Professions Council of South Africa, 2016).

Informed consent: All potential participants were fully informed of the nature of the study by reading an information sheet (Appendix E) and the researcher explained the details of the information sheet to each participant. There were no potential risks to being involved in the study and it was emphasised that participation was voluntary and withdrawal from the study would not be penalised.

Confidentiality: The researcher ensured that each participant was randomly allocated a numerical identifier that ensured anonymity. Confidentiality was also achieved by the removal of any identifying information from the interview transcriptions and audio recordings.

Dignity and Autonomy: The dignity and autonomy of the participants was maintained by obtaining informed consent prior to the interview process, by providing the participants with an information sheet regarding the study and ensuring that the participants understood it. The researcher actively involved the participants in the decision-making process regarding their involvement in the study (Kirchhoffer, 2019).

Beneficence and Non-Maleficence: After informed consent was obtained, the researcher made it clear to the participants that if they felt unable to continue through the duration of the study, they were able to withdraw from the study at any time and would receive no negative consequence. The researcher handled the sharing of information with empathy and had arranged for specific counselling support for the participants should they become upset or distressed during the interview (Pietilä et al., 2019).

Trustworthiness: Trustworthiness was ensured by the researcher by addressing the following components:

Credibility: The researcher made use of reflexive self-analysis to ensure credibility (Stahl & King, 2020). The researcher kept a journal throughout the research process with detailed daily entries. This ensured that the researcher was constantly reflecting on the research findings. This journal contributed to acknowledging and checking any personal biases that arose through the data collection and interpretation process. The researcher's supervisor conducted an independent analysis and the findings of this analysis were discussed and evaluated to ensure no personal biases.

Transferability: The researcher aimed to facilitate transferability of the data collected into different contexts (Stahl and King, 2020) by creating thick descriptions of the experiences of the research participants, and detailed descriptions of the primary healthcare setting in Johannesburg. It is hoped that this description and transparency

will support opportunities for identifying what, if any, findings can be transferred or generalised to other settings. However, there are multiple and complex differences between different contexts, environments and households. Some of these differences include household composition, social networks and broader socio-economic factors, which is challenging to accommodate in a study with a small sample size. Therefore, the transferability of the findings should not be taken for granted, especially due to the small sample size of this study. It is hoped, however, that some of the findings related to the manner of engagement with the occupational therapist are transferable across and within different healthcare settings.

Dependability: As an occupational therapist who has worked within the public healthcare sector and prescribed home programmes, the researcher could have a pre-existing frame of reference through which the data was viewed. The researcher therefore applied reflexive auditing throughout the process, facilitating a method to check the researcher's personal biases (Stahl & King, 2020). Reflexive auditing is a process whereby the researcher described and made clear her involvement in the decisions made in the research process and the influence of their personal biases on these decisions (Stahl & King, 2020).

Confirmability: Objectivity and a level of accuracy within the data was established by the researcher. As the researcher included 12 primary caregivers as participants within the study, coding saturation was reached, facilitating confirmability of the data (Stahl & King, 2020).

1.3.7 Conclusion

A descriptive qualitative research design was utilised to gain nuanced, in-depth understanding of the barriers and facilitators experienced by primary caregivers when implementing occupational therapy home programmes. Using semi-structured interviews allowed the interviewer to gain the nuanced and in-depth data required to answer the research question. This study sample was small in size but manageable for the researcher to conduct.

CHAPTER 2: SUBMISSIBLE MANUSCRIPT

This chapter follows the format of a manuscript prepared for submission to a journal. The manuscript has been submitted as an original research article to the South African Journal of Occupational Therapy.

2.1. Manuscript Details

This manuscript has been written in accordance with the South African Journal of Occupational Therapy submission guidelines (Appendix M).

2.2. Details of Author Contribution

The primary researcher in this study is Ella Topham.

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Acknowledgments, sources of funding and conflict of interest: No conflict of interest

Details of Author Contributions

CRediT terms	Ella Topham	Janine van der Linde
Conceptualization	X	X
Methodology	X	X
Formal analysis	X	X
Investigation	X	
Resources	X	
Data curation	X	X
Writing manuscript- draft	X	X
Writing manuscript- reviewing and editing	X	X
Supervision		X

2.3. Abstract

2.3.1. Background

The South African public healthcare system struggles with inequities and limited resources, impacting service delivery at primary healthcare facilities. Occupational therapists use home programmes to support children with disabilities, but caregivers face challenges in implementing them effectively. This study aimed to identify and

describe the facilitators and barriers caregivers experience when carrying out occupational therapy home programmes in primary healthcare settings.

2.3.2. Methods

A qualitative descriptive research design was used. Purposive sampling methods selected primary caregivers of children with mild to moderate disabilities receiving outpatient occupational therapy services and home programmes from Hillbrow CHC. Data were collected using semi-structured interviews. The data were then analysed using thematic analysis.

2.3.3. Findings

Five themes were identified: understanding of home programmes; family dynamics; child-centric factors; faith, strength and responsibility and the broader context. The findings showed that both individual factors and the interaction of environmental and intrinsic factors specific to the child and primary caregivers influenced home programme implementation.

2.3.4. Conclusion

This study explored the facilitators and barriers affecting primary caregivers' implementation of occupational therapy home programmes. While all caregivers successfully carried out the programmes, they highlighted how factors within their immediate and broader environments influenced the ease or difficulty of implementation. The findings suggest that household and socioeconomic factors played a larger role in implementation than the activities themselves, offering valuable insights for occupational therapists when working with children with disabilities and their caregivers.

2.3.5. Contribution/Implications for Occupational Therapy Practice

- Occupational therapists need to understand how barriers and pressures present in the larger environment influence the smaller household contexts of primary caregivers, in turn affecting the opportunity to implement home programme activities.
- It is recommended that occupational therapists facilitate practical and verbal demonstrations of activities as well as opportunities to ask questions. This, and actively discussing adaptations primary caregivers make, will support

collaboration with occupational therapists, contributing to the commitment to keep implementing the home programme.

- It is important for occupational therapists to understand how primary caregivers perceive their relationships with the clinic and occupational therapy services as this relationship frequently forms part of their support networks. This can further improve the collaborative relationships with primary caregivers.

2.4 Key words

Primary caregivers

Home programmes

Occupational therapy home programmes

Children with disabilities

Primary healthcare facilities

2.5 Article

2.5.1 Introduction

Evidence suggests that primary caregivers involved in implementing home programmes as an additional form of intervention experience challenges inherent in their caregiving role (Novak and Honan, 2019). Understanding how these challenges impact on caregivers' ability to implement home programme activities is therefore important for occupational therapists providing services. In South African primary healthcare settings, outpatient occupational therapy services are accessed only monthly. This is due to the reduced number of healthcare professionals and little time or resources available for more frequent appointments (Richards and Galvaan, 2018). Literature indicates home programmes are a valuable part of occupational therapy service provision for a variety of populations, especially in resource-constrained environments (Jejelaye et al., 2019). Home programmes can be used to support gains made in therapy between monthly appointments at primary healthcare facilities. However, little is known about challenges experienced when home programmes are implemented in South African contexts (Davies, 2016). This led to the research question: 'What are the barriers and facilitators experienced by primary caregivers of children to implementing a home programme prescribed by an occupational therapist in a public healthcare setting?' Investigating the barriers and facilitators primary caregivers experience and the influence of these on their ability to perform required activities is important for occupational therapists providing services. Understanding these barriers and facilitators could contribute to improved development and prescription of home programmes in South African public healthcare settings.

2.5.2 Literature Review

2.5.2.1. Occupational Therapy Intervention in Primary Healthcare in South Africa

The South African healthcare system continues to be affected by historical inequity, with poor distribution of resources and health professionals at all levels of care, resulting in over-burdened and under-resourced healthcare facilities within the public sector (Coovadia et al., 2009). Clinics and community health centres (CHCs) are the primary

healthcare facilities accessed by 80% of patients in South African communities. Services are constrained by time and resources, reducing the quality of interaction between healthcare professionals and service users (Conradie et al., 2022). These constraints affect the development of person-centred, contextually appropriate services for children, especially when working closely with primary caregivers and, when relevant, other family members (Jansen van Vuuren et al., 2021).

Authors agree that professionals such as occupational therapists working within primary healthcare settings encounter significant challenges influencing their ability to provide high quality, effective care to service users. The shortage of occupational therapists within primary healthcare facilities and the public sector as a whole means there is currently a ratio of 1: 11 000 (Conradie et al., 2022; Richards and Galvaan, 2018). This shortage of healthcare professionals means that service users are frequently only given short, (30 to 45 minute), monthly therapy sessions, influencing the quality of services provided. Clients accessing services at primary healthcare facilities include adults recovering from injury or adults with disabilities. Children with disabilities as well as their caregivers and families frequently access services on primary level. As described in one study it was found that visits made by clients to clinics provided little time or resources for lengthy or in-depth discussions between occupational therapists and primary caregivers. One way of providing support to caregivers in between monthly appointments at clinic facilities, is for occupational therapists to develop home programmes that are designed to be used in the home environment and support gains between appointments (Msengana et al., 2019).

2.5.2.2. Occupational Therapy Intervention with Children with Disabilities in South Africa

Occupational therapy intervention with children with disabilities focuses on improving children's functional performance in activities such as activities of daily living (ADLs), their ability to explore and engage with their physical, social and cultural environments to improve their ability to engage with and participate in different life roles (Novak and Cusick, 2006 ; Novak and Honan, 2019). As children are embedded within the family unit and participation in family activities is important interventions usually seek to involve primary caregivers throughout the therapy process.

2.5.2.2.1. Role of Primary Caregivers

Primary caregivers of children with disabilities face significant demands, including accessing occupational therapy. However, benefits for both children and caregivers, such as emotional and physical support gained from therapy appointments, can offset these challenges. Research by Cloete and Obaigwa (2019) in Kenya found that therapy supported caregivers in adjusting to their child's diagnosis. Understanding caregivers' experiences, stressors and burdens of caregiving is vital for healthcare professionals. These factors impact their ability to provide care for their child (Bester, 2020 Pretorius and Steadman, 2018). Literature emphasises the importance of collaboration between caregivers and therapists to enhance services and promote caregiver wellbeing(Novak and Honan, 2019). For family-centred care, therapists must understand caregivers' daily routines and home environments (Beckers et al., 2020; Novak, 2011). Acknowledging the positive aspects of caregiving further improves therapy outcomes (Demers, 2022). While this collaborative approach is well-documented in Australia and the United Kingdom, other countries may have different healthcare landscapes with dynamics affecting these relationships.

2.5.2.3. Home Programmes

2.5.2.3.1 Importance of Home Programmes and use with Children with Disabilities

Home programmes are therapeutic activities carried out in the home environment to work towards achieving wellbeing and functionality outcomes (Novak and Berry, 2014). Effective home programmes aim to integrate therapeutic activities into daily contexts and routines of individuals and their families. This focus can promote family-centred care (Novak, 2011). Home programmes can be verbal or written, sometimes supported by pictorial or video instructions, and are tailored to individual clients (Novak and Cusick, 2006). Involving clients, particularly primary caregivers, in designing home programmes supports alignment with family goals and daily routines, making them easier to implement and more meaningful (Bester, 2020; Smidt et al., 2020). For children, primary caregivers play a key role in the development and implementation of the programme, which increases motivation and improves the likelihood of success (Finet, 2016; Novak and Berry,

2014).The literature shows that how a programme is implemented is more influential than the activities themselves, highlighting the importance of caregiver involvement (Novak and Berry, 2014).

Cerebral Palsy (CP) is a neurological disorder affecting 2 in 1000 births, impacting motor development and potentially influencing cognitive, socio-emotional, and language skills (Donald et al., 2020). Children with CP often require caregiver assistance for daily activities due to their complex physical and developmental needs. Home programmes can support these children and their families, helping with engagement in daily activities (Novak and Honan, 2019). Most research on home programmes for CP focuses on interventions like constraint-induced movement therapy, primarily in countries like Australia, the United Kingdom, and the United States(Milton et al., 2019; Novak et al., 2013, 2009; Novak and Cusick, 2006; Novak and Honan, 2019; Smidt et al., 2020) . However, findings on caregiver involvement in these programmes are mixed, with limited research in South African primary healthcare settings. While there are studies on caregiver experiences with CP in South Africa (Bester, 2020), few explore primary healthcare settings. Children with Down syndrome also benefit from occupational therapy intervention due to delays in motor, emotional, and social development (Diamandopoulos and Green, 2018). Although Walker et al.(Walker et al., 2020) highlight the need for family support through home programmes, research in this area remains limited. The lack of targeted home programmes for children with intellectual disabilities like Down syndrome may explain the scarcity of studies on this topic (Wuang et al., 2013).

2.5.2.3.2. Use of Home Programmes in the South African Context

Studies from the global North show that home programs can improve motor function and daily activity engagement, especially for children with CP in Australia (Beckers et al., 2020; Milton et al., 2019; Novak, 2011; Novak and Berry, 2014; Novak and Cusick, 2006; Novak and Honan, 2019). Key factors influencing effectiveness include therapist guidance, consistent practice, incorporating the programme into daily routines, and caregivers managing competing demands. Similar findings were reported by British occupational therapists (Milton et al., 2019). Though research is limited, home programmes are an important aspect of occupational therapy in South Africa's public sector, particularly for outpatient rehabilitation clients (Jansen van Vuuren et al., 2021). They are often used as

support for children with disabilities and their families, but there is little literature on their design, implementation, and effectiveness (Russell et al., 2016).

Home programmes designed to improve children's occupational performance are often prescribed to primary caregivers (Bester, 2020), yet in South Africa, caregivers are not actively involved in designing these programs (Jansen van Vuuren et al., 2021), affecting their ability to implement them effectively (Angeli et al., 2019). The unique South African healthcare landscape needs further research and study to guide best practices for home programme development for occupational therapists, especially those working in resource-constrained settings. Caregivers also face environmental barriers that hinder their ability to manage caregiving demands (Fewster et al., 2020), with limited information on the challenges and experiences specific to home programme implementation (Bester, 2020a; Reddy et al., 2019).

There are no South African national guidelines for home programme development, implementation, or prescription (Smidt et al., 2020). Home programmes at the primary healthcare level are often generic, which can create caregiver strain rather than providing support (Bester, 2020). This suggests current practices lack client- or family-centeredness and are not yet contributing to social transformation or primary healthcare goals. Occupational therapists at the primary level in South Africa face large client loads and limited resources (Ned et al., 2020). Without structural changes, home programmes will not yet reach their potential, limiting their contribution to transformative occupational therapy practices.

2.5.3.3. Barriers and Facilitators in Implementing Home Programmes

Barriers

Caregivers of children with disabilities often face shared challenges, such as limited time and the demands of managing the home environment, making it difficult to implement home programmes (Angeli et al., 2019; Bester, 2020). Novak and Cusick (2006) highlighted the need for clinical guidelines to create effective home programmes, emphasising collaboration between therapists and caregivers. While this is an ideal model, the implementation of this is not always feasible in practice, especially in resource-constrained public healthcare settings in South Africa. The clinical guidelines may also

not consider the emotional, social, and physical difficulties caregivers face, including managing challenging behaviours and developmental delays in their children(Bester, 2020). Additionally, a lack of community and family support further exacerbates their emotional burden, with some caregivers facing stigma due to traditional beliefs about the cause of disability (Khan et al., 2020). Financial constraints in South Africa often force caregivers to rely on government grants, and caregiving responsibilities, especially reduced availability of time can prevent them from engaging in full-time employment (Bester, 2020; Trafford, 2023). These pressures, along with other contextual barriers such as financial or resource limitations in the home or broader community environment, can negatively impact caregivers' self-identity and well-being, a challenge common across various settings (Reddy et al., 2019)

Facilitators

Social support from family, healthcare teams, and communities can ease the burden on primary caregivers, allowing more time, physical and emotional capacity to implement occupational therapy home programmes (Davies, 2016). Research suggests caregivers cope better when learning from and sharing with others with similar experiences (Cloete and Obaigwa, 2019), which may apply to home program implementation as well. Support from family members and healthcare professionals has been highlighted as supportive for primary caregivers in studies, particularly in African and South African contexts (den Besten et al., 2016). The five components of the model home program by Novak and Cusick (2006) – collaboration, goal setting, activity selection, implementation support, and outcome evaluation – are described as facilitators for effective programme implementation, though there is limited research from the caregivers' perspective. There is also limited research on the use and implementation of this model in the South African context. Due to limited research available in this area, the aim of this study is to explore and describe the barriers and facilitators experienced by primary caregivers in the implementation of occupational therapy home programmes in a public health care setting.

2.5.3 Research methods and design

2.5.3.1 Study design

This study uses an descriptive, qualitative study design based on an inductive research strategy. Descriptive qualitative research designs can be used to identify, describe and understand problems and experiences of populations or groups (Creswell and Creswell, 2018).

2.5.3.2. Participants, population and sample

The research population consisted of primary caregivers caring for children with disabilities between the ages of two to eight currently attending outpatient occupational therapy services at Hillbrow CHC on a monthly basis. Participants were recruited using purposive sampling methods. The Hillbrow CHC occupational therapist identified participants-based on the eligibility criteria for inclusion. The study aimed to recruit a homogenous sample of participants and 12 participants is enough to achieve data saturation, according to my understanding of Guest, Bunce and Johnson (Guest et al., 2006). All participants attending outpatient groups were invited to participate in the research study on the day they were attending clinic. Twelve primary caregivers of children with CP or Down syndrome consented to participate and according to Neuman (2014) this was sufficient to achieve coding saturation.

2.5.3.3. Research tools and data collection

Interview questions were developed from the existing literature and piloted amongst a group of occupational therapists with experience of home programmes. The semi-structured interview tool allowed participants to expand on their ideas and to share relevant experiences which did not directly relate to the questions asked. The data was collected by the researcher over December 2023, January and March 2024 at Hillbrow CHC. The researcher used an audio recorder for audio recordings of the interviews. The researcher removed all identifying data from interview transcripts manually. The audio recordings were transcribed identifying data utilising the free transcription software Descript (Liyanagunawardena, 2019). The researcher confirmed the transcriptions were correct by manually checking them against the audio recordings. All files and transcriptions were saved onto a password-protected device for data protection.

2.5.3.4 Data analysis and interpretation

Atlas.ti software (Soratto et al., 2020)was used to assist with coding and thematic analysis between December 2023 to April 2024. Thematic analysis allowed multiple different perspectives to be investigated for similarities and differences which were explored throughout the six phases of data analysis and writing: 1) familiarising with the data by reading the interview transcripts; 2) using Atlas.ti and manually generating initial codes; 3) identifying provisional themes in the data; 4) reviewing themes by evaluating their central organisjng concepts; 5) naming and defining themes; and 6) producing a research report which included this journal article for submission (Nowell et al., 2017). Further data was collected by the researcher keeping a journal with detailed entries, that enabled reflection on the research findings and reflexive self-analysis to check for personal biases (Stahl and King, 2020).

Coding was checked by the research supervisor who did a second analysis for comparison of findings. Coding saturation was reached during the analysis stage after several rounds of coding interviews, facilitating confirmability of the data (Stahl and King, 2020). The researcher found that coding saturation was reached when no new codes were generated (Braun and Clarke, 2021b).

2.5.5. Ethical considerations

Ethical clearance was obtained from the Human Research Ethics Committee at the University of the Witwatersrand, Johannesburg prior to contact with research participants (ethics certificate clearance number: XXX). Further permission was gained from the Johannesburg Health Research Committee, the clinic and rehab department managers from Hillbrow CHC. Participants signed consent for participation and for audio recordings of the interviews.

2.5.4. Findings

2.5.4.1. Demographic and participant information

All twelve interviewees were mothers of the children receiving occupational therapy services at Hillbrow CHC, and nine were caring for other children in addition to their child with disabilities. Two interviewees were formally employed and four were self-/informally employed. The remaining six were unemployed (Table I) but all the primary caregivers described having limited financial resources.

Table I: Demographic information of research participants (primary caregivers)

	Relation-ship to Child	Age	Employment Status	Marital Status	Other children at home	Family structure and living arrangement
1	Mother	43	Self-employed (informal) Piece jobs	Married	Daughter, 8	Husband living with participant and children. Sharing a flat.
2	Mother	40	Unemployed	Married	Daughter, 20	Husband living with participant and children. Living in a house.
3	Mother	47	Self-employed (informal) Selling at market	Married; husband not living in South Africa	Child, 19 Child, 16	Participant and children living alone. Living in a room in a shared flat.
4	Mother	46	Unemployed	Married	Son, 22 Daughter, 14	Husband living with participant and 2 children. Living in a flat.
5	Mother	30	Self-employed (informal) Piece jobs	Unmarried	Daughter, 8	Participant living with sister and niece, together with her 2 children.
6	Mother	39	Employed (formal)	Unmarried	None	Participant living alone with children. Renting room outside a house.
7	Mother	48	Employed (formal)	Unmarried	None	Participant living alone with child. Renting a room in a flat.
8	Mother	31	Unemployed	Unspecified	None	Participant living alone with child. Renting a shack.
9	Mother	41	Unemployed	Married	Son, 11	Husband living with participant and children. Renting a room inside a house.
10	Mother	38	Self-employed (informal) Piece jobs	Unspecified	Daughter, 19 Son, 15	Participant living with children.
11	Mother	37	Unemployed	Married	Child, 14 Child, 12	Husband living with participant and children. Living in a flat.
12	Mother	30	Unemployed	Unmarried	Daughter, 10 months	Participant living together with boyfriend and two children. Boyfriend recently left. Living in a flat.

The study included primary caregivers 12 children: five aged 2-4 years, six aged 4-6 years, and one aged 8. These ages indicate significant developmental dependence, regardless of disabilities. The children had cerebral palsy (n=5), Down syndrome (n=4), and mixed or unspecified diagnoses (n=3). Of the 12, five were fully dependent in all ADLs, four were independent in some activities but fully dependent in others, two were partially independent, and one was mostly independent but needed support with toileting.

These levels of impairment and disability, create significant demands in providing care due to their increased muscle tone, described as “stiffness” by some participants, poor head and trunk control and reduced fine motor skills. Of the four children with cerebral palsy, three were completely dependent on their caregivers for engagement in activities of daily living. The increased tension within these children’s muscles also influenced how easily the primary caregivers could implement certain home programme activities, such as stretching, positioning and tummy time activities.

Table II: Demographic information relating to the children

Child of participant	Gender	Age	Diagnosis	Length of time receiving OT services from Hillbrow CHC	Level of dependence on primary caregiver
1	Female	6	Unspecified (by primary caregiver; medical diagnosis: Cerebral Palsy)	5 years	Dependent for all ADLs and play. Dependent for sitting and positioning.
2	Female	6	Cerebral Palsy	5 years	Able to complete changes in position independently. Dependent for all ADLs and play.
3	Female	5	Down Syndrome	4 years	Independent in dressing, feeding, washing, mobility and play. Requires support for toileting.
4	Male	2	Down Syndrome	2 years	Independent in sitting. Dependent for all ADLs and play.
5	Male	3	Down Syndrome	3 years	Partially independent in mobility (cruising) and feeding. Dependent for dressing, washing, play and toileting.
6	Female	2	Down Syndrome	9 months at Hillbrow CHC Previously attended Zoa	Partially independent in mobility (cruising). Dependent for all ADLs and

				clinic for 1 year	play.
7	Female	6	Unspecified (by primary caregiver; medical diagnosis: Cerebral Palsy)	5 years	Partially independent in mobility (crawling) and feeding. Still requires support. Dependent for dressing, washing, play and toileting.
8	Male	3	Cerebral Palsy	2 years	Dependent for all ADLs and play. Dependent for sitting and positioning.
9	Male	8	Cerebral Palsy	6 years	Dependent for all ADLs and play. Dependent for sitting and positioning.
10	Male	3	Cerebral Palsy	2 and a half years	Dependent for all ADLs and play. Dependent for sitting and positioning.
11	Male	5	Cerebral Palsy	4 and a half years	Dependent for all ADLs and play. Dependent for sitting and positioning.
12	Male	4	Described as spinal cord injury by primary caregiver (medical diagnosis Cerebral Palsy)	3 years	Independent in sitting, crawling and feeding. Dependent for dressing, washing and toileting.

2.5.4.2. Home programme activities

The primary caregivers described home programme activities as including stretching, positioning, strengthening, ADLs, play, sleep, communication, concepts and tummy time (Table III).

Table III: Home programme activities described by research participants

Categories	**Characteristics**	**Frequency of activity described by participants (total n=12)**	**Percentage**
Types of activities and exercises	Stretching	8	66.67

	Positioning	11	91.67
	Strengthening	4	33.33
	Activities of daily living	12	100
	Play	5	41.67
	Sleep	4	33.33
	Communication	11	91.67
	Concepts	3	25
	Tummy time	6	50
Classification of home programmes according to the Occupational Therapy Practice Framework (4th Edition)	Activities of daily living (ADLs)	12	100
	Health management	12	100
	Play	5	41.67
	Rest and sleep	4	33.33
	Education	3	25
	Social participation	11	91.67
Duration of implementation	6-12 months	1	8.33
	1-2 years	1	8.33
	2-3 years	2	16.67
	3-4 years	3	25
	4-5 years	1	8.33
	5-6 years	4	33.33
Frequency of implementation	3x daily	2	16.67
	Daily	6	50
	Multiple times weekly	3	25
	Unspecified	2	16.67

Primary caregivers of children with Down syndrome did not report increased muscle stiffness, but positioning activities were included in the home programme to improve head control and mobility. All caregivers emphasised activities supporting engagement in ADLs, highlighting the focus on meaningful family activities. Eleven of the 12 caregivers also received activities focusing on communication, reinforcing the programme's emphasis on supporting caregiver-child engagement. Most participants (n=8) received stretching activities for increased muscle tone, while others focused on play (n=5), sleep (n=4), and

developmental concepts (n=3). Tummy time (n=6) and strengthening (n=4) were recognised as supporting the child's muscular development.

2.5.4.3. Themes

Interviewees identified factors that either facilitated or hindered their ability to implement home programme activities. Notably, few of the challenges described were directly related to the activities themselves. Thematic analysis revealed that these factors were related to the household, child, and caregiver, which were further broken down into five key themes. It is important to remember that these themes occur within a broader socio-economic context of social and economic instability.

Table IV: Summary of six key themes and description of categories and codes

Themes	Categories	Codes
Understanding of home programmes	I can do this	Exercises are doable, I'm encouraged
		Exercises can be enjoyable
		Demonstration of exercises
	I understand and so I can adapt	Individualised home programmes
		Doing and learning something new
		Adapting exercises as needed
Family dynamics	Caregiving is demanding	My child is not like other children
		Emotional demands of caregiving
		Responsibilities of caring for children with disabilities
		Physical demands of caregiving
	Family duties and responsibilities	Other children to care for
		Participation in ADLs
		Support from other people
		Lack of support from family and other people
		Family dynamics
	Environmental demands and resources	Time constraints
		Participation in ADLs
		Physical resources within home environment
	Personal challenges	Personal and/or physical difficulties
		Physical demands of caregiving
		Emotional demands of caregiving
Child-centric factors	Child's internal drive and motivation	Child is pushing back or doesn't want to
		Sense that child is trying
	Influence of impairments	Exercises can be difficult
		Physical impairments of child
Faith, strength and responsibility	Duty to do my best for my child	Only I can do what must be done
		Sense of duty and responsibility
		I want my child to be happy
	Trying to do the right thing	I'm managing/doing my best

		Perseverance and putting in effort to make things work
		I'm trying
	Understanding contributing to responsibility	Knowledge, learning, understanding and acceptance
		Doing and learning something new
		Trust in what I'm told by healthcare professionals
	Progress as a source of motivation	Home programmes making a difference
		Seeing progress and improvement
	Belief	Faith and strength
The broader context	Resources and support	Monthly appointments
		School as a resource
	Reduced accessibility	Accessibility challenges
		Transport difficulties
	Finding things challenging	Life is tough, things are hard
		In this alone
		Financial strain
Overall impact of home programmes	Positive experiences with home programmes	Exercises are doable, I'm encouraged
		Satisfaction with home programmes
		Exercises can be enjoyable
	Types and description of home programmes	Caregivers' description of home programmes
		Home programme activities-stretching
		Home programme activities-positioning
		Home programme activities-ADLs
		Home programme activities-tummy time
	Individualised activities and adaptation	Adapting exercises as needed
		Individualised home programme activities
		Demonstration of exercises

Theme 1: "They tell me these things that I must keep doing": understanding of home programmes

Every participant interviewed said they understood the home programme activities, how to do them and why they were implementing them. How the activities were demonstrated at the clinic also facilitated their implementation and, when necessary, adaptation within the home environment. They described how a combination of trusting the occupational therapists and the way the information was conveyed helped them to understand why the activities were necessary and how to do them. This then enabled their occasional adaptation of the activities. One participant described adapting the recommendation to support the child's drinking, by using a tablespoon instead of an adapted cup.

> **Participant 11:** ***"****Yeah, sometimes just like with a spoon, with a spoon drinking water. Instead of using a cup, we tried using a cup which was cut open. It didn't work for us, so we ended up using a spoon. And a spoon is working better for it. It's working better more than this."*

This understanding of how and why the home programme activities needed to be implemented was vital for facilitating progress and improvement in their children's impairments.

Eight participants described the activities as enjoyable and easy to implement at home. Being given exercises that were easy to understand and engage with, as well as to adapt, facilitated primary caregivers' ability to implement the home programme activities effectively.

> **Participant 6:** ***"****Even if sometimes she's stubborn, but she enjoys some of the exercises. Before she was failing even the clap hands. Then they said I must teach her how to clap hands, how to laugh, how to hold things."*
>
> **Participant 8:** *"…the other ones are easy. […] it's hard but not that hard."*

Theme 2: Family dynamics.

Participants detailed their household composition and the roles of family members. While caregiving was primarily seen as the participants' responsibility, some described how household dynamics supported home programme implementation. Siblings were often active contributors; for example, one participant shared how her child's siblings helped teach activities outside the home programme, like coughing and clearing the child's throat. She saw this as increasing the impact of the home programme and reported with pride:

> **Participant 10:** "*Because now he can do some of the things that I didn't teach him…You can say [speaking to her child] "cough." He can say...[imitates coughing noise]...If you say "kick" you can kick someone. So I didn't teach him. So they help me a lot."*

In this instance other family members' involvement and support brought an additional appreciated perspective to the home programme's implementation and effectiveness. In

contrast, however, caring for other children, for example supporting them with homework, sometimes made doing the home programme activities more challenging.

These responsibilities and expectations placed on the participants, together with the physical and emotional demands of caregiving created a sense of pressure and demand that participants had to navigate. Supporting their child with disabilities and meeting their complex needs influenced the amount of time available to successfully complete the other necessary activities within the household. In addition, the child's physical, socioemotional and/or cognitive impairments created a specific, and sometimes challenging interplay between the members of the family. In these situations, the complex pressures were described as reducing the quality of the home programme activities implemented.

Theme 3: "Sometimes he just doesn't want to": child-centric factors.

Ten of the twelve primary caregivers described how factors specific to their child influenced how easily they were able to implement home programme activities. Some children's physical impairments created the greatest challenge but in four a further difficulty was communication and reduced cognitive and socioemotional functioning.

The home treatment programmes for children with CP primarily focused on physical improvement. While impairments and physical difficulties affected participation in meaningful activities, intrinsic factors such as perceived motivation supported caregivers in implementing activities. Four participants emphasised how their child's willingness to engage made it easier to carry implement the activities. This motivation was linked to the child enjoying the activities, and caregivers highlighted the importance of ensuring the child was happy and relaxed, particularly before activities like stretching or tummy time.

> **Participant 10:** *"So I feed him first, I make him happy first. When I see he's okay now, then I can do exercises."*
>
> **Participant 11:** *"If he's smiling, you know he likes it. If he doesn't smile…then I know that mm-mm this is wrong."*

Participants described how challenging it was to implement occupational therapy home programme activities when the child resisted or did not want to engage in the activities. Distraction or the child's reduced ability to focus for long periods was also highlighted by two primary caregivers as a barrier to consistent and effective implementation of activities.

Theme 4: Faith, strength and responsibility.

The participants described that as well as a sense of duty and responsibility to provide the best possible care for their child with disabilities, as well as other child(ren) within the household, calling on supportive resources such as faith and personal beliefs helped them navigate this challenging landscape. For three participants, their faith provided the strength required to care for their child, implement the home programme and serve as a source of resilience to overcome further challenges.

Participant 6: *"Yes, but with God nothing is impossible."*

Participant 12: *"God never doing wrong."*

Participant 9: *"But at the end of the day, we can't judge. God knows best."*

For a larger number of participants, a sense of duty and responsibility to provide the best possible care for their child served a similar function as that of faith and belief, but whatever the reason, inherent within the role of primary caregiver was a sense of duty to carry out all necessary activities to the best of their ability. It was evident in the interviews that these included home programme activities.

All the participants were mothers of the children attending occupational therapy and they articulated the importance of motherhood in defining how they faced challenges and responsibilities.

Participant 4: *"Because I am a mother, I put it on the line for the kids."*

Participant 9: *"Because if you love your child and want change, you will try anything."*

When asked if she had found any of the home programme activities difficult or challenging, participant 4 responded:

Participant 4: *"As a mother you're not supposed to do like that."*

When examined in context, this quotation demonstrates how participant 4 had a deeply entrenched sense of duty to provide the best possible care for her child, which extended to holding only positive perceptions of the home programme.

Throughout their narratives, there was a sense of resilience amongst the participants as it was clear that navigating how to care for a child with complex physical, psychosocial and emotional needs is demanding. Having to also engage in other activities related to running the household adds to the pressure. This sentiment was clear in several

interviews, but the primary caregivers also described how their internal belief systems and other personal factors supported navigation of this challenging and complex landscape.

Theme 5: ‘‘It’s hard, it’s complicated’’: the broader context.

Balancing their child’s complex needs with those of the household, and income generation was already challenging for interviewees, prior to having to navigate the additional activities of the home programme. This necessitated adapting routines.

> **Participant 7:** ***“****Because I am coming from work and I’m tired. I want to stretch my child. I try to finish cooking. And then I do the bathing. After that I want to start stretching.”*
>
> **Participant 2:** *“For her [child]? I can create time for herself. I do less for home.”*

Issues present within the larger community exacerbated household challenges. All participants faced accessibility challenges, particularly in accessing educational and physical resources for their children’s care. Only five children attended school—either a crèche or special needs school—which provided both learning for the children and valuable knowledge for caregivers, especially regarding feeding and nutrition. This supported management of the child’s daily routine. Knowledge from sources beyond the clinic also had a positive impact. Additionally, with meals provided at school, caregivers had more time for home programme activities, and two caregivers found that school-based learning aided in implementing these activities.

The financial strain experienced by participants was described in general terms as *“things being hard”* or *“it’s a lot”*. Half of the primary caregivers were unemployed, and others were only informally employed on a part-time basis and few received financial support from partners or husbands. This made it challenging for the primary caregivers to travel to and from clinic monthly as well as attending appointments with specialists.

All participants reported having limited time for the occupational therapy home programmes. The six economically active participants mentioned that work and travel left little time to implement focused home programme activities. Despite this, caregivers found ways to make time by adjusting their routines and observing their child's willingness, ensuring even short periods were used to maintain consistent engagement in the activities.

Participant 6: *"Yes but I try and I pray to God to give me a time, even if I come to work tired, if I find her not sleeping yet, I try to find that 30 minutes to do something."*

Participant 7: *"You want to have your time and with time they're [the activities] easy."*

Time, knowledge and practical skills all contributed to primary caregivers implementing home programme activities easily and effectively. Another factor that was described less frequently but formed part of the tapestry of the broader social environment was community perceptions of disability. Two participants described how negative beliefs influenced the response of their extended families and other community members towards their child. One of these participants described how this contributed to her sense of isolation.

Participant 11: *"For us, the disadvantage that we have is that when you have a child like him, families, they do distance themselves."*

While feeling isolated did not appear to have a direct influence on how she put home programme activities into practice, it was a contributing factor to the challenges and difficulties she experienced, and the pressure she felt under.

The rich and complex narratives provided by the participants showed that the contents of the home treatment programmes were well understood, and that the caregivers felt supported by the occupational therapists, other specialists and professionals that they engaged with. The key issues which served to either facilitate or limit the extent to which they could implement the home treatment programme were related instead to other factors, often linked to their social, domestic and economic environment (Table V).

Table V: Facilitators and barriers to home programme implementation

	Facilitators	*Barriers*
Household	Other able, willing and supportive adults within the home environment.	Other children (frequently younger children) in the household need care.
	Semi-regular source of income and finances.	Few financial resources.
	Easier access to knowledge and physical, practical resources, such as those found at school.	Reduced access to school and similar resources.

Caregiver	Strong supportive social networks.	Social isolation and feeling alone.
	Small periods of flexibility within household routines to implement occupational therapy home programmes.	Time spent on other activities in and outside of the household.
	Sense of duty and responsibility to provide the best possible care for their child.	Feeling that because of this duty, caregiver alone can implement home programme activities.
	Resilience, faith and strength.	Physical and emotional demands of caregiving.
	Flexibility in managing household responsibilities to support making discrete pockets of time available.	Multiple competing responsibilities related to maintaining wellbeing of family members.
	Feeling overwhelmed by child's physical and psychosocial impairments and level of dependence.	Seeing progress and improvements in child's functioning and engagement because of home programme activities.
	Feeling that despite environmental challenges home programme activities are doable.	Finding that some home programme exercises can be difficult.
Child	Perceived willingness and internal motivation to participate and engage in home programme activities.	Physical impairments create challenge to engage in home programme activities.
	Distractibility and difficulty focusing on the home programme activities.	Focused attention and active engagement in home programme activities.

Theme 6: Overall impact of home programmes

It was common among this specific sample of women that they reported seeing progress in their child because of the home programme implementation. This increased their motivation to continue with the home programme. For one participant the most significant progress the home programme facilitated was her son and husband developing a meaningful relationship, for example laughing together, and how he was better able to participate in important family activities. Other participants described how seeing their child progress and develop made them happy and contributed to a sense of positivity.

> **Participant 5: "***Well, I think, oh, you're happy. Like, if you see your kids starting to crawl, to learn to walk, it makes you happy, you see. That's, yes, it makes you happy."*
>
> **Participant 6:** *"Yes, they give me better exercises. I try it at home and I see the changes."*

Table VI: Types of progress seen because of home programme implementation (sub-themes of theme 6)

Types of progress and improvements seen	Descriptions from primary caregivers
Sitting posture, head and neck control	**Participant 12:** ***"****He's sitting nicely and crawling."* **Participant 10:** ***"****The other thing is when he's putting a pillow on his tummy, trying to balance his head, trying to exercise his head."*
Control of voluntary, goal-directed movement	**Participant 4: "***The difference you see when you are teaching, even to hold things. Yes. Last time I don't know to hold, if you are giving the thing, don't want, if you are giving the thing, don't want. But for now she knows how to hold and put in the mouth."* **Participant 5: "***He's just improving. Like he's improving in everything. The walking, the talking, everything about him. Like you can see everything. And I can see he's listening nicely. Everything*."
Fine motor skills	**Participant 7:** *"She can open it [her hand]…she can open it sometimes"*
Expressive language; verbal communication	**Participant 9:** *"Yeah, it's made a difference in a way that we can talk, we can laugh, we can communicate and you know."*
Understanding familial roles and relationships	**Participant 9:** ***"****He can say thank you. So he knows even my name. He calls me by my name. When he's in that mode of communicating, he will shout my name. He will call his brother [insert his brother's nickname]. That is his brother. Instead of saying [full name], he'll say [nickname]."*
Increased independent engagement in ADLs	**Participant 12:** ***"****He's eating himself. He's feeding himself."*
Improved ability to engage with concepts and demonstrate understanding verbally or by writing	**Participant 2:** "She's able to make ABCD up to Z and make their words and to know how those other things sound."

Ability to communicate needs, wants and emotions	**Participant 2:** *"Then she can be able to say something. Let's watch a movie. After the movie, like cartoons, then what did you learn? Because we normally do that for school. What did you learn from that? She can be able to say."*
Increased meaningful communication and mutual engagement within family unit and household.	**Participant 9:** ***"****Yeah, it's made a difference in a way that we can talk, we can laugh, we can communicate and you know."*
Ability participate meaningfully and play in parent and sibling relationships.	**Participant 7:** *"No, me I'm not tired. [she says] Mama, come play. Mama, let's go. Mama let's play."*

2.5.4 Discussion

There were few significant differences in how primary caregivers of children with cerebral palsy, Down syndrome and other unspecified diagnoses described their experiences. As a result, the discussion focuses on overarching ideas, with differences identified where they occur.

The home programme and its implementation exist at the centre of this interaction as demonstrated by Figure 1 below.

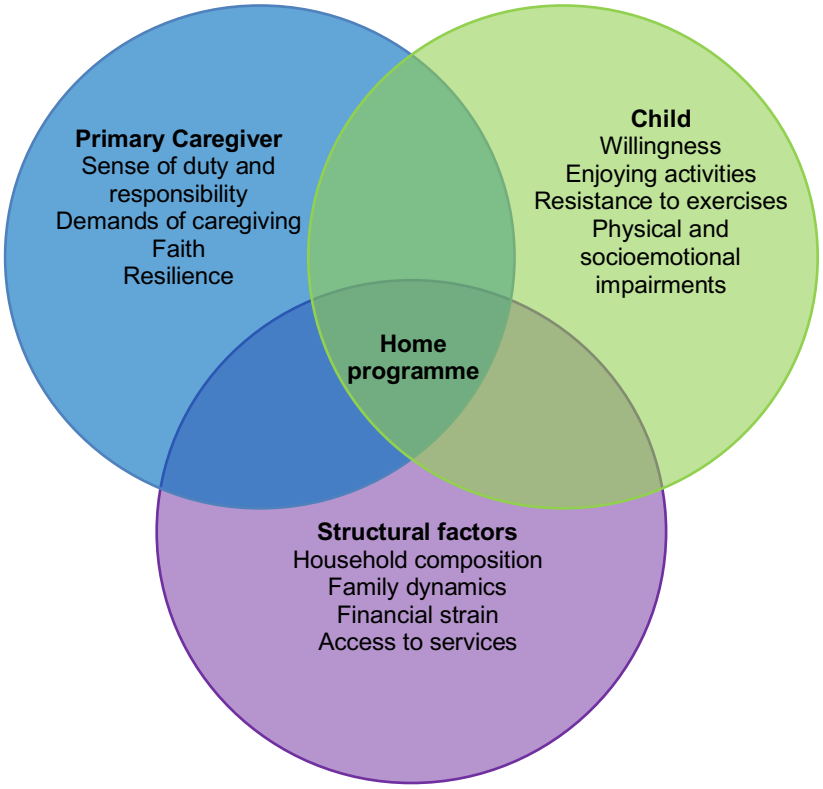

Figure 1: Interplay of factors

Understanding this interaction is important for occupational therapists developing and prescribing home programmes to understand. Foundational to this understanding and interplay of factors is the understanding of the interaction between person, environment and occupation, described in the person-occupation-environment model (Novak and Cusick, 2006a). Understanding how these three elements interact and the transactive nature between them, described in the model, can support understanding of the interaction of factors described by primary caregivers in this study. The primary caregivers in this small sample demonstrated an ability to implement the home programme despite challenges in their environments and supported by facilitators.

Multiple factors impacted on how primary caregivers implemented occupational therapy home programmes. The degree to which these served as barriers or facilitators came through the complex interplay of the factors with each other as well as the broader socioeconomic and healthcare context. Home programmes are implemented where these factors intersect. It was described by Novak at el. (Novak et al., 2009) that the effectiveness of home programmes can be influenced by the physical and social

environment, which was evident in the factors described by the participants in this study. To implement home programmes consistently, the primary caregivers need a consolidated understanding of the activities prescribed and how to do them, which was demonstrated by all participants.

Literature shows that involving primary caregivers in home programme development and implementation enhances effectiveness, but limited research exists on programme characteristics influencing family engagement (Beckers et al., 2020). Household composition, however, played a key role. Primary caregivers who received help from other household members with domestic tasks or the programme itself found it supportive, as it allowed more time for home programme activities. Time was a crucial factor for family engagement, but when caregivers had young children or lacked support, it significantly reduced their available time and energy. Despite this, all caregivers adapted their daily routines to create small opportunities for programme activities in short periods of time, reflecting both a solid understanding of the activities and how the programme integrated into their daily lives. This aligns with literature on designing home programmes that are embedded within a family's daily routine and context (Novak, 2011; Novak and Berry, 2014). The interaction between primary caregivers, children and the wider household environment influenced how programmes were implemented, but the home programmes themselves also made a difference to the children's participation in meaningful and important activities within the family unit. This symbiotic progress was observed in measurable outcomes, such as the child's physical functionality, voluntary control of movements, gross and fine motor skills and postural control and level of independence in daily activities. It is well-documented how home programmes can be as effective as therapist-delivered interventions to contribute to achieving health and functionality goals (Novak, 2011; Novak et al., 2009; Novak and Honan, 2019). However, just as important but less easily quantified was progress in children's communication and ability to engage meaningfully with their primary caregivers and family. This improvement, increased caregivers' motivation to navigate challenges to implementing the home programme.

Limited financial resources and difficulties in accessing education and healthcare also impacted on how the home programme was implemented, but much more significant was the amount of time available to primary caregivers. This directly influenced how they

implemented home programme activities as they had to balance multiple responsibilities, often within and outside the home. The physical and emotional demands of providing care for children with disabilities while still meeting other demands also required honing and developing a sense of resilience. A sense of duty and/or faith contributed in varying degrees to caregivers' resilience and perseverance in consistently implementing home programme activities. Again, visible progress in their child's functioning and engagement in daily activities and recognising that it was because of their efforts made it more manageable to navigate these challenges and continue to draw on personal resources to carry out the home programme.

Strong support networks were an important facilitating factor for caregivers and occupational therapists were frequently described one of these, due in part to their longitudinal relationship with the caregivers and children. Within resource-limited environments the primary caregiver and child often receive services from several occupational therapists, however as children may receive services at the same facility from a few months old, knowledge and understanding can still develop over time between primary caregivers and occupational therapists. This continuity of care, not necessarily with individual professionals but with occupational therapy services, meant the home programmes were prescribed by professionals with a strong understanding of the caregiver and child. This relationship also supported participants to feel able to independently make changes to the home programme when they felt these were necessary. This longitudinal relationship can afford the collaboration between occupational therapists and primary caregivers that has been described in literature as important to facilitate successful home programme implementation (Novak, 2011; Novak and Cusick, 2006). That they felt, and were, able to do this, and shared these changes with the occupational therapists reflects an understanding of the nuances of their child's needs, the objectives of the home programme and a sense of ownership over how to implement it.

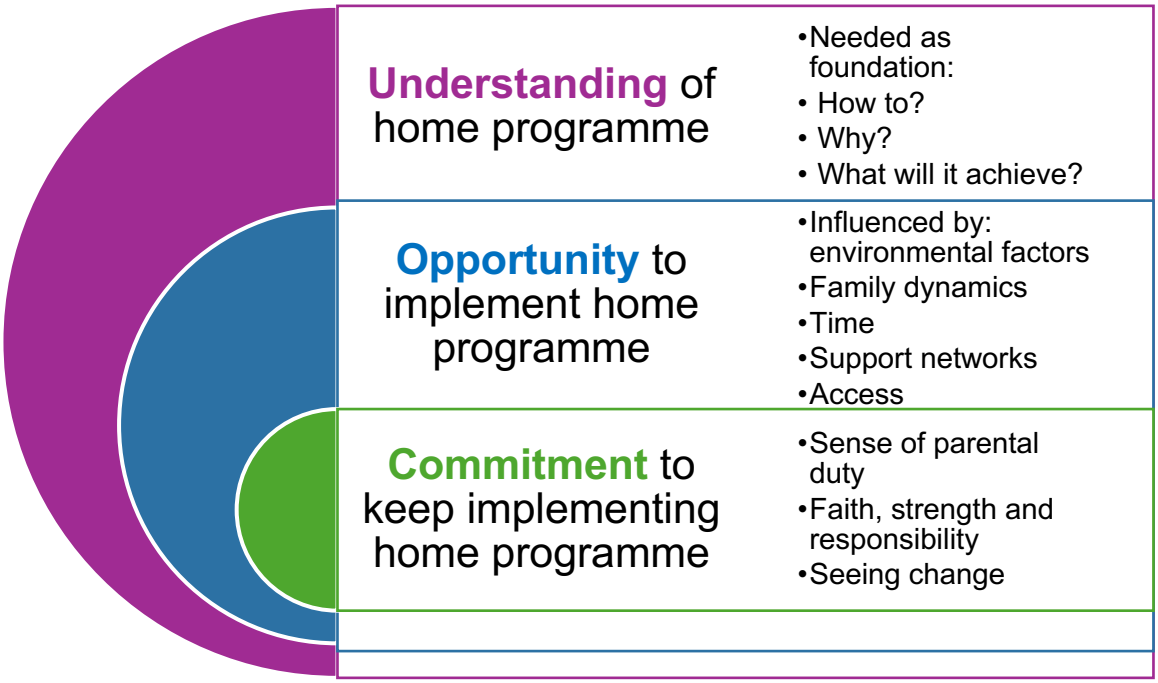

Figure 2: Elements of successful, long-term and effective home programme implementation.

Figure 2 illustrates how connected elements of home programme implementation work together to improve the children's functionality and skills, as valued by primary caregivers. Central to this is caregivers' understanding of the home programme's goals, the purpose of each activity, and how to carry them out. As noted in theme 1, all participants showed a clear understanding and commitment to the activities. While barriers impacted the participants' opportunity to implement it, the other elements were well-established in this sample. Caregivers' adaptations to their routines enabled continued implementation, contributing to commitment, progress and effectiveness of the home programme.

The effectiveness of the home programmes was evident through the progress reported by the children's primary caregivers. This effectiveness was influenced by the factors in the five themes and their interaction. All participants in this sample faced challenges to varying degrees, yet the caregivers successfully implemented the activities, leading to progress. The programmes' effectiveness may have influenced other factors, as caregivers' motivation grew with the progress seen, which likely strengthened their resilience to overcome continued challenges in their home and community.

Occupational therapists are well positioned to understand the interconnections between the caregiver, child and their environment. Because the primary caregivers understood the purpose of the home programme exercises, they were able to increase the potential effectiveness of the programme by adapting how activities were implemented to create an achievable balance between the child's needs and the resources available. This consolidated understanding demonstrated by the participants in this small sample aligns with what is well-established in literature as being important for successful home programme implementation within the home environment (Beckers et al., 2020). In this study the monthly clinic appointments appeared to have significantly contributed to all the primary caregivers' implementation of home programmes. In contrast, for some participants the household environment and broader socioeconomic context were also helpful but for others they created the main challenges to consistent and effective implementation over a prolonged period.

2.5.5 Conclusion

This study explored barriers and facilitators experienced by primary caregivers implementing home programmes prescribed by occupational therapists at Hillbrow CHC. All primary caregivers managed to implement the programmes but described what made it easier or more difficult, and how they adapted the activities and their timing to make the most of their available resources. This insight showed how their domestic, cultural and socioeconomic environments had more influence over facilitating or limiting implementation of activities than the actual exercises themselves. As participants understood the purpose of the activities as well as how to do them, they were able to adapt them when necessary. This, and the progress they observed in their children, helped primary caregivers overcome barriers which might otherwise have reduced their ability or motivation to continue over the long-term. Facilitators and barriers to implementing home programmes are shaped by the broader context of primary caregivers' and their children's lives. Home programmes are influenced by factors specific to the child, caregiver, and home environment. While some facilitators and barriers align with existing literature, others are specific to the South African context, particularly challenges within the broader social environment and accessibility issues in individual

households. Occupational therapists' skills support home programme development that considers the reality daily living, but this study demonstrates the importance of supporting primary caregivers adapt activities when needed. This requires mutual knowledge sharing. Long-term clinic relationships make occupational therapists key within primary caregivers' support networks, offering opportunities to collaborate on refining home programme design and implementation in primary healthcare settings.

2.5.6 Recommendations

- Conducting further research together with depth from qualitative studies in this area would provide a strong evidence base for development of policy and guidelines for clinical practice.
- Guidelines for the development of home programmes appropriate to the complex healthcare landscape of South Africa are necessary. These guidelines could serve to inform occupational therapy practice as well as policies within the National Department of Health.
- Occupational therapists need to understand how barriers and pressures present in the larger environment influence the smaller household contexts of primary caregivers, in turn affecting the opportunity to implement home programme activities. It is recommended that occupational therapists facilitate practical and verbal demonstrations of activities as well as opportunities to ask questions. This, and actively discussing adaptations primary caregivers make, will support collaboration with occupational therapists, contributing to the commitment to keep implementing the home programme.
- It is important for occupational therapists to understand how primary caregivers perceive their relationships with the clinic and occupational therapy services as this relationship frequently forms part of their support networks. This can further improve the collaborative relationships with primary caregivers.

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The authors would like to acknowledge the participants who participated in this study as well as Hillbrow CHC for the support of the facility.

2.5.8 Competing interests

The authors declare that they have no financial or other associations that may have inappropriately influenced this study.

2.5.9 Authors' contributions

This research was conceptualised as an action of the researcher for the achievement of her Master's of Science in Occupational Therapy.

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2.5.11 Data availability

The raw data is not publicly available for this study.

2.5.12 Disclaimer

The views and opinions expressed in this article are those of the authors and do not necessarily reflect the position of any affiliated institution of the authors.

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CHAPTER 3: SYNTHESIS

This chapter discusses the strengths and limitations of this study, and provides recommendations for future research, policy development and clinical application.

3.1. Introduction

This study's objectives were to identify and describe the barriers and facilitators primary caregivers experienced when implementing occupational therapy home programmes in a public healthcare setting. By interviewing 12 primary caregivers caring for children with disabilities attending Hillbrow CHC and using thematic analysis to analyse the data, the barriers and facilitators were identified. However, the barriers and facilitators were not only identified as discrete individual factors but rather interconnected factors at play within the individual household contexts of primary caregivers as well as the sociopolitical context of the broader community. The complex interplay of the barriers and facilitators was shown to affect the primary caregivers' opportunity to implement the home programme activities.

3.2 Strengths and limitations of study

3.1.1. Strengths

This study utilised a qualitative, descriptive research methodology. This methodology and sample size was appropriate to effectively answer the research question as it facilitated nuanced and in-depth understanding of the experiences of primary caregivers implementing occupational therapy home programmes for children in their care.

There is already existing knowledge on primary caregivers' experiences and their role, and this study builds on and expands this knowledge. However, as there is little already known about primary caregivers' experiences relating specifically to home programmes, this study has generated new knowledge by providing insight into the facilitators and barriers experienced by primary caregivers when implementing occupational therapy home programmes within primary healthcare settings, it has also considered and acknowledged the unique and complex South African healthcare landscape.

3.1.2. Limitations

As this study was conducted at only one site, in a specific urban setting and with a small sample size, transferability of the results generated from the study is limited. The results may not be applicable to different healthcare settings and contexts. This study describes a homogenous sample of participants at one clinic and transferability could be improved by including more clinics. While the sample can be described as homogenous as they all attended the same clinic, an element of heterogeneity is present as the primary caregivers were caring for children of different ages and developmental stages. This may have been a limitation on the interpretation of the data. When choosing a sample, the different ages and developmental stages of the primary caregivers' children attending the clinic was not considered as a potential influencing factor. In hindsight, it should have been addressed and should be considered as a limitation. Due to the small sample size, there could be reduced diversity and perspective amongst the participants of the study. While this study gained a rich and in-depth understanding of primary caregivers, a broader perspective could be gained through further research.

3.3 Recommendations

Further research into this topic is recommended. By expanding and including a variety of research settings, with larger sample sizes both increased depth and breadth of understanding can be achieved, and experiences of different caregivers including men.

Conducting this further quantitative research together with depth from qualitative studies in this area would provide a strong evidence base for development of policy and guidelines for clinical practice.

Guidelines for the development of home programmes appropriate to the complex healthcare landscape of South Africa are necessary. These guidelines could serve to inform occupational therapy practice as well as policies within the National Department of Health. The guidelines described by Novak and Cusick (Novak and Cusick, 2006) could provide the basis for the development of more applicable guidelines to the South African context. These guidelines describe the steps of optimal home programme implementation as: 1) develop collaborative relationships with primary caregivers; 2) set mutually agreed goals; 3) select therapeutic activities; 4) support implementation and 5) evaluate

outcomes (Novak and Cusick, 2006). This model was developed in 2006, and a more recent model that is more applicable to the South African context should also be considered.

Occupational therapists need to understand how barriers and pressures present in the larger environment influence the smaller household contexts of primary caregivers, in turn affecting the opportunity to implement home programme activities. It is recommended that occupational therapists facilitate practical and verbal demonstrations of activities as well as opportunities to ask questions. This, and actively discussing adaptations primary caregivers make, will support collaboration with occupational therapists, contributing to the commitment to keep implementing the home programme.

It is important for occupational therapists to understand how primary caregivers perceive their relationships with the clinic and occupational therapy services as this relationship frequently forms part of their support networks. This can further improve the collaborative relationships with primary caregivers.

3.4 Implications for occupational therapy

Occupational therapists, especially those working within the public sector and primary healthcare facilities, need to understand how barriers and pressures present in the larger environment influence primary caregivers. This influence affects the household context of primary caregivers and this, in turn affects the opportunity to implement home programme activities.

It is important for occupational therapists to facilitate practical and verbal demonstrations of home programme activities as well as opportunities to ask questions in the children and primary caregivers' monthly appointments. This, and actively discussing adaptations that primary caregivers make to home programme activities will support collaboration with occupational therapists. This collaboration is not only recommended for best practice of home programme design and implementation but will contribute to the primary caregivers' commitment to keep implementing the home programme.

Occupational therapists should understand how primary caregivers caring for children with disabilities perceive their relationships with the primary healthcare facility and occupational therapy services accessed. This relationship is valued by primary caregivers and frequently forms part of their support networks. Understanding and emphasising the

value of this relationship will only further improve and contribute to the collaborative relationships with primary caregivers.

3.5. Main Findings

It was evident from the interviews conducted with the participants that the barriers and facilitators were related to intrinsic factors within both the primary caregiver and the child. It was reported by the primary caregivers that both their internal motivation and the perceived levels of motivation of the child were influencing factors on how the home programme activities were implemented. The primary caregivers also reported how significant their internal belief systems, sense of duty and responsibility to provide the best possible care for their child were to facilitate the implementation of the occupational therapy home programme.

As well as these intrinsic factors, extrinsic factors both within the immediate household environment and the broader socio-economic context either facilitated or hindered how the primary caregivers were able to implement occupational therapy home programmes effectively. The dynamics of each household, such as caring for other children and meeting the demands of household management activities including meal preparation, cleaning and washing served as barriers to implementing the home programme activities easily and effectively. This, together with some of the primary caregivers being formally employed meant that time was less available in the primary caregivers' day to implement the home programmes effectively. Time was something described by the primary caregivers as a significant facilitator or barrier to home programme implementation. With more time available, primary caregivers found it easier to implement the home programme activities. However, despite reduced time available in large, discrete periods, the primary caregivers' internal sense of duty and responsibility meant that they found whatever small periods of time there was available and to build the home programme activities around these other activities. Support networks in various forms were identified as an important facilitator for implementing home programmes by the primary caregivers. While some primary caregivers described support from extended family and other social networks, the support received from the occupational therapists and the facility of the CHC overall was described by all of the participants as important and beneficial. Interestingly, very few of the barriers described by primary caregivers related to the home programme activities

themselves. Eleven of the twelve participating primary caregivers reported that the home programmes contributed positively and made a difference for their child, and by extension, themselves. This related to seeing improvement in their children's impairments and overall engagement. The progress and improvement in the child's physical impairments as well as their ability to engage in meaningful and important family activities was identified by primary caregivers as a source of motivation to continue implementing occupational therapy home programme activities. This motivation and positive influence contributed not only to their ability to continue implementing home programmes but to their resilience in navigating the challenges and pressures of their home and broader contexts. Interestingly, while Down syndrome and cerebral palsy have different presentations and areas of difficulty and the intervention can be different, the information about home programmes, barriers and facilitators did not differ significantly based on the child's diagnosis.

While this may have been due to the small sample size and the young age of the children with Down syndrome, this finding is perhaps related to how few barriers and challenges experienced by primary caregivers were related to the home programme activities themselves. The participants described how they found it relatively doable to implement home programme activities. It was either factors specific to the child, such as resistance or willingness or factors specific to the caregiver, such as physical and emotional fatigue that facilitated or hindered how effective their implementation of home programme activities was. The home programmes included activities related to support for activities of daily living, positioning, stretching and tummy time. Primary caregivers reported that they felt able to adapt and make changes to home programme activities if they felt it necessary. This ability to adapt and make changes to the home programme activities reflects an understanding of why implementing the home programme activities is necessary and important for their child.

3.5. Conclusion

This study set out to identify and describe the barriers and facilitators experienced by primary caregivers when implementing occupational therapy home programmes. These home programmes were prescribed by occupational therapists working at Hillbrow CHC and aimed to support both the child receiving services and the primary caregiver. Perhaps

of most importance, it was found that the facilitators and barriers described by the primary caregivers, do not exist in isolation. They exist within a larger context but also interact with one another. This interaction and intersection of the factors specific to child, caregiver and home environment as well as the facilitators and barriers had the greatest level of influence on how effectively the occupational therapy home programmes were implemented by primary. This transaction is what is already well-understood by occupational therapists in their practice. However, as well as working to understand this interaction of factors, occupational therapists need to facilitate a relationship with and empower primary caregivers with understanding of what they're doing and why, regarding home programme implementation. This understanding is reflected in the primary caregivers' ability to adapt and change home programme activities when necessary. Supporting the primary caregivers' ability to understand and independently adapt home programme activities will work towards developing a more effective and balanced working relationship between the primary caregivers and the occupational therapists providing the home programme. This will work to support, refine and contribute to more effective home programme design and implementation in primary healthcare settings.

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APPENDICES

Declaration: Student's contribution to article(s) and agreement of co-author(s)

I, Ella Topham, student number 831320, declare that this Thesis/Dissertation/Research Report is my own work and that I contributed adequately towards research findings published in the article(s) stated below which are included in my Thesis/Dissertation/Research Report.

Signature of Student: 

Date: 25/02/2025

Name of Primary Supervisor: Dr Janine van der Linde

Signature of Primary Supervisor: 

Date: 25/02/2025

Agreement by co-authors: By signing this declaration, the co-authors listed below agree to the use of the article(s) by the student as part of his/her Thesis/Dissertation/Research Report. In cases where the student is not the 1st author of a published article, the primary supervisor must explain (under comments) why the student is entitled to use the paper for his/her degree purposes.

Article 1:

Title:

Journal name, year, volume and page numbers:

Authors	Name	Signature	Date
1st author	Ella Topham		25/02/2025

2nd author	Dr Janine van der Linde		25/02/2025

Comments by primary supervisor:

The primary supervisor supports the submission of the article and the above agreement.

Appendix A: Ethics Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG	HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research and Innovation)

TO:	Ms E Topham School of Therapeutic Sciences Department of Occupational Therapy Medical School University E-mail: 831320@students.wits.ac.za
CC:	Supervisor: Dr J van der Linde <Janine.vanderLinde@wits.ac.za> and <HREC-Medical Research Office@wits.ac.za>
FROM:	Mr Iain Burns Human Research Ethics Committee (Medical) Tel: 011 717 1252 E-mail: Iain.Burns@wits.ac.za
DATE:	2023/05/24
REF:	R14/49
PROTOCOL NO:	**M220837** (This is your ethics application reference number. Please quote it in all enquiries, oral or written, relating to this study.)
PROJECT TITLE:	*The barriers and facilitators experienced by primary caregivers when implementing Occupational Therapy home programmes within a primary healthcare setting*

Please find attached the Clearance Certificate for the above project. I hope it goes well and that an article in a recognized publication comes out of it. This will reflect well on your professional standing and contribute to Government funding of the University.

MSWorks2000/Iain0007/Clearscan.wps

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

R49 Ms E Topham

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M220837

NAME: **(Principal Investigator)**	Ms E Topham
DEPARTMENT:	School of Therapeutic Sciences Department of Occupational Therapy Medical School University
PROJECT TITLE:	*The barriers and facilitators experienced by primary caregivers when implementing Occupational Therapy home programmes within a primary healthcare setting*
DATE CONSIDERED:	2022/08/26
DECISION:	Approved unconditionally
CONDITIONS:	
NOTE:	If contact information regarding student study participants is required, please contact the Registrar's office - <Nicoleen.Potgieter@wits.ac.za>
SUPERVISOR:	Dr J van der Linde
APPROVED BY:	GB Penny Dr GB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	2023/05/24

This Clearance Certificate is valid for 5 years from the date of approval. An extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office secretariat on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to submit details to the Committee. **I agree to submit a yearly progress report**. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in **August** and therefore reports and re-certification will be due in the month of **August** each year. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).

Signature of Principal Investigator _____ Date _____

Appendix B: Research Protocol

CANDIDATE'S SURNAME: **TOPHAM**	FIRST NAME/S: **ELLA**	STUDENT NUMBER: **831320**
CURRENT QUALIFICATIONS: **BSC OCCUPATIONAL THERAPY- WITS UNIVERSITY (2017)**		
TEL: **0826160125**	CELL: **0826160125**	E-MAIL: **831320@students.wits.ac.za** / FAX: **N/A**
DEGREE FOR WHICH PROTOCOL IS BEING SUBMITTED: **MSC OCCUPATIONAL THERAPY**		
PART-TIME OR FULL-TIME: **PART TIME**	Sex: **F**	M
FIRST REGISTERED FOR THIS DEGREE:	TERM: **1**	YEAR: **2022**
DEPARTMENT: **OCCUPATIONAL THERAPY**		
TITLE OF PROPOSED RESEARCH: **THE BARRIERS AND FACILITATORS EXPERIENCED BY PRIMARY CAREGIVERS WHEN IMPLEMENTING OCCUPATIONAL THERAPY HOME PROGRAMMES WITHIN A PRIMARY HEALTHCARE SETTING**		
CANDIDATE'S SIGNATURE: 	DATE: **17/06/2022**	
SUPERVISOR 1 (NAME & SURNAME): Dr Janine van der Linde	100% Supervision	
SUPERVISOR'S QUALIFICATIONS: PhD		
SUPERVISOR'S DEPARTMENT: Occupational Therapy		
SUPERVISOR'S ADDRESS / TEL / E-MAIL: Janine.VanDerLinde@wits.ac.za 011-727-3701		

SYNOPSIS OF RESEARCH:

Introduction and justification for study: Home programmes are a useful and important supplementary therapy tool used by occupational therapists in all settings. For children receiving occupational therapy services at a primary healthcare level, home programmes are often prescribed to the children's primary caregivers. While there is literature available on the experiences of primary caregivers inherent in the role of caregiving, there is less literature available on the specific barriers and facilitators relating to the implementation of these home programmes. By contributing to this gap in the available literature, this study could potentially contribute to the development of effective home programme development and prescription by occupational therapists, especially in primary healthcare settings.

Aim: To explore and describe the barriers and facilitators experienced by primary caregivers in the implementation of occupational therapy home programmes in a public health care setting.

Proposed methodology: The proposed methodology of this study is a qualitative methodology with a descriptive qualitative study design.

Expected outcomes: The expected outcomes of this research are results of narrative interviews describing the barriers and facilitators experienced by primary caregivers when implementing occupational therapy home programmes.

WITS ETHICS NOT REQUIRED:	Yes No	IF Y SUPPLY ETHICS CLEARANCE CERTIFICATE AS ATTACHMENT AND INCLUDE ETHICS NUMBER HERE:
WITS ETHICS PENDING:	Yes No	
WITS ETHICS APPROVED:	Yes No	
(circle appropriate symbol)*		
***Please note the final human ethics clearance certificate or animal ethics certificate must be available prior to starting research**		

As supervisor/s, I/we confirm that I have read the protocol which has been submitted for assessment.		
SIGNATURE OF SUPERVISOR/S:	 ……	17/06/2022…… ……
PROTOCOL ACCEPTED BY HEAD OF DEPARTMENT/RESEARCH COORDINATOR	 ..... SIGNATURE	17/06/2022 ..... DATE
SIGNATURE PG OFFICE STAFF ……..	REGISTERED YES….. NO…..	STAMP

11 March 2019/M

The Barriers and Facilitators Experienced by Primary Caregivers when Implementing Occupational Therapy Home Programmes within a Primary Healthcare Setting

Background and need for the study

Including primary caregivers as active collaborators in the therapy process is an important aspect of working towards effective practice in the resource-limited environment of the public healthcare sector in South Africa (Richards & Galvaan, 2018). In order for occupational therapy interventions, and especially home programmes, to be as effective as possible for this client population, it is vital that primary caregivers are active participants in the process of prescribing therapy interventions that should be done at home. Home programmes are used by occupational therapists treating a variety of client populations, including children. For this population, a home programme can include a variety of activities or exercises prescribed by the therapist to the children's primary caregiver aimed to continue developing the skills addressed in therapy (Finet, 2016; Novak & Berry, 2014).There is evidence suggesting that home programmes and home-based interventions have a greater chance of making gains and working towards therapeutic goals when primary caregivers are empowered and actively involved in these interventions (Akamoglu & Meadan 2018).

Caregivers caring for children with difficulties are however faced with many burdens and experience difficulties inherent in the role of caregiving (Reddy et al., 2019). Engaging in all of the activities included in caring for children and adults with difficulties places demand and expectations on the primary caregivers. Understanding the experiences of primary caregivers and the influence of these experiences on their ability to perform their required activities is therefore important for healthcare professionals, like occupational therapists, providing services to the individuals under their care.

Problem statement

Home programmes are a valuable part of occupational therapy practice and are frequently used by occupational therapists to support gains made in therapy (Okeyere et al, 2016). Home programmes are especially useful and necessary within the South African healthcare context and notably on a primary healthcare level where there is a large number of service users in relation to the number of occupational therapists available to provide services (Jansen van Vuuren et al., 2021; Richards & Galvaan, 2018).

On an outpatient basis, clients are able to access occupational therapy services often only once a month. These appointments are also often short and are carried out relatively quickly, which influences the quality of services that are provided by occupational therapists in these environments (Richards & Galvaan, 2018). Home programmes are therefore important to

supplement the time between therapy sessions to ensure clients are still receiving some form of therapy services. As described by Richards and Galvaan (2018), it was found that visits made by clients to clinics are often fast and there is little time or resources available for lengthy or in-depth discussions. The reduced number of therapists available as well as reduced access to resources are time-limiting factors influencing the length and quality of interaction between occupational therapists and primary caregivers (Richards & Galvaan, 2018). This limited time and other important resources available in these visits limits the capacity for occupational therapists to actively involve and empower primary caregivers relating to the therapy services for their child.

A client population for whom home programmes are especially useful is children who are receiving occupational therapy services. These home programmes aimed at improving the occupational performance of children are frequently prescribed to the primary caregiver (Bester, 2020). It is understood that for these home programmes to be useful and effective, the children's primary caregivers should be active participants in both the design and implementation of the home programmes (Jansen van Vuuren et al., 2021). Understanding and acknowledging these areas is important for the therapists working together with both the children and the caregivers (Fewster et al., 2020). However, the primary caregivers are frequently not involved in this process, negatively influencing their ability to apply the home programmes in their home environments (Angeli et al., 2019). This lack of involvement in home programme development reduces the ability of the primary caregivers to implement the home programmes effectively. Together with this occurring in the clinic environment, primary caregivers also encounter barriers and facilitators within their environment that influence their ability to meet all of the demands of caregiving effectively (Fewster et al., 2020).

Research question

What are the barriers and facilitators experienced by primary caregivers of children to implementing a home programme prescribed by an occupational therapist in a public healthcare setting?

Aim of the study

To explore and describe the barriers and facilitators experienced by primary caregivers in the implementation of occupational therapy home programmes in a public health care setting.

Objectives of the study

To identify and describe the barriers and the effects of these barriers experienced by caregivers when implementing occupational therapy home programmes in a public healthcare setting.

To identify and describe the facilitators experienced by caregivers when implementing occupational therapy home programmes in a public healthcare setting.

Significance of the study

The benefit and importance of home programmes as a supplementary treatment tool within the public healthcare sector is an area that is understood within the field of occupational therapy (Jansen van Vuuren et al., 2021). There is also available literature on the benefit and usefulness of home programmes to support children who are receiving occupational therapy services, however, less of this literature appears to be situated within a South African context. The experiences of caregivers and caregiving as a role have also been explored in existing literature (Fewster et al., 2020). Despite this, there is little existing literature available on how caregivers experience the implementation of occupational therapy home programmes. This study could potentially provide insight into this area and provide information to occupational therapists prescribing home programmes within the public healthcare setting, specifically clinics. By developing an understanding of caregivers' experiences implementing home programmes, this study has potential to inform evidence-based practice specifically relating to the prescription of occupational therapy home programmes.

Literature Review

It is acknowledged that within the primary healthcare setting within South Africa (as well as other resource-constrained environments) that for healthcare interventions to be most effective they must move beyond the physical facilities in which they practice (Richards & Galvaan, 2018). The World Health Organisation's (WHO) model of chronic care, used in primary healthcare settings within South Africa, puts forward that involving the client and their family or community members is important (Jansen van Vuuren et al., 2021b). Not only would empowering and involving primary caregivers in the process work towards more holistic healthcare services, but this aspect could also serve to ensure the healthcare services being prescribed are more effective. Within primary healthcare settings, there is increasing emphasis being placed on ensuring that when services are accessed, they are as effective and impactful as possible (Chinchai & Khamwong, 2017). This highlights how involving the abovementioned parties in their healthcare treatment and rehabilitation is hugely beneficial for the individuals receiving healthcare services (Jansen van Vuuren et al., 2021). Occupational therapists providing services to client populations in public health care settings involve home programmes that are designed to be used in the home environment in their treatment of client populations (Msengana et al., 2019).

Home programmes or home-based interventions are acknowledged as a useful and effective clinical tool, especially in resource-limited environments (Chinchai & Khamwong, 2017). In the public healthcare setting in South Africa, home programmes are often issued to clients receiving out-patient rehabilitation services (such as occupational therapy) at clinic, district or tertiary hospital level. In these environments, clients frequently attended therapy sessions, at a minimum, on a monthly basis and received services only once a month (Richards & Galvaan, 2018). Home programmes have been found to support the outpatient therapy in achieving gains relating to functional goals even with clients attending outpatient appointments once a month (Msengana et al., 2019). The benefit and clinical usefulness of home programmes in occupational therapy has been well-established in the literature.

The implementation of home programmes is very dependent on the primary caregivers as they need to execute the intervention in their home environment. This is especially true in providing services to children, as occupational therapists need to include and collaborate with the primary caregivers of children receiving services. Within the South African context, the term ‘caregivers’ or ‘primary caregivers’ does not exclusively refer to parents (Mthembu et al., 2016). While parents are often the primary caregivers for children, the term refers to any person providing care of any form such as physical, emotional and social to a person with difficulties, an illness or disabilities (Mphuthi, 2010). There is also literature that is emerging relating to what supports and interventions could be useful and necessary for primary caregivers and how healthcare professionals can support primary caregivers in this area (Fewster et al., 2020). While the individuals for whom they are caring present with different difficulties, there are common shared experiences and difficulties inherent in fulfilling the caregiving role (Bester, 2020).

Currently there is information available about the experiences of primary caregivers, however, there is little current available literature relating particularly to the experiences of primary caregivers with regard to the occupational therapy services and especially home programmes (Bester, 2020). While the importance of the use of home programmes within the public healthcare setting in South Africa is well-documented (Jansen van Vuuren et al., 2021), there is less available information relating specifically to challenges, facilitators and barriers to the implementation of home programmes and the experiences of primary caregivers (Bester, 2020; Mthembu et al., 2016; Reddy et al., 2019).

Methodology

Study design/Type of research

The study design that will be used in this study will be an exploratory, qualitative study design. The researcher will make use of an inductive research strategy as thematic analysis will be used to code the information gained from the narrative interviews. Narrative interviews will be used by the researcher to gain rich, in-depth and detailed information relating to the barriers and facilitators experienced by primary caregivers regarding occupational therapy home programmes (Creswell & Creswell, 2018; Denzin & Lincoln, 2018).

Research context

As the research is particularly focussed on exploring and describing barriers and facilitators experienced by primary caregivers within a primary healthcare setting, the research will be situated within the public healthcare sector in South Africa. Specifically, the research will be conducted within a primary healthcare facility, clinic or community health centre in Johannesburg. The occupational therapy department at the University of the Witwatersrand has affiliations to clinics within the Johannesburg Metro Area.

Research population/participants

Sample and sample size

Sampling:

The research population consists of primary caregivers of children between the ages of zero to six currently attending outpatient occupational therapy services on a monthly basis. The researcher will use purposive sampling methods to select the research sample. The sample will be made up of between 10 to 12 primary caregivers of children. By using 10 to 12 participants the researcher will aim to achieve coding saturation (Neuman, 2014).

Eligibility criteria

- Primary caregivers that meet the following criteria would be eligible for inclusion in the research sample:
- Primary caregivers of children with mild to moderate disabilities attending outpatient occupational therapy services at a Johannesburg clinic will be included.
- Primary caregivers that are comfortable being interviewed in English or comfortable with being interviewed with the support of a translator and answering in-depth and qualitative questions.
- Primary caregivers caring for children between the ages of six months to six years.

- Primary caregivers caring for children attending outpatient occupational therapy services at a primary healthcare facility.
- Caregivers who have received an implemented an occupational therapy home programme over the time period of six months to a year will be included.
- Caregivers who have received a home programme that was prescribed by the occupational therapist that was verbal, handwritten or printed.
- Caregivers who were given generalised or specific individualised home programmes for the children receiving therapy.

Data collection methods and procedure

The data collection tool of the interview questions was developed from the existing literature and was circulated amongst a group of occupational therapists with knowledge relating to home programmes and primary caregivers.

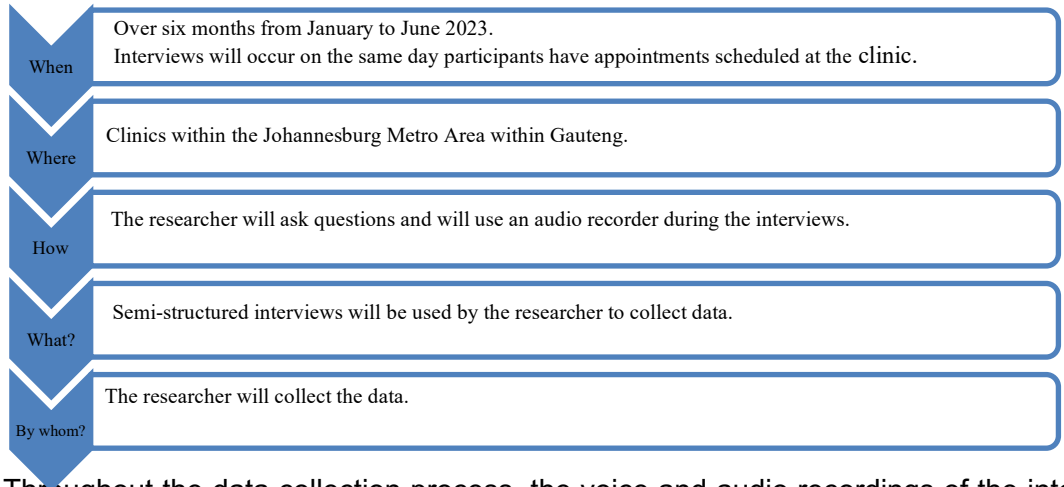
Prior to the start of the data collection process, the researcher will obtain permission and consent from the following organisations and individuals:

Faculty of health science Assessor's committee.

The Ethics Committee of Wits University; the Gauteng Primary Healthcare Ethical Committee; the clinic manager of the facility where the research will be conducted and the Occupational Therapy Department of Wits University.

The primary caregivers being interviewed.

The following flow diagram demonstrates the data collection procedure that will be followed by the researcher:



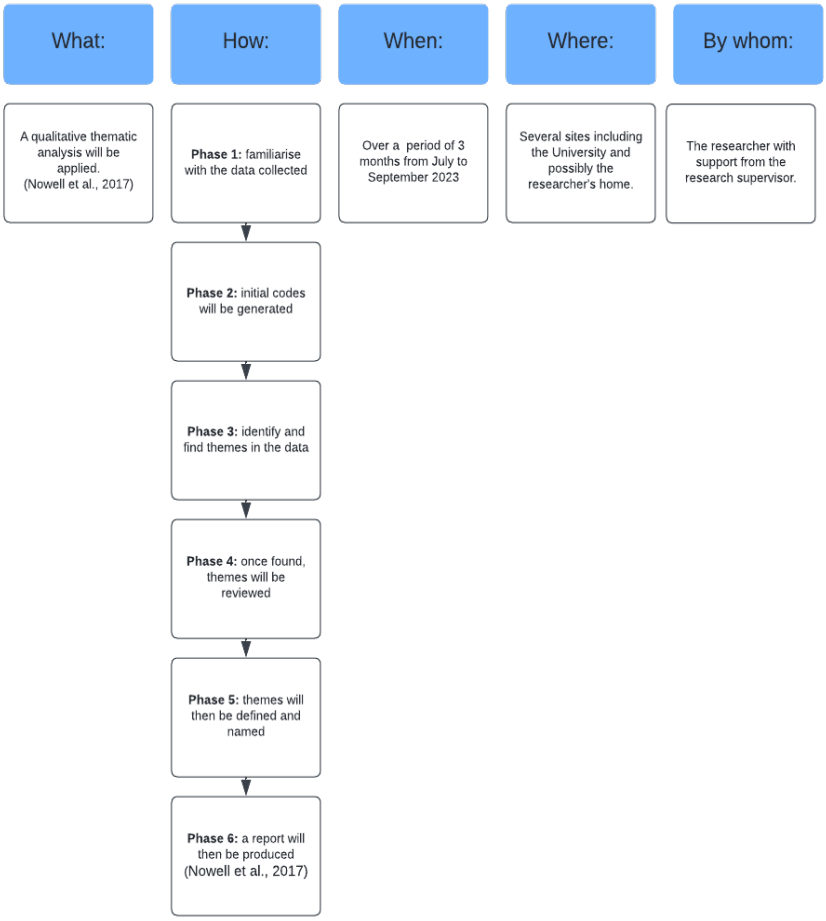
Throughout the data collection process, the voice and audio recordings of the interviews will be recorded onto a password-protected device that will only be accessed by the researcher and the researcher's supervisor.

Exploratory study

An exploratory study will be used by the researcher to ensure the quality and appropriateness of using semi-structured interviews to collect data. The exploratory study will also allow the researcher to refine the questions, ensuring that they will provide insight to answer the research questions outlined above. Three primary caregivers caring for children attending occupational therapy services at the same primary healthcare facility where the research is taking place will be included. If the same themes are found within the exploratory study and data collection and if the method is not altered, the researcher will use and include the data gathered from the exploratory study. (L. W. Neuman, 2014)

Data analysis and interpretation

The researcher will make use of a qualitative thematic analysis method to analyse and interpret the data. MaxQda software will be used to assist with the thematic analysis. Thematic analysis will allow the researcher to provide a comprehensive insight into the data collected. A further benefit of thematic analysis is that it allows for multiple different perspectives to be investigated for similarities and differences (Nowell et al., 2017). The researcher will apply the six different phases of thematic analysis, including: 1) familiarising with the data; 2) generating initial codes; 3) identifying themes in the data; 4) reviewing themes; 5) naming and defining themes; and 6) production of a report to the data that was collected during the narrative interviews conducted at the Johannesburg primary healthcare facility. By following the specific phases, the researcher will be striving towards and reinforcing trustworthiness (Nowell et al., 2017). The flow diagram below demonstrates the data analysis and interpretation that will be followed by the researcher.



Trustworthiness

Trustworthiness will be ensured by the researcher by addressing the following components:

Credibility: The researcher will make use of reflexive self-analysis to ensure credibility (Stahl & King, 2020). By keeping a journal throughout the research process with detailed daily entries, the researcher will be constantly questioning the findings and, in this way, will be checking any personal biases that may arise.

Transferability: By asking in-depth questions within the semi-structured narrative interviews, the researcher will aim to create thick descriptions of the experiences of the research participants. This coupled with detailed descriptions of the primary healthcare setting in Johannesburg, the researcher will aim to facilitate transferability of the data collected between different contexts (Stahl & King, 2020).

Dependability: The researcher will acknowledge the possible influences of biases or personal interpretation on data collection and analysis. As an occupational therapist who has worked within the public healthcare sector and prescribed home programmes, the researcher may have a pre-existing frame of reference through which the data will be viewed. The researcher will therefore apply reflexive auditing throughout the process, facilitating a method to check

the researcher's personal biases (Stahl & King, 2020). Reflexive auditing is a process whereby the researcher describes and makes clear their involvement in the decisions made in the research process and the influence of their personal biases on these decisions (Stahl and King, 2020).

Confirmability: Objectivity and a level of accuracy within the data will aim to be established by the researcher. As the researcher will be including 10 to 12 primary caregivers as participants within the study, coding saturation should be reached, facilitating confirmability of the data (Stahl and King, 2020).

Data management

Interviews will be recorded on a phone and voice recorder. A consent form for recording can be found in Appendix D. Caregivers will not use their name but will receive a number e.g., client 1 to ensure confidentiality.

Data management:

Storing and managing data: Voice files will be uploaded to Redcap for secure storing and managing of the voice files. Redcap has password protection and data is stored on the Wits University server that has an appropriate firewall to maintain confidentiality. Redcap will be accessed on a password-protected computer that will only be accessed by the researcher and the researcher's supervisor.

Voice files will be transcribed into text files for analysis of the data. A second reader will be used to check that the transcription of the voice recordings is correct. The researcher will transcribe the data from the audio recordings of the interviews but a transcriber may possibly be used, if necessary. The transcriber will only have access to the appropriate files with no confidential information that can allow for identification of the primary caregiver. This will also be saved on Redcap for data management.

Data will only be shared by the student and supervisor while analysing the these.

Only student and supervisor will have access to data on the Redcap system.

Confidentiality: The researcher will ensure that each participant is randomly allocated a numerical identifier to ensure anonymity. Confidentiality will also be achieved by removing any identifying information from the interview transcriptions and audio recordings. As the primary caregivers participating in the research care for children with difficulties, which would be considered a vulnerable population, extra care will be taken to ensure that this vulnerable population is protected through anonymity of data. In the event that a transcriber is used during the data collection and analysis process, the transcriber will sign a transcriber confidentiality form.

Ethical considerations

Ethical clearance will first be obtained after the assessor's meeting from the:
Human Research Ethics Committee at the University of the Witwatersrand
National Research Database: https://nhrd.hst.org.za
For clinics in Johannesburg Metro the protocol and provisional ethics letter will be submitted to the Johannesburg Health District Research Committee (DRC) https://afrocp.wordpress.com/research/joburg-district-research/research-application/
The clinic where interviews will be held and permission from primary caregivers (please see the attached appendices-information sheet; consent forms; permission letter)
Dignity and Autonomy: The dignity and autonomy of the participants will be maintained by obtaining informed consent prior to the interview process by providing the participants with an information sheet, regarding the study and ensuring that the participants understand the information. The researcher will actively involve the participants in the decision-making process regarding their continued involvement in the study.

Beneficence and Non-Maleficence: After informed consent has been obtained, the researcher will make it clear to the participants that should they feel unable to continue through the duration of the study, they are able to withdraw from the study at any time, and will receive no negative consequence for doing so. The researcher will handle the sharing of information with empathy and therefore if a participant becomes visibly distressed during the interview, the interview will be terminated. The researcher will also arrange potential counselling support at the clinic should it be required (Pietilä et al., 2019).

Time frame of the project

	2022												2023											
Research phase	Jan-Mar			Apr-Jun			Jul-Sept			Oct-Dec			Jan-Mar			Apr-Jun			Jul-Sept			Oct-Dec		
School assessor's submission & permission																								
Ethics committee submission																								
Data collection																								

Data analysis																								
Write-up																								
Submission of publication																								
Submission for examination																								

Budget

The budget (indicated by the table below) includes potential participant transport should the participants be required to come to the clinic for research purposes on a day that is not the scheduled day of their appointment visit. The below has been calculated to cover all 12 interview sessions conducted at the research site. Please note that the below costs are all estimates and will be funded by the researcher.

Item	**Cost**
Petrol for interviewer travelling to research site Calculated using the average distance of all clinics in the Johannesburg Metro Area from Wits Parktown Education Campus multiplied by AA rates	28.2km x 3.55 R100.11
Stationery and printing Calculated at an estimate of R2 per page of black and white printing - Information sheets - Participant consent forms - Consent forms for audio recording - Information sheet for clinics - Interview questions (for researcher) - Paper for recording answers from interviews	 12 x R4 12 x R4 12 x R4 8 x R4 2 x R4 R79 R263
Cellular and data costs Calls to clinic managers, research supervisor and potential calls and messages to research participants to arrange follow up interviews if necessary	**R50**
Potential participant transport	**R150**
Transcription cost	**R9000**
Total	**R9513.11**

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Appendix C: Approval of Title Letter

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

30 January 2024
Person No: 831320
PAG

Ms E Topham
20 6th Street
Linden
2104
South Africa

Dear Ms Ella Topham

Master of Science in Occupational Therapy: Approval of Title

We have pleasure in advising that your proposal entitled *The Barriers and Facilitators Experienced by Primary Caregivers when Implementing Occupational Therapy Home Programmes within a Primary Healthcare Setting* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

Appendix D: Draft of Questions for Participant Interviews

Interview Questions for Primary Caregivers Implementing Occupational Therapy Home Programmes

Thank you so much for agreeing to take the time to do this interview with me. I really appreciate you taking the time to talk to me. If at any time you feel uncomfortable, please let me know and we can take a break if you need to or stop completely. Let me know if there is anything I can do to make you feel more comfortable. Anything you tell me will be kept completely confidential and none of your personal information will be shared with anyone.

I just wanted to reassure you that there are no right or wrong answers to any of the questions I ask and if I ask you a question after something you've told me or something you've said it's just to make sure I understand you.

1. Ask for comprehensive demographic information:
   - Age and gender of caregiver
   - The number of children in their care and their ages
   - The family structure and how many people live at home
2. How long does it take you to get to the clinic and how much does it cost?
3. Could you help me understand why your child has to come to the clinic for occupational therapy (OT)?
4. What is the difficulty your child has?
5. How long have you been coming and bringing your child to OT and to the clinic?
6. Can you tell me about the things your OT has given you to do at home (home programme) with your child/the child you're looking after?
7. What things that the OT has given to you do at home have gone well? Why do you feel that these have gone well?

8. What things that the OT has given to you do at home that you feel have been more challenging? Why have these things been more challenging?
9. I was wondering whether you've made any changes to any activities you've been given by the OT at the clinic?
10. What difference, if any, is OT making for these difficulties you've told me about?
11. What difference do you feel the OT activities you're doing at home is making for your child?
12. Do you feel that the OT activities you're doing at home are making a difference for your child and for you?
13. What difference do you feel the OT activities you're doing at home is making for you?
14. Is there anything that you think could be done with the activities/home programme that could have been done better?
15. You've been so helpful. I'd really love your thoughts on what you feel the influence of the OT home programme has been for you at home?
16. Is there anything else you would like to tell me about?

Thank you so much. I so appreciate you taking the time to talk to me and answer my questions. I know how valuable your time is.

Appendix E: Participant Information Sheet

WITS UNIVERSITY

PARTICIPANT INFORMATION SHEET

The Barriers and Facilitators Experienced by Primary Caregivers when Implementing Occupational Therapy Home Programmes within a Primary Healthcare Setting

Good day, my name is Ella Topham and I am a student in the process of completing my Masters of Science degree in occupational therapy.

I am doing research on the experiences of primary caregivers when implementing home programmes for children in their care. Research is a process used in seeking new knowledge. In this study I want to learn about experiences related to implementing occupational therapy home programmes given to caregivers by occupational therapists working at primary healthcare facilities, like the clinic you are attending. This study is aiming to allow for understanding of occupational therapy home programmes and could provide insight into how occupational therapists can work towards improving this aspect of their service.

I am asking / inviting you to take part in this research study to share your experiences.
The study would entail the following:

1. The study is of a qualitative and descriptive nature and will therefore require me to ask you some questions about your experience using and implementing occupational therapy home programmes that have been prescribed to you at this facility.
2. There are approximately 15 questions that I will be asking and this process should only take an hour of your time to complete. I acknowledge that this is quite a lot of time and that your time is valuable so your participation would be greatly appreciated.
3. I will record your answers to the questions by writing them down as well as using an audio recorder to record our interview. All of the information will be anonymized and will be kept in a very safe place and will be access controlled.

Risks of being involved in the study: If there is anything that we discuss during the interview that you find upsetting or if you experience any distress, I have made arrangements that you can receive counselling support from a social worker/counsellor working at this clinic. This support, should it be required, is free and will be of no cost to you.

Benefits of being in the study: In this study, there will be no direct benefit to you, the participant. However, your involvement in this study will be very helpful in the possibility of developing better treatment for subsequent patients/clients making use of occupational therapy services at this facility and others like it. Your role and support would therefore be valuable, important and appreciated in this area.

You (the participant) will be given pertinent information on the study while involved in the study and after the results are available.

Participation is voluntary and refusal to participate will involve no penalty or loss of benefits to which you (the participant) are otherwise entitled. There is no requirement to provide a reason for withdrawing and

any data collected on such a person will in default be destroyed, unless you (the participant) specifically consent to its retention and use within the study.

Reimbursements for "out of pocket" expenses may be allowed, but there is to be no payment or cost associated with participation, *e.g.,* if you are ever required to travel to the clinic on a day that is not your designated appointment day to complete interviews, you will be reimbursed your travel costs to and from the clinic.

Confidentiality: Personal information will be treated in the strictest confidence and will only be available to the researcher (principal investigator (PI)) and her supervisor. The only exceptions - and all of them are rare - would normally be:

1. personal information may be disclosed if required by law
2. the Human Research Ethics Committees of the University may exceptionally require personal data to respond to a formal complaint, or for a compliance audit

If results are published, this may, exceptionally, lead to cohort, or more rarely, individual identification. All data collected in the course of the study will be securely retained for two (2) years, if a scientific publication arises from the study and six (6) years, if there is no publication. Thereafter it will be destroyed accordingly.

Anonymity will be guaranteed by removing all personal particulars and identifiers from the information gathered. The information will be stored online in an access-controlled manner.

Contact details of researcher: Should you want to get further information, or report adverse events, please feel free to contact:
Ella Topham (the researcher) on:
email: 831320@students.wits.ac.za
phone: 082 616 0125

Janine van der Linde (the researcher's supervisor) on:
email: janine.vanderlinde@wits.ac.za
phone: 011 717 3713

The outputs of the study will be a research report and they will be made available to you to read after the study is completed

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.
If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Thank you for reading this Study Information Sheet.

Date: June 2022

Appendix F: Participant Consent Form

WITS UNIVERSITY

PARTICIPANT CONSENT FORM

The Barriers and Facilitators Experienced by Primary Caregivers when Implementing Occupational Therapy Home Programmes within a Primary Healthcare Setting

1. I have been given a Participant Information Sheet which explains the nature and processes involved in this study, which is attached hereto;
2. I was given time to read it, or had it read to me, in the language I best understand;
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory;
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be;
5. I understand that there will be no immediate benefit to me, should I agree to participate, nor will I receive any payment; conversely, participation will not cost me anything but my time;
6. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw at any time and would not be required to give any reasons; if that happened, any data collected about me for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained;
7. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study, I am free to speak to any of these contacts.

Contact details:

Ella Topham, Principal Investigator, telephone no. 082 616 0125, or by e-mail at: 831320@students.wits.ac.za

Janine van der Linde, Supervisor, on telephone no. 011 717 3713, or by e-mail at: janine.vanderlinde@wits.ac.za and

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za

Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

Name of Participant: _____
Date: _____
Place: _____
Signature or mark _____
Witnessed by:

Name of Witness: _____
Signature: _____
Date: _____

Appendix G: Consent Form for Audio Recording

CONSENT FORM FOR AUDIO RECORDING

The Barriers and Facilitators Experienced by Primary Caregivers when Implementing Occupational Therapy Home Programmes within a Primary Healthcare Setting

I hereby consent to audio recording of the interview and I understand that:

- The recording will be stored in a secure location (a locked cupboard or password protected computer and hard drive) with restricted access to the researcher (principal investigator) and the research supervisor.
- The recording will be transcribed and any information that could identify me will be removed,
- The recordings will be erased within either (a) two (2) years of the publication of the research findings, or (b) six (6) years, if no publications arise from this research
- Anyone wishing to access this information in the future will first have to obtain the approval of the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg
- Direct quotes from my interview, without any information that could identify me, may be cited in the research report or other write-ups of research.

Name of Participant: _____
Date: _____
Place: _____
Signature or mark _____

Witnessed by:

Name of Witness: _____
Signature: _____
Date: _____

Appendix H: Letter Requesting Permission to Conduct Research at Johannesburg Clinics

University of the Witwatersrand,
School of Therapeutic Sciences, Department of Occupational Therapy
Khanya Building, 7 York Road Parktown
Phone: 011 717 1000

02 June 2022

Dear Sir/Madam,

Re: Permission to conduct research at clinics within the Johannesburg Metro Area

My name is Ella Topham,

I am studying for a MSc Occupational Therapy at the School of Therapeutic Sciences at Wits University. I am seeking permission to do research at a clinic(s) within the Johannesburg Metro Area.

I am conducting research on the barriers and facilitators experienced by primary caregivers when implementing an occupational therapy home programme that has been prescribed from a primary healthcare facility. While there is well-established understanding of the experiences of primary caregivers, there is less knowledge available on experiences related to implementing occupational therapy home programmes. Home programmes are a useful and widely used tool within occupational therapy practice and could be useful to contribute to social transformation and development within occupational therapy in South Africa.

This understanding could contribute to how occupational therapists put together and prescribe home programmes, not only specifically to primary caregivers of children but to their client population at large. This knowledge could contribute to the development of improved home programmes and occupational therapy practice. I have chosen to conduct my research at a clinic(s) within the Johannesburg Metro Area because understanding the experiences of primary caregivers within a primary healthcare setting could work towards development of occupational therapy services in the public sector.

The research will entail collecting data from primary caregivers of children attending occupational therapy at the clinic(s).

I will invite the abovementioned primary caregivers to participate in this study. If they agree, they will be asked to be interviewed. The participants will be required to set aside 45 minutes to an hour aside and date collection will take place during the working hours of the clinic, when the participants will be bringing the children in their care to the clinic for an occupational therapy appointment. The participants' responses in the interview will be audio recorded.

Participants will be asked to give their written or verbal consent before the research begins. Their responses will be treated confidentially, and identities (their names and the name of the organisation) will be anonymous. Individual privacy will be maintained in all published and written data resulting from the study.

The results will be communicated in the form of a research report.

The research participants will not be advantaged or disadvantaged in any way. They will be reassured that they can withdraw their permission at any time during this project without any penalty. There are no foreseeable risks in participating in this study. While there are no foreseeable risks, there could be potential for the participants to become upset or distressed during the interview process. Arrangements have been made to access free counselling services at the clinic should this occur. The participants will not be paid for this study.

All research data will be destroyed within either (a) two (2) years of the publication of the research findings, or (b) six (6) years, if no publications arise from this research

I therefore request permission in writing to conduct my research at your organisation. The permission letter should be on your organisation's headed paper, signed and dated, and specifically referring to myself by name and the title of my study.

Please let me know if you require any further information. I look forward to your response as soon as is convenient.

Yours sincerely,

Ella Topham
phone: 082 616 0125
email: 831320@students.wits.ac.za

Janine van der Linde
email: janine.vanderlinde@wits.ac.za
phone: 011 717 3713

Appendix I: Information Sheet for Clinics

WITS UNIVERSITY

INFORMATION SHEET FOR CLINICS

The Barriers and Facilitators Experienced by Primary Caregivers when Implementing Occupational Therapy Home Programmes within a Primary Healthcare Setting

Good day, my name is Ella Topham and I am a student in the process of completing my Master's degree in occupational therapy.

I am doing research on the experiences of primary caregivers when implementing home programmes for children in their care. Research is a process used in seeking new knowledge. In this study I want to learn about experiences related to implementing occupational therapy home programmes given to caregivers by occupational therapists working at primary healthcare facilities, like the clinic you are attending. This study is aiming to allow for understanding of occupational therapy home programmes and could provide insight into how occupational therapists can work towards improving this aspect of their service.

I am requesting to conduct research at your clinic in order to interview primary caregivers caring for children attending occupational therapy services at your facility.
The study would entail the following:

1. The study is of a qualitative and descriptive nature and will therefore require me to ask the primary caregivers questions about their experience using and implementing occupational therapy home programmes that have been prescribed to them at this facility.
2. The interviews will be conducted on the same day that the client has an appointment for the child in their care at the clinic.
3. There are approximately 15 questions that I will be asking and this process should only take an hour to complete. I acknowledge that this is quite a lot of time and that the time of everyone working and attending the clinic is valuable.
4. I will record your answers to the questions by writing them down as well as using an audio recorder to record the interviews. All of the information will be anonymized and will be kept in a very safe place and will be access controlled.

In order to reduce the risk of participating in the study, it would be appreciated if counselling support could be made available at the clinic should the participants become upset or distressed when sharing personal experiences.

In this study, there will be no direct benefit to the participants. However, their involvement in this study will be very helpful in the possibility of developing better treatment for subsequent patients/clients making use of occupational therapy services at this facility and others like it.

The participants will be given pertinent information on the study while involved in the study and after the results are available.

Participation is voluntary and refusal to participate will involve no penalty or loss of benefits to which the participants would be otherwise entitled. There is no requirement to provide a reason for withdrawing and

any data collected on such a person will in default be destroyed, unless the participants specifically consent to its retention and use within the study.

Reimbursements for “out of pocket” expenses may be allowed, but there is to be no payment or cost associated with participation, *e.g.,* if the participants are ever required to travel to the clinic on a day that is not their designated appointment day to complete interviews, they will be reimbursed your travel costs to and from the clinic.

Confidentiality: Personal information will be treated in the strictest confidence and will only be available to the researcher (principal investigator (PI)) and her supervisor. The only exceptions - and all of them are rare - would normally be:

1. personal information may be disclosed if required by law
2. the Human Research Ethics Committees of the University may exceptionally require personal data to respond to a formal complaint, or for a compliance audit

If results are published, this may, exceptionally, lead to cohort, or more rarely, individual identification. All data collected in the course of the study will be securely retained for two (2) years, if a scientific publication arises from the study and six (6) years, if there is no publication. Thereafter it will be destroyed accordingly.

Anonymity will be guaranteed by removing all personal particulars and identifiers from the information gathered. The information will be stored online in an access-controlled manner.

Contact details of researcher: Should you want to get further information, or report adverse events, please feel free to contact:
Ella Topham (the researcher) on:
email: 831320@students.wits.ac.za
phone: 082 616 0125

Janine van der Linde (the researcher’s supervisor) on:
email: janine.vanderlinde@wits.ac.za
phone: 011 717 3713

The outputs of the study will be a research report and they will be made available to you and the participants to read after the study is completed

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg (“Committee”). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.
If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Thank you for reading this Study Information Sheet.

Date: June 2022

Appendix J: NHRD Approval

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Research Committee of Johannesburg Health District

Enquiries: Prof S. Moosa |researchjoburg@gmail.com

DATE: 01 June 2023

ATT: Ms Ella Topham

EMAIL: 831320@students.wits.ac.za

Dear Madam

STUDY TITLE: **The Barriers and Facilitators Experienced by Primary Caregivers Implementing Occupational Therapy Home Programmes within a Primary Healthcare Setting**

NHRD REF. NO.: GP_202303_043

OFFICIAL APPROVAL

The District Research Committee has reviewed your application. This letter serves as a final approval letter for this study.

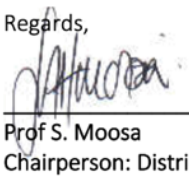
The following conditions must be observed:

- The facilities in which the research will be conducted are listed below
- These facilities will be visited from: 2023/06/10 to 2024/05/24
- Participants' rights and confidentiality will be maintained all the time.
- Neither the District nor the facility will incur any additional cost for this study.
- No resources (Financial, material, and human resources) from the above facilities will be used for the study.
- The study will comply with Publicly Financed Research and Development Act, 2008 (Act 51 of 2008) and its related Regulations.
- You will submit a copy (electronic and hard copy) of your final report. In addition, you will submit an annual progress report to the District Research Committee.
- If this is academic research, then your supervisor and the University will ensure that these reports are being submitted timeously to the District Research Committee.
- The district must be acknowledged in all the reports/publications generated from the research and a copy of these reports/publications must be submitted to the District Research Committee.
- You will liaise with the manager/s listed below as relevant before initiating the study.

We reserve our right to withdraw our approval, if you breach any of the conditions mentioned above. Please feel free to contact us if you have any further queries.

On behalf of the District Research Committee, we would like to thank you for choosing our District to conduct such an important study.

Regards,



Prof S. Moosa
Chairperson: District Research Committee
Johannesburg Health District
As delegated by Mrs M.L. Morewane, Chief Director, Johannesburg Health District, and Mr. Frans Moseane, AThe Barriers and Facilitators Experienced by Primary Caregivers Implementing Occupational Therapy Home Programmes within a Primary Healthcare Settingcting ED Health, City of Johannesburg

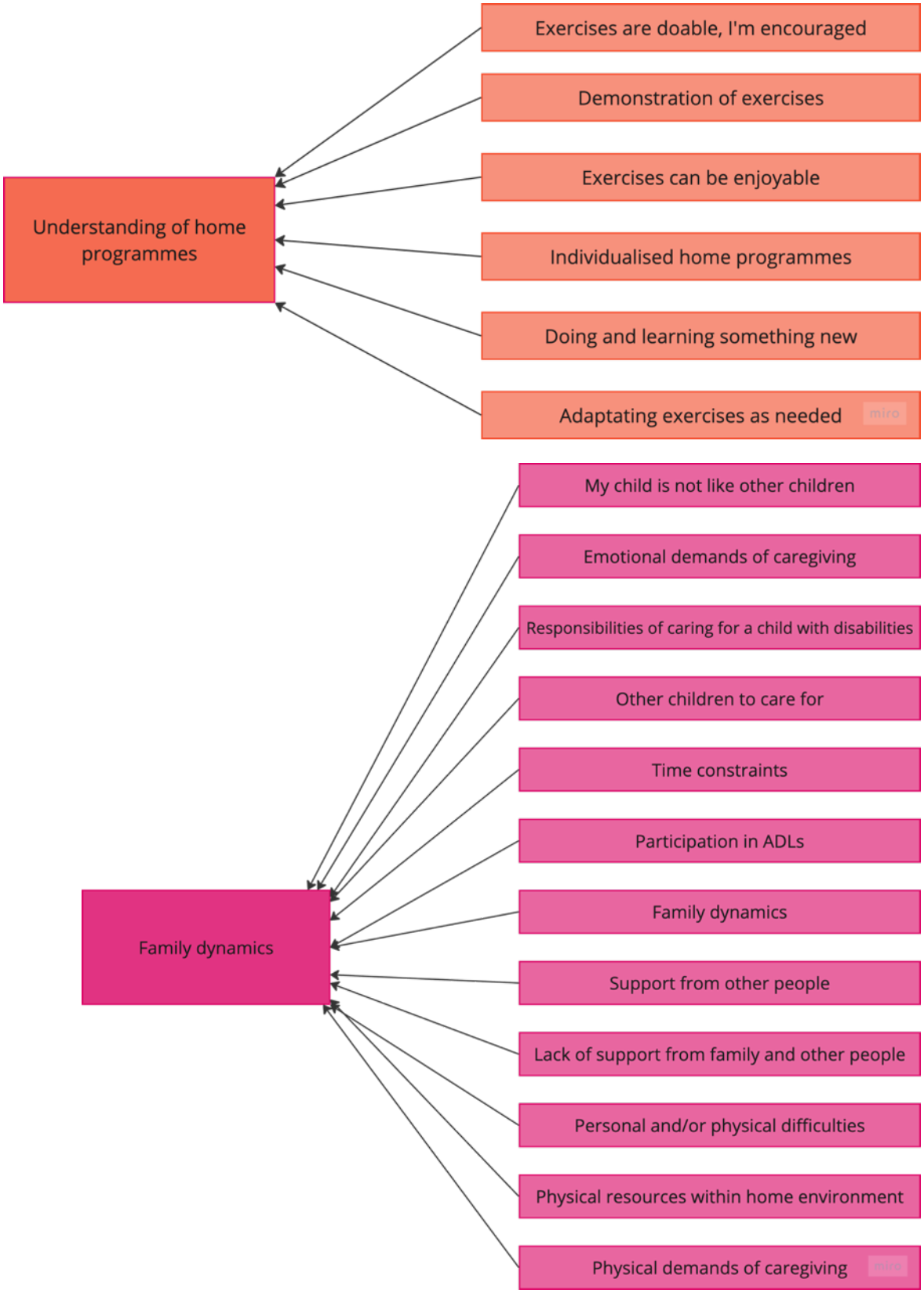
List of Facilities Approved

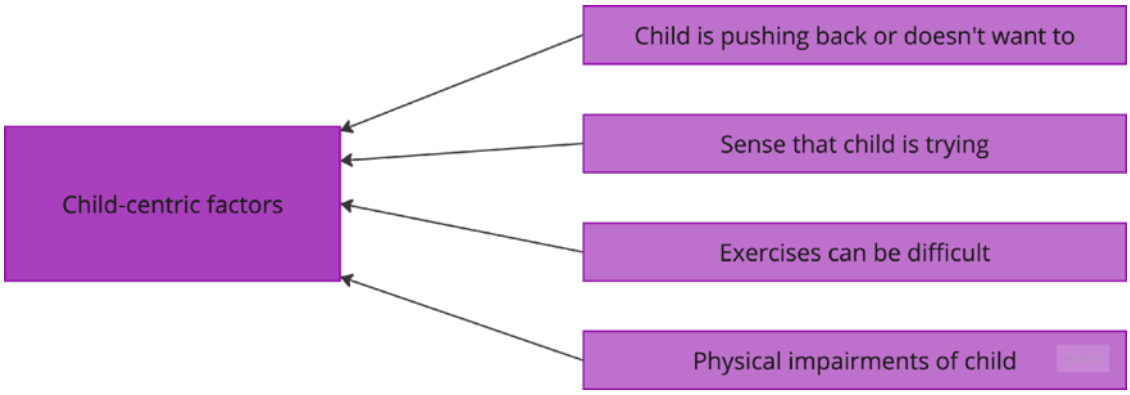
- Hillbrow CHC

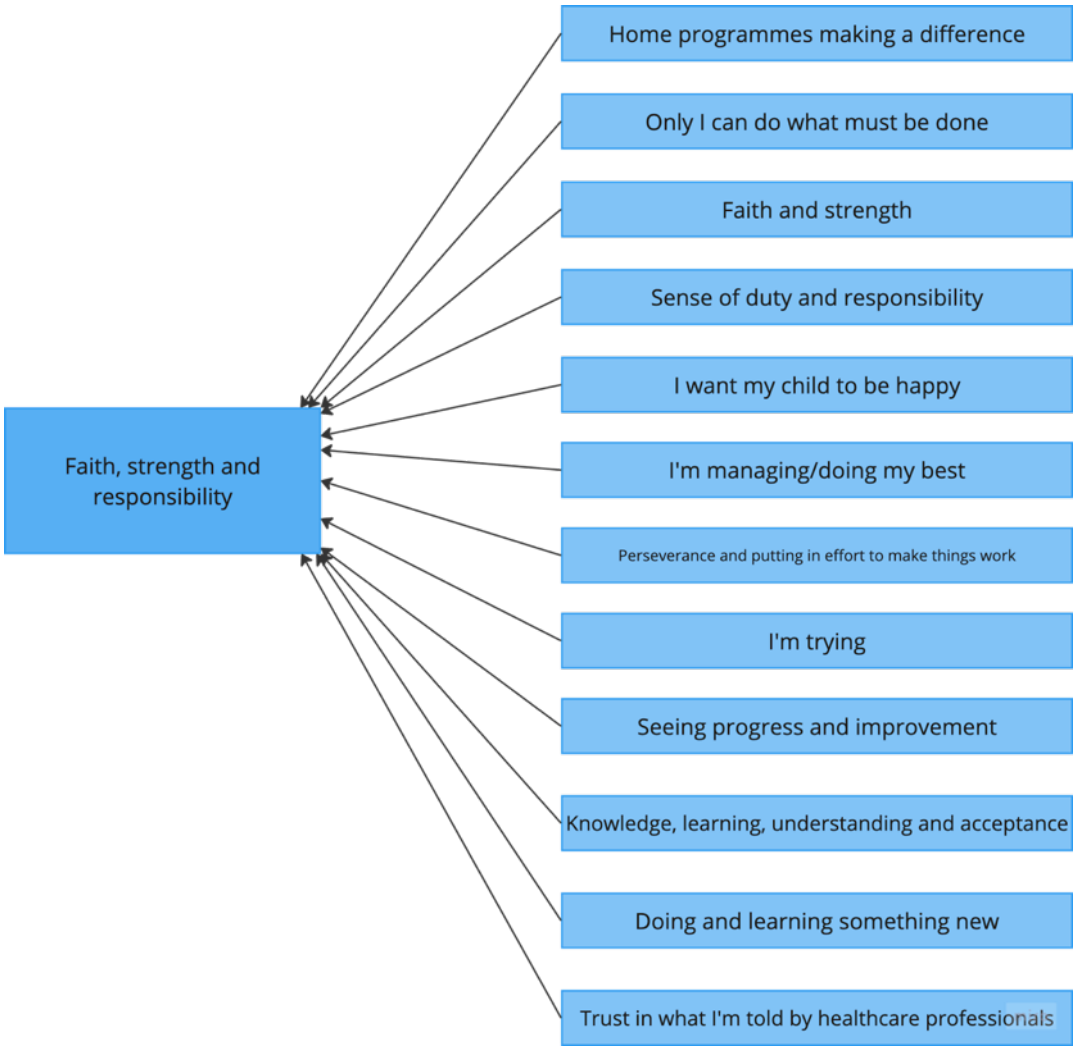
List of Managers

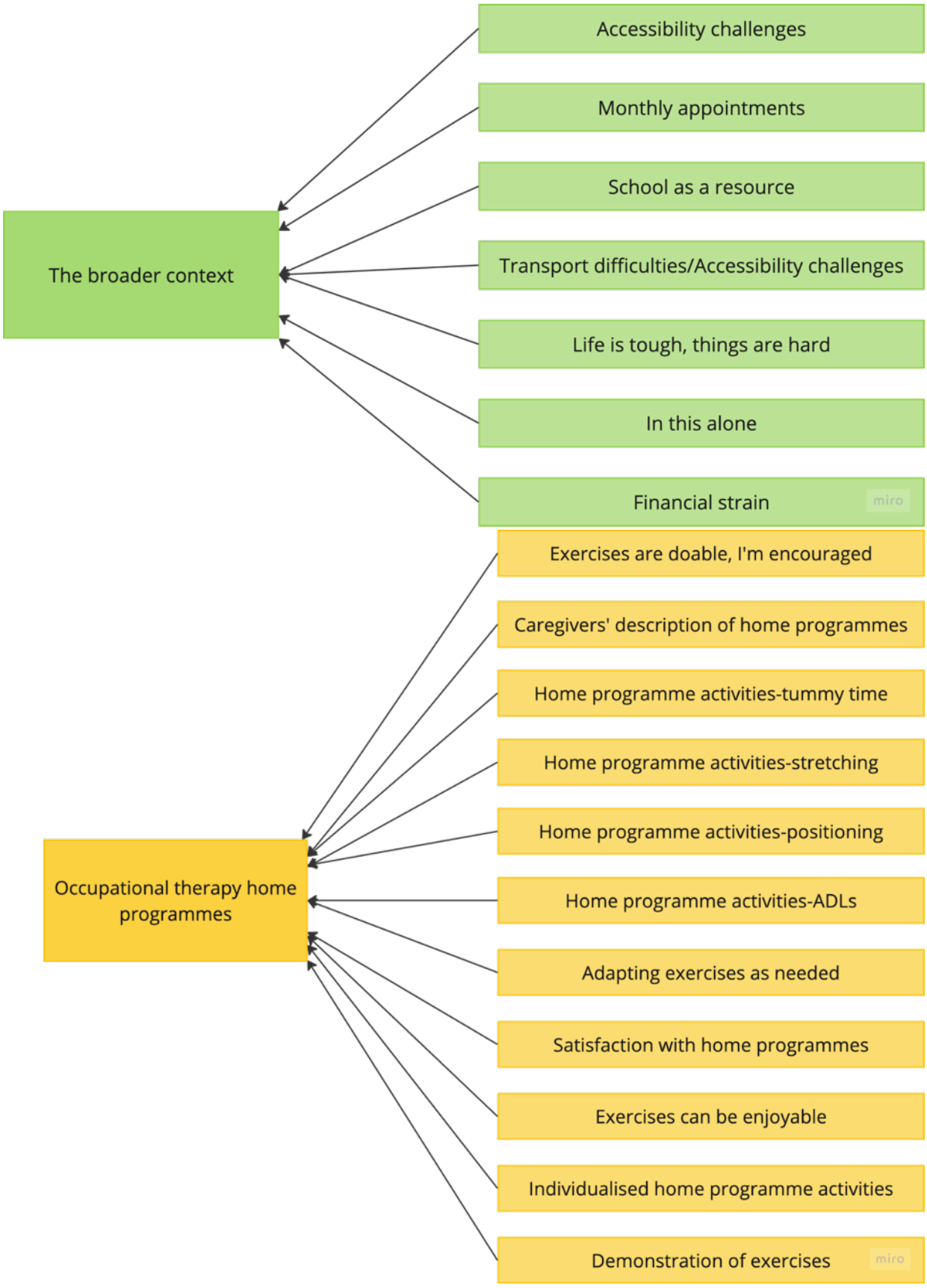
Sub District/ Hospiital	Sub District Manager/ Area Manager	Contact No.	Cell phone	Email
ABCEF	Ms Lombuso Matlala	011 440 1259	082 307 0267	Lombuso.Matlala@gauteng.gov.za

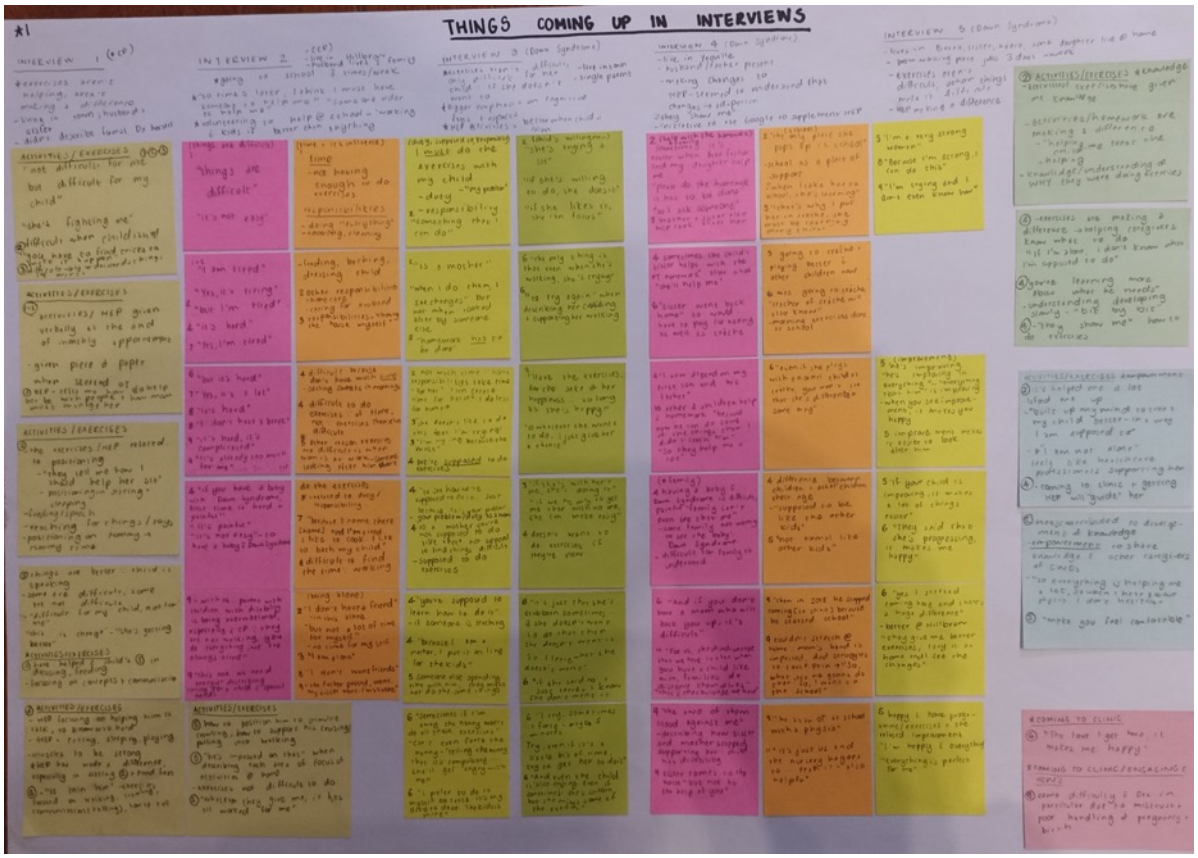
Appendix K: Data Analysis Thematic Maps

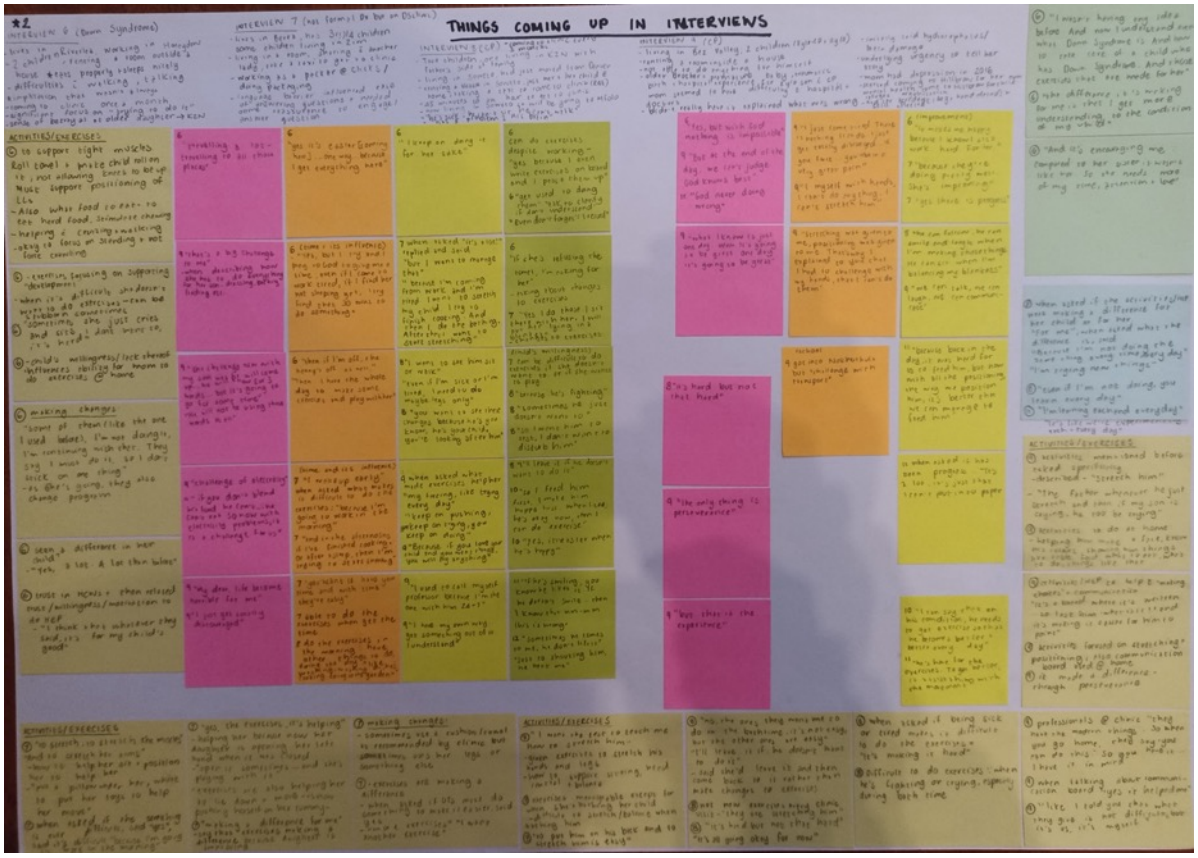


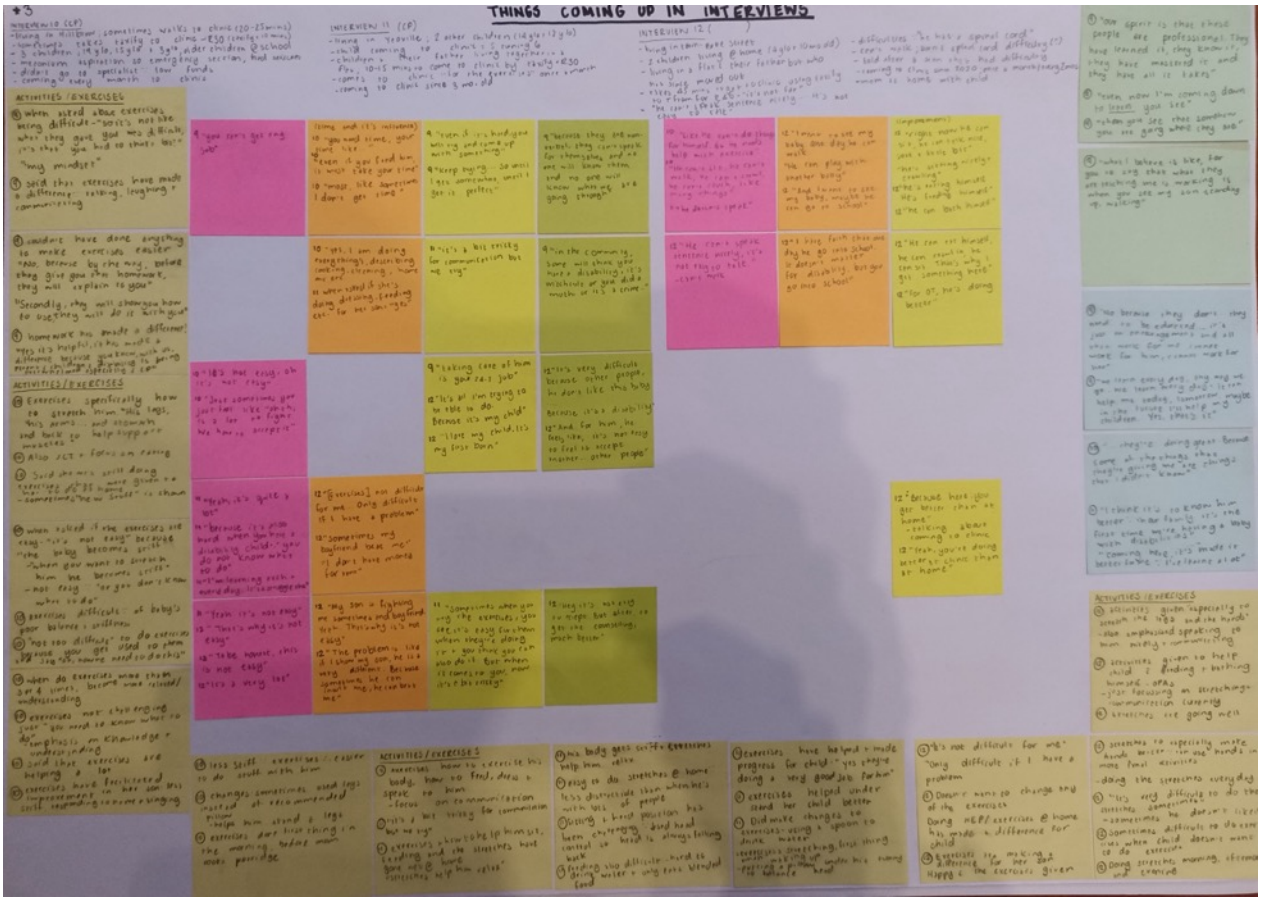

Child-centric factors
Child is pushing back or doesn't want to
Sense that child is trying
Exercises can be difficult
Physical impairments of child


Faith, strength and responsibility
Home programmes making a difference
Only I can do what must be done
Faith and strength
Sense of duty and responsibility
I want my child to be happy
I'm managing/doing my best
Perseverance and putting in effort to make things work
I'm trying
Seeing progress and improvement
Knowledge, learning, understanding and acceptance
Doing and learning something new
Trust in what I'm told by healthcare professionals


The broader context
Accessibility challenges
Monthly appointments
School as a resource
Transport difficulties/Accessibility challenges
Life is tough, things are hard
In this alone
Financial strain
miro
Occupational therapy home programmes
Exercises are doable, I'm encouraged
Caregivers' description of home programmes
Home programme activities-tummy time
Home programme activities-stretching
Home programme activities-positioning
Home programme activities-ADLs
Adapting exercises as needed
Satisfaction with home programmes
Exercises can be enjoyable
Individualised home programme activities
Demonstration of exercises
miro


THINGS COMING UP IN INTERVIEWS


THINGS COMING UP IN INTERVIEWS


THINGS COMING UP IN INTERVIEWS

Appendix L: Turnitin Report

E Topham 831320 Research Report

ORIGINALITY REPORT

10%	4%	9%	2%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	wiredspace.wits.ac.za Internet Source	1%
2	Joshi, Shruti. "Factors Affecting the Implementation of Occupational Therapy Home Programmes for Children with Learning Difficulties in Gauteng", University of the Witwatersrand, Johannesburg (South Africa), 2025 Publication	1%
3	Davies, Lauren. "Current Occupational Therapy and Physiotherapy Practice in Implementing Home Programmes for Young Children With Cerebral Palsy in South Africa", University of the Witwatersrand, Johannesburg (South Africa), 2025 Publication	1%
4	Jan Hollenbeck, Amy Wagenfeld. "Foundations of Pediatric Practice for the Occupational Therapy Assistant", Routledge, 2024 Publication	<1%
5	Karen Jacobs, Nancy MacRae. "Occupational Therapy Essentials for Clinical Competence", Routledge, 2024 Publication	<1%
6	Jejelaye, Anthony Oluwaseun. "Intergration of Occupational Therapy Services at Primary Healthcare Level in South Africa", University	<1%

of the Witwatersrand, Johannesburg (South Africa), 2025
Publication

7	ajod.org Internet Source	<1%
8	cors.archive.org Internet Source	<1%
9	Labuschagne, Elsie Susanna. "Sensory Processing in Women Diagnosed with Genito-Pelvic Pain/Penetration Disorder", University of the Witwatersrand, Johannesburg (South Africa), 2025 Publication	<1%
10	Smith, Robyn. "Neurodevelopment, Quality of Life and Burden of Care of Young Children Who Have Undergone Cardiac Interventions in Central South Africa: Three-Month and Six-Month Post Cardiac Intervention Outcomes", University of the Witwatersrand, Johannesburg (South Africa), 2025 Publication	<1%
11	Seward, Caroline Claire. "Psychometric Properties of the Self-Care Inventory for Children With Cerebral Palsy in a Resource-Constrained Urban South African Context", University of the Witwatersrand, Johannesburg (South Africa), 2025 Publication	<1%
12	Lachenicht, Michelle. "Children with Cerebral Palsy Living in a Resource Constrained Community: the Efficacy of a Thumb Opponens Splint - a Case Study", University of the Witwatersrand, Johannesburg (South Africa), 2025	<1%

Publication

13	Submitted to University of Witwatersrand Student Paper	<1 %
14	Struwig, Nadia. "The Relationship Between Coping Strategies Utilised by Community Service Occupational Therapists and Their Experience of Burnout", University of the Witwatersrand, Johannesburg (South Africa), 2025 Publication	<1 %
15	Amy Wagenfeld, Jennifer Kaldenberg, DeLana Honaker. "Foundations of Pediatric Practice - for the Occupational Therapy Assistant", Routledge, 2024 Publication	<1 %
16	Lindner, Hendrina Cecilia. "Experiences and Perceptions of Stroke Survivors and Occupational Therapists on Community Reintegration Post Stroke in the Western Cape", University of the Witwatersrand, Johannesburg (South Africa), 2025 Publication	<1 %
17	Iona Novak, Anne Cusick. "Home programmes in paediatric occupational therapy for children with cerebral palsy: Where to start?", Australian Occupational Therapy Journal, 2006 Publication	<1 %
18	www.scielo.org.za Internet Source	<1 %
19	Buurman, Laetitia. "The Relationship Between Visual Perceptual Skills, Visual Motor Integration Skills and Oculomotor Control, in	<1 %

	Learners Attending a LSEN School", University of the Witwatersrand, Johannesburg (South Africa), 2025 Publication	
20	van Zyl, Elécia N.. "A Pilot Study Exploring the Effect of an Integrated Learning Therapy Home Programme Together With Occupational Therapy on Child Development", University of the Witwatersrand, Johannesburg (South Africa), 2025 Publication	<1 %
21	Moses N. Ikiugu, Steven D. Taff, Sarah Kantartzis, Nick Pollard. "Routledge Companion to Occupational Therapy - Theories, Concepts and Models", Routledge, 2025 Publication	<1 %
22	vital.seals.ac.za:8080 Internet Source	<1 %
23	"Occupation-Centred Practice with Children", Wiley, 2010 Publication	<1 %
24	www.researchgate.net Internet Source	<1 %
25	Hughes, Ashleigh Ann. "The Effect of Neoprene Thumb Abductor Splints on Upper Limb Function in Children with Cerebral Palsy", University of the Witwatersrand, Johannesburg (South Africa), 2025 Publication	<1 %
26	hdl.handle.net Internet Source	<1 %

27	eldorado.tu-dortmund.de Internet Source	<1 %
28	Charles H. Christiansen, Carolyn M. Baum, Julie D. Bass. "Occupational Therapy - Performance, Participation, and Well-Being", CRC Press, 2024 Publication	<1 %
29	shop.zsl.org Internet Source	<1 %
30	Chhania, Bhavika Harrilal. "Comparing the Effectiveness of Two Occupational Therapy Stroke Upper Limb Home Programmes", University of the Witwatersrand, Johannesburg (South Africa), 2025 Publication	<1 %
31	Nicolson, Tasha. "Developmental Motor Outcomes of Children Aged Nine to Twenty-Four Months With Hypoxic Ischaemic Encephalopathy Based on the Thompson Score", University of the Witwatersrand, Johannesburg (South Africa), 2025 Publication	<1 %
32	Joana Nana Serwaa Akrofi, Tsu-Hsin Howe, Janet Njelesani. "Embracing Multiple Philosophical Orientations in Occupational Therapy to Enhance Cultural Sensitivity", The American Journal of Occupational Therapy, 2025 Publication	<1 %
33	www.kidshealthzone.com Internet Source	<1 %
34	Marta Gasparin, William Green, Christophe Schinckus. "Slow design-driven innovation: A	<1 %

response to our future in the Anthropocene epoch", Creativity and Innovation Management, 2020
Publication

35	Submitted to Mississippi State Board for Community & Junior Colleges Student Paper	<1%
36	Doris Pierce. "Occupational Science for Occupational Therapy", Routledge, 2024 Publication	<1%
37	Mophosho, Zanele. "The Implementation of Nurse Initiated and Managed Antiretroviral Therapy in the City of Johannesburg Clinics: Perceived Facilitators and Barriers", University of the Witwatersrand, Johannesburg (South Africa), 2025 Publication	<1%
38	Dacre, Susan Margaret. "The Use of Occupational Therapy Groups as a Treatment Modality with Primary School Learners", University of the Witwatersrand, Johannesburg (South Africa), 2025 Publication	<1%
39	Fingleson, Danielle Louise. "Parents' Knowledge of the Sensory Integrative Approach within Occupational Therapy at a Remedial School", University of the Witwatersrand, Johannesburg (South Africa), 2025 Publication	<1%
40	Submitted to University of Derby Student Paper	<1%
41	Submitted to Edith Cowan University Student Paper	<1%

42	Mufamadi, Ntsieni Maureen. "Assessment of the Awareness, Knowledge, and Perceptions of Healthcare Workers Regarding the Underreporting of Organophosphate Poisoning in the Institutions in Johannesburg District, Gauteng Province.", University of Johannesburg (South Africa), 2024 Publication	<1 %
43	www.archives.palarch.nl Internet Source	<1 %
44	5dok.net Internet Source	<1 %
45	Joseph, Rowena Y. "Exploring the Effect of a Sensory-Based Intervention on Occupational Participation and Anxiety in Child Victims of Trauma Within the South African Context", University of the Witwatersrand, Johannesburg (South Africa), 2025 Publication	<1 %
46	etd.aau.edu.et Internet Source	<1 %
47	www.coursehero.com Internet Source	<1 %
48	Ash, Simon Alistair. "A Comparison of Two Week Versus Two Month Anaesthetic Training for Internship Doctors", University of the Witwatersrand, Johannesburg (South Africa), 2025 Publication	<1 %
49	Submitted to Chapman University Student Paper	<1 %

Appendix M: Author Guidelines for Journal

Guidelines for Publishing in the South African Journal of Occupational Therapy

The South African Journal of Occupational Therapy (SAJOT) accepts scientific articles, scientific letters, scoping /systematic/integrative reviews, commentaries, opinion pieces and book reviews for publication.

The language of the Journal is English (abstracts may be provided in Afrikaans or the Vernacular as well as in English).

All articles that are published in SAJOT may be found at https://www.sajot.org.za/, www.scielo.org.za.,. EBSCOHost, Google Scholar or OTDBASE. In addition, articles are preserved via Portico which is a digital preservation service provided by ITHAKA, a not-for-profit organisation with a mission to help the academic community use digital technologies to preserve the scholarly record and to advance research and teaching in sustainable ways.

POST-ACCEPTANCE PUBLICATION FEES

In line with the policy of most Open Access Journals, all submissions to the SAJOT are subject to a publication fee of R5000-00 (Approx. US$350) per article once the submission is accepted for publication.

The fee is waivered in the following instances:

- If at least one of the listed authors of the article is a member of the Occupational Therapy Association of Southern Africa (OTASA). (Proof of OTASA membership will be verified by the OT office prior to publication.)
- If an application for exemption is submitted and subsequently granted by the OTASA Chairman of the Publications Committee (see details below).
- If the submission is either a book-review, commentary or opinion piece.

This post-acceptance publication fee will be applied to cover both retrospective and prospective processes involved in peer-reviewed articles, including:

- Peer-review management
- Manuscript preparation (e.g., copy editing)
- Journal production (e.g., layout)
- Open-access online publication and hosting
- Indexing (e.g., PubMed)
- Archiving

Please note that authors from LMIC countries (particularly those in Africa) may also apply for exemption from or reduction of the publication fee.

Applications for exemption from the publication fee can be made to the chair of the publications committee Helen Buchanan (helen.buchanan@uct.ac.za)

Those authors eligible for payment of fees will receive an invoice from the OTASA office and payment will need to be made to OTASA within the stipulated time.

GUIDELINES FOR SUBMISSION

The following are included in these instructions:

2.3 Guidelines for publishing a review: literature -, scoping -, systematic -, rapid -, integrative -, narrative -, rapid -, and meta-analysis review
2.4 Guidelines for writing an opinion piece
2.5 Guide to writing a commentary
2.6 Instructions for book reviews
3. Guide to submitting an article online.

.

The relevant guidelines to authors (which follow) must be consulted for the layout and the format of the article, tables, diagrams and referencing.

1. GENERAL GUIDELINES & INSTRUCTIONS (APPLICABLE TO ALL SUBMISSIONS)

- Manuscripts must be submitted via the SAJOT web site; the author must retain a copy of the script.
- New/unregistered authors must submit the title page of the submission to the Editor-in-Chief, at sajot@otasa.org.za. A username and password will then be provided to enable the author to complete the online article submission. (See Guide to submitting an article online below).
  Users already registered as authors do not need to go through a repeat of the registration process but simply use their existing username and password.
- Users who are having problems with the username and password should contact the Editor-in-Chief at sajot@otasa.org.za
- Please insert a note in the 'footer' that gives the title of the article and the date at each submission.
  This is important for tracking purposes and will ensure that the correct version of the script is used for publication.
  This footnote will be removed at publication.
- The main manuscript must contain all illustrations, tables, graphs or photographs. Supplementary files need to be loaded with the submission of research articles, scientific letters, reviews, commentaries, and opinion pieces. The following 3 supplementary files are required:
  - A title page with affiliations of authors at the time of the study as well as a section on the contribution of each listed author (refer to "Authorship criteria" under Policies), a declaration of any conflicts of interest, funding and data availability.
  - 15 multiple-choice questions (MCQ's) see format in APPENDIX A below.
  - Plagiarism Check report / certificate

The Manuscript

1. The manuscript needs to be uploaded first. This should include the abstract if applicable and all the illustrations, tables, graphs should be included in the correct place within the manuscript.
2. Please include the **ethics clearance number** and from whom it was obtained (if applicable to the study). The ethical clearance certificate must be available if requested. The ethical clearance number must also be recorded in the article when it is submitted for publication **as part of the methodology section of the article.**

Supplementary files:

1. **Title Page**

Each Manuscript must include a separate Title Page loaded as a Supplementary File. When submitting the article do not include any author information on the article itself

This page **must** include:

The title of the article	
For each author	full name
	all academic degrees and where these were obtained
	present post held and affiliation
	status as undergrad student or postgrad student at time of research and affiliation
	complete address
	telephone number
	e-mail address
	ORCID number
	HPCSA number and OTASA membership number if applicable
	Ethical clearance number – Institution where obtained
	Acknowledgments, sources of funding and conflict of interests
	Names and email address of suggested reviewers As a special request the author is asked to provide the names, place of work, and email contact details of two people who they believe have the skills and expertise to review the article

The **ORCID** must also be recorded in the relevant place on the SAJOT web site when the article is being submitted using **http//: and not https://** on the electronic submission page. To obtain an ORCID reference number and to learn about the benefits of being registered, go to: **www.orcid.org** . The ORCID will be included as part of the metadata of your article when it goes to publication. Please check that the ORCID number resolves to the author's name before submitting.

Contribution of the authors, including funding

Contribution of the author in the manuscript/research process needs to be described. To claim authorship, each author must meet ALL 4 the criteria listed in the **PUBLICATIONS AND MALPRACTICE POLICY** document available on the website. In cases where contributing authors do not meet all 4 the criteria, they should be listed under 'Acknowledgements' in the main manuscript.

Conflict of interests

Conflict of interests in terms of sponsorship and funding need to be declared. Any funding received must be stated

Data availability

The availability of data for 10 years post-publication should be indicated - either from the corresponding author or a database.

2. The Multiple-Choice questions (MCQs)

- For CPD purposes, 15 multiple choice questions with the correct answer clearly marked should be set. See format in Appendix A
- Criteria for the setting of the MCQ content as prescribed by the HPCSA are that they should be
    - clear and concise, reflecting understanding

This page **must** include:

The title of the article	
For each author	full name
	all academic degrees and where these were obtained
	present post held and affiliation
	status as undergrad student or postgrad student at time of research and affiliation
	complete address
	telephone number
	e-mail address
	ORCID number
	HPCSA number and OTASA membership number if applicable
	Ethical clearance number – Institution where obtained
	Acknowledgments, sources of funding and conflict of interests
	Names and email address of suggested reviewers As a special request the author is asked to provide the names, place of work, and email contact details of two people who they believe have the skills and expertise to review the article

The **ORCID** must also be recorded in the relevant place on the SAJOT web site when the article is being submitted using **http//: and not https://** on the electronic submission page. To obtain an ORCID reference number and to learn about the benefits of being registered, go to: **www.orcid.org** . The ORCID will be included as part of the metadata of your article when it goes to publication. Please check that the ORCID number resolves to the author's name before submitting.

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- Criteria for the setting of the MCQ content as prescribed by the HPCSA are that they should be
    - clear and concise, reflecting understanding

- each MCQ question must have only one possible correct answer and may be
- multiple choice stem with multiple or single answers,
- true/ false – maximum 20%;
- should contain no commercial product promotion and/ or satire

3. **Plagiarism Check report / certificate**

'Cross Ref' or 'Turn-it-in' or 'Authenticate' certificate must be attached with an acceptable level (usually 15% or less depending on the use of terminology in the manuscript

REFERENCING:

Vancouver style referencing is used and each reference in the text must be indicated by a number in the text. This number should be inserted in superscript without brackets e.g.[12]. A reference list should be provided on a separate numbered page following the article text. References must be cited **in the order that they appear in the text**.. Please check references from predatory journals are avoided. Predatory journals can be checked at https://predatoryjournals.com/journals/ or https://beallslist.net/.

ALL references must be linked through **CrossRef, i.e., each reference must show its DOI number** (if it has one). To find the DOI number go to **https://search.crossref.org/**. A window that askes to copy and paste or type in the title of the article or book and search. The full information on the article will appear. **Please note** that the DOI reference must be spaced so that it falls on one line and is not split between two lines. See examples of referencing below:

See what styles to use in Mendeley and Endnote to format references and examples of referencing in Appendix B.

General Requirements

	Abstract (words)	Pages	Tables and figures	Words (without tables and references)	References
Research Articles	200	±16-19	8	5000-7000	Max 35 for the literature review section. Max 60 references
Scientific Letters	n/a	±5-8	2	1400-2500	Max 15
Reviews	200	±16-19	8	5000-7000	Max 60 references
Opinion Piece	200	±5-8	2	1500-2000	Max 15
Commentary	200	±5-8	2	1500-2000	Max 15
Book Reviews	n/a	n/a	n/a	500	

Manuscripts must be clearly typed in **MS Word 1.5 spacing with a legible font (Arial, size 11 is preferable)**. Set English (South Africa) as the default language. Occupational therapy and occupational therapists should not be capitalised or abbreviated.

Use no more than three levels of headings as follows

- 1st level headings are **BOLD AND IN UPPERCASE**
- 2nd level headings are **Bold, lowercase**
- 3rd level headings are not bold but *Lowercase and in italics*

If quoting from a reference the following format must be used: Gibson[2:30] stated that "Occupational therapy is an important service for the rehabilitation of persons suffering from HIV/AIDS". where 2 is the reference number and 30 is the page number on which the quote appears. All quotes from literature must be in quotation marks " ". Quotes from participants in qualitative research should be in quotation marks and italics.

Tables must be editable and should have the heading at the top of the table and labelled with Roman letters e.g., Table II.

Figures must be editable and should be labelled at the bottom of the figure with Arabic numbers e.g., Figure. 2.

Tables and figures (which may include graphs) **should not be scanned** but formatted and included in place in the manuscript. Figures should be clear to the reader when photocopied.

Figures which consist of illustrations, diagrams or photographs may be of any size. They must be very sharp, taken close-up, and photographs should have a lightish, over-all tone and without dark backgrounds. If the photograph, diagram and illustrations photocopy well, they will print well. Please check this before you send the manuscript.

The following websites may be helpful for authors to consult either during the research process or during the write up process:

- Equator Network (http://www.equator-network.org/), a database library that allows you to find and use reporting guidelines for different study designs. Provides a decision tree and examples that assist you with choosing the most appropriate reporting guideline for your study.
- Typeset (https://www.typeset.io/), an online research communication platform that autoformats documents and helps ensure they are 100% compliant with journal submission guidelines.
- Authoraid (http://www.authoraid.info/en/), a free global network that provides online mentoring, collaboration, and support for researchers in low and middle-income countries.
- Standards for Reporting Qualitative Research: A Synthesis of Recommendations (https://journals.lww.com/academicmedicine/fulltext/2014/09000/standards_for_reporting_qualitative_research__a.21.aspx)

POST-SUBMISSION PROCESS:

Desk Edit Stage:

All submissions will undergo a desk-edit by an editorial team member. During this process, the assigned editor will check the following:

- whether all general requirements as outlined in the Table above have been met;
- the overall contribution of the article to the profession and whether it falls within the scope and aim of SAJOT;
- whether all supplementary files have been submitted in the required format;
- whether all listed authors meet the authorship criteria
- the general 'readability' of the manuscript, format, referencing etc.

Based on the above, the assigned editor will decide whether:

- the article can be accepted and sent for review
- some minor revisions are required before sending the manuscript for review,
- the article needs to be re-submitted anew for consideration (soft decline)

or

- to decline the article

Review Stage

Once accepted for review, two suitable reviewers are assigned to review the manuscript. All manuscripts undergo two anonymous double blind peer reviews. The reviewers are required to comment on the knowledge claim, scientific worth and clinical relevance of the article and its suitability for publication in SAJOT. (To ensure a blind review see section below). The comments are returned to the authors by the editor with a directive (based on the recommendations of the reviewers) for further action required. Recommendations could be:

- to accept the article without revision;
- to request some revisions to be made;
- to subject the article to a second review round;
- or to decline the article.

Copy-Editing Stage

Once the final, revised version of the manuscript has been uploaded, it will be sent to the Copy-editing phase of the workflow. During this stage, two editors will edit the article and prepare it for conversion to PDF. The authors will then be requested to perform a final proofread of the copy-edited manuscript and when required, the final PDF version thereof. After approval from the authors, the submission will be scheduled for publication.

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Checking the Manuscript before Submission
Confirmation that the following items **have been attended to** will be required as part of the submission process.

- The submission has not been previously published, nor has it been before another journal for consideration (or an explanation has been provided in Comments to the Editor).
- The submission file is in Microsoft Word file format.
- All references have been checked to see that they comply with the requirements (see References above).
- The text is Arial 11, 1.5 spaced; employs italics, rather than underlining (except with URL addresses); and all figures and tables have been placed in the text.
- The text adheres to the stylistic and bibliographic requirements outlined above
- The instructions for **Ensuring a Blind Review** have been followed.
- A colleague has read the article to provide objective peer input, inconsistencies, spelling and grammar in addition to running a spell-check with English, South Africa as the default setting. Authors for whom English is a second language should have their article edited by a professional English-language editor or editing service. During

the review process, articles may be returned to the author to arrange such a service, if improvements to language and clarity are required.

- 15 Multiple Choice Questions (MCQs) based on the article content are prepared in the supplementary file section of the article submission. In addition, it is advisable to email these to the managing editor at sajot@otasa.org.za . **NB The article will not be sent for review until these have been received or posted on the web site.**
- The details of all the authors have been included in the submission.
- Ethical approval for the study has been sought and explained in the article and an approval number is given but the institution where obtained is replaced by XXX to ensure a blind review.
- The title of the article is on the article submission- see Title page
- The abstract has separately been included in the submission block on the webpage and is also included in the **Manuscript.**
- The article has undergone a **plagiarism check.**
- Permission has been obtained from the co-authors to publish the article and to use their names.
- The relevant acknowledgements have been provided at the end of the manuscript.
- As a special request the author is asked to provide the names, place of work, and email contact details of two people who they believe have the skills and expertise to review the article.

Ensuring a blind review

To ensure the integrity of the blind peer review of the submission to this journal, every effort is made to prevent the identities of the authors and reviewers from being known to each other.

It is primarily the duty of the author to remove any possible identification from the text submitted as indicated below. The reviewer is obliged to keep his/her comments/opinions about the article confidential and communicate these only to the editor; should the reviewer have prior knowledge of or involvement with (incidental or otherwise) the author or the article in question, the editor should be informed of the situation and the situation reviewed if needed.

The editor is the only person who has access to all the information about authors and reviewers. Any issues concerning a review / edit/ authorship / copyright etc. about a SAJOT submission must be brought to the attention of the editor directly – the editor is the only person authorised to deal with these issues and will do so in a strictly confidential manner.

This process applies to the authors, editors and reviewers (who upload documents as part of their review), checking to see that the following steps have been taken with regard to the text and the file properties:

- The authors of the document have deleted their names from the text, and substituted "Author". . This includes ensuring that the names used in the acknowledgements section have also been substituted with an X. Names will be inserted during the copy edit process.
- With Microsoft Office documents, author identification should also be removed from the properties of the file.

See how to remove your Identity from track changes and comments on documents in Appendix C

Continuing education points

CEU points are accredited as follows:

- Principal authors of a scientific article, literature (scoping/systematic/integrative) review: 15 CEUs and co-authors 5 CEUs.

- Principal authors of scientific letters, commentaries, book reviews or opinion pieces: 5 CEU's and co-authors 3 CEU's.

2. GUIDELINES FOR AUTHORS

2.1 GUIDELINES FOR AUTHORS OF RESEARCH ARTICLES (for Additional Guidelines for authors of QUALITATIVE RESEARCH, click here)

Articles submitted to the SAJOT must be original and must not have been published elsewhere. Articles should contain new information, have a unique knowledge claim that add to existing knowledge, resolve controversy or provoke thought and discussion. The content of the article must justify the length, which should be about **16-19 pages (**between **5000- 7000 words)**.

Authors should consult the article "The pitfalls of "salami slicing" which highlights focusing s on *quality* rather than *quantity* of publications" by Fenseca M. Editage Insights. Nov 4; 2013.https://www.editage.com/insights/the-pitfalls-of-salami-slicing-focus-on-quality-and-not-quantity-of-publications

FORMAT:

Abstract, Implications for Practice and Keywords

The article must be accompanied by an abstract not **exceeding 200 words** in length. The abstract must contain a succinct structured summary of the study: headings should be used in the abstract (introduction, methodology, results, conclusion). There should be no references or abbreviations in the abstract.

The implications of the research for Occupational Therapy Practice should be clearly and concisely stated using bullet points under a separate heading. This should not be a repetition of points mentioned in the Conclusion section of the manuscript.

Key words: a list of "key words" which contain words that might be helpful for tracking your article. Try not to 'repeat' key words from the title of the article, as this will limit the search opportunities.

Introduction

This should provide a brief rationale for the study and an outline of the research aims or questions. The introduction should present a clear indication of the need for and purpose of by the article. Authors should not assume that the readers know the **context** in which the article is set. The content needs to be organised in a coherent and logical manner and may require concise descriptions and definitions of terms to elucidate the content as well as the aim of the study. The literature review may be included in the introduction.

Literature Review

A separate review of the **relevant literature** can be provided. This should be a **critical** appraisal of the current relevant literature identifying the limitations in the work already conducted on the subject and a rationale for the study.

The aim or objectives of the study should appear at the end of the literature review

Methods

The section on **research methods** should include (when appropriate):

- the research design used,
- the population and criteria for selecting the population sample,
- the research tools used,
- the method of data collection,

- the methods used to analyse the data including details of the statistical methods, information on validity, reliability, trustworthiness and credibility.

Details of the ethical clearance and informed consent must be provided without the name of the institution at this stage (replace name with XXXX)

Results/Findings

The results must be presented in a way that makes them accessible to the readers and are clearly linked to the aims and methods of the research.

Discussion

The discussion should summarise the main findings and explore the reasons for these. New knowledge must be highlighted, and the limitations of the study given. The implications for occupational therapists and or other health professionals/groups/ contexts must be outlined and the contribution that the study makes to the current state of knowledge of the profession/s stated. Limitations must also be discussed.

Conclusion

The conclusion must be brief, drawing the article to a close by relating the results to the aim of the research and indicating the key findings this research has added.

Acknowledgements
All assistance and funding for the research must be acknowledged and any conflict of interests stated.

Tables and figures
Articles may include up **to eight (8) tables or figures** and should be numbered and **clearly labelled and included in the manuscript** in the appropriate place. All figures, tables, and images will be published under a Creative Commons CC-BY license, and permission must be obtained for use of copyrighted material from other sources (including published/adapted/ modified/partial figures and images from the internet). It is the responsibility of the authors to acquire the licenses, follow any citation instructions requested by third-party rights holders, and cover any supplementary charges.

For additional information, please see the 'Image manipulation' section of our policies and publication ethics

2.2 ADDITIONAL GUIDELINES FOR AUTHORS OF QUALITATIVE RESEARCH:

Introduction
Please find below a summary of guidelines for the write up qualitative research projects, drawn from the following valuable readings:

1. Anderson, C. (2010). Presenting and evaluating qualitative research. American Journal of Pharmaceutical Education, 74 (8) Article 141. https://acrobat.adobe.com/link/review?uri=urn:aaid:scds:US:5bea3070-6690-30b7-bd68-e72c29d1e824
2. O'Brien, Bridget C. PhD; Harris, Ilene B. PhD; Beckman, Thomas J. MD; Reed, Darcy A. MD, MPH; Cook, David A. MD, MHPE. Standards for Reporting Qualitative Research: A Synthesis of Recommendations. Academic Medicine 89(9): p 1245-1251, September 2014. https://doi.org/10.1097/ACM.0000000000000388

3. Sandelowski M. (1998). Writing a good read: strategies for re-presenting qualitative data. Res Nurs Health, 21(4):375-82. https://doi.org/10.1002/(sici)1098-240x(199808)21:4<375::aid-nur9>3.0.co;2-c.
4. Setati, M. 'Re'-presenting qualitative data from multilingual mathematics classrooms. *Zentralblatt für Didaktik der Mathematik* 35, 294–300 (2003). https://doi.org/10.1007/BF02656693

Introduction and literature review
A good introduction…

- provides a snapshot of the focus of the manuscript
- provides a focused background information to the research, including relevant literature related to the focus of the paper
- clearly states and justifies the research question in relation to the existing knowledge base
- Reflection of the influence of the researcher(s) on the data, including a consideration of how the researcher(s) may have introduced bias is included.

Methods
A comprehensive and detailed methods section…

- clearly states and justifies the qualitative research design used describing a clear link between the research question and the research design
- describes in detail the data collection methods and justifies the selection of these methods in relation to the research design selected. For example, motivate your selection of interviews or focus groups or both. Examples of the data collection tools can be referred and/or included as appendices where relevant.
- describes the study population and study setting
- explains and justifies the selection criteria for inclusion of the study participants*
- describes how participants were recruited and by whom
- includes a brief explanation of those who were invited to participate but chose not to
- describes the process by which ethical clearance and/or research permissions from sites was obtained
- describes how ethical considerations were applied during the study, for example:
    - how informed consent was gained
    - how anonymity and confidentiality were ensured
    - measures to prevent harm to participants
    - measures to support participants who become distressed as a result of engagement the data collection process (where applicable)
- describes the data collection process (duration and schedule), the methods of recording data (e.g., audio or video recording) and the procedures for transcribing data. The decision to stop data collection should be described and justified
- describes in detail the processes by which accurate translation of informed consent and data collection tools took place
- details how data sources** were managed i.e., organised, and stored securely

- describes and justifies how the data were analysed. Was computer-aided qualitative data analysis software such as NVivo (QSR International, Cambridge, MA) used? How the researcher/s arrived at ''data saturation'' or the end of data collection should be described and justified
- describes how criteria of trustworthiness (credibility, confirmability, transferability, and dependability) were applied in the study. Suggested readings: https://eric.ed.gov/?id=EJ1320570

*Qualitative research necessitates having a small sample because of the detailed and in-depth nature of these studies. Sample sizes are not calculated using statistics. Instead, qualitative researchers should describe their sample in terms of characteristics and relevance to the wider population. Purposive sampling is common in qualitative research. Particular individuals are chosen with characteristics relevant to the study who are thought will be most informative. Purposive sampling also may be used to produce maximum variation within a sample. Participants being chosen based for example, on year of study, gender, place of work, etc. to improve representativeness. Convenience samples involve the researcher choosing those who are either most accessible or most willing to take part. This may be fine for exploratory studies; however, this form of sampling may be biased and unrepresentative of the population in question. Theoretical sampling uses insights gained from previous research to inform sample selection for a new study.

**Data sources in qualitative research

- Data generated for qualitative studies can include the following:
- Audio recordings and transcripts from in-depth or semi-structured interviews
- Structured interview questionnaires containing substantial open comments including a substantial number of responses to open comment items.
- Audio recordings and transcripts from focus group sessions.
- Field notes (notes taken by the researcher while in the setting/s where studies are taking place)
- Video recordings
- Images
- Documents (reports, meeting minutes, e-mails)
- Diaries, video diaries
- Observation notes
- Press and other media clippings
- Photographs

Findings

General

In qualitative research, it is prudent to include a summary table of all participants with relevant demographic information presented. For example, if you are conducting a study exploring student experiences of studying occupational therapy it will be important to reflect aspects such as their *year of study, gender, race, educational history* as well as other aspects that have

been shown to shape learning experiences. In this way, when the reader looks at a quote from a participant, they can review back to this summary to gain insight into from whose perspective the information was provided. This assists the reader to connect with and interpret the comments/quotes shared. In order to increase the validity of your results, it could add value to your findings/results if the data are quantified, e.g. "11 out of the 15 participants felt that.." and then supporting this finding with one or two direct quotes from 2 of the 11 participants.

Example

Table 1. Participant information

Participant name	Age	Gender	Year of study	Prior learning
Sam***	19	Not disclosed	Second	Grade 12

*** Pseudonym used

The researcher should select quotes that are most representative of the research findings. Including large portions of data in a research paper is not necessary. It is also important to provide all relevant information to contextualise each quote. When presenting quotes provide at least three participant details (identifiers) to link the quote to the participant presented in the summary table. See example below.

Example

The student described using deep learning, drawing on learning from a previous module:

"I found that while using the e-learning programme on ergonomics I was able to apply the knowledge and skills that I had gained in last year's human biology and anatomy courses." **(Sam, 19, second year student)**

Discussion
The discussion section…

- Discusses the findings within the existing literature presented in your literature review
- Discussed the strengths and limitations of the research
- Describe future directions for research

Conclusion
The conclusion…

- should be a brief and to the point conclusion of the main points of the paper and not a repetition of the discussion
- should present the take home message and emphasize what the study adds to policy and practice

Appendix N: Proof of Submission for Peer Review

Submission Acknowledgement Inbox ×

Blanche Pretorius via Khulisa Journals <Journals@assaf.org.za> Unsubscribe 19:12 (4 minutes ago)

to me

Ella Topham:

Thank you for submitting the manuscript, "The Barriers and Facilitators Experienced by Primary Caregivers when Implementing Occupational Therapy Home Programmes within a Primary Healthcare Setting" to South African Journal of Occupational Therapy. With the online journal management system that we are using, you will be able to track its progress through the editorial process by logging in to the journal web site:

Manuscript URL: https://journals.assaf.org.za/index.php/sajot/authorDashboard/submission/21399
Username: etopham

If you have any questions, please contact me. Thank you for considering this journal as a venue for your work.

South African Journal of Occupational Therapy

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Appendix O: Confirmation to Conduct Research at Hillbrow CHC

Hillbrow CHC <Hillbrow.CHC@gauteng.gov.za> Thu, 29 Jun 2023, 18:25

to me

Hello

Thank you for sending the follow up email regarding the study. I have seen the attached documents from the initial email, and I agree with everything. You can call me on 060 584 7377 for an appointment.

Regards
Nkhensani Ringane(Facility Manager)

Get Outlook for Android

From: Ella Topham <eltopishere@gmail.com>
Sent: Thursday, June 29, 2023 3:06:56 PM
To: Hillbrow CHC <Hillbrow.CHC@gauteng.gov.za>
Subject: Re: Conducting Research at Hillbrow CHC

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