



UNIVERSITY OF CAPE TOWN
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

Exploring perceptions of support amongst caregivers in First Thousand Day-friendly churches in the Western Cape

By

Anna Folly

FLLAKO001

SUBMITTED TO THE UNIVERSITY OF CAPE TOWN

In partial fulfilment of the requirements for the degree MSc Occupational Therapy

Faculty of Health Sciences
UNIVERSITY OF CAPE TOWN

Date of Submission: February 2025

Supervisor(s): Associate Professor Amshuda Sunday and Dr Sarosha Pillay
Division of Occupational Therapy, Faculty of Health Sciences, University of Cape Town

The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

DECLARATION

I, Anna Folly, hereby declare that the above thesis is my own unaided work, both in concept and execution, apart from the normal guidance from my supervisor and contributions from others as outlined in the acknowledgements. The assistance I received with data collection, analysis and manuscript review from co-authors of the publications that form part of this thesis is described for each relevant chapter.

Neither the whole nor any part of the above thesis has been in the past, or is being, or is to be submitted for a degree at this university, or any other university.

I grant the University of Cape Town free licence to reproduce the above thesis, in whole or in part, for the purpose of research.

I am now presenting the thesis for examination for the degree of MSc Occupational Therapy.

Signature:

Date: February 2025

ACKNOWLEDGEMENTS

To my wonderful network of friends and family, for your constant encouragement, patience and enthusiasm in this whole process. As well as those who stayed.

To my two experienced supervisors, for your ongoing enthusiasm, guidance, feedback and patience with me throughout this process amidst all your other duties and responsibilities.

To Sikunye, for the location, resources, vision and opportunity to participate alongside you and the wonderful staff that worked over and above to accommodate this research project under tight deadlines.

To the church leaders for their willingness to be the intermediary link between Sikunye and the caregivers.

To the wonderful caregivers that participated in the focus group and subsequent member checking, thank you for your time and knowledge. Thank you for sharing the most intimate parts of your lived experience for this study.

To all caregivers with children in the First Thousand Days, First Thousand Day-friendly churches and all those who interact with those in their First Thousand Days. You are doing so much, and it's been an honour to see a little more of that through this study.

Lastly, to my heavenly Father, who has given me vision, direction and ability to persevere even when the going got tough. All of this is for you and your glory.

ABSTRACT

Introduction

According to The United Nations Children's Fund (UNICEF) (2018) the First Thousand Days (FTD) of life, which is the period from conception to two years old, is a unique window of opportunity. There is a wide body of evidence pointing to the role of stable and responsive caregiving to ensure the thriving of children. Sikunye, a Non-Government Organisation (NGO) birthed from Common Ground Church seeks to equip and mobilise churches to become FTD-friendly. The implementation of Sikunye's FTD strategies is carried out collaboratively by church volunteers. However, there is a paucity in understanding how the beneficiaries of FTD services, namely, the caregivers, are experiencing the current strategies that are being promoted. Therefore, this research study aimed to explore the perceptions of support amongst caregivers within FTD-friendly churches.

Methods

The study made use of a qualitative, descriptive inquiry, using an interpretivist approach. Data was collected in the form of a focus group with five participants from five FTD-friendly churches. Data was analysed using an inductive approach and thematic analysis. The focus group was conducted in English. However, isiXhosa-translated consent forms and information leaflets were provided. The focus group lasted 2 hours.

Findings

The main theme that emerged from the study was "They say it takes a village and it really does": The support of an FTD-friendly church community is needed for the raising of a child. This describes the perceptions of caregivers in their FTD who felt that there are many aspects that need to be present within a church to feel supported. It requires the members of that church to create that experience. Two categories emerged from the findings. Category one: Types of support needed from my village (church) to raise a child. Category two: How I feel about the type of support received from my village (church) to raise a child. Recommendations from caregivers around the importance of creating a context that allows caregivers to express their needs whilst feeling surrounded by their community were made. This in turn fosters other pillars of support, such as prayer, equipping and preparing, collaborating and referring and lastly, creating warm and welcoming spaces.

Discussion

Caregiver support is shaped by a complex, interconnected set of factors that work together fluidly rather than in isolation, with tangible elements like physical spaces enhancing intangible feelings of connection. This integrated approach, especially within faith communities, reinforces the importance of strengthening existing community-based supports.

Conclusion

There are many contextual factors, influencing caregiver experience of support and it is not possible to look at each in a silo. An integrated model of support is required. Support is not as rigid, isolated and clearly defined as we think it is, but it is integrated, fluid, connected and works in tandem continuously with one another to complement and strengthen one another. This ensures a comprehensive experience of support. A collaborative and community-driven approach is needed to support caregivers in their FTD, this study shows how churches are uniquely positioned to ensure the thriving of children in their FTD.

CONTENTS PAGE

DECLARATION	1
ACKNOWLEDGEMENTS	2
ABSTRACT	3
CONTENTS PAGE	5
List of Tables and Figures	8
Abbreviations	0
Definition of terms	1
CHAPTER 1: Introduction	3
1.1 Background and Context of the Study	3
1.2 Problem Statement	5
1.3 Research Question	5
1.4 Purpose of the study	6
1.5 Rationale	6
1.6 Aim	7
1.7 Objectives	7
1.8 Researcher assumptions	7
1.9 Summary	8
CHAPTER 2: Literature review	9
2.1 Introduction	9
2.2 Early Childhood Development in South Africa and the FTD	9
2.3 The Importance of the FTD	9
2.4 The Importance of Responsive Caregiving	10
2.5 The role of church and spirituality on caregiving	11
2.6 South African Policy and Early childhood development and existing initiatives	13
2.7 Previous Research and Research Gap	14
2.8 Conclusion	15
CHAPTER 3: Methodology	17
3.1 Introduction	17
3.2 Research Approach	17
3.3 Research Design	17
3.4 Research Paradigm	17
	5

3.5 Study Population and Sampling	18
3.5.1 Study population	18
3.5.2 Table 1: Inclusion Criteria for Churches	18
Figure 1: Map of the Distribution of Churches	20
3.5.3 Table 2: Inclusion Criteria for Caregivers	20
3.6 Ethics Approval	21
3.7 Recruitment strategy	22
3.7.1 Table 3: Outlining Participant Description	22
3.8 Data Collection	23
3.9 Data Management	24
3.10 Data Analysis	25
3.10.1. Table 4: Describing the Process of Data Analysis	25
3.11 Trustworthiness and Rigour	26
3.12 Ethical Considerations	27
3.13 Description of risks and benefits	28
3.14 Reimbursement for participation	29
3.15 Emergency care and insurance for research-related injuries	29
3.16 What happens at the end of a study	30
3.17 Conflicts of Interest	30
3.18 Summary	30
CHAPTER 4: Findings	32
4.1 Introduction	32
4.2 Overarching theme and categories	32
4.2.1 Table 5: Overarching Themes and Categories	32
4.2.2 Category One: Types of support needed from my village (FTD-friendly church) to raise a child	33
4.2.3 Category Two: How I feel about the type of support received from my village (church) to raise a child.	36
4.3 Summary	39
CHAPTER 5: Discussion	40
5.1 Introduction	40
5.2 How are caregivers experiencing the six pillars of support in their FTD churches?	40
5.3 Which pillar of support has been most pivotal in creating a sense of support?	43
5.4 Summary	46
	6

CHAPTER 6: Limitations, Recommendations and Conclusions	47
6.1 Introduction	47
6.2 Limitations to the study	47
6.3 Recommendations	47
6.4 Conclusion	48
REFERENCES	50
APPENDICES	55
Appendix 1a: Information sheet	55
Appendix 1b: Alternative google consent form	57
Appendix 2: Participant consent form	60
Appendix 3 Research Assistant Confidentiality Agreement	64
Appendix 4: Focus group Interview guide	66
Appendix 5: Sikunye initiatives	69
Appendix 6: Email sent to key gatekeeper	71

List of Tables and Figures

3.5.2 Table 1: Inclusion Criteria for Churches	18
3.5.3 Table 2: Inclusion Criteria for Caregivers.....	20
3.7.1 Table 3: Outlining Participant Description.....	22
3.10.1 Table 4: Describing the Process of Data Analysis	25
4.2.1 Table 5: Overarching Themes and Categories	32

Abbreviations

ASD	Autism spectrum disorder
ECD	Early Childhood Development
FTD	First Thousand Days
NCF	Nurturing Care Framework
NIECDP	National Integrated Early Childhood Development Policy
SDG	Sustainable Development Goals
UNICEF	United Nations International Children's Emergency Fund

Definition of terms

The First Thousand Days (FTD): This refers to the period spanning between conception up until a child's second birthday. It is a crucial phase for brain development and rapid neural plasticity is found here to ensure the long-term health and well-being of the child (UNICEF, 2008).

Early Childhood Development (ECD) Centre: A designated area for children between the ages of 0 up until they reach formal schooling (usually Grade R). This facility offers opportunities for early learning to stimulate the development of the child's cognitive, social and emotional functioning (Republic of South Africa, 2015).

ECD programmes: These refer to initiatives that support children before they start formal schooling, with a focus on activities that stimulate the physical, cognitive and socio-emotional development of the child (Republic of South Africa, 2015).

Developmental difficulty: This includes challenges or impairments that hinder a child's ability to reach their developmental milestones. These include delays in cognitive, motor and social functioning because of environmental and personal factors (Republic of South Africa, 2015).

Early intervention: These are a set of specialised services and supports provided by caregivers or professionals given to young children with disabilities or developmental delays, or those at risk of developing delays (vulnerable children). These services ensure a child can meaningfully participate in activities of daily living (Republic of South Africa, 2015).

Vulnerable children: Children at increased risk of experiencing developmental delay due to a lack of access to ECD services because of a variety of socio-political, physical, psycho-social and economic risk factors leading to poor developmental outcomes (Republic of South Africa, 2015).

Primary caregiver: An individual who may or may not be related to the child who takes primary ownership of meeting the daily care needs of the child without compensation or remuneration. (Republic of South Africa, 2015).

First Thousand Day-friendly church: A First Thousand Days-Friendly Church refers to a local faith-based community actively committed to supporting families with children under two through structured practices that align with the six strategies outlined by Sikunye to promote nurturing care and child well-being. (Ressel, 2022).

Sikunye: An independent and registered non-profit organisation from Common Good. Sikunye works to inspire, mobilise and equip churches to support parents, caregivers and families to provide responsive care for their children in the First Thousand Days of life (Ressel, 2022).

Nurturing care framework (NCF): An evidence-based model that is founded on the principles of universal health coverage and primary health care. It integrates a variety of governmental policies, programs, and services to ensure children's long-term well-being (WHO, 2019).

Nurturing care: This refers to conditions that enable caregivers to provide emotionally supportive environments that encourage opportunities for early learning. This care allows children to thrive and protects them from risk factors (WHO, 2019).

Caregiving: The act of providing physical, emotional, financial and developmental support to another, usually in the context of a family, health or social service (Pearlin et al., 1981).

Support: This refers to the holistic provision of emotional, financial and practical assistance designated to promote conditions for responsive caregiving for the flourishing of young children. It is the collective responsibility of individuals, family units, communities and systems (WHO et al., 2018).

CHAPTER 1: Introduction

1.1 Background and Context of the Study

This chapter positions the study through describing the importance of the First Thousand Days (FTD) for childhood development, the role of caregivers in this stage and how local faith communities, namely First Thousand Day-Friendly (FTD-friendly) activated churches can contribute to improving caregivers' experiences of support in the Western Cape province of South Africa.

According to UNICEF (2018) and Ritcher et al. (2017) the FTD of life, which is the period from conception to two years old, is a unique window of opportunity for early childhood development (ECD). This is the time where the most rapid period of brain development and highest neural plasticity is found. The National Integrated Early Childhood Development Policy (NIECDP) (Republic of South Africa, 2015) promotes early childhood as a critical period for children in which the foundation for optimal growth and development occurs enabling children to reach their full potential. The Centre on the Developing Child at Harvard University (2016) found that the brain grows up to 80% of its adult size during the FTD. The growth of grey matter during this period is exponential, with synapses growing to form connections at a rate of a million per second from the third trimester up to age two laying the groundwork for brain function later in life. In the child's brain there are almost double the number of synaptic connections (The Centre on the Developing Child at Harvard University, 2016). During late childhood (7-11 years of age up until puberty) this grey matter shrinks significantly due to a process called "pruning", where unused neural connections are eliminated. The pruning process is influenced by the child's experience and environmental interactions. Neurons that are activated in the same circuit become more established and fire together (The Centre on the Developing Child at Harvard University, 2016). This highlights the critical importance of experience in shaping synaptic connections especially in the early years of life.

According to Bhardwaj, Sambu and Jamieson (2017) for children to thrive, they need nurturing care as outlined in the Nurturing Care Framework (NCF). This includes good healthcare, nutrition, security, safety, responsive caregiving, and early learning. Although scientific and policy advances are putting ECD at the forefront of efforts to improve human development

(Ritcher et al., 2019), much work still needs to be done. Increasing the commitment to ECD is essential in ensuring the realisation of the Sustainable Development Goals (SDGs) (Robert, Parris & Leiserowitz et al., 2005). Failure to do so will lead to consequences not only with regards to the development of the child, but also by extension, the development of our country.

Daelmans, Manji and Raina (2021) found that if caregivers in their FTD were adequately supported to provide nurturing care for their children, the children were more likely to overcome adversities and reach their full potential. Du Toit, Coetzee and Beeton (2013) as well as McGadney (1995) found that community organisations within African communities, such as the church, act as key stakeholders in the provision of services to ensure that caregivers feel adequately supported in providing responsive caregiving for their children.

Lundie and Hancox (2020) found that the church is uniquely positioned and equipped to strengthen and equip families with what they need, to have a strong start to life. A local church has assets and strengths that should be identified and utilised as the church plays a vital role as a social actor (Lundie & Hancox, 2020). The church is recognised as having a trusted voice of influence in society; therefore, the church should use its voice and influence to raise awareness and advocate for children in their FTD (Lundie & Hancox 2020). In 2017, research was conducted by Common Good, a Christian NGO born from Common Ground Church in Cape Town. This study was entitled “The Local Church and the FTD of a Child's Life: A Mixed Methods Study from South Africa” (Lundie & Hancox, 2020). The findings of this research concluded that churches are ideally positioned and equipped to strengthen and care for families in their FTD. In 2019, Common Good launched Sikunye to support churches and communities to help children in their FTD thrive, by partnering with churches to make them FTD-friendly. Sikunye (Ressel, 2022) aligns itself with the NCF for ECD. The framework builds on the foundation of universal health coverage, with primary healthcare at its core (WHO, 2019).

Sikunye created six pillars of care that speak to the various health, social and educational elements, namely, good health, adequate nutrition, safety and security, responsive caregiving and opportunities for learning. There are currently more than 600 churches activated within Sikunye in South Africa and more than 100 churches activated within the Western Cape. Refer to Appendix Four for additional information and graphics. The first pillar is "**Speaking Up**". Churches have trusted voices in communities and can use preaching and teaching to share the opportunity of the FTD and God's desire for children's well-being. The second pillar involves

"Prayer". The congregation is encouraged to pray for and with families experiencing challenges during the FTD. The third pillar emphasises **"Surrounding Families"**. Church members are encouraged to support expecting families by building relationships that are nurturing as well as through practical assistance and active listening of the needs of the caregivers. The fourth pillar is **"Collaboration and Referral"**. Churches need to acknowledge that they are not healthcare professionals and cannot provide all the necessary care and support that families require. Therefore, they collaborate with other organisations and refer families to healthcare facilities to ensure they receive the required care, support, and information. The fifth pillar is **"Equipping and Preparing"**. This involves sharing information and resources through antenatal or postnatal classes, utilising reliable resources from the Sikunye website, or hosting healthcare professionals to deliver talks. Lastly, the sixth pillar is known as creating **"Warm and Welcoming Spaces"** is crucial as physical meeting spaces are also significant. Churches must ensure that their facilities are accessible for families with young children.

In conclusion, these six strategies offered by Sikunye form the basis from which to explore and understand how caregivers perceive pillars of support in FTD-friendly churches.

1.2 Problem Statement

Almost 50% of children in South Africa are at risk of not reaching their developmental potential (Black et al., 2017; Richter 2017). These children often live under lower socio-economic conditions. Responsive caregiving is pivotal in ensuring a child's full developmental capacity is reached (Black et al., 2017). Sikunye (Ressel, 2022) currently provides six strategies of support aligned with the NCF to facilitate responsive caregiving. Although literature points to the importance of ECD as well as responsive caregiving (Britto et al., 2017), no research to date has been carried out to describe how the caregivers of children within their FTD are experiencing support from the current initiatives that are being implemented within FTD-friendly churches. This research seeks to bridge this knowledge gap.

1.3 Research Question

How are caregivers experiencing the six strategies of support as outlined in the NCF, offered by Sikunye?

1.4 Purpose of the study

The purpose of this study was to explore perceptions of the support caregivers are experiencing from Sikunye across the six strategies as outlined in the NCF. Occupational therapy is concerned with occupational engagement across all domains of life. Through exploring the occupation of caregiving, this research can bring deeper insights into how occupational therapists can utilise the NCF to mitigate potential risks to children in their FTD of life (The Centre on the Developing Child at Harvard University, 2016). Munambah, Gretschell and Sunday (2020) found that caregiving can be a vehicle through which caregivers experience the transformative power of occupation to pursue aims, overcome challenges and achieve well-being. Context, specifically the culture in which the child grows up and spirituality present in the home should not be underestimated. If the practice seeks to ascribe to a holistic approach; we need to be able to understand the needs, concerns, hopes and expectations of caregivers involved and the potential future role of occupational therapists. This can be achieved by harnessing the power of local social communities to promote the implementation of preventative programs to ensure that children thrive (Munambah, Gretschell & Sunday, 2020).

1.5 Rationale

This research serves to complement the published study conducted by Sikunye: “The Local Church and the FTD of a Child’s Life: A Mixed Methods Study from South Africa” (Lundie & Hancox, 2020), which explored how churches are creating supportive spaces and interacting directly with church leaders. Their results showed that the church has an important and significant role. Recommendations from collaboration with the organisation found that it would be important to gather data on how the caregivers themselves are experiencing this support within their churches. In addition, the World Health Organization (WHO, 2019) expressed that it is important to ensure that parents and caregivers are supported to provide nurturing care through actively involving the wider economic landscape, including churches and other community-based services (Marlow et al., 2024). The study can help to inform Sikunye’s strategies to support churches in their FTD journey as well as broader policy.

1.6 Aim

The aim of the study was to explore how caregivers in FTD-friendly churches are experiencing support across the six strategies as outlined in the NCF offered by Sikunye in the Western Cape.

1.7 Objectives

The objectives of the study were:

- To explore and describe the perceptions of caregivers on what a FTD-friendly church entails, and what they need to feel supported.
- To explore and describe how the caregivers perceive the support across the six strategies (pray, speak up, surround families, equip, and prepare, create welcoming spaces, refer and collaborate) to facilitate the thriving of children.
- To explore and describe which of the six strategies that Sikunye has established are most pivotal in creating a sense of support for the caregivers.

1.8 Researcher assumptions

Korstjen and Moser (2018) argue that it is important for the researcher to disclose any biases, preferences and preconceptions that may be present between themselves and the relationship of what is being researched. My first assumption was that I came in pre-supposing that caregivers are experiencing some sense of support through the initiatives being provided by Sikunye.

Secondly, our values and belief systems are never separate from ourselves, thus although I am not part of the organisation itself, I had been attending one of the churches that was a beneficiary of the program. In addition, I am also an occupational therapist who is working in the realm of paediatrics, thus coming in with a knowledge base of experience working with caregivers and their children. Thus, I have had to become aware of the personal and religious influences that may be informing the research questions and in turn the results gained. In addition, I've needed to become aware of what this variation in knowledge base may communicate to caregivers in their FTD to ensure that I do not enforce my own 'expert' knowledge onto the caregivers.

Lastly, caregivers may feel coerced to respond favourably to the organisation as they may be grateful for the input they have received. This risk was reduced by emphasising that there is no 'right' answer. That their experience and interpretation of events is most what the researcher is in pursuit of. It was also disclosed that this information would remain private and that their responses will serve to better help them and other caregivers feel supported. I sought to reduce the risks of my assumptions and positionality through reflective and appropriate framing of the research questions and by emphasising that the honest and authentic lived experiences of the caregivers is where the expert knowledge lies.

1.9 Summary

The FTD of life, from conception to two years, has been highlighted as a critical, never to be repeated, window of opportunity where marked neural plasticity and brain growth is found (WHO, 2019). The NCF has highlighted nurturing care to include healthcare, nutrition, safety, responsive caregiving, and early learning as essential for children to thrive (Bhardwaj, Sambu & Jamieson, 2017). Churches have been identified as key social actors who are strategically positioned to support caregivers through this period (Ressel, 2022). Although evidence points to this crucial period in a child's life, there is a lack of literature that seeks to explore how caregivers feel supported in this time. There is a paucity in the interaction of the role of faith-based organisations in fostering nurturing care in caregivers of children in their FTD. The upcoming chapters of this study will explore how caregivers in the Western Cape are experiencing support from FTD-friendly churches. The following chapters will offer an exploration of caregiver experiences in the context of FTD-friendly churches. This study served to improve targeted support offered by Sikunye to create an environment that ensures the thriving of children and their caregivers in their FTD.

CHAPTER 2: Literature review

2.1 Introduction

This chapter will provide a comprehensive overview on the literature pertaining to the importance and state of ECD in South Africa, particularly the FTD, the importance of responsive caregiving as outlined by the NCF and the role of churches and spirituality on the experiences of caregivers. Literature was reviewed following a search of the following databases: EBSCOHost, Psych info OTSeeker, CINAHL, ERIC and Google Scholar. The following search terms were used to identify literature sources from both national and international sources. These include: caregiver, parent, caregiving, FTD, early years, early childhood, early childhood development, support, church, spirituality, occupational therapy, nurturing care framework, Africa, South Africa, Western Cape.

2.2 Early Childhood Development in South Africa and the FTD

The importance of ECD has been highlighted from the beginning of time with the familiar slogan: 'children are the future' (Richter, Naickerii, & Draperiii, 2024). This saying expresses the belief that children are instrumental in the trajectory of the country's development. In addition, there are three foundational principles that underpin all human development (Richter, Naickerii, & Draperiii, 2024). According to Naudeau et al., 2012, that human development is continuous and sequential across a lifespan, secondly that development is progressively built on top of other skills and abilities e.g. a child will walk before they are able to run. Lastly, that our genetic and social potential is greatly shaped by our context and early year experiences. These factors interact with one another to either reinforce or hinder development (Naudeau et al., 2012). Nurturing care includes factors such as breastfeeding, responsive caregiving, safety, protection and opportunities for early learning. All these factors serve to maximise and promote human development to ensure positive outcomes.

2.3 The Importance of the FTD

The period from conception up until the second year of life is known as the FTD and the period where the potential of a child's brain is established. This is the most critical period of synaptic proliferation found here and is the period where the foundations for the rest of development

unfold (WHO, 2019). Development begins in the womb and interacts with the environment, providing the blueprint for the rest of a child's development. Bhardwaj, Sambu & Jamieson (2017), states that nurturing care as outlined in NCF and at the heart of the realisation of SDGs. It is thus essential for the healthy development of children. These include good healthcare, nutrition, security, safety, responsive caregiving, and early learning. These environments coupled with health family units, community support, responsive services and sound policy are necessary to ensure that caregivers can provide nurturing care for their children (Marlow et al., 2024). Failure to do so will lead to consequences not only with regards to the development of the child, but also by extension, the development of South Africa.

Occupational therapists play a critical role in supporting children with disabilities during this period. Philpott (2018) highlights the importance of early identification and intervention in early childhood development (ECD) settings, particularly within the framework of South Africa's Disability Policy.

According to Philpott (2018), Occupational therapists are instrumental in implementing inclusive practices within ECD centres by adapting activities and environments to support participation for all children, including those with disabilities, beyond direct intervention to include advocacy and capacity building within community-based programmes, ensuring that children at risk of developmental delays are supported through accessible and appropriate services from the FTD.

2.4 The Importance of Responsive Caregiving

Caregiving is defined as: "the behavioural expression of (one's) commitment to the well-being or protection of another person" (Pearlin et al., 1981, p. 583). Hermanns et al., (2012) states that the act of caregiving (precedent) is described by caregiver (antecedent). They sought to further explore the concept of caregiving, there is a lack of a generally accepted definition of caregiving. Responsive and positive relationships are important for a child's holistic development (Lindland et al., 2016). Lindland et al. (2016) describe several protective factors that contribute to strong brain development and positive outcomes. Protective factors such as good health and nutritional status, a clean environment free from toxins, access to safe and quality early learning opportunities can build resilience within children. In addition, responsive, protective, and stimulating relationships with primary caregivers can counteract the afore-mentioned risk factors

(Lindland et al., 2016). Marlow et al., (2024) refers to the phrase 'intuitive parenting' which is a term to describe caregivers who breastfeed, know how to respond to distress signals given off by their child and monitor how their child is fairing from a physical and psychological point of view (Marlow et al., 2024). Caregivers also tend to speak slower and more repetitively, exaggerating their intonations and seek to anticipate their child needs. This shows that responsive caregiving is also intuitive to caregivers.

The Centre on the Developing Child at Harvard University (2016) found that stable, responsive caregiving has the power to override other risk factors, and that children who end up thriving are most often those who have had this protective factor. Britto et al., (2017) show that the evidence now strongly suggests that caregivers need to be supported in providing nurturing care and protection for young children to thrive. Sectors of health, social development and education need to work together to ensure that this critical period of development is harnessed through multi-sectoral intervention packages anchored in nurturing care (Britto et al., 2017).

2.5 The role of church and spirituality on caregiving

Pandya (2018) sought to explore the effect of spirituality and spiritual training on the lives of parents of children with autism spectrum disorder (ASD). The study was a cross-country pre and post-test experimental design that was conducted over the span of a year and included 1687 caregivers of children with ASD across 15 different countries (Pandya, 2018). The results showed that Christian parents from European countries, the United Kingdom, United States, Canada and Australia had higher post-test scores, supporting the view that spirituality and spiritually sensitive interventions improves and builds resilience for parents of children who have ASD (Pandya, 2018).

Several studies in the South African context have explored experiences of caregivers of children with disability (Du Toit, Coetzee & Beeton 2013; Demmer, 2011; Munambah, Gretsshell & Sondag 2020). A study on mothers' experiences of caring for children with severe brain injury in disadvantaged communities (Du Toit, Coetzee & Beeton 2013) found that these mothers often felt a sense of isolation due to the burden of having to take on the main care responsibilities for their child with a disability (Du Toit, Coetzee & Beeton 2013). It was found that their faith served as a main form of strength to be able to cope with their difficult circumstances and carry the

burden of caring for a child with a significant disability. All four of the study participants were part of a church community and expressed that a strong belief in God and the power of prayer was crucial in feeling strengthened to fulfil their role as caregiver (Du Toit, Coetzee & Beeton 2013).

Demmer (2011) conducted an explorative study looking at the experiences of families caring for an HIV-infected child in Kwa-Zulu Natal. The study reported that poverty, stigma and a lack of support exacerbated the difficulties of caregivers in meeting the demands of their children. Here it was found that some caregivers felt supported through their religion and felt more empowered to gain the necessary strength to care appropriately for their child, while others expressed that they did not get as much support as they would have liked from their church as they felt that disclosing their status would ostracise them from their community.

This shows an important distinction between one's desire to acquire strength from their religious belief and their willingness and feelings of safety related to retrieving support from the surrounding religious community, showing that one can exist without the other. Oftentimes the barrier to the experience of support was intangible, it related to perceived ostracisation or exclusion of self, based on one's perceptions of how others would interpret their circumstances (Demmer, 2011). It would thus be important to take note of the unseen elements of support, namely personal trust in church leadership, as well as how the tangible and intangible structures present in facilitating or hindering caregivers from accessing other types of support. This shows that the social environment, namely culture, spirituality, beliefs and attitudes in an environment are an important aspect to consider in the experience of caregiver support.

Another study conducted by Munambah, Gretsshell and Sondag (2020) looking into the experiences of mothers with children who have HIV-related Neurodevelopmental Disorders in Zimbabwe came to similar findings. It was found that although God was seen as a source of inspiration, comfort and hope, mothers were ambivalent towards the church as an entity of support despite these caregivers being members of the church. This shows that there exists an interplay and interdependence between contextual, personal and environmental factors in shaping one's experience of support for the occupation of caregiving. Although support structures may be present, this does not equate to caregivers feeling confident and safe enough to avail of this support.

2.6 South African Policy and Early childhood development and existing initiatives

Black et al., (2017) found that 250 million children (43%) younger than the age of five, in low-income and middle-income countries are at risk of not reaching their developmental milestones. Profound differences in the development of children arise depending on whether they are exposed to a range of protective factors and/or risk factors. (Lindland et al., 2016).

South Africa's National Development Plan (NDP) has clear commitments to ECD, although this is not consistently seen in practice (Britto et al., 2019). The NDP encapsulates ECD as services providing comprehensive care for family planning, healthy pregnancy, postnatal support, nutritional support, breastfeeding advice, birth registration, social security and poverty relief. It also seeks to support caregivers in the provision of appropriate early learning opportunities. (Lindland et al., 2016). From the NDP, the NIECD policy was born. The NIECD policy includes various laws and policies focusing on ECD and takes on a life-course approach to human development. This policy posits that ECD is firstly a right for all young children, and secondly a public good. The National Department of Social Development was designated as the official department to take charge of the implementing and coordinating essential packages of services across all sectors of government (Department of Social Development, 2016). However, progress has not been consistent and there is still much work that needs to be done to ensure that services not only allow for the survival of children but also their thriving. The NIECD policy states that the following risk factors predict poor ECD outcomes: poverty; malnutrition; stunting; low birthweight; infectious diseases in pregnant women, infants and children; environmental toxins; stress; exposure to violence; psychosocial risks; disrupted caregiving (absent parents, ill parents, non-parent caregivers or abandonment); and disabilities (Department of Social Development, 2016). Although there are clear commitments evident in the NIECD Policy prioritising caregiver support, little progress has been realised in the accomplishment of their goals. This is partially owing to COVID-19 lockdown leading to a reduction of attendance in early learning programmes (Slemming & Bamford, 2018). In addition, the first national study looking to monitor whether children were on track in achieving their developmental milestones found that many were below the baseline, and this number continues to increase. This trend suggests a greater need to invest into the effective implementation of policy at a grass root level (Slemming & Bamford, 2018).

The Department of Health is responsible for the delivery of the comprehensive package of ECD services for children in their FTD. There has since been a paradigm shift from pure survival of children to one that encapsulates the principles of nurturing care. The priority in actualising this was partially realised in the creation of the Road to Health Book (RTHB) to support healthcare workers to provide the necessary services through comprehensive screening to support children in this age bracket.

The Western Cape government's First 1000 Days programme is also a best-practice model that is re-orienting their services to target pregnant women and young children with a particular focus on maternal mental health (Slemming & Bamford, 2018). The First 1000 Days programme is implemented through integrated services across health, social development, and education sectors, ensuring that pregnant women and young children receive coordinated support. This includes maternal mental health screening, nutritional guidance, early learning stimulation, and home visits by trained community health workers (Slemming & Bamford, 2018).

There were three areas where implementation of a program targeting specific NIECD Policy commitments were not being met. These were: "Support for infant development, service referral and access through home visits for vulnerable caregivers", "support for infant development, pregnancy and maternal support through clinic and community-based support groups for women and babies" and lastly "building capacity of childminders to support infant development and stimulation" (Slemming and Bamford, 2018). Inherent in these targeted supports is an emphasis on caregiver capacity building. These three areas highlight the need for further investigation into the role of community-based supports in providing care for vulnerable caregivers to build the capacity of caregivers to nurture their children.

2.7 Previous Research and Research Gap

Murphy et al. (2007) explored the health of caregivers with children who have disabilities and found that there was a correlation between the health of the caregiver and the child. Caregivers in the study were reported to have neglected their own health to prioritise their child's needs (Murphy et al., 2007). It was found that support provided by community and support groups alleviated negative emotions experienced by caregivers (Murphy et al., 2007). The study highlighted the need for caregivers to feel long-term support in their role of caregiving (Murphy et al., 2017). This study seeks to bridge that gap through exploring the caregivers' perceptions

of the support that they receive from FTD-friendly churches. A study conducted by Adebisi et al., (2016) found that although parents and caregivers from low-income areas in South Africa have a good understanding of what their children require to thrive during their FTD of life, this did not automatically equate to having the necessary skills, resources and capacities to do so. They recommended finding solutions to address the intrinsic and extrinsic barriers within these communities that could hinder parents from providing their children with what they require to thrive (Adebisi et al., 2016).

Mc Gadney (1995) states that there has been a scarcity of research looking into the role of black churches as a source of informal support for Africans, which is unfortunate as he suggests that historical and present-day data points to the prominent space that the black church has taken up as a source of spurring socio-political and economic change within the community. Mc Gadney's (1995) study found that according to members in the community, the support gained by African American churches placed second, right after support provided by biological kin. This all highlights the necessity of looking into this age-old institution as a key-stakeholder to drive social change. This further strengthens the rationale to explore how South African caregivers are experiencing support from their local churches.

2.8 Conclusion

As development is integrated and interrelated where physical, cognitive, socio-emotional and language interplay to facilitate or hinder development, so functions support. Just as there exist different contexts in which a child functions, the implication would then be that the child would need to be considered as a whole, with each domain of their socio-emotional, physical and emotional life working in tandem with one another. Each aspect of development acts as a domino effect on the other. Thus, this study will seek to explore what the interplay of various types of support present in an FTD-friendly church serves. This will be done by exploring the different types of strategies put forward by Sikunye. In so doing, the study can provide valuable insights on how caregivers are experiencing the support offered to them, why this is the case and how to better integrate elements of support ensure optimal results to allow for the holistic thriving of children.

In conclusion, this chapter has highlighted the importance of ECD, particularly the FTD of life as the foundation upon which other critical skills are built to ensure the health and well-being of

children. Responsive caregiving, as articulated by the NCF is vital in ensuring that stable and positive relationships between children and their caregivers are created to override the risk factors from adverse environments. Despite clear commitments in South African policy to improve ECD, challenges such as poverty, inequality and resource constraints continue to hinder the desired progress. Translation of policy into targeted and effective integrated support for caregivers and their children is critical to moving towards actualising the priorities clearly delineated in our policies. Due to the complex interplay between individual child factors, the social, economic, physical and psychological capacities of the caregiver as well as the broader systemic issues, the expert opinions of those most affected, namely the caregivers need to be fore fronted and integrated into all levels of decision making. The need for an integrated and multi-sectoral approach to supporting caregivers is required.

The role of churches and spirituality was identified as an important, however under-explored area in the literature. Despite evidence pointing to the necessity of meeting the practical, social and emotional needs of caregivers, thereby improving resilience in caregivers, particularly those who have children with disabilities, much work still needs to be done. This highlights the importance of leveraging churches as key-stakeholders in empowering caregivers to feel supported in their FTD journey.

There have been a few studies that have explored the experience of caregivers of children with disability, this highlighted that faith was an important aspect of their experience of supportiveness. However, these studies are yet to explore caregivers of children without disability and within their FTD of life within a church that is actively being supported to create a FTD-friendly environment to support the thriving of caregivers and their children.

CHAPTER 3: Methodology

3.1 Introduction

This chapter seeks to explore how the objectives were achieved. It begins by describing the research approach, design and paradigm to best answer the question of how caregivers are being supported in FTD- friendly churches. It describes the sampling method, recruitment process and how the data was collected, analysed and managed whilst remaining ethical and ensuring the trustworthiness and rigidity of the data.

3.2 Research Approach

The approach for the study was qualitative, Savin-Baden and Major (2023) state that this approach to research is appropriate as it will allow for in-depth exploration of the experiences of caregivers in FTD-friendly churches and provide rich in-sights into how caregivers are currently experiencing the supports that are availed to them.

3.3 Research Design

A qualitative descriptive design was selected for this research study, as Sandelowski (2000) states that it provides a straightforward and pragmatic approach to research. This approach avoids theoretical abstractions and inferences and seeks to ensure that the research focuses on the language of the participants. This design would allow for the capturing of the nuanced accounts of the caregiver's experiences in their own words. By applying this design, the researcher can come to a comprehensive and low inference understanding of the perceptions of caregiver support to answer the desired objectives of the study (Sandelowski, 2000).

3.4 Research Paradigm

An interpretivist method of research seeks to understand an individual's knowledge of reality (Schwandt, 1994). The research relied on the shared experiences and the insights that caregivers have gained from being part of a FTD-friendly church in the Western Cape. The disadvantages that are associated with an interpretivist design is that it is very prone to bias (Schwandt, 1994). However, making use of critical reflexivity, I recognised that I am not

separate from subjects being researched. Thus, through the disclosure of my assumptions, I assisted in deepening the level of qualitative data gleaned. The research is not generalisable, however, this is not the aim of qualitative research (Cresswell & Miller, 2000).

3.5 Study Population and Sampling

3.5.1 Study population

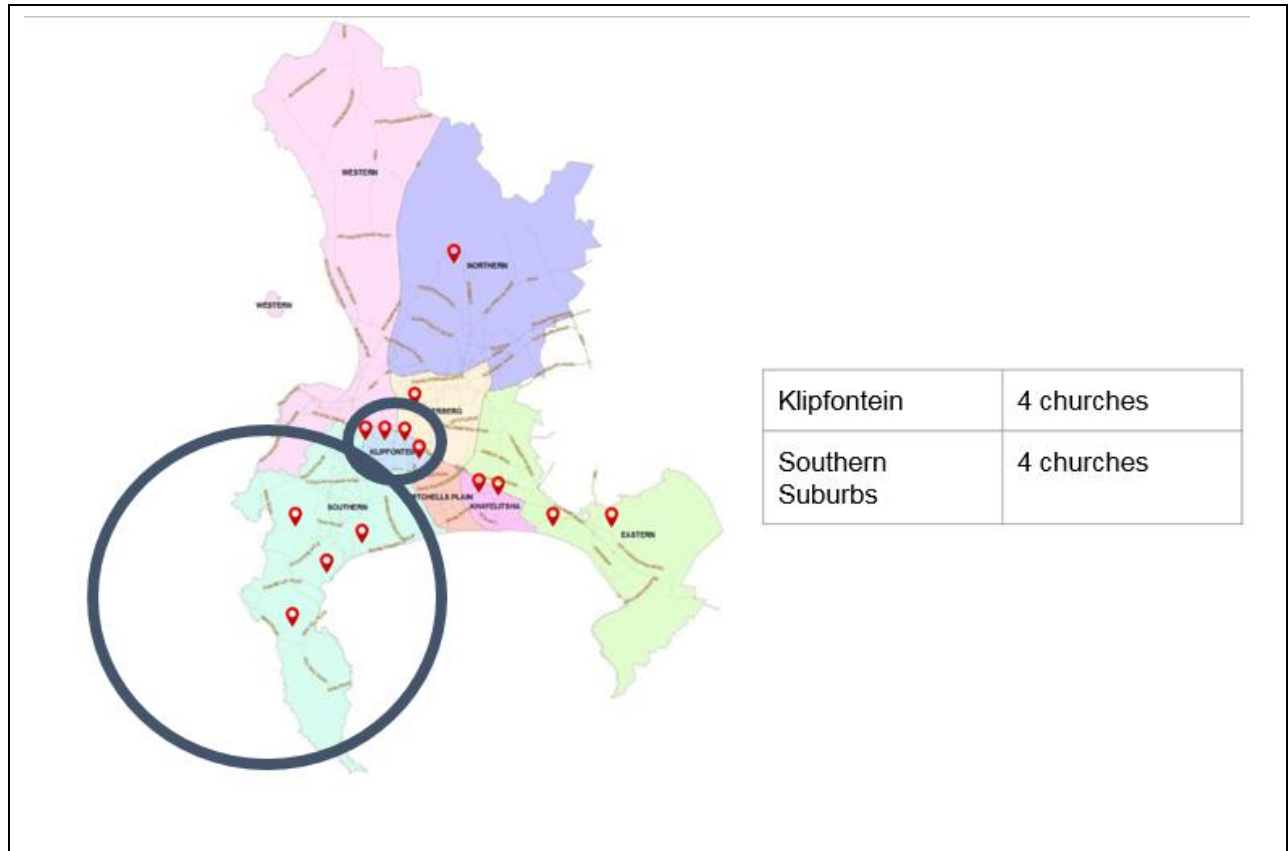
At the time of this study, there were a total 119 activated churches within the Western Cape: with the number of caregivers in the FTD ranging between 0-30 caregivers per church. The study population included all caregivers with children in their FTD who attend churches that are considered “activated FTD-friendly churches” with Sikunye. To gather data for this study, purposive sampling was used. The purposive sampling technique is the deliberate choice of participants due to the qualities the participant possesses (Etikan & Alkassim, 2016). Although, there are also disadvantages of purposive sampling, namely bias. However, if selection is based on a strict criterion this can be avoided (Sharma, 2017). From the 119 churches across the Western Cape, the below selection criteria was applied to reduce this number to eight churches who were recruited to participate in the study. One participant was selected from each church. Table 1 below describes the inclusion and exclusion criteria for the selection of churches for the study.

3.5.2 Table 1: Inclusion Criteria for Churches

Criteria	Motivation for criteria
Churches should have signed up in 2020 or 2021.	This ensures that these churches are engaging with the most recent initiatives that Sikunye has made available, whilst still ensuring selected churches have had sufficient time to implement the initiatives within their church.

<p>Churches need to be based in Cape Town.</p>	<p>This ensures that the focus of the study is narrowed. Interviews will also be conducted in person; thus, this allows churches to provide caregivers who are able to meet in person.</p>
<p>Churches must have attended at least one Sikunye event in the past 12 months.</p>	<p>This will ensure that churches recruited are from churches who are actively engaging with the organisation.</p>
<p>Churches should be located within the two most highly populated sub districts within the western Cape.</p>	<p>This will ensure that the districts that are selected to participate within the research have a greater potential of acquiring more churches, thus increasing the variety of potential caregivers gained.</p>
<p>Churches need to have at least one caregiver within their church that is caring for a child in their first-thousand days.</p>	<p>This will ensure that the churches that are recruited to participate have potential caregivers that can be recruited to participate within the study and those caregivers have experience caring for children within their first thousand days.</p>
<p>Churches should have access to telephone or email.</p>	<p>Churches will be contacted via telephone calls/email; therefore, they need to have access to these mediums.</p>

Figure 1: Map of the Distribution of Churches



3.5.3 Table 2: Inclusion Criteria for Caregivers

Criteria	Motivation for criteria
Caregivers should be part of an FTD-friendly activated church.	Explained in table one

Caregivers should be located within the two most highly populated sub districts within the Western Cape.	Explained in table one.
Participants need to have been attending the FTD-friendly churches since 2020 or 2021.	This ensures that these caregivers are engaging with the most recent initiatives that Sikunye has made available, whilst still ensuring They have had sufficient time in churches to experience the initiatives.
Participants should be from churches that have attended at least one Sikunye event in the past 12 months.	Explained in table one.
Participants must be able to communicate in English. Although no real time translation will be provided, information sheets, consent forms and scripts will be translated in isiXhosa should participants require this to refer to.	These are the languages that are spoken within the churches; thus, caregivers are most likely to also speak in this language.
Participants should have access to a telephone (mobile or landline).	After being informed in-person about the study, focus groups will be arranged with the participants via telephone; therefore, they need to have access to this medium. In addition, member checking will also occur telephonically.

3.6 Ethics Approval

Ethics approval was obtained from the Faculty of Health Sciences Human Research Ethics Committee (HREC 662/2023). Once clearance was approved, permission was obtained from the pastors or key members of the church that oversee the FTD initiatives via email (Appendix 6) via email addresses obtained through Sikunye’s database.

3.7 Recruitment strategy

The researcher requested that gatekeepers (pastor or key member) inform and recruit the caregivers of the research. This happened at the weekly church gathering. Information sheets (refer to Appendix One A) pertaining to the study were provided by the gatekeepers, clearly explaining to participants what was required of them, where and when the study was being done. Participants were informed about who else would be in the research. This information was provided in the caregiver's language of preference using terms that were easily understandable, and they were given time to reflect or consider the study before they provided their contact details. To avoid coercion participants were made aware that no negative repercussions would occur if they did not agree, and this would not negatively affect their relationship with church members or Sikunye. Research conducted in 2017 by Sikunye involved pastors, however, this current research does not directly involve them. The researchers remained sensitive to how this could have potentially reduced willingness of church leaders to communicate with caregivers.

Interested caregivers were invited to write down their contact details, namely, their cell phone number on a google form or a hard copy with a screening checklist (refer to Appendix One B) inclusive of the selection criteria for caregivers. Thereafter, they were contacted by the researcher who explained the study to them in more detail, allowing sufficient time and privacy to decide. Only one caregiver per church was recruited to participate in the study. All the information was re-explained on the day of the focus groups, where they were also provided with informed consent forms (refer to Appendix Two), the person obtaining consent was adequately trained. The information sheet was available in isiXhosa. In addition, on the screening checklist there was a section where caregivers could indicate whether they would require written translation into isiXhosa.

3.7.1 Table 3: Outlining Participant Description

Participant Code	Marital Status	Gender	Location Type	Caregiver Role
PC	Married	Female	Suburban	Primary caregiver of a child in FTD
PZ	Single	Female	Urban	Primary caregiver of a child in FTD
PN	Single	Female	Urban	Caregiver of children in FTD

PS	Married	Female	Urban	Primary caregiver of a child in FTD
PM	Married	Female	Suburban	Primary caregiver of a child in FTD

3.8 Data Collection

Focus groups were the main source of data collection. Krueger (2014) states that the intent of focus groups is not to infer but to understand, neither was it to generalise but to determine the range of perceptions and gain rich insights. Owen (2001) used focus groups to gain insight into women experiencing mental health difficulties because of the unique nature of the sample and the possible vulnerabilities that come with it. Thus, focus groups encouraged participation from participants who may have otherwise been reluctant to be interviewed or feel as if their contribution was not valuable (Owen, 2001). One focus group took place at the Sikunye’s base in Observatory; five participants were present on the day from various FTD friendly churches. The group was facilitated by the main researcher and co-facilitated by a member of the Sikunye team. There was one focus group generating two hours of data, and the researcher found that this was sufficient to address the research questions and objectives

The main facilitator was the main researcher, as the main researcher had experience in facilitating groups and workshops in the past. The co-facilitator was a member of Sikunye and a caregiver who signed a confidentiality agreement. The researcher briefed the co-facilitator from Sikunye covering ethical protocols, neutrality in facilitation, and data confidentiality. The positionality of the co-facilitator as caregiver allowed other caregivers to experience a sense of solidarity as they could better relate to the experience of the caregivers themselves. Seeing as the facilitators are likely to be seen as the “experts” in the group. It was important to recognise the implications of these power dynamics and disclose from the beginning that the space was one for listening and not judging. In addition, it was emphasised that the caregiver’s ability to care is not being scrutinised, rather it is a space that seeks to listen to their needs of how they can be better supported.

A babysitter with prior experience in childcare was present on the day of the study so that caregivers were not deterred by a lack of childcare, as well as to minimise disruptions during the

focus group. The babysitters were a part of Common Good and had a background check to ensure the welfare of the children, however, caregivers who had brought their children chose to keep them with them in the room on the day of the study. Before the focus group commenced, the researcher ensured that informed consent had been gained from participants, this is evident in the copy of their signed consent forms. The focus group lasted for 2 hours. The co-facilitator took field notes and recorded non-verbal interactions, during and immediately after the group. The focus group was audio-recorded with the consent of the participants. The focus group was held in English.

An interview guide was used, (refer to Appendix Four). The tool itself was divided into three sections; each section based on a separate objective of the study. This ensures that the questions asked did not deviate from the aim of the research study and that the answers to the questions served to answer the overarching research question.

At the end of the focus group, a follow-up interview for member checking was agreed upon with respect to date, time and place. This was done individually and telephonically, during this interview, follow-up questions were asked to clarify the information the participants had given previously, to prevent miscommunication and ensure credibility of the answers. This was approximately 30 minutes to one hour. This entailed returning the interview transcript with the specific responses highlighted that the participant had said. The researcher asked them to verify that the transcript captured what had been said. These sessions were not audio-recorded but the researcher took notes. Data that had been incorrectly interpreted was clarified.

3.9 Data Management

The UCT Data management plan was followed to assist the researcher with questions related to the data collected (UCT DMP, 2019). The transcriptions will be stored for ten years after the completion of the study as per ethical guidelines on an electronic device in a password-protected file which only the researcher and supervisors have access to. The recordings were uploaded to a private online Microsoft file directly after data collection. The file was encrypted with a password that no one has access to, except the researcher, to ensure privacy.

3.10 Data Analysis

Data collection and analysis proceeded simultaneously. Digital recordings were transcribed verbatim by the researcher. These transcripts were checked by the co-facilitator who had attended the groups for accuracy and any missing data.

Thematic analysis was used, and the researcher made use of an inductive approach. Data was analysed following Braun and Clarke's (2006, p.87) six phases of thematic analysis being: "(1) familiarising yourself with your data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes and (6) producing the report. In phase one, audio files were transcribed verbatim by the primary researcher". The primary researcher listened to focus group audio files alongside interview transcripts for accuracy. Transcripts were de-identified and imported into an excel spreadsheet to assist in organising, managing and analysing data. In phase two, researchers generated a set of initial codes based on similar responses from caregivers. In phase three, the researcher coded independently the first interview transcript, refined and achieved consensus on the codes. Codes were then collated into potential themes. The process of collating the codes, searching, reviewing, defining and naming the themes happened concurrently as the researcher continuously checked back to the coded extracts from the data gained from initial focus group as well as member checking interview to ensure accuracy of interpretation and that the identified units related to the research questions (Braun & Clarke, 2006). Phase four (reviewing themes) occurred once member checking had taken place to ensure that any new information captured from the member checking interview is evident within themes. The co-researcher, present on the day of the interview as well as the research supervisors assisted in reviewing and confirming the themes over phases three to five. In phase six, specific extracted examples were selected for the results section and reflected the research questions and literature.

3.10.1 Table 4: Describing the Process of Data Analysis

Phase	Description
Phase 1: Familiarising with the Data	Transcription of audio files verbatim by listening to the audio-recordings alongside the interview

	transcripts.
Phase 2: Generating Initial Codes	Initial codes generated to organise the transcribed data.
Phase 3: Searching for Themes	Microsoft Excel was used to manage and analyse data. Codes were then collated into potential categories and then themes.
Phase 4: Reviewing Themes	The themes were reviewed alongside supervisors and co-researchers for consistency with the data and the research questions; ensuring member checking input was integrated.
Phase 5: Defining & Naming Themes	Themes were named and defined to properly reflect the data and answer research questions and objectives.

3.11 Trustworthiness and Rigour

According to Krefting (1991), there are four foundations of trustworthiness which include credibility, transferability, dependability, and confirmability (Krefting, 1991).

Credibility: The researcher made use of researcher triangulation, where several investigators participated in collection and analysis (co-facilitator, facilitator and translated scripts were available). Data-triangulation was applied using focus groups and field notes to provide a more holistic view of the caregivers' experiences. Lastly, triangulation of time was also applied through gaining data on two separate occasions, one to collect the data and the second for member checking which was done telephonically.

Transferability was also ensured by use of a thick description of the participants' context and experiences. Here, the behaviour and experiences and body language of participants was clearly explained, and all research processes delineated. Participants included five female caregivers, from low- to middle-income households, all residing in urban communities in the Western Cape. Two were single mothers, and three were married.

Dependability and Confirmability was ensured through making concerted efforts to ensure that data remained as unbiased as possible. Although neutrality is not achievable, making use of reflexivity and bracketing made the researcher aware of any assumptions that may be present, in this case it was assumed that caregivers are experiencing a sense of support from their church. Supervisors also had access to the diary. Making use of a diary for the reflection of assumptions as well as the platform to challenge these assumptions (Korstjens, 2018). In addition, member checking ensured that the results were an accurate representation of the participants' perspectives (Krefting, 1991).

3.12 Ethical Considerations

The following ethical principles were considered:

This research is compliant with the Helsinki Declaration of 2013 (World Medical Association, 2013). Minimal risk of participants during the research process was ensured by applying the following ethical principles to ensure informed consent.

Autonomy: This was achieved through respecting the opinions and decisions of the participants without projecting personal perceptions on participants. Acquiring informed consent in a language they understand, as well as ensuring confidentiality using pseudonyms were both ways to ensure this. Consent was gained from participants prior to recording the interview and they were informed that they were allowed to withdraw at any time. The focus groups were framed to support autonomy by posing questions in a respectful and non-condescending manner.

Beneficence: This research sought to strengthen existing strategies to support caregivers. The research findings also sought to directly serve the participants and caregivers in general through the knowledge, practices or interventions that resulted from the research.

Non-maleficence: The research proposal was sent for ethical clearance from HREC. Participants that experienced psychological distress were immediately referred onto psychological services. An effort was made to reduce the power imbalance in the focus groups by minimising direct questioning so that the caregivers could raise and discuss issues of relevance to them such that they felt free to talk in as much depth as is comfortable without interruptions. When caregivers felt they needed to take a break, that was also respected, as well

as if they wanted to discontinue the study as a whole. Questions were posed in a respectful manner.

Privacy and confidentiality: Focus groups were conducted privately. Participants were anonymised and de-identified. Recordings and field notes from observations were stored in a password encrypted medium. Data was de-identified to ensure privacy. Data will be stored for ten years and thereafter deleted (Wellcome Trust: University of Cape Town, 2023). The researcher emphasised at the beginning that the focus group can never be entirely confidential, because we cannot guarantee that members will maintain confidentiality amongst themselves. Nevertheless, participants were asked to keep information shared in the focus group confidential.

Justice: It was important to ensure equal opportunity of being selected through providing information sheets and consent documents at a Grade three level of education and accessible in the caregivers' home language. In addition, each member group was given a fair chance to participate within the focus group. This was ensured through the weighing of potential risks and benefits of the study. The same questions were asked across the caregivers thus ensuring that risks were distributed equitably. Participants were not excluded based on gender and convenience.

3.13 Description of risks and benefits

Risk classification

This was classified as a low-risk study as the anticipated benefits are greater than the harms or discomfort ordinarily encountered in daily life. Participants were not vulnerable people (except for some of the caregivers who may be of low socio-economic status as well as those who may be experiencing postnatal depression). There were no risks that were incurred physically, socially or economically, however there was a potential for psychological risk. There are also no risks that were incurred to the researcher. The location of the study was at a central location on a safe premises on the NGO base in Observatory with security present. Children were on the same premises in a secure room with a babysitter with prior experience in childcare.

Minimising risk

The potential of unauthorised access or tampering was eliminated by ensuring that all data was kept safe in password protected files on the researcher's password protected computer. Focus groups were done in a private enclosed area, to protect the privacy of the participants. Corruption of data can occur during the malfunction of systems that may affect the content of data that is being stored, which will adversely affect data collection. To prevent this, data was stored on a private project site on Microsoft (OneDrive). To ensure that information was accurately translated into the participants' language of choice, a transcriber proficient in the language was used to assist in the data collection phases. Participants who displayed signs of psychological distress, were referred on to counselling services.

Potential benefits

Although the anticipated benefits are greater than harm, participants did not benefit directly from this research. However, by participating they contributed to a better understanding of how Sikunye and their church can better support them and other caregivers across South Africa. In turn, this would serve to benefit them should the church take up the recommendations.

Alternatives to participation

Participants will be informed that they may choose to not participate in this study with no negative consequences. They will still be able to enjoy the full benefits provided for in their church and by the Sikunye Team.

3.14 Reimbursement for participation

Participants did not receive remuneration. However, light refreshments were provided during the focus groups as well as a small token of appreciation (a chocolate bar). In addition, they were compensated a minor transport stipend for the cost that transport incurred, should they require this. Participants were phoned by researchers and thus did not incur any airtime costs.

3.15 Emergency care and insurance for research-related injuries

No injuries were incurred during focus groups. However, if there was psychological distress that was picked up due to the sensitive nature of the questions, the researcher referred participants to counselling services, specifically the Jubilee Community Church Health Centre which offers counselling services and is on the same premises as the NGO (Sikunye's) base.

3.16 What happens at the end of a study

Participants will receive a copy of the research report on request. No pictures of participants or the use of the participants name, or any identifying details were used in the research report and other forms of presentation of information. All valuable information will be used to inform future strategies that Sikunye may create to assist the study population and caregivers in churches around South Africa. This will be done through providing a copy of the report for Sikunye to have access to. In addition, a verbal feedback meeting with the researcher was offered on request to present results. Knowledge will be disseminated in the form of a peer reviewed journal article.

3.17 Conflicts of Interest

Neither the researcher nor additional research staff (the Sikunye team nor the co-facilitator) received an incentive for recruiting participants or for any other purposes directly related to the study. This study was an extension of existing research, there may be incentive to use the current study to validate findings of the previous one. In addition, a member from the Sikunye team with previous training running groups and workshops, as well as a thorough understanding of the organisational aims was the co-facilitator. This may be a conflict of interest as they are directly involved in the creation and implementation of the strategies at Sikunye. Reflexivity was a tool used to minimise bias amongst the research team. Mitchell et al., (2018 p.678) calls us to the “process of a continual internal dialogue and critical self-evaluation of researcher’s positionality”. This will entail us turning the lens in on ourselves and recognising how our situatedness within the research may affect how the data was collected and analysed. Thus, that is why member checking, triangulation during data analysis, an audit trail and a process journal was used during the research process (Buetow, 2019).

3.18 Summary

In conclusion, this chapter sought to outline how the objectives of study were achieved. A qualitative approach with a descriptive design making use of an interpretivist paradigm was used. This ensured an in-depth account of the caregivers’ experiences, focusing on the meaning of what the caregivers were saying to gain a better understanding of the phenomenon

under exploration. The population included five caregivers from five different churches in the Western Cape who met the inclusion criteria. Caregivers were recruited through gatekeepers. A focus group was conducted with the main researcher and co-facilitator and analysed using thematic analysis. Methods such as triangulation were used to ensure trustworthiness and ethical principles were followed such as using informed consent. Ethics approval was renewed by the University of Cape Town Human Research Ethics Committee in December 2023.

CHAPTER 4: Findings

4.1 Introduction

The thematic analysis from the data revealed an overarching theme, namely **"They say it takes a village, and it really does"** with two supporting categories. The first category: *"Types of support needed from my village (FTD-friendly church) to raise a child"*. This category focuses on the social, emotional and psychological aspects of support experienced by the caregivers. The second category: *"How I feel about the type of support received from my village (FTD-friendly church) to raise a child"*. This category focuses on the perceived lack of support related to the challenges and limitations of existing support structures.

4.2 Overarching theme and categories

This theme emphasizes the necessity of a supportive community, reflecting the African proverb that it requires a village to raise a child. It highlights the role that a FTD-friendly church can play in supporting caregivers with children in their FTD. The main theme that emerged from the study: **"They say it takes a village, and it really does"**. This theme explores how there are many different aspects of support that are needed by caregivers from a FTD-friendly church in order to feel supported. This describes how members of a church are needed to create those feelings of support. This chapter elaborates on how well they perceive this support received from their village (church) to raise a child. It is captured in two categories.

4.2.1 Table 5: Overarching Themes and Categories

Overarching Theme "They say it takes a village, and it really does"	
Category One	Category Two
Types of support needed from my village (FTD-friendly church) to raise a child.	How I feel about the type of support received from my village (FTD-friendly church) to raise a child.

<p>Subcategories:</p> <ol style="list-style-type: none"> 1. Psychosocial support 2. Practical, material and structural support 3. Childcare-focused support 	<p>Subcategories</p> <ol style="list-style-type: none"> 1. Perceptions of not being supported 2. Perceptions on the appropriateness of support 3. Positive Perceptions of existing support and suggestions for future support
--	--

4.2.2 Category One: Types of support needed from my village (FTD-friendly church) to raise a child

This category describes the varying supports those caregivers named as being fundamental in raising a child in their FTD-friendly church. Namely: Psycho-social support, practical, material and structural support as well as childcare-focused support.

4.2.2.1 Psycho-social Support

Social, psychological and emotional support was experienced through child protection policies to ensure childminders are treating the children appropriately. In addition, counselling services and understanding from other members in the church community allowed caregivers respite from the full-time occupation of caregiving. Lastly, timely and appropriate support groups were pivotal for experiencing social connection through FTD-friendly church programmes.

One participant expressed the need for professional types of support such as from social workers, expressing that there is a limitation to the level of support that can be offered through caregiver social connection.

So, I think they need counselling, someone supporting them. Someone who is professional who can help them with these problems. Yeah so, I tried to talk to my friend. I have a friend. She's a social worker. I tried to talk to her. So, she promised to help them to refer them up. (PS)

Caregivers also elaborated on having other types of support such as more consideration and compassion for parents with young children and single parents by making an intentional effort to hear what is going on and not expect the same of them as they would other members of their

congregation. They express a desire for a unique type of compassion geared towards parents in their FTD. One caregiver experienced the level of support from church members varied depending on marital status.

I just would love some ... grace towards parents with young kids that you aren't going to attend every event, sometimes you are going to have to leave earlier because my child needs to sleep. (PC)

So it would it would be nice to have a little bit more of a focus on you know, essentially what we spoke about: single moms - so that I mean I get greeted when I go in but like it would be nice to have like someone really dedicated to like: "is this your first time, is this your first time out with baby?" Like that kind of thing. It was hard navigating that on my own obviously as you got older, but it would be nice to have more of that focus on surrounding families with coming to church and closer and to also encourage people to come to church and not stagnate. (PM)

So, I think for me, a woman who isn't married, if we could get support like the people who are married that would be great. (PZ)

4.2.2.2 Practical, Material and Structural Support

Some of the caregivers expressed a need for practical, material and structural support through the provision of meals, childcare, essential baby items, and dedicated spaces.

This subcategory communicates the importance of a physical space where caregivers can care for the needs of their child. They also express it would be helpful to have a separate room for fathers to allow mothers to participate in church activities.

I feel there should be a separate one (room) for men, like not that I'm saying that everybody needs to be separated, but I think it would be great if mom wants to worship and then mom can hand him the baby bottle so that he can go to a separate room with other dads possibly and then it might be a thing. (PM)

Caregivers expressed the necessity of practical support in the form of having a meal roster or to have baby showers to acquire necessary baby items they otherwise may not have had.

Baby showers are very important, because some pregnant women don't have anything. So, by the time you leave the baby shower you can have bathing things, bath towels, clothes. (PN)

4.2.2.3 Childcare-Focused Support

Discussions around the needs for dedicated spaces and child minders for young children attending the FTD-friendly churches were explored. This included dedicated spaces for children, childcare services, family-oriented events, and inclusive opportunities for children in their FTD.

One caregiver expressed that she would like spaces and child minders for children who are in their FTD just as there are activities for children who are older.

*There is nothing for my child who is 3 or younger. So, we must keep the young ones like this *pointed to her child on her lap*. So, I wish they could, like you mentioned, rooms for moms and children like the young ones, like this, it will be nice. (PN)*

I would appreciate it (babysitting), I don't know if it should come from the church, but I don't know where else it should come if it doesn't come from the church. Because I don't have, I don't have family living with me. (PC)

Many caregivers felt that there was a need for activities that are age-appropriate, and child centred to facilitate inclusion of these children and including them into the types of service opportunities available.

Other ways of how we can serve should be considered so I think just to consider those with younger children who are not necessarily considered for that type of serving, but other types of serving, you know that an outreach or like a fun day or something like that could involve the children and maybe raise funds or whatever. (PM)

I think another thing which would be nice is there are a lot of family days, but it would be nice, like if there's Mom days or moms and babies' days. (PM)

The category "Types of support needed from my village (FTD-friendly church) to raise a child" highlights the various forms of support that caregivers require from their church community. This includes psycho-social support, such as emotional understanding and professional counselling services; practical, material, and structural support, like meal rosters, baby showers, and

dedicated childcare spaces; and childcare-focused support, including age-appropriate activities and childcare services. Collectively, these elements ensure caregivers feel supported in raising their children within an FTD-friendly church environment.

4.2.3 Category Two: How I feel about the type of support received from my village (church) to raise a child.

This category relates to how caregivers experience the existing types of support received from their village (their FTD-friendly church). This sub-category will be elaborating on caregivers' experiences of support when they are available and how appropriate they might be.

4.2.3.1 Perceptions of not being supported

Caregivers highlighted the perceived lack of support relating to challenges and limitations of existing support structures such as psycho-social, practical, material and structural support and childcare-focused support.

Caregivers felt that unmarried mothers did not receive the same support as married mothers and expressed the need for regular check ins.

If you are not married and have a child, you don't get the full support as someone who is married. No one checks up on you or asks how you are doing (PZ).

Caregivers express the need for dedicated spaces for children in their FTD in order to carry out necessary tasks such as changing nappies and breastfeeding.

In our church, no because we have been changing places, from one place to another, you don't have a stable place to worship in, so we could worship maybe in a classroom. So those kinds of things can't be provided there like matt facilities. (PZ)

Even us we are doing like that (breastfeeding outside) because we don't have a place to worship so you must do it in the church. (PZ)

And in our previous venue, there wasn't really a space to breastfeed privately. And to me, that's an issue, if there's a man in the room, I don't feel comfortable. If there's any

woman, I don't mind but if there's a Man, I will go to sit in the bathroom on the toilet to breastfeed my baby because I wasn't comfortable with a man being there. (PC)

One caregiver expressed challenges related to a lack of family support or having to care for family members. She felt that the church was an additional 'baby' she had to tend to and be responsible for.

And we struggle sometimes because even as we don't have family members who are with us, and even in the family, we are the ones who help most of the time. And the church, I can say is another baby for us, since we have this one. (PS)

4.2.3.2 Perceptions on the appropriateness of support

Perceptions on the lack of support relating to having received some support, but not the type or extent of support necessary are further elaborated on in this sub-category.

One caregiver expresses that there was an assigned person in the church to assist her on her FTD journey, however this was not appropriate for her as she did not ask nor seek it out.

So, they used to like to assign someone from the first 1000 days group or like a mom, usually another one and then we did the training and then they would assign that person to you as a mom. Also, to be fair, when my first one was born, I wasn't, like, at that time, I didn't feel like I necessarily needed support in that way. (PC)

There were discussions regarding the appropriateness of the support gained from online platforms such as WhatsApp groups to offer support. Some caregivers found that it was either not appropriate or did not feel it was appropriate for meeting their needs.

We have a whatsapp group, but they are always talking about the bible. But not practical things about the baby. (PZ)

Another caregiver expressed that they did not feel comfortable sharing and expressing their needs on this platform.

It's only this Whatsapp group we're going to focus mostly on to talk about the Bible. You don't really feel like you can share a lot. You don't want to feel like you are a cry-baby, so sometimes you hold back. You also don't want to share too much and there will be

some who feel like it is maybe a lot to take in. People also don't want to talk because they think others will talk behind each other's backs. (PZ)

4.2.3.3 Positive Perceptions of existing support and suggestions for future support

Positive perceptions arising from existing support structures relating to three pillars of support offered by Sikunye were also explored by caregivers. These included: surrounding families, speaking up and creating warm and welcoming spaces.

Some caregivers express that online platforms such as WhatsApp have facilitated the process of creating a safe space because it has the relevant people in those groups.

Even us we have the WhatsApp group and that WhatsApp group is divided. We have for the ministers. One for the father and mothers. We have one for the men, and we have one for women. It's a safe space for us also because we talk there, we pray for each other they hear everything, and we support each other. (PS)

One caregiver expresses that she values more practical forms of support.

I think surrounding families to me, I feel is most supportive, yeah sorry it's maybe... like we shouldn't say it but it's difficult like prayers. You know, I don't know, I want to believe that, but I think that's a difficult one to see, like to evaluate, like pray, with surrounding families. I can see someone brought me a meal or someone's asking me at church like: 'How are you doing with all the boys?' like it feels more practical, more in my life feels more practical than spiritual. (PC)

One caregiver expresses the importance of a dedicated space to allow for connection with other moms.

I also like the moms' room. You are able to connect and talk about things like "ah, they aren't sleeping" or "how are you doing this" or "they aren't eating" and who can help me with this, I like that. (PC)

Another caregiver expressed that if church leaders were more vocal about their needs this will in turn empower caregivers to feel that they can also open up and share.

I think to speak up - because if the church can speak openly, I think also from our side we can speak up and tell how we feel, and they can learn what we need. (PS)

4.3 Summary

In summary, caregivers require various types of support from their FTD-friendly church, including emotional, practical, and childcare-focused support. While there is recognition of existing supports available, caregivers also reflect and explore the appropriateness of these support structures.

CHAPTER 5: Discussion

5.1 Introduction

This research aimed to explore how caregivers in FTD-friendly churches experience support across the six strategies outlined in the NCF offered by Sikunye. This discussion will elaborate on how caregivers experience support in relation to these pillars as well as the components outlined in the NCF which is a global initiative designed to promote the health, development, and well-being of young children from pregnancy to age three. According to Bhardwaj, Sambu and Jamieson (2017), children need nurturing care to thrive. The NCF is aligned with the goals of the pillars of support offered by Sikunye. This chapter will discuss the findings of the caregiver focus group. The aim of the study was to explore how caregivers in FTD-friendly churches are experiencing support across the six strategies as outlined in the NCF offered by Sikunye. This will be done by exploring objectives from the study, which were, firstly, to explore and describe the perceptions of caregivers on what an FTD-friendly church entails, what they need to feel supported and how they are experiencing the support across the six strategies (pray, speak up, surround families, equip, and prepare, create welcoming spaces, refer and collaborate). Lastly, this chapter will explore and describe which of the six strategies that Sikunye has established are most pivotal in creating a sense of support for the caregivers.

This chapter will start by describing, firstly how caregivers are experiencing the six pillars of support in their FTD-friendly churches and secondly which pillar of support has been most pivotal in creating a sense of support.

5.2 How are caregivers experiencing the six pillars of support in their FTD churches?

Caregivers did not specify explicitly what they believed an FTD-friendly church entailed, however made subjective reference to their experience as a caregiver in an FTD-friendly church. Murphy et al., (2007) explored the mental health of caregivers with children who have disabilities and found there was a correlation between the health of the caregiver and the child. Caregivers were reported to neglect their own health to prioritise their child's needs (Murphy et al., 2007). Caregivers in this study felt that their own mental health and wellbeing was a

necessary priority in order to adequately provide nurturing care for the child. It was found that support provided by community and support groups alleviated negative emotions experienced by caregivers. This study sought to bridge that gap through exploring the caregivers' perceptions of the support they receive from FTD-friendly churches and existing literature around what caregivers require to feel supported.

Without enabling environments to actively support caregivers in their role, children in South Africa will not be able to thrive (Marlow et al., 2024). Sikunye refers to this as warm and welcoming spaces (Ressel, 2022). Caregivers in the study experienced support by accessing warm and welcoming spaces in the form of designated breast-feeding rooms. The NCF speaks to the component of adequate nutrition as fundamental in allowing children to thrive (Richter et al., 2019), by ensuring that there are designated breast-feeding rooms, this allows the opportunity for caregivers to tend to the nutritional needs of breast-feeding infants. Security and safety in the NCF are encapsulated in this pillar too, this component refers to ensuring a safe environment for caregivers and their children. Caregivers explored the importance of having child protection policies to safeguard children, in addition female only rooms for breastfeeding were deemed necessary to create feelings of safety. Designated breastfeeding rooms allowed this need to be realised.

In line with the pillar of “warm and welcoming spaces”, caregivers elaborated on the importance of a physical space and what it communicates in terms of belonging and safety. Breastfeeding rooms provided a sense of dignity for the mother and a place to connect with like-minded people. These physical spaces set the groundwork for another supportive pillar of “surrounding families” to come into play.

The NCF refers to the importance of opportunities for early learning. This is the provision of opportunities for children to engage in age-appropriate play, communication, and other learning activities through stimulating a child's cognitive, emotional, and social development (Mustard, 2006). In South Africa, UNICEF recently conducted a study on caregiver knowledge, attitudes and practices regarding play-based learning for children from birth to six years old. This study found that many caregivers, especially those from a lower socio-economic status did not have the confidence to support their children with early learning (Marlow et al., 2024). This is supported by Adebisi et al., (2016) who found that caregiver knowledge did not equate to caregiver capacity to implement necessary practices to support childhood development.

This could be one of the reasons that caregivers expressed the need to have child-focused and inclusive activities within the church. In addition, the need to have inclusive spaces for children younger than three years of age. This pillar could be further strengthened by ensuring that child-focused activities that incorporate opportunities for early learning include indigenous forms of knowledge (Marlow et al., 2024).

Marlow et al., (2024) expresses that the strengthening of norms of responsive caregiving and creating innovative solutions to supporting caregivers in the FTD need to be based on knowledge that emanates from the local community. One caregiver in the study referred to a lack of programs to support caregivers in FTD-friendly churches. Another caregiver expressed how there were antenatal sessions being offered at a different church and was referred by her friends to attend that course. She expressed that she found these courses beneficial and educational. These antenatal classes can be further strengthened by including indigenous perspectives. In addition, another caregiver spoke about how she referred one of her church members to see a professional counsellor to support her mental well-being. This indicates that there are already existing programs within local communities that caregivers find themselves in. Further exploration to identify where this knowledge is located and how caregivers can access these supports is recommended.

Some caregivers expressed that environments are set up in a way to reduce paternal engagement in the care of children. For example, some caregivers found that they were uncomfortable to breastfeed in one room where males were present, thus advocating for the necessity of separate rooms for fathers to ensure equal participation in the care needs of the child. Marlow et al., (2024) found that fathers need to be more actively involved in the caring of their children. One way to do this would be actively engaging men within existing programmes and mobilising social resources such as community and religious leadership support as well as peer support networks. An increased paternal involvement in caregiving is necessary and strengthened by one caregiver expressing the need for a separate room for fathers to tend to the needs of the child. Prayer could accompany these solutions to allow for a shift in mindsets and challenge entrenched cultural norms and spur change.

Prayer is a religious tool that can be used to catalyse change (Ressel, 2022). There were mixed responses pertaining to the usefulness of prayer from caregivers. One caregiver referred to the strain that marital issues had on child rearing, and the need for support from church leaders. Some caregivers found that a WhatsApp group dedicated to praying for one another was very

helpful, others found that the online platform was not appropriate for speaking about issues related to caregiving. Another caregiver expressed the need for more practical support rather than spiritual support. One caregiver discusses the appropriateness of a church programme that tried to individually reach out and cater to each mother in their FTD. This caregiver felt this was not appropriate to her needs and that she did not ask for this type of support. However, another caregiver expressed that having a person designated to ask her about her child would have led to her feeling cared for and supported. This highlights that caregivers have different needs and expectations of support and that it is necessary to provide support that caregivers have expressed to be beneficial. The online WhatsApp group is an example of the same type of support that is experienced differently across caregivers and subsequently evoked a different sense of support for different people. This showed that support needs have a client-centred approach. The four pillars, namely, prayer, collaboration and refer as well as equip and prepare and creating warm and welcoming spaces were found to be necessary aspects of support. Occupational performance and participation, as articulated within the person – environment - occupation - performance (PEOP) model encompass the dynamic interaction between an individual and meaningful occupations, framed by the person's intrinsic characteristics, the environment, and the inherent demands of the occupation. These interconnected elements collectively shape a person's ability to engage in occupation, which ultimately has a profound impact on their overall well-being and quality of life (bass et al., 2024). However, the next fundamental pillars, namely speaking up and surrounding families were unique in nature, in that they were seen as the basis from which caregivers felt that they were able to access other types of support, and its usefulness permeated throughout the four pillars.

5.3 Which pillar of support has been most pivotal in creating a sense of support?

Responsive caregiving, as outlined in the NCF involves understanding and responding to children's signals, creating emotional bonding, and fostering attachment through positive, consistent, and responsive interactions. From this study, it was found that being vocal about one's needs was a crucial pillar for allowing responsive caregiving. Caregivers must be able to respond to a child's needs, providing a secure and stable emotional environment, however, to do so, caregivers themselves need to feel a sense of being nurtured and cared for in order to provide nurturing care to their children.

A study conducted by Adebiji et al., (2016) found that although the parents and caregivers from low-income areas in South Africa have a good understanding of what their children require to thrive during their FTD of life, this did not automatically equate to having the necessary skills and resources to do so. The church is recognised as having a trusted voice of influence in society; therefore, the church should use its voice and influence to raise awareness and advocate for children in their FTD.

Some caregivers felt that the voices of those in power, namely the pastors, need to be utilised and fore-fronted by advocating for the needs of caregivers in their FTD. This will allow those who feel marginalised, such as single and unmarried mothers to stand up and speak for themselves.

The power of a voice took central stage and ended up being an important pillar of support across all caregivers. There was a shared experience amongst caregivers that if people in the church spoke up about issues pertaining to the FTD, then caregivers would feel as if they could speak up about it too.

Adebiji et al., (2016) found that there was a need to find solutions to address the intrinsic and extrinsic barriers that could hinder parents from providing their children with what they require to thrive. Similarly, the study conducted by Adebiji et al., (2016) highlighted that churches are often unaware of the needs of caregivers due to caregivers not being vocal about their needs. This is due to a myriad of reasons, such as feeling that people will not properly care for them if they do open themselves up and may experience feelings of further ostracisation. This is evidenced by one caregiver expressing a fear of having her private information shared with the rest of the community or that she will be labelled as someone who is weak and only complains.

There was a relationship between intrinsic and extrinsic barriers to accessing support. If the surrounding space and physical environment were communicating a sense of support, this empowered caregivers to speak more openly about the barriers to accessing support.

This leads into the last most pivotal pillar of “surrounding families”. The phrase “it takes a village to raise a child” originates from an African proverb and conveys the message that it takes many people, “the village”, to provide a safe, healthy environment for children, where children are given the security that they need to meet their potential (Marlow et al., 2024). In the context of caregiving, this requires communities to be generous with supporting each other. All caregivers

expressed that the pillar of “surrounding families” to be one of the most important pillars in experiencing a sense of support.

Good health in the NCF refers to timeous access to appropriate care including adequate nutrition, immunisations, and disease prevention measures for mothers and children. Bamford (2019) states that caregiver mental health and emotional well-being are key factors that enable caregivers to provide responsive care. Women are more at risk of poorer mental health in contexts of poverty where they are the solely responsible for the care of young children and the upkeep of their household (Bamford, 2019). An unmarried mother in this study felt that she did not have access to the same support and resources as a caregiver who is married. Caregivers report that many of the other types of support were available to them because they experienced the pillar of “surrounding families”. For example, one caregiver heard about an antenatal class because she was connected to other mothers in the church who advised her to attend – thus allowing her to avail of support that would be categorised under the pillar of “collaborate and refer”. Some caregivers experienced this support in the form of body breaks, which is time where the baby is away from their caregiver. This helped the caregiver’s mental health and ability to better bond with the baby. Caregivers also expressed that when the church community comes together to organise a baby shower, they can have the practical needs of the child and mother met. In addition, meal rosters were also important in meeting the nutritional requirements of the mother so that they can in turn focus on the needs of the child. Just as “surrounding families” was the basis for availing certain types of support, again, the warm and welcoming environments themselves, such as the mom’s rooms were places to connect and offer advice to other caregivers experiencing similar challenges. These findings support literature conducted by Marlow et al. (2024) and Britto et al., (2017) who state that programmes should allow caregivers to collaboratively problem solve and overcome challenges by sharing success and difficulties amongst themselves.

Britto et al., (2017) argue that caregivers need to be supported in providing nurturing care and protection for young children to thrive. The NCF integrates multiple elements including health, nutrition, safety, responsive caregiving, and early learning to ensure that children receive the care they need to thrive, while emphasising the collective responsibility of families, communities, and governments in achieving these goals. From the findings we can see the same is true for pillars of support. Different types of support, both tangible and intangible, need to be present and continuously interacting with one another to facilitate and maximise feelings of being supported amongst caregivers.

5.4 Summary

There are many factors influencing caregiver experience of support, and it is not possible to look at these factors in silos. Although the last objective sought to explore which pillar was most pivotal in creating a sense of support. It was found that some caregivers had greater or lesser experiences of support across the different types of support offer and benefited proportionally to their need and desire for the support. It was found that there were tangible elements of support, namely a physical space for breast-feeding that lead to intangible elements of support, for example feeling seen and connected. Speaking up and surrounding families creates a culture in a church that triggers other pillars of support, such as prayer, equipping and preparing, collaborating and referring, creating warm and welcoming spaces. Support is not as rigid, isolated and clearly defined as we think it is, but it is integrated, fluid, connected, and works in tandem continuously with the various pillars of support to complement and strengthen one another. This in turn offers a comprehensive experience of support. This supports Marlow et al., (2024) findings that there is a need to direct our efforts towards strengthening natural support systems, such as friends, families and communities rather than trying to create new systems. A context in which this can be actualised is within local faith communities, thus highlighting how FTD-friendly churches are uniquely positioned to support caregivers as they navigate caring for children in their FTD.

CHAPTER 6: Limitations, Recommendations and Conclusions

6.1 Introduction

This chapter provides recommendations for practice, future research and further learning for government and other organisations

6.2 Limitations to the study

It is acknowledged that there was significant difficulty recruiting caregivers who were willing and available to go through the data collection process. As a result, although it was anticipated that there would be one participant from the selected eight FTD-friendly churches, only five were present on the day. Secondly, data was collected from only five churches within two of the most-highly populated sub-districts, who became activated between 2020 or 2012 within the Western Cape. Thus, their perspectives may not be representative of the situation in other districts and provinces or churches that have been activated before or after those dates. However, given that the same resources and initiatives are presented to all other FTD-friendly churches in other provinces, it can be assumed that the situation is the same in some of the others. Further research would be necessary to determine and evaluate the experiences of caregivers around wider contexts.

6.3 Recommendations

1. The study can further practice for Occupational Therapy Practice or other organisations such as ECDs to support caregivers in their FTD.
 - Occupational therapists may find this valuable for understanding the needs of the caregivers and the specific ways in which they feel supported to create or strengthen strategies for caregiver support.

- Occupational therapists should start thinking beyond the four walls of a treatment room and working with local organisations and other faith-based communities to offer integrated services through appropriate networking and collaboration.
 - Occupational therapists should create integrated support plans that combine elements from multiple pillars, such as blending practical support with spiritual encouragement, as “warm and welcoming spaces” allow for networking opportunities that cultivate the strategy of “surrounding families.”
 - Occupational therapy can use this information to gain more insights into the occupation of caregiving and create holistic and client-centred occupation focused assessments and interventions to support caregivers in their FTD through prioritising the needs and experiences of caregivers.
2. This study can also be used to complement future research that seeks to address and improve on responsive caregiving.
- Future research can make use of the valuable qualitative information provided by the caregivers to create strategies that caregivers found to be most supportive.
 - This research investigates two sub-districts within the Western Cape, there can be future studies that explore caregiver perceptions of support across the seven sub-districts as well as the rest of South Africa.
3. Lastly, this study may also be valuable for churches and other organisations and initiatives that seek to create FTD-friendly spaces that will enable children to thrive.
- It has been shown that the church is an important social actor. Churches and other faith-based organisations should use their influence to advocate for broader policy. They should also support for caregivers to create initiatives that speak directly to their needs so as to identify gaps that exist in current policy.

6.4 Conclusion

This study highlighted the critical role of FTD-friendly churches as social actors in supporting caregivers, using strategies outlined by Sikunye inspired by the NCF. Through interconnected strategies and collaborative efforts, practitioners, organisations, communities and caregivers can continue to work together to address various aspects of need to ensure a sense of being supported. By creating warm and welcoming spaces, speaking up, prayer, collaborating and

referring and equipping and preparing, churches can enhance the caregiving experience, ensuring that caregivers feel both supported and empowered.

The findings reveal that effective support is multifaceted and integrated, thus requiring a holistic approach. Pillars such as "speaking up" and "surrounding families" emerged as foundational pillars in empowering caregivers to access additional types of support and creating a sense of support. The church's influence as a trusted voice can also extend beyond direct support to advocacy, helping shape broader societal changes that benefit caregivers.

Ultimately, this study underscores the importance of a collaborative, community-driven approach to caregiving. Churches should be encouraged to embrace this integrated support model, which reinforces natural support systems, values unique experiences of the individual caregivers in their church by providing platforms where they feel seen and heard. This framework not only enhances the well-being of caregivers but also lays the groundwork for a thriving, resilient community, embodying the African proverb that "it takes a village to raise a child."

REFERENCES

- Adebiyi, B. O., Goldschmidt, T., Benjamin, F., Sonn, I. K., & Roman, N. V. (2021). Exploring the perspectives of south african parents and primary caregivers living in low-income communities on what children need to thrive within the first 1000 days of life. *Children*, 8(6), 483.
- Bamford, L. (2019). The first 1,000 days: Ensuring mothers and young children thrive. *South African Child Gauge*. Cape Town: Children's Institute, University of Cape Town, 71-80.
- Bass, J. D., de Sam Lazaro, S. L., Baum, C. M., & Marchant, J. K. (2024). The person-environment-occupation-performance (PEOP) model—an OTJR focused issue. *OTJR: Occupational Therapy Journal of Research*, 44(3), 449-454.
- Bhardwaj, S., Sambu, W., & Jamieson, L. (2017). Setting an ambitious agenda for children: The Sustainable Development Goals. *South African Child Gauge*, 22-32.
- Black, M. M., Walker, S. P., Fernald, L. C., Andersen, C. T., DiGirolamo, A. M., Lu, C., ... & Lancet Early Childhood Development Series Steering Committee. (2017). Early childhood development coming of age: science through the life course. *The Lancet*, 389(10064), 77-90.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Britto, P. R., Lye, S. J., Proulx, K., Yousafzai, A. K., Matthews, S. G., Vaivada, T., ... & Lancet Early Childhood Development Series Steering Committee. (2017). Nurturing care: promoting early childhood development. *The Lancet*, 389(10064), 91-102.
- Buetow S. (2019). Apophenia, unconscious bias and reflexivity in nursing qualitative research. *International Journal of Nursing Studies*, 89, 8–13.
- Center on the Developing Child at Harvard University. (2016). *Applying the Science of Child Development in Child Welfare Systems*. Retrieved (<http://www.developingchild.harvard.edu>).

- Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory into practice*, 39(3), 124-130.
- Daelmans, B., Manji, S. A., & Raina, N. (2021). Nurturing care for early childhood development: global perspective and guidance. *Indian Pediatrics*, 58(Suppl 1), 11-15.
- Department of Social Development. White Paper on the Rights of Persons with Disabilities. 2016.
- Demmer, C. (2011). Experiences of families caring for an HIV-infected child in KwaZulu-Natal, South Africa: an exploratory study. *AIDS care*, 23(7), 873-879.
- Du Toit, C., Coetzee, Z., & Beeton, H. (2013). Mothers' experiences of caring for a child with severe brain injury in a disadvantaged community in the Cape Flats. *South African Journal of Occupational Therapy*, 43(2), 17-22.
- Etikan I., Musa, S. A., & Alkassim, R. S. (2016). Comparison of convenience sampling and purposive sampling. *American journal of theoretical and applied statistics*, 5(1), 1-4.
- Hermanns, M., & Mastel-Smith, B. (2012). Caregiving: a qualitative concept analysis. *Qualitative Report*, 17, 75.
- Korstjens, I., & Moser, A. (2018). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *European Journal of General Practice*, 24(1), 120-124.
- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American journal of occupational therapy*, 45(3), 214-222.
- Krueger, R. A. (2014). *Focus groups: A practical guide for applied research*. Sage publications
- Lindland, E., Richter, L., Tomlinson, M., Mkwanazi, N., & Watt, K. (2016). Early means early: Mapping the gaps between expert, stakeholder, and public understandings of early childhood development in South Africa. A frame works research report. *A frame works research report*.
- Lundie, R. E., & Hancox, D. M. (2020). The Local Church and the First Thousand Days of a Child's Life: A Mixed Methods Study from South Africa. *Christian Journal for Global Health*, 7(3), 6-22.

- Marlow, M., Mawoyo, T., Chideya, Y., Mdluli, L., & Tomlinsoni, M. (2024). It takes more than a village: Why children need their caregivers, community and country to work together to enable nurturing care. *Enhancing early childhood development*, 88.
- McGadney, B. F. (1995). Family and church support among African American family caregivers of frail elders. *African American Research Perspectives*, 2(1), 35-44.
- Mitchell J., Boettcher-Sheard N., Duque C., Lashewicz B. (2018). Who do we think we are? Disrupting notions of quality in qualitative research. *Qualitative Health Research*, 28(4), 673–680.
- Munambah, N., Gretschesell, P., & Sunday, A. (2020). Being a mother of a child with HIV-related Neurodevelopmental Disorders in the Zimbabwean Context. *South African Journal of Occupational Therapy*, 50(1), 35-40.
- Mustard, J. F. (2006). Experience-based brain development: Scientific underpinnings of the importance of early child development in a global world. *Paediatrics & child health*, 11(9), 571-572.
- Murphy, Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: caregiver perspectives. *Child : Care, Health & Development*, 33(2), 180–187. <https://doi.org/10.1111/j.1365-2214.2006.00644.x>
- Naudeau, S., Kataoka, N., Valerio, A., Neuman, M. J., & Elder, L. K. (2012). *Investing in young children: An early childhood development guide for policy dialogue and project preparation*. World Bank Publications.
- Owen, S. (2001). The practical, methodological and ethical dilemmas of conducting focus groups with vulnerable clients. *Journal of advanced nursing*, 36(5), 652-658.
- Pandya, S. P. (2018). Spirituality to build resilience in primary caregiver parents of children with autism spectrum disorders: A cross-country experiment. *International Journal of Developmental Disabilities*, 64(1), 53-64.
- Pearlin, L. I., Menaghan, E. G., Lieberman, M. A., & Mullan, J. T. (1981). The stress process. *Journal of Health and Social behavior*, 337-356.

- Republic of South Africa. 2015. National Integrated Early Childhood Development Policy. Pretoria: Government Printers.
- Ressell, A. (2022, May 18). *Sikunye (Common Good) | Connect • Care • Thrive*. Sikunye (Common Good). Retrieved October 21, 2022, from [https://Sikunye \(Common Good\).org.za/](https://Sikunye (Common Good).org.za/)
- Richter, L. M., Daelmans, B., Lombardi, J., Heymann, J., Boo, F. L., Behrman, J. R., ... & Lancet Early Childhood Development Series Steering Committee. (2017). Investing in the foundation of sustainable development: pathways to scale up for early childhood development. *The lancet*, 389(10064), 103-118.
- Richter, L. M., Tomlinson, M., Watt, K., Hunt, X., & Lindland, E. H. (2019). Early means early: understanding popular understandings of early childhood development in South Africa. *Early Years*, 39(3), 295-309.
- Richter, L., Naickerii, S., & Draperiii, C. (2024). The science of early childhood development. *Enhancing early childhood development*, 44.
- Robert, K. W., Parris, T. M., & Leiserowitz, A. A. (2005). What is sustainable development? Goals, indicators, values, and practice. *Environment: science and policy for sustainable development*, 47(3), 8-21.
- Sandelowski, M. (2000). Whatever happened to qualitative description?. *Research in nursing & health*, 23(4), 334-340.
- Savin-Baden, M., & Major, C. (2023). *Qualitative research: The essential guide to theory and practice*. Routledge.
- Schwandt, T. A. (1994). Constructivist, interpretivist approaches to human inquiry. *Handbook of qualitative research*, 1(1994), 118-137.
- Sharma, G. (2017). Pros and cons of different sampling techniques. *International journal of applied research*, 3(7), 749-752.
- Slemming, W., & Bamford, L. (2018). The new Road to Health Booklet demands a paradigm shift. *South African Journal of Child Health*, 12(3), 86-87.

“UCT DMP | University of Cape Town.” UCT Libraries, 2019, lib.uct.ac.za/digitalservices/systems/uct-dmp. Accessed 9 Jan. 2025.

UNICEF: Office of Research-Innocenti. The First 1000 Days of Life: The Brain’s Window of Opportunity. Available online: <https://www.unicef-irc.org/article/958-the-first-1000-days-of-life-the-brains-window-of-opportunity.html> (accessed on 10 October 2022).

Wellcome Trust: University of Cape Town (no date) *UCT Libraries*. Available at: <https://lib.uct.ac.za/digitalservices/documentation-funder-guidelines/wellcome-trust#:~:text=Institutions%20are%20expected%20to%20have,a%20minimum%20of%2010%20years>. (Accessed: 03 July 2023).

World Health Organization. Nurturing care framework: why nurturing care? [Internet]. Geneva: World Health Organization, 2019. http://www.who.int/maternal_child_adolescent/child/nurturing-care-framework-rationale/en/ (accessed 21 October 2022).

World Health Organization, United Nations Children’s Fund, & World Bank Group. (2018). *Nurturing care for early childhood development: A framework for helping children survive and thrive to transform health and human potential*. World Health Organization.

World Medical Association. (2013). World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. *Jama*, 310(20), 2191-2194.



UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences



Department of Health and Rehabilitation Sciences

Divisions of Communication Sciences and Disorders; Nursing and Midwifery; Occupational Therapy;
Physiotherapy; Disability Studies

F45 Old Main Building, Groote Schuur Hospital
Observatory, Cape Town, W Cape, 7925
Tel: +27 (0) 21 406 6401/ 6428/ 6628/ 6534
Fax: +27 (0) 21 406 6323

APPENDICES

Appendix 1a: Information sheet

I am an Occupational Therapy Masters student conducting a research project alongside Sikunye. You may be familiar with this organisation. They have been partnering with your church to help you and your baby thrive. Your church has committed to being First Thousand Day Friendly, meaning they want to see you and your child thrive by supporting your unique needs. I am looking to understand your experiences. Your feedback will help us in answering the question: “In what ways do you feel supported as a caregiver in your First Thousand Day friendly church?” Your views around how the church has created helpful programmes in the First Thousand Days of your child’s life would be appreciated.

It is very important that you fully understand what the research project involves and how you can be involved. Your participation is completely your choice! Do not feel pressure to Participate! You are also allowed to stop any time in the research journey without any consequences.

This project has been approved by the Faculty of Health Sciences Human Research Ethics Committee at the University of Cape Town (HREC reference) and will be carried out according to the ethical guidelines and principles of the International Declaration of Helsinki.

The research project will take place at **Common Good**. It will focus on understanding how the church can better support you as a caregiver through your church. This will be held at a central location in **Observatory, Cape Town**, there will be free babysitting services if required. You will be compensated a minor transport stipend for the cost that transport would incur (R2/km), should they require this. There will be one group discussion with caregivers from other churches lasting between 60-90 minutes. Followed by a telephone call ranging between 30 minutes to one hour. The focus groups will be recorded, and participants will be informed to keep information shared in the focus group confidential, however, we cannot guarantee members in the focus groups will maintain confidentiality amongst themselves.

If you are interested, please leave your name and cell phone number on the form below and we will be in contact with you soon! Please fill out the checklist and write YES or NO.

Name	Contact number	I have been attending my church since 2020/2021	I am able to communicate in English	I would need written translation into isiXhosa	I have access to a telephone	I am pregnant or have a child that is younger than 2 years old	I would require babysitting services
e.g. Anna Folly	e.g. 066 234 8145	Y	Y	N	Y	Y	Y

Appendix 1b: Alternative google consent form

Invitation to participate in research with Sikunye

Event Timing: February 2024 (date to be confirmed)

Event Address: 21 Nelson Road, Observatory, Cape Town

Contact us at: 066 234 8144 or FLLAK0001@myuct.ac.za || 063 711 03601 or
ruth.lundie@sikunye.org.za || www.sikunye.org.za

** Indicates required question*

1. Email *

2. First and Last Name *

3. Contact number *

4. I have access to a telephone and Whatsapp and consent to being contacted through these mediums *

Mark only one oval.

Yes

No

5. The name of your church

6. I have been attending my church since 2020/2021 *

Check all that apply.

Yes

No

7. I am pregnant or have a child that is younger than 2 years old *

Mark only one oval.

Yes

No

8. I can communicate in English *

Check all that apply.

Yes

No

9. I would need a written translation into isiXhosa *

Check all that apply.

Yes

No

10. I would require babysitting services during the discussion group *

Mark only one oval.

Yes

No

11. I would require transport to get to the venue *

Mark only one oval.

Yes

No

12. Please could you give an indication of your availability preference in terms of times during the month of February *

Check all that apply.

Morning (between 8-12)

Afternoon (Between 12-4)

Late afternoon - Early evening (Between 4-7)

Please specify any other times that would suit you

Other: _____

13. Please write any other queries or questions below *

This content is neither created nor endorsed by Google.

Google Forms



UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences



Department of Health and Rehabilitation Sciences

Divisions of Communication Sciences and Disorders; Nursing and Midwifery; Occupational Therapy;
Physiotherapy; Disability Studies

F45 Old Main Building, Groote Schuur Hospital
Observatory, Cape Town, W Cape, 7925
Tel: +27 (0) 21 406 6401/ 6428/ 6628/ 6534
Fax: +27 (0) 21 406 6323

Appendix 2: Participant consent form

Name of person _____

Phone number _____

Invitation to participate: You are invited to participate in this research study because you are a parent or caregiver of a child within their First Thousand Days, in a First Thousand Day-friendly church in the Western Cape.

Purpose: This study aims to explore how you are experiencing support across the six strategies offered by Sikunye at your First Thousand Day-friendly church. The information that you provide will be shared with Sikunye. You will remain anonymous.

Procedures to be followed:

1. To determine what you believe a First Thousand Day friendly church entails and what you need to feel supported.
2. To determine how you perceive support across the 6 strategies (pray, speak up, surround families, equip, and prepare, create welcoming spaces, refer and collaborate).
3. To determine which of the 6 strategies that Sikunye (Common Good) has established are most pivotal in creating a sense of support for you.

Why were you invited to participate?

You are the carer of a child in the First Thousand Days and are part of a First Thousand Day friendly church. We would like to interview you to find out more about the support you are experiencing from your church at this time.

What will your responsibilities be?

You will be required to attend a focus group of approximately 1 and a half hours with two researchers, during which you will be asked a few questions with other caregivers from other First Thousand Day-Friendly churches. You will then be contacted via telephone for another follow-up session of approximately 30 minutes to 1 hour to ensure that the information we have recorded and analysed is correct and accurate. You will need to travel to a central location for the focus group, however petrol money will be reimbursed if required. There will also be babysitting services available at the location for the duration of the focus group.

Will you benefit from participating in this research project?

By participating you will contribute to a better understanding of how Common Good (Sikunye) and your church can better support you as a caregiver. In addition, if your church takes up the recommendations, and are still a part of the Sikunye initiatives, then you will benefit from the improvements.

Who will have access to your personal information?

Only the researcher in this study will have access to the personal information of the participants. All information will be always kept confidential and in a safe place. In the event of publication, your identity will remain anonymous and confidential. After 10 years, this information will be deleted. All members of the group will be informed to keep information shared in the focus group confidential, however, we cannot guarantee members in the focus groups will maintain confidentiality amongst themselves.

Are there any risks associated with your participation in this research project?

Some of the questions that you will be asked may result in you becoming emotional. The researcher will try as far as possible to ensure that you are comfortable. You are encouraged to discuss any uncomfortable feelings that you experience from participating in the focus group with the researcher. If you feel that you wish to stop taking part in the study, you are free to do so at any time. If you feel that you require additional support and counselling, you will be

referred to onsite counselling services provided by the Jubilee health centre, they can be contacted telephonically at 021 447 3630 or at health@jubilee.org.za. They are located on 21 Nelson Rd, Observatory, Cape Town.

What will happen in the unlikely event of an injury that may occur as a result of your participation in this research project?

We as researchers will not be held liable in the unlikely event that any form of injury occurs as a direct result of participating in the research.

What alternatives are there if you do not agree to participate?

Participation in this study is completely voluntary. If you choose not to participate in the research, your choice will be respected with no negative consequences to this, from either your church or Sikunye. You will still be able to enjoy the full benefits from whatever initiatives may still be running through Sikunye at your church.

Will you be paid for participating in the research project and are there any costs associated with participating?

As a participant of the study, you will not benefit directly from the study itself and its findings. The minimal compensation will include light refreshments during the focus groups as well as a small token of appreciation. You will also receive a copy of the research report on request.

Interviews will take place at a local and central area that you will need to travel to. However, transport costs will be reimbursed for those that require this (R2/km travelled).

Declaration by participant

By signing this document, I(write full name), agree to participate in a research project entitled: *Exploring the perceptions of support amongst caregivers in First Thousand Day friendly churches in the Western Cape.*

Signature:.....

I declare that:

- I have read or had this read to me and that it is written in a language in which I understand and am comfortable with.
- I had the opportunity to ask questions, and my questions were satisfactorily answered.
- I understand that participation in this research project is voluntary, and I may withdraw from the research project at any time and with no consequences.
- I agree to be audio-taped

Participant rights

If you have any questions regarding your participation in the study, you can contact the primary researcher:

- Anna Folly by telephoning 066 234 8144 or emailing FLLAKO001@myuct.ac.za

You can also contact the following people if you have any questions, comments or complaints about the study process:

- A/Professor Marc Blockman. Human Research Ethics Committee. Old Main Building of Groote Schuur Hospital, Floor E52, Room 23, Observatory, 7925. Telephone: (021) 4066496
- Sarosha Pillay by telephoning 082 706 8999 or emailing saroshapillay@gmail.com
- Amshuda Sondag by telephoning (021) 406 6046 or emailing a.sondag@uct.ac.za

Appendix 3 Research Assistant Confidentiality Agreement

This Study *Exploring perceptions of support amongst caregivers in First Thousand Day friendly churches in the Western Cape* is being undertaken by Anna Folly at The University of Cape Town.

This study has 3 objectives. These objectives are:

- To determine what you believe a First Thousand Day friendly church entails and what you need to feel supported.
- To determine how you perceive support across the 6 strategies (pray, speak up, surround families, equip, and prepare, create welcoming spaces, refer and collaborate).
- To determine which of the 6 strategies that Sikunye (Common Good) has established are most pivotal in creating a sense of support for you.

Data from this study will be used to (explain what will happen to the data):

I _____ agree to:

1. Keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g. disks, tapes, transcripts) with anyone other than the Principle Investigator(s)
2. Keep all research information in any form or format secure while it is in my possession
3. Return all research information in any form or format to the Principle Investigator(s) when I have completed my research tasks
4. After consulting with the Principle Investigator(s), erase or destroy all research information in any form or format regarding this research project that is not returnable to the Principle Investigator(s) (e.g. Information stored on a hard drive)

Research Assistant: _____

Assistant Signature: _____

Date: _____

Principle Investigator: _____

Principal Investigator Signature: _____

Date: _____

For Questions regarding participants rights and ethical conduct of research, contact the The UCT (University of Cape Town) FHS Human Research Ethics Committee can be contacted on 021 406 6338 in case participants have any questions regarding their rights and welfare as research subjects on the study.

Appendix 4: Focus group Interview guide

Objective 1: To determine what you believe a First Thousand Day (FTD) friendly church entails and what you need to feel supported.

1. What role do you think your church should play in the First Thousand Days of a child's life (pregnancy or while the child was under 2)?
2. What current initiatives are you aware that your church is doing, if any, to support you within your First Thousand Days?
3. What do you feel your church is not doing that you feel would support you better during the First Thousand Days of your child's life?

Objective 2 To determine how you perceive support across the 6 strategies (pray, speak up, surround families, equip, and prepare, create welcoming spaces, refer and collaborate).

Which, if any of these initiatives is your church is implementing?

Speak up:

1. Does your church speak openly God's heart for children and the role? If yes, how do they do this? This can be through preaching about the role our church has to play in the First Thousand Days having baby dedications etc.
2. Is your church aware of many of the issues you are facing? In what ways have they raised awareness and taken action to address issues you and people like you may be experiencing?

Surround families:

1. Does your church know and listen to your needs so as to know how to better serve, support and connect you to each other? If yes, how do they do this? Is it through creating mom's groups, mentorship, visiting rosters, family outings/ WhatsApp groups or any other means?
2. Is your church aware of barriers / challenges / difficulties that you may be facing and are they starting to address them. If yes, how do they do this? Is it through arranging

transport/accompaniment to clinic, looking after baby, meals, clothing swops, nappy drives or any other means

Equip and Prepare:

1. Does your church try to facilitate informal peer sharing for people in their first thousand days. If yes, how do they do this? Is it through Mom's groups, trusted Mentor Moms /Dads or another means?
2. Does your church make available trusted resources (from Sikunye), pamphlets, or arrange expert speakers, such as nurses, social workers, doctors for families? If yes, which resources or expert speakers have been made accessible
3. Do families in your church have access to formal courses (e.g., offering it themselves, making your premises available or referring to others). If yes, which courses have been made available?

Collaborate and Refer

1. Does your church actively refer you to necessary First Thousand Dayservices in other churches, NGOs, government, or make arrangements to accompany you or provide transport etc. where needed. If yes, which services have you been referred to?
2. Does your church work with other churches, NGOs, or government services on joint projects for children in their first thousand days? If yes, who do they work with?

Warm and Welcoming Spaces

1. Does your church consider the needs of people in first thousand days when planning church meetings and events and try to address the barriers / stereotypes / unwelcome attitudes within your congregation to make you feel welcome. If yes, how has your church considered your needs?
2. Does your church make changes to accommodate you and your child so that your family is accommodated (e.g. changing mat facilities, having a space for breast-feeding, security, hygiene). If yes, what changes have been made?
3. Does your church have a Child Protection Policy that is being consistently implemented and reviewed? If yes, how do they implement this policy?

Prayer

1. Does your church have specific first thousand days prayer platforms / activities focused on families in first thousand days (e.g., intercessory group for expecting moms, prayer wall for children in first thousand days). Do you feel like you can share testimonies of answered First Thousand Day prayers? Why or why not?
2. Does your church include specific first thousand days issues in their corporate prayers (e.g., stunting, fatherless children, illness, safety and security of children, single mums, teenage mums). What issues, if any, are incorporated into prayers and how often?


Objective 3 To determine which of the 6 strategies that Sikunye (Common Good) has established are most pivotal in creating a sense of support for you.

1. How effective do you think these strategies are in ensuring that you feel supported?
2. In your opinion. If you could rate the strategies from most beneficial to least beneficial, how would you rank them?
3. Why is the aforementioned strategy most effective in making you feel supported?

Appendix 5: Sikunye initiatives

The Church has the potential to create modern day villages that surround and strengthen all parents and caregivers with children in the First Thousand Days (FTD) of life.

Like no other, The Church has the capacity and mandate to connect and care for parents and caregivers so that they, in turn, can provide responsive care for their little ones.




Church communities across South Africa are committing to become FTD-friendly.

This is achieved by initiating one or a number of the following activities:

- **Speak up** around FTD and the opportunity for Christians to connect and care for families in this stage of life.
- **Surround families** and provide support and encouragement that no other service provider can.
- **Create warm, welcoming and safe spaces** to help families feel supported and that they belong.
- **Pray** for and with families to bless and encourage them.
- **Equip and prepare** parents and caregivers to be able to provide responsive care.
- **Collaborate** with other churches and service providers to better serve families.

Together we can create opportunities for greatness to grow and thrive in our nation.



pray

Churches are already praying in different places and times. Do the prayer times that you have include praying for and with families in the First Thousand Days? Are you encouraging congregations to pray into the big issues that families are facing in this stage? The fruit of this is that when we pray for and with families, we are embracing them in our communities of faith. We are standing with them before the God who loves them and their young child. And when we pray for the big issues in our community that affect families, we are asking the all-powerful God to move, to act, to make the pathway level for families to overcome these challenges.



surround families

Surrounding families is all about looking for ways to build supportive relationships with caregivers. This includes finding Practical ways to come around expecting and new families in nurturing relationships – and building the modern-day village around them. At the heart of this it is about the relationships and showing love. It is about coming around families and creating spaces or opportunities in your church to allow for these types of relationships to grow and develop.

collaborate and refer



The church must do what the church can do – and then collaborate with others and refer families to ensure they get the care, the support and information they need. Your church is not a hospital or a clinic, but wonderfully it can refer families to those service providers to see that every family gets enough of the kind of care they need in this important season.

One way to get started is to see who is in your church already. Maybe there is someone who works in a local NGO or government facility. Maybe one of their family members does. Look inside your church, and when you know what services are available to families, you can share that information with them.

equip and prepare



There is so much information out there about parenting. But sometimes new parents don't know where to turn to find a trusted source. Churches can provide intentional equipping and preparing for families to ensure they are more ready to enter this important life stage. This can help them feel more confident and also know where to turn to find answers to new questions they have.

Parents that are better equipped and confident in their knowledge have a positive impact on their child's brain growth – with lifelong impact.

create welcoming spaces



The place and spaces in your church send a message to people about what you believe about families and young children. The community of believers also send messages to parents – through their looks, comments and how warmly welcomed in a family might feel. By creating a warm and welcoming space for parents with young children, you can help families feel at home – a place and community they love to be part of, especially in the first thousand days.

Appendix 6: Email sent to key gatekeeper

Good day _____

We are looking to understand the experiences of caregivers in your First Thousand Day-friendly church! We are asking your church to partner with us conducting research in association with a student in the health science faculty at the University of Cape Town.

The study seeks to explore how caregivers feel supported in First Thousand Day-friendly churches and in which ways we can better support them. Should you wish to assist us, we would greatly appreciate an indication of interest to this email. We are wanting to conduct focus groups with 1 caregiver within your church to help us gain feedback on their experiences.

Participation from caregivers in your church in this study is completely voluntary.

The study is due to take place towards the end of January/February. Please do not feel under any pressure to Participate! Should your church choose not to participate you will continue to receive support from Sikunye. However, your participation will assist us greatly in contributing to a better understanding of how Sikunye can better support your church and caregivers across South Africa.