COVID-19 and children who experience special educational needs: Caregivers' experiences, coping strategies, and support needs.

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Declaration

I, Jenna Fernandes, declare that this research report is my own, unaided work. It is being submitted in partial fulfillment of the requirements for the degree of Masters in Education (Educational Psychology) in the faculty of Humanities, University of the Witwatersrand, Johannesburg. It has not been submitted before any other degree of examination at this or any other university.

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Abstract

Every aspect of parenting becomes magnified when caring for a child who experiences special educational needs, especially during a pandemic. Despite the wide recognition that the pandemic intensified existing stressors for caregivers of children who experience special educational needs as indicated by reports of significant declines in mental health, there is a scarcity of research exploring caregivers' experiences during the pandemic, and especially within the South African context. Therefore, the aim of this study was to explore the experiences of South African caregivers, their available support structures, coping strategies, and support needs. An exploratory qualitative research design was employed, in which twelve caregivers of children who experience special educational needs participated in semi-structured interviews. Reflexive thematic analysis was used to analyse the data, and subsequently, the researcher developed five intersecting themes and fourteen subthemes. Notably, the five themes were, "exhausted to the bone", twice as isolated, finding the light in the dark, soldiering on and learning to cope, and a wish for change and advocacy. Critically, the results of the research study suggest that despite the difficulties experienced by caregivers, there were opportunities for growth and development. However, there is a deep desire for there to be more understanding and tolerance of differences.

Keywords: Caregivers' Experiences, Coping Strategies, COVID-19 Pandemic, Reflexive Thematic Analysis, Special Educational Needs, Support Needs,

Contents

Declaration ii

Acknowledgments iii

Abstract iv

Chapter One: Introduction 9

1.1 Introduction 9

1.2 Research Aim 10

1.3 Rationale 11

1.4 Research Questions 12

1.5 Research Report Structure 12

Chapter Two: Literature Review 14

2.1 Introduction 14

2.2 Special Education Needs 14

2.3 Caregiving and Special Education Needs 18

2.4 The COVID-19 Pandemic in South Africa 23

2.4.1 Contextualising COVID-19 23

2.4.2 Impact of COVID-19 on children and caregivers 25

2.5 Theoretical Framework 28

2.6 Conclusion 30

Chapter Three: Methods 32

3.1 Introduction 32

3.2 Research Design 32

3.3 Sampling and Sample 33

3.4 Data Collection 37

3.5 Procedure 38

3.6. Data Analysis 40

3.7 Qualitative Rigour 42

3.8 Reflexivity 44

3.9 Ethical Considerations 45

3.10 Summary 47

Chapter Four: Data Analysis 48

4.1 Introduction 48

4.2. "Exhausted to the bone" 49

4.2.1 Managing worries and anxiety around COVID-19 50

4.2.2 Pandemic life as a balancing act 52

4.2.3. Managing the pandemic's impact on child's functioning 54

4.3 Twice as isolated 57

4.3.1 Cut off from support structures 58

4.3.2 Lack of understanding as a form of isolation 60

4.4 Finding the light in the dark 63

4.4.1. Enhanced Connections 63

4.4.2 Personal Growth 66

4.4.3 "It takes a village" 68

4.5. Soldiering on and learning to cope 72

4.5.1 Coping through connection 72

4.5.2 Individual coping strategies 74

4.5.3 "Crossing that bridge when we get there" 75

4.6 A wish for change and advocacy 76

4.6.1 Awareness as a support need 77

4.6.2 Inclusivity and shared spaces 79

4.6.3 Advocacy and self-empowerment 80

4.7 Summary 82

Chapter Five: Discussion and Conclusion 83

5.1 Introduction 83

5.2 Discussion of findings 83

5.3 An integration of the findings with the theoretical framework 89

5.4 Implications of the Research Study 91

5.5 Strengths and Limitations 94

5.6 Recommendations for future research 96

5.7 Conclusion 96

References 99

Appendices 114

Appendix A: Permission Letter 114

Appendix B: Ethical Clearance 117

Appendix C: Short Poster 118

Appendix D: Participation Information Sheet 119

Appendix E: Informed Consent 121

Appendix F: Interview Schedule 123

Chapter One: Introduction

1.1 Introduction

The African proverb, "it takes a village to raise a child", rings especially true for parents who care for a child considered to experience special educational needs (Leitch et al., 2019). Globally, the literature indicates that many parents of children experiencing special education needs feel isolated and unsupported due to the lack of resources to aid their understanding of the difficulties their child experiences (Dreyer, 2015; Mitchell & Holdt, 2014; Tokatly-Latzer et al., 2020). Within the Southern African context, parents of children experiencing special educational needs have found that various therapies and specialised educational facilities provide a supportive network for themselves and their children (Mitchell & Holdt, 2014; Taderera & Hall, 2017). Notably, such support networks are vital in light of the challenges these caregivers and children tend to experience, such as community attitudes toward disability, cultural beliefs, and institutional challenges (Taderera & Hall, 2017). Therefore, parents of children who experience special educational needs are confronted with a variety of stressors and challenges and require reliable support structures.

Considering the challenges parents of children with special educational needs experience, the COVID-19 pandemic has disrupted many supportive networks that parents rely on and has intensified existing stressors. This is evident through increased financial strain and insecurity (Gittings et al., 2021; Morelli et al., 2020), which results in difficulties accessing vital therapeutic services (Lee et al., 2020). Additionally, the lack of access to support systems (Brown et al., 2020; Tokatly-Latzer et al., 2020; Weaver & Swank, 2021) subsequently resulted in declines in parental mental health (Lee et al., 2020; Russell et al., 2020). Over and above these challenges, caregivers also reported having difficulties coping with the pre-existing physical, mental, emotional, and behavioural difficulties experienced by children experiencing special education needs (Marchetti et al., 2020). These lead to a

perpetuating cycle of increased caregiver distress and burnout as well as increased anxiety and difficulties within children (Dreyer, 2015). This highlights the importance of understanding the experiences of parents of children experiencing special education needs, as well as their support needs during the pandemic, as prolonged parental stress can lead to long-term negative consequences for both parent and child.

Arguably, the family system is the most influential component in child development (Weeland et al., 2021). With this said, disaster outcomes tend to be worse amongst children of highly distressed caregivers and other family members (Russell et al., 2020). It has further been posited that caregiver stress during the pandemic has a spill-over effect on family dysfunction and children's mental health and well-being (Russell et al., 2020; Weeland et al., 2021). Alarmingly, caregiver stress and decline in caregiver mental health during the pandemic is widely prevalent (Bate et al., 2021; de Araújo et al., 2021; Lee et al., 2020; Marchetti et al., 2020; Weaver & Swank, 2021; Weeland et al., 2021). Despite this recognition, there are relatively few studies that have explored parental distress among caregivers of children who experience special educational needs, yet the literature highlights that these two groups are most vulnerable during the pandemic (Lee et al., 2020).

Notably, the literature uses the terms parent and caregiver interchangeably. However, for this study, and recognising that in the South African context families do not follow the traditional nuclear family structures (Hall & Mokomane, 2018), the term caregiver will be used to describe both parents, extended family, or any individual who looks after and provides for the child.

1.2 Research Aim

This research study aimed to explore the experiences of caregivers of children who experience special education needs during the COVID-19 pandemic. Additionally, the study

explored how caregivers coped with the drastic changes brought about by COVID-19 and the type of support structures available as well as the support that caregivers may still need.

1.3 Rationale

Caregivers experience a multitude of challenges when parenting a child who experiences special education needs. However, few studies have explored the positive and more challenging experiences of caregivers within the South African context and in the broader context of the COVID-19 pandemic. Much of the literature exploring caregivers' experiences revolve around their experience and feelings about their child receiving a diagnosis (Mitchell & Holdt, 2014; Reddy et al., 2019; Sedibe & Fourie, 2018). Additionally, research has focused exclusively on particular disorders and learning difficulties (Dreyer, 2015; Jackson & Andipatin, 2019; Tokatly-Latzer et al., 2020). This is problematic and leaves a considerable gap within the research, as many caregivers do not have the resources to get their child assessed and diagnosed yet notice a delay in their child in terms of developmental milestones (Dreyer, 2015; Taderera & Hall, 2017). Additionally, it does not acknowledge the potential for comorbidities or the range of special educational needs amongst children (Alba et al., 2022; Gérain & Zech, 2018).

Despite the pandemic causing many disruptions and intensifying underlying vulnerabilities within the South African context (Gittings et al., 2021), there is limited research exploring the experiences of caregivers, in general, during the pandemic. To the author's knowledge, there are no published South African-based studies that have explored the experiences of caregivers who parent children experiencing special education needs during COVID-19. In terms of global literature, much of the research was conducted during the intense moments of lockdown and higher alert levels (Tokatly-Latzer et al., 2020). This leaves a considerable gap in knowledge as the longer-term effects brought about by COVID-19 have remained unexplored.

Finally, considering that caregiver response has a considerable impact on the well-being of the child, it is posited that families of children who experience special education needs should be supported and interventions need to be as parent-focused as much as they are child-focused (Tokatly-Latzer et al., 2020). Therefore, it is critical to understand the experiences, coping strategies, and support needs that a caregiver may require when parenting a child that experiences special education needs during the pandemic. Additionally, the knowledge obtained through this study could be used to inform policy and practice and to highlight the need for community interventions, such as psychoeducation, and parental support groups.

1.4 Research Questions

The main research question is what are the experiences of caregivers who parent a child that experiences special education needs, during the COVID-19 pandemic? More specifically the research study explored:

1. What coping strategies did caregivers employ when caring for a child who experiences special education needs, during the COVID-19 pandemic?
2. What support structures were available to caregivers of children experiencing special education needs, during the COVID-19 pandemic?
3. What types of support do caregivers of children experiencing special education needs still require?

1.5 Research Report Structure

Briefly, Chapter One provided an overview of the research study. More specifically, there was a discussion about the research aims and the rationale for the study. The research questions were also presented.

Chapter Two explores the available literature regarding parenting and special educational needs within the context of the COVID-19 pandemic. First, a discussion will take

place surrounding the debates and definitions of special educational needs before exploring the complexities of parenting a child who experiences such needs. For contextualisation, the literature around COVID-19 will be presented before discussing the impact of the pandemic on caregivers and children. Then, Bronfenbrenner's bioecological model will be discussed as the theoretical framework.

Chapter Three outlines the methods for the research study, including the research design, sample and sampling, data collection, procedure, data analysis, qualitative rigour, and researcher reflexivity. Ethical considerations are outlined.

Chapter Four presents the developed themes from the analysis, while the results are written in Chapter Five. Notably, included in this chapter, are the research study’s limitations, applicability and relevance will be discussed, as well as the recommendations and implications for future research.

Chapter Two: Literature Review

2.1 Introduction

The following chapter will provide a review of both international and local literature regarding parenting and special educational needs within the broader context of the COVID-19 pandemic. First, this chapter will provide an understanding of the term special education needs with a particular focus on the White Paper 6 policy. Following this, a more in-depth discussion will take place regarding the complexities of parenting a child who experiences special educational needs. Notably, this discussion will first explore caregiving at the individual level, then the familial level before moving onto the societal level. For contextualisation, the chapter will then review the literature on the impact of the COVID-19 pandemic on both caregivers and children. Finally, the bioecological model is used as a theoretical framework to highlight the necessity of this study as well as provide an understanding of caregivers' experiences and support needs.

2.2 Special Education Needs

Arguably, the definition of special educational needs has been contentious, especially in light of the language used around the term. More specifically, the contention lies between the two distinct perspectives of the medical model of disability and the social model of disability (Runswick-Cole & Hodge, 2009). The medical model implies that a child experiencing special education needs has an internal deficit, and therefore, the 'problem' is located within the child (Department of Education [DBE], 2001; Haegele & Hodge, 2016; Runswick-Cole & Hodge, 2009). Consequently, the child, or individual experiencing special educational needs, needs to be fixed as they ‘have’ something which makes them deviate from what is considered as the norm within society (Maiese, 2021; Runswick-Cole & Hodge, 2009; Sarto-Jackson, 2018). Notably, such beliefs as well as the language used by the medical model, namely ‘child with special needs’, results in exclusionary and discriminatory

practices (DBE, 2001). It is further posited that the discriminatory or exclusionary terminology used by the medical model influences how others perceive and interact with the child (Haegele & Hodge, 2016; Taderera & Hall, 2017). Critically, this could have consequences for both child and parental well-being.

Arising from the concerns surrounding children being viewed as 'special' and in 'need', which perpetuates exclusionary practices, the social model of disability came to fruition (Runswick-Cole & Hodge, 2009). The social model sought to shift the focus from an individual deficit view to one that acknowledges the environmental barriers and perceptions that individuals who experience special education needs face daily (Haegele & Hodge, 2016). Central to the social model is the belief that many issues associated with disability, or difficulties, could disappear if society's attitudes towards individuals experiencing special educational needs changed. This is further supported by a meta-review conducted by Van Mieghem and colleagues (2020) in which it was found that attitudes towards individuals experiencing special educational needs was dependent on others' knowledge of disabilities. The more knowledge and awareness individuals had about differences, or disabilities, the less negative their attitude (Van Mieghem et al., 2020). Thus, in the social model of disability, an individual is understood to experience difficulties associated with their environment rather than having an innate abnormality (Runswick-Cole & Hodge, 2009). Notably, a key criticism of the social model of disability, is that it does not account for individual differences between individuals with disabilities, or those that experience special education needs (Haegele & Hodge, 2016). Arguably, the focus is too centred on the environment rather than the individual, which may discount personal experiences.

Some have further argued that the term 'special educational needs' is outdated and will always carry exclusionary connotations (Runswick-Cole & Hodge, 2009). Instead, a rights-based approach should be explored, and the term 'special educational rights' should be used.

Critically, the term special educational rights is closely aligned with inclusive education practices whereby the focus is on increased understanding, acceptance and appreciation of diversity as well as respect for all individuals (Van Mieghem et al., 2020). For this paper and in line with South Africa's educational policies, namely, the White Paper 6, the term 'children experiencing special education needs' will be used. This term recognises that the difficulties children experience is not solely due to intrinsic factors. In terms of the definition, special education needs is an umbrella term used for individuals who require specialized attention due to learning difficulties, emotional and behavioural difficulties, mental disorders, physical disabilities and medical conditions (American Psychological Association, 2022; DBE, 2001).

Notably, this definition of special educational needs aligns closely with the United Nations Convention of the Rights of Persons with Disabilities, whereby disability is defined as a long-term physical, mental, intellectual, or sensory impairment, which when interacting with various environmental barriers, hinders the individual's full participation in society (United Nations, 2006). It should be noted that the framework for special education needs, and inclusive education is fundamentally guided by the Salamanca Statement (UNESCO, 1994), which advocates for the rights and progress of all individuals while also combating discriminatory attitudes to create welcoming and inclusive societies (Makhalemele et al., 2021). Thus, special education needs is sometimes synonymously used with developmental disabilities, referring to any individual who experiences difficulties which impair their physical, learning, and behavioural functioning (Olusanya et al., 2018).

Alarmingly, the prevalence of children who experience special educational needs within the South African context is difficult to pinpoint for several reasons. Often the data around prevalence of children who experience special educational needs is unreliable and conflicting due to the confusion around disability and impairment, as well as the general defining and measuring of special educational needs (African Child Policy Forum, 2011).

Donald and colleagues (2020) state that in developed contexts, or the global north, it is less complicated to track children who experience special educational needs as these contexts specifically look at intrinsic factors. Notably, this aligns with the medical model's perspective, as questions about special educational needs appear to be binary (Department of Social Development et al., 2012). Thus, statistics centre around whether or not the child has a condition that requires a specific form of educational help. However, in the South African context, gathering information about special educational needs or disabilities is not as straightforward. Caregivers of children who experience special educational needs may not identify their child as experiencing difficulties due to shame, stigma or cultural beliefs surrounding normal functioning (African Child Policy Forum, 2011; Department of Social Development et al., 2012). Furthermore, measuring special educational needs often takes place through caregiver-reported surveys, which indicate that diagnoses or difficulties are not verified by clinical diagnostic evaluations (African Child Policy Forum, 2011; Department of Social Development et al., 2012).

Further complicating the measurement of special educational needs within the South African context is the existence of severe social and educational disadvantages (Donald et al., 2020) continuing from the legacy of Apartheid. Here, it is recognised that some special educational needs may arise due to extrinsic factors. Extrinsic factors include multi-dimensional poverty, limited access to quality education and inadequate learning support (Donald et al., 2020; Donald et al., 2019; Spaull, 2015). Notably, this way of measuring special educational needs aligns with the social model of disability, whereby the focus is on disadvantage and being 'disabled' by the environment. Nonetheless, within the South African context, scholars and statisticians alike are cautioned to acknowledge that special educational needs are the result of differing degrees of intrinsic and extrinsic factors and how these factors may interact or reinforce each other (Donald et al., 2020).

Although establishing the prevalence of children who experience special educational needs in South Africa is a challenging task, and often the data is unreliable and underestimated, it is posited that 2.1 million South African children were classified as having a disability (Department of Social Development et al., 2012). A longitudinal study conducted in 195 countries found that in sub-Saharan Africa, the burden of developmental disabilities increased substantially from 1990 to 2016 (Olusanya et al., 2018). The most recent statistics support this finding as they indicate that 10.8 million South African children between the ages of 5 and 14 experience a disability, and 10.4 million individuals between the ages of 15 and 24 experience a disability (StatsSA, 2020a). Thus, the prevalence of disability and special educational needs is increasing within the South African context, supporting Donald and his colleagues' (2020) notion of the interaction between intrinsic and extrinsic factors contributing to a child experiencing special educational needs.

2.3 Caregiving and Special Education Needs

Every aspect of parenting becomes magnified when caring for a child who experiences special education needs, especially during a pandemic (Cluver et al., 2020; Tokatly-Latzer et al., 2020). Unsurprisingly, research has consistently found that caregivers of children who experience special educational needs are more likely to experience high levels of stress than those caregivers with typically developing children (Asbury et al., 2021; Barnett et al., 2003; Caicedo, 2014; Dreyer, 2015; Jackson & Andipatin, 2019; Sedibe & Fourie, 2018; Shenaar-Golan, 2015). Notably, parents of children who experience special education needs are often plagued with feelings of guilt, fear, anxiety, hopelessness, and powerlessness (Dreyer, 2015; Sedibe & Fourie, 2018). Many of these feelings are a result of the social, educational, and psychological difficulties that children experiencing special education needs undergo daily (Jackson & Andipatin, 2019; Taderera & Hall, 2017).

Within the South African context, research has indicated that caregivers are deeply concerned about their children being socially excluded as other children appear to have a preference to play with those children who can engage and interact more easily (Jackson & Andipatin, 2019). Compounding this anxiety is the caregivers' sense of powerlessness and distress as they want to protect and help their child but may not necessarily know how (Dreyer, 2015; Jackson & Andipatin, 2019; Reddy et al., 2019). Consequently, caregivers may often blame themselves or feel like failures (Sedibe & Fourie, 2018). Therefore, caregivers of children experiencing special education needs are more likely to experience high levels of distress and anxiety, which may create or maintain anxiety in their child (Dreyer, 2015). Hence, it becomes crucial for support to be parent-focused as much as it is child-focused.

While much of the distressed feelings can be attributed to caregivers' concerns for their child's well-being and future, research has acknowledged that such caregivers also need to overcome personal emotional burdens related to their child's difference. More specifically, Sedibe and Fourie (2018) found that caregivers of children experiencing special education needs undergo something akin to a grieving process. Here, the authors suggested that South African caregivers should be provided with more emotional support and counselling. Similarly, Jackson and Andipatin (2019) found that fathers of children experiencing dyspraxia were confronted with a sense of grief due to the possibility of not being able to live the ideal life they had created and hoped to share with their child. It was further posited that having a child with different needs means that caregivers also had to grieve the loss of having an 'ideal child' (Jackson & Andipatin, 2019). Notably, this grieving process caregivers experience due to the ‘hoped for’ child, who never comes, has been cited in the literature for the past few decades (Barnett et al., 2003). Furthermore, Reddy and colleagues (2019) highlighted that caregivers of autistic children experienced emotional turmoil as they tried to

adjust and adapt to their new reality, while Barnett and colleagues (2003) reported that caregivers also need to adjust their expectations and hopes for the child. Thus, caregivers need to go through this complex personal process among other complicated feelings.

Over and above adjusting to a new reality, caregivers may frequently feel isolated in trying to deal with and understand the difficulties their children experience (Dreyer, 2015). Notably, this feeling of isolation is primarily due to the challenging, time-consuming, and costly processes involved when attempting to understand the child's difficulties (Mitchell & Holdt, 2014; Reddy et al., 2019). Further exacerbating the isolation are the various obstacles caregivers face, with specific references to the limited access to information, the few available support structures, and the financial implications (Dreyer, 2015; Mitchell & Holdt, 2014; Taderera & Hall, 2017). Additionally, some caregivers report that they do not receive sufficient support from family and friends (Dreyer, 2015). Arguably, caregivers of children experiencing special educational needs may feel isolated when caring for their children, as friends and family members may be unsure of how to assist the caregiver and the child (Barnett et al., 2003). Thus, they may avoid becoming involved, leading to increased feelings of being alone.

With this in mind, caregivers of children experiencing special education needs also need to be mindful of and potentially navigate compromised family functioning and dynamics (Shenaar-Golan, 2015). The literature indicates that caregivers often put and maintain the needs of their child experiencing special education needs above their own needs and those of the family. In essence, the needs of the family become peripheral to that of the child experiencing special educational needs (Jackson & Andipatin, 2019). Consequently, caregivers tend to neglect their own needs resulting in physical, mental, and emotional exhaustion that, in turn, affects familial relationships (Asbury et al., 2021; Leitch et al., 2019; Reddy et al., 2019; Sedibe & Fourie, 2018). Difficulties within family relationships include a

lack of communication, challenges with solving problems and making decisions together, as well as stress, tension and conflict arising between family members (Asbury et al., 2021). Notably, the demands and needs of a child experiencing special educational needs also affected spousal relationships with increasing inter-spousal conflict and challenges with intimacy (Jackson & Andipatin, 2019; Reddy et al., 2019). Additionally, caregivers reported experiencing guilt and challenges in their relationships with their typically developing children as caregivers spent less time with them (Reddy et al., 2019). Given the interrelated process and the potential spill-over effect that caregiver stress can have on family dysfunction and children's well-being, it becomes crucial to explore caregivers' experiences to understand which interventions are required to support and maintain the well-being of families and, thus, children experiencing special educational needs (Haffejee & Levine, 2020; Morelli et al., 2020; Russell et al., 2020; Wang et al., 2020; Weeland et al., 2021).

On the societal level, children who experience special educational needs are often viewed as a bad omen or curse in the family (Malapela et al., 2020; Mostert, 2016). In some cases, the difficulties a child experiences are believed to be a result of witchcraft or ancestral anger due to the family committing a sin or being socially deviant (Ndlovu, 2016). Consequently, the caregiver and child are frequently discriminated against due to the stigma surrounding differences (Reddy et al., 2019; Rohwerder, 2018). Such experiences of ostracism or rejection of the child who experiences special educational needs, or even the family, further complicate caregiving. More specifically, there is a lack of community support, and in some instances, caregivers may hide their children from society to avoid such discrimination (Malapela et al., 2020). Notably, this increases feelings of guilt and loneliness in caregivers, which affects their self-esteem and their ability to respond sensitively to their children, thus, affecting the parent-child relationship (Jackson & Andipatin, 2019). Malapela and colleagues (2020) also highlighted that caregivers became concerned, or experienced

heightened anxiety when thinking about their child's future and the social exclusion and rejection, when the caregiver is no longer around. In their study, Reddy and colleagues (2019) reported that parents felt frustrated by cultural and religious explanations of differences and difficulties. Often, the belief is that the child is experiencing difficulties due to ineffective parenting and poor discipline (Reddy et al., 2019). Hence, Taderera and Hall (2017) argue that challenges faced by parents are exacerbated by community attitudes and cultural beliefs. However, it should be noted that stigmatisation surrounding difference is not unique to the Southern African context, but occurs globally (Leitch et al., 2019).

While the reviewed literature thus far has highlighted the complexities of parenting a child who experiences special educational needs, it has done so through a grim picture. However, not all parenting or caregiving experiences of children who experience special educational needs are negative. Caregivers tend to cope with and adapt to the additional demands of caring for a child who experiences special educational needs, and caregivers tend to remain relatively resilient (Barnett et al., 2003; Leitch et al., 2019). It is posited that despite the challenges and ambivalent feelings, caregivers find joy in parenting and caring and report high satisfaction levels (Barnett et al., 2003; Reddy et al., 2019). Furthermore, Reddy and colleagues (2019) found that caregivers of children on the Autism spectrum experienced personal growth leading to personal transformation and facilitating positive character traits such as perseverance, understanding, compassion, tolerance, and patience while developing help-seeking behaviours. Shenaar-Golan (2015) highlighted that although marital conflict is likely, having a child who experiences special educational needs can lead to greater cooperation between spouses as they can share the physical, mental, and emotional burden. Furthermore, in some African cultures, disabilities are seen as a gift, and such a child should be nurtured and treated with care (Mostert, 2016). Thus, caring for a child who

experiences special educational needs is filled with many complexities, both positive and negative.

2.4 The COVID-19 Pandemic in South Africa

2.4.1 Contextualising COVID-19

South Africa's quick and decisive response to the COVID-19 pandemic has been widely praised (Gittings et al., 2021; Haffejee & Levine, 2020; South African Government, 2020; Stigerler & Bouchard, 2020). Despite South Africa's overburdened and under-resourced public health system, Naidu (2020) argues that South Africa had a slight advantage in dealing with the pandemic as they could learn from other countries affected by the virus, as well as already having experience with viral pandemics, such as the Human immunodeficiency virus (HIV), and Tuberculosis (TB). In addition, South Africa has experienced epidemiologists, good public health policies as well as experience in dealing with individuals who refuse treatment for infectious and lethal diseases (Naidoo et al., 2017; Naidu, 2020). Over and above the experience of dealing with pandemics, or epidemics, the South African government also introduced various social and economic relief measures to mitigate some of the disastrous effects of the pandemic (Haffejee & Levine, 2020). Thus, it would appear that South Africa was better-equipped than most low- to middle-income countries (LMICs) to deal with the COVID-19 pandemic.

However, while South Africa's response was praised, it is known to be one of the most restrictive and strictest responses to COVID-19 on the African content as well as globally (Gittings et al., 2021; Stiegler & Bouchard, 2020). The lockdown at the beginning of the pandemic, which began on the 26th of March 2020, meant that South Africans were not allowed to leave their homes unless they required medical attention or needed to buy essential goods, such as groceries (Broadbent et al., 2020; South African Government, 2022). With the restrictions, all places of worship and recreational activities were shut down, while economic

activity also came to a relative standstill (Broadbent et al., 2020; Haffejee & Levine, 2020). Notably, during this time, the lockdown was enforced by the South African Police Service and military personnel (Gittings et al., 2021). Thus, many South Africans had restricted access to stress-relieving activities and income-generating activities and were confined to their residences.

In light of this, Broadbent and colleagues (2020) criticised the South African government's lack of consideration for the unique circumstances of South Africans and their local context. In particular, it was suggested that responses to the COVID-19 pandemic should be contextually relevant and should be aligned with social justice principles to address broader health and socioeconomic inequalities otherwise more harm than good will occur (Kelley et al., 2020). More specifically, the collective trauma of the COVID-19 pandemic had to be considered within the context of South Africa's history, which is characterised by inequalities from Apartheid, the HIV pandemic, and social and transgenerational trauma (Naidu, 2020). Research and statistics highlight that over 3 million people lost their jobs (Spaull et al., 2020). Consequently, the expanded unemployment rate rose to 42.3% (StatsSA, 2020b). Food insecurity doubled (Spaull et al., 2020), resulting in hunger riots, shop looting and brutal police confrontations (Stiegler & Bouchard, 2020). South Africa also saw an increase in violence against women (Stiegler & Bouchard, 2020). Educational services were also shut down, with many children unable to attend school due to limited access to resources (Chisango & Marongwe, 2021). Statistics also indicate that half a million children have dropped out of school due to factors such as poverty, unemployment, and food insecurity (Spaull et al., 2021). Thus, the COVID-19 pandemic exacerbated underlying inequalities and heightened psychosocial stress within the South African context.

2.4.2 Impact of COVID-19 on children and caregivers

As more research comes to light, there is an acknowledgement that the pandemic has profoundly affected children and their caregivers. Based on the initial data, children with pre-existing mental health difficulties were more likely to experience worsened symptoms, and there was an increase in the occurrence of new disorders in children (Lee et al., 2020; Russell et al., 2020). Additionally, Jiao and colleagues (2020) noted that children were experiencing elevated anxiety and traumatic stress. More recent research has confirmed this, as children and adolescents reported higher levels of anxiety, depression, loneliness, stress, fear, and sleep disturbances (Deng et al., 2022; Theberath et al., 2022). In their review, Theberath and colleagues (2022) explain that children, especially those with developmental challenges or special educational needs, are at a higher risk for poor mental health due to the lack of peer contact and opportunities for self-regulation. Although the pandemic led to the exacerbation of mental health difficulties over time, especially in the initial few months, Deng and colleagues (2022) found that in late 2021, mental health difficulties, especially anxiety, began to decline in children. However, in their longitudinal study, Toseeb and Asbury (2022) found that depressive symptoms remained stable, while symptoms of anxiety only eased in some special educational needs categories.

Considering the inconsistent findings within the literature surrounding the impact of the pandemic on children's mental health (Newlove-Delgado, 2023), healthcare professionals' initial insistence on addressing the psychological needs of children during the pandemic and monitoring for potential long-term effects (Liu et al., 2020; Morelli et al., 2020; Wang et al., 2020), remains valid. Over and above the psychological impacts of the pandemic on children, there is concern about how children's functioning and development may be affected, especially for children who already experience challenges. Notably, these concerns arose as caregivers were concerned about the amount and quality of education their children received

and the lack of access to vital therapeutic support services (Evans et al., 2020; Tokatly-Latzer et al., 2020). Thus, the pandemic negatively impacted mental health and child development and learning.

Interestingly, some children appeared to have benefitted from the changes that were brought about by the pandemic (Tokatly-Latzer et al., 2020). Crucially, the child's ability to cope with seemingly no harmful effects was directly related to how their caregivers coped with stressors and how they modelled coping strategies (Russell et al., 2020; Tokatly-Latzer et al., 2020). Notably, caregivers play a protective role in maintaining the overall well-being of children (Spinelli et al., 2020; Wang et al., 2020). Thus, it is critical to review and discuss the literature on the impact of the pandemic on caregivers and psychological distress.

An abundance of research highlights that the pandemic has increased parental distress (Lee et al., 2020; Marchetti et al., 2020; Morelli et al., 2020; Spinelli et al., 2020; Toseeb & Asbury, 2022), which is a risk for parental burnout (Mikolajczak et al., 2018). This risk was exacerbated as the pandemic resulted in many caregivers losing access to their support networks while also trying to manage difficulties such as the loss of loved ones and the loss of income due to the pandemic (Evans et al., 2020; Morelli et al., 2020). Solutions, or coping strategies, offered for parental burnout include increased self-care, positive parenting programmes, counselling courses, and family therapy (Bate et al., 2021; Cluver et al., 2020). However, these interventions may not be entirely sustainable or accessible to all, considering that South Africa is under-resourced, and caregivers already incur many costs when caring for a child who experiences special educational needs. Thus, South African caregivers' positive and negative experiences of parenting children who experience special educational needs during the pandemic must be explored to understand how caregivers coped and supported themselves, as well as which interventions are required to support and protect the long-term well-being and empowerment of caregivers and their families.

Much of the research into parenting during the pandemic has focused almost exclusively on white middle- to upper-class mothers (Bate et al., 2021; Marchetti et al., 2020; Tokatly-Latzer et al., 2020). Fathers have often been excluded from studies, although there is mention that fathers have a higher risk of experiencing parental burnout (Russell et al., 2020). Thus, research is needed which represents the diverse socioeconomic, cultural, and racial backgrounds of South Africans and a more equally represented sample. Furthermore, most of the literature on parenting experiences during the pandemic has either been general commentaries, reviews and meta-reviews or has employed quantitative methodologies (Morelli et al., 2020; Spinelli et al., 2020). Qualitative studies have focused on parenting experiences of autism spectrum disorder (Tokatly-Latzer et al., 2020) or have looked at parenting experiences more generally during the pandemic (Bate et al., 2020; Evans et al.,2020; Shum et al., 2023; Weaver & Swank, 2021). South African literature on parenting children who experience special educational needs pre-pandemic has focused on the experiences surrounding receiving a diagnosis for the child and the related costs (Dreyer, 2015; Mitchell & Holdt, 2014; Reddy et al., 2019). Jackson and Andipatin (2019) exclusively explored fathers' experiences of parenting a child with dyspraxia, as well as notions of fatherhood and masculinity. Furthermore, their research findings highlighted the sense of grief, guilt, frustration, and burnout that caregivers of children who experience special educational needs undergo. Notably, much of the literature has focused on the negative and distressing experiences of parenting a child who experiences special educational needs, thus highlighting the need to explore caregivers coping strategies and support needs.

Despite these challenges, research into caregivers' experiences has highlighted the pandemic's positive and meaningful impact in some instances. In particular, family relationships and interpersonal bonds were strengthened (Shum et al., 2023) as families could reconnect and spend more time together (Evans et al., 2020; Weaver & Swank, 2021).

Additionally, stereotypical family roles were challenged as fathers could exhibit 'motherly' behaviours and play the part of the nurturer (Gelir & Duzen, 2021). Furthermore, caregivers had opportunities to learn more about their children and their abilities (Gelir & Duzen, 2021). Therefore, while the pandemic had many negative consequences, it also had positive moments and opportunities.

2.5 Theoretical Framework

Having a child who experiences special educational needs affects the family unit (Jackson & Andipatin, 2019; Russell et al., 2020). Community attitudes and support structures may also affect the coping abilities of parents and families who have children that experience special educational needs (Taderera & Hall, 2017). Although many theories are linked to understanding the caregivers' experiences, this study will be underpinned by Bronfenbrenner's bioecological model (Bronfenbrenner & Morris, 2006). Notably, this framework is suitable for the current research project as it looks at the child and caregiver’s environment and external influences holistically. It also helps assist and design interventions (Schweiger & O'Brien, 2005).

Notably, the bioecological model, or the Process-Person-Context-Time model (PPCT; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006), posits there are four interacting dimensions, namely, process factors, person factors, contexts, and time. The process dimension represents the various forms of interaction between the person dimension and the context dimension over time (Rosa & Tudge, 2013; Smit et al., 2020). Additionally, the process dimension refers to interactions that occur in families, schools, friend groups and local communities (Donald et al., 2020). These interactions, or proximal processes, are critical to understanding development and well-being (Bronfenbrenner & Morris, 2006). Hence, caregivers' ability to cope with the pandemic may be related to their innate abilities

and strategies. However, it is also influenced by external relationships, broader community attitudes, and governmental policies over time.

Person factors refer to the biopsychological characteristics of the individual and include force, resource, and demand characteristics (Donald et al., 2020; Smit et al., 2020). Notably, these characteristics influence the direction and power of the proximal processes (Bronfenbrenner & Morris, 2006; Rosa & Tudge, 2013). Force characteristics include the temperament and personality of the individual as well as their belief systems (Smit et al., 2020). Resource characteristics determine whether an individual can effectively engage in proximal processes (Rosa & Tudge, 2013). Notably, this includes innate abilities, knowledge, skills, experiences, and social and material resources, as well as developmental liabilities (Bronfenbrenner & Morris, 2006; Smit et al., 2020). Demand characteristics either enhance or disrupt proximal processes, which include age, gender, and ethnicity (Bronfenbrenner & Morris, 2006; Rose & Tudge, 2013). Thus, a caregiver and child's personality, belief system, access to resources, and physical characteristics can influence the caregiver's experience of the pandemic and in turn their ability to cope.

Context refers to previous versions of Bronfenbrenner's ecological model, whereby different environmental layers may directly or indirectly influence proximal processes (Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Morris, 2006; Rosa & Tudge, 2013). Briefly, the microsystem is the direct, immediate environment of the caregivers and includes proximal interactions with familiar people, such as friends and family (Donald et al., 2020). The mesosystem refers to the continuous linking interactions between microsystems. The exosystem includes other systems in which the individual is not directly involved but is still influenced (Smit et al., 2020). Political, economic, social, and cultural values, beliefs and practices comprise the macrosystem (Smit et al., 2020). Thus, the macrosystem includes the wider community and societal system (Donald et al., 2020). These different layers influence

the individual, and reciprocally, the individual can influence the environment (Rosa & Tudge, 2013). Notably, the COVID-19 pandemic had a significant impact on these environmental layers.

Another essential element of this framework is the notion of time. More specifically, over time, an individual's well-being may be impacted by various changes brought about by different events and experiences (Bronfenbrenner, 1989; Rosa & Tudge, 2013). Such changes may be external to the individual, such as changes in their lifestyle or environment, or they may be internal, such as becoming sick (Rosa & Tudge, 2013). Critically, Rosa and Tudge (2013) explain that these changes can be categorised as normative or non-normative. The former refers to change which is expected, such as a child going to school or a caregiver going to work, while the latter refers to unexpected change. In the context of this research, the COVID-19 pandemic was an external event and a non-normative experience as there was a sudden change in an individual's daily living and way of being, as highlighted previously.

Notably, Bronfenbrenner and Morris (2006) further refine the concept of time according to three levels, namely, micro-time, meso-time, and macro-time, previously referred to as the chronosystem. Briefly, micro-time refers to episodes of proximal processes; meso-time refers to the consistency of interactions over time, and macro-time is the changes within and across generations (Bronfenbrenner & Morris, 2006; Donald et al., 2020; Rosa & Tudge, 2013; Smit et al., 2020). While these concepts are challenging to investigate individually due to the nature of this research, there is the recognition that caregivers' experiences are being explored and reflected upon over a specific timeframe, namely the pandemic.

2.6 Conclusion

To conclude, the definition and understanding of special educational needs are debated due to conflicting views from the medical model and social model. Furthermore, the

prevalence of special educational needs among children is difficult to determine due to definitional differences and understanding. Further complicating this is South Africa's lack of resources. Nonetheless, caregivers of children who experience special educational needs face many challenges and process many complicated feelings. Current literature highlights that the pandemic has exacerbated underlying challenges and feelings as access to vital support networks was limited. In addition, caregivers needed to manage other difficulties over and above caring for the child who experiences special educational needs. However, opportunities to bond and enhance understanding between individuals were a positive aspect of the pandemic. The bio-ecological model is critical in understanding caregivers' experiences as different intrapersonal and interpersonal characteristics interact with the environment across time.

Chapter Three: Methods

3.1 Introduction

This chapter provides information about the methods used in this research study. More specifically, it outlines the research design, the sampling strategy and sample, the data collection instrument, as well as the general procedure. Subsequently, the approach used for data analysis will be outlined in detail, followed by a discussion on qualitative rigour and researcher reflexivity. To conclude, this chapter will discuss the ethical considerations taken into account throughout the research.

3.2 Research Design

Considering the research sought to explore and gain an in-depth understanding of the subjective experiences that caregivers of children who experience special educational needs had during the COVID-19 pandemic, a qualitative methodology was employed. Notably, the use of qualitative methods allowed for the in-depth and holistic exploration of caregivers' experiences, stressors, coping strategies, and the understanding of their current available support structures and the support they may still require (Moser & Korstjens, 2018). In addition, a qualitative approach allows for the development of knowledge in under-researched areas (Fossey et al., 2002), such as the experiences of caregivers of children who experience special education needs during the pandemic.

Notably, this study was grounded within the interpretivist paradigm, given the focus of the study. Interpretivism emphasises that reality is subjective and can differ considerably between individuals (Alharahsheh & Pius, 2019) as individuals create and construct their internal realities through their experiences (Terre Blanche et al., 2006). Thus, interpretivist research does not aim to provide generalisable knowledge but rather to provide an in-depth understanding of human experiences within a particular context. Additionally, the

interpretivist paradigm recognises that knowledge is obtained through how individuals make meaning of their experiences (Alharahsheh & Pius, 2019).

As previously highlighted, there is limited research on the experiences of caregivers of children who experience special education needs during the pandemic within the South African context. Therefore, an inductive exploratory approach was used. This approach allowed for a preliminary investigation as well as potentially laying the foundation for future research into this field (Given, 2008). Additionally, exploratory research allowed for the exploration of caregivers' experiences, stressors, coping strategies, and support needs in a holistic, flexible, and open-ended way as the researcher can focus on gaining an intimate understanding of the participant's experiences (Given, 2008). Furthermore, the inductive nature of this design allowed for deeper insight and enabled a broader understanding of the caregivers' experiences (Tokatly-Latzer et al., 2020).

3.3 Sampling and Sample

The current study recruited caregivers that parent a child who experiences special educational needs. Critically, the participants were recruited through a privately registered special educational needs school in Johannesburg. Notably, this school was chosen, in particular, as their fee structure is based on a sliding scale, thus, there was a greater likelihood of having a diverse socio-economic sample. Furthermore, the children who attended this school were more likely to experience special educational needs as they could not cope in a mainstream or remedial educational environment, due to intrinsic and extrinsic factors.

Considering that participants were selected due to their specific experiences and qualities (Patton, 2014), a non-probability purpose volunteer sampling technique was employed. More specifically, the study adopted a mixed purposeful sampling technique as it allowed the researcher to find information-rich cases (Patton, 2014). This is essential as the study sought to explore the in-depth experiences of caregivers with children who experience

special educational needs. Notably, snowball sampling was employed as an additional technique as the researcher was unable to get a sufficient number of volunteer participants from the privately registered school (Patton, 2014). Subsequently, individuals who participated in the study were asked to inform other parents, or caregivers, that they know whose child attends a privately registered special educational needs school. In the case that individuals were interested, they were asked to contact the researcher to participate in the study.

Given the scarce research in this area and within the South African context, the ideal sample would have included participants from varying cultural, ethnic, and socio-economic groups, as well as being more gender balanced. The intention to recruit a diverse participant sample is especially vital in the South African context in light of the vast diversity and different experiences. However, as the study relied on voluntary participation, this was not attainable. Nonetheless, the openness of the study to both parents and caregivers of children who experience special educational needs resulted in varying degrees of special educational needs and allowed for more caregivers' experiences to be shared. As expressed in the reviewed literature, some diagnoses tend to be more researched than others (Mitchell & Holdt, 2014; Reddy et al., 2019), or the interaction between intrinsic and extrinsic factors is left unexplored (Donald et al., 2020). Hence, the exploratory nature of this research study.

The sample consisted of 12 participants who met the inclusion criteria (See Table 3.3.1). Notably, participants were included in the study, if they were directly involved and responsible for the caring and parenting of the child who experiences special educational needs. Thus, this included individuals who cared for a child either in the capacity of a parent, legal guardian, or extended family member. To protect the participants' identity and, therefore, confidentiality, each participant and their child were assigned a pseudonym. Notably, most of the sample consisted of females. Participants were mostly in the 40s age

range (58.3%; n = 7), while while the rest of the sample fell within the 30s age range (30.8%; n = 4), except for one participant whose age fell within the 50s range. In terms of marital status, 2 (15.4%) indicated that they were single, while 6 (50%) indicated they were married, and 4 (30.8%) indicated they were divorced. With regards to the participants' race, 5 (38.5%) participants stated that they were Black, 1 (7.7%) participant identified as coloured, while the rest of the sample indicated they were white (50%; n = 6). In terms of educational attainment, 1 (8.3%) participant completed Grade 10, 3 (23.1%) participants had obtained their matric, although 2 were studying further, 3 (23.1%) participants obtained a diploma, while 5 (38.5%) went on to study further and obtained degrees. Notably, based on the occupations of the caregivers, the sample appears to be centred around the middle-class.

Table 3.3.1: Participant Demographics

Pseudonym	Gender	Age	Race	Marital Status	Highest Qualification
Camilla	Female	40s	White	Divorced	Matric
Kyla	Female	40s	White	Married	Diploma
Mr T	Male	50s	Black	Married	Degree
Mrs M	Female	40s	Black	Married	Diploma
Amara	Female	30s	Black	Divorced	Degree
Ms Zee	Female	40s	Black	Single	Matric
Imani	Female	40s	Black	Married	Diploma
Lessie	Female	30s	Coloured	Divorced	Grade 10
Dalia	Female	40s	White	Divorced	Degree
Emma	Female	30s	White	Married	Degree
Olivia	Female	30s	White	Single	Matric

Valerie	Female	40s	White	Married	Degree

The study was open to all caregivers of children who experience special educational needs, which allowed for diversity among the special educational needs categories. More specifically, the special educational needs categories included Traumatic Brain Injury (TBI), physical impairments, Autism Spectrum Disorder (ASD), including Asperger's Syndrome and Pervasive Developmental Disorder (PDD), Attention Deficit Hyperactivity Disorder (ADHD), Global Developmental Delay (GDD), Mosaic Down Syndrome, PCDH19 – Epilepsy and Auditory Processing difficulties. Furthermore, the children's ages ranged between 6 and 17 years of age. Most of the children were diagnosed as experiencing special educational needs via medical doctors, whilst others, were diagnosed through psychiatrists and psychologists via referrals from speech therapists, occupational therapists, and physiotherapists, as well as observations from teachers. Notably, the age at which a diagnosis was received varied across the sample, with some indicating developmental difficulties since birth while others received a diagnosis at later ages.

It should be noted that while there is no set rule for sample size in qualitative research (Patton, 2014), smaller samples are generally used due to the in-depth nature of qualitative research. The literature, as reviewed by Braun and Clarke (2021a), often states that twelve interviews are standard practice in qualitative research, as data saturation, deemed as the 'gold standard', is likely to occur. However, Braun and Clarke (2021b) warn against using 'data saturation' uncritically by adopting positivist values. More specifically, saturation should not indicate the frequency of a code, but instead, data saturation should be related to the purpose and aims of the analysis (Braun & Clarke, 2021b). It is suggested that the term 'information power' be adopted, whereby the "more information the sample holds, relevant to the actual study, the lower amount of participants is needed" (Malterud et al., 2016: p. 1). Notably,

information power is determined by the aim of the study, sample specificity, use of an established theory, quality of dialogue and the analysis strategy (Malterud et al., 2016). Considering the exploratory nature of this research study, more participants are required. Here, it is noted that a sample of six to ten participants may be adequate due to their diverse experiences of parenting a child who experiences special educational needs (Malterud et al., 2016). Notably, the research recruited twelve participants to ensure and highlight the patterns which were relevant to the research aims.

3.4 Data Collection

Data was collected through individual semi-structured interviews. Semi-structured interviews are beneficial as they allow individuals to express themselves and verbalise their experiences in their own words (Given, 2008). Furthermore, a semi-structured interview is beneficial as it enables flexibility and a more open-ended discussion, yet there is still guidance and a clear direction (Cresswell & Cresswell, 2018). Critically, the researcher attempted to ensure that participants did not divulge too much information that may have been irrelevant to answer the research questions. However, to ensure the quality of the data by not harming the rapport with the participants (Clarke & Braun, 2013), the researcher remained responsive and empathetic to the participants' accounts. Furthermore, the participants had the option to have interviews face-to-face, while observing COVID-19 protocols, such as social distancing, and the wearing of facemasks. Alternatively, participants could have their interviews online. Face-to-face interviews allowed the researcher to reflect upon the nuances of each participant, while online interviews were more convenient and appeared to allow more sensitive topics to be discussed (Levitt, 2020).

Notably, the interview schedule was self-developed and drew on existing local and international literature as a guide (Jackson & Andipatin, 2019; Russell et al., 2020). The interview schedule includes a demographic section and open-ended questions which enabled

flexibility and organic discussions (see Appendix F). The interview schedule was divided into four broad sections which sought to elicit the overall experiences of the caregivers, how they coped with challenges, what support was available to them, and what support they would have liked to receive.

The interview schedule was first piloted to ensure that the schedule addressed the research questions. Based on the outcomes of the pilot interviews with two caregivers from the special educational needs school, the interview schedule appeared to answer the research questions appropriately. Thus, while there were no significant changes to the interview schedule, it should be noted that the researcher adjusted the interviewing technique. More specifically, the interview schedule was followed in a more conversational manner as it allowed for a more natural flow of thought and allowed for moments of reflection, without judgement. The conversational manner also appeared to make participants' feel more comfortable with sharing their experiences, which allowed more in-depth and truthful or painful discussions.

3.5 Procedure

As ethical clearance was contingent on receiving permission from the privately registered special educational needs school, the principal and founder of the school were approached (see Appendix A). Critically, it was explained that no identifying information, such as the name of the school or that of the participants, will be reflected in the research study. While anonymity could not be guaranteed due to the nature of the interviews, the identity of the school and participants would be kept strictly confidential and would not be disclosed to anyone else.

Upon receiving ethical clearance from the University of the Witwatersrand's Human Research Ethics Committee – Non-Medical (see Appendix B), the school was asked to place an advert in their school newsletter (see Appendix C). Caregivers who were interested in

participating were contacted via email or phone call and were given a Participant Information Sheet (see Appendix D) and a consent form (see Appendix E) prior to the interview. In addition, the consent form also included a section confirming consent to be video- or audio-recorded. Through email or during the phone call, the purpose of the study was explained, and a convenient time, date and location for the interview were discussed. It should be noted that the research advert was shared by caregivers from the school amongst parent support groups and awareness groups on social media. A total of twenty-four participants expressed interest in the study. However, five were excluded from the study as their children attended a government special educational needs school. Other participants either did not continue with setting up an appointment time or subsequently decided not to participate.

Given the context of the COVID-19 pandemic, some interviews were conducted online, either via Microsoft Teams, Zoom or, in some circumstances, WhatsApp calls. Some participants preferred face-to-face interviews, and COVID-19 protocols were observed (South African Government Gazette, 2022). Participants were provided with the option for interviews to be conducted in a private space, such as the school. Alternatively, some of the participants specified a location, which included coffee shops and their place of work.

Once the interview process began, the researcher established rapport with each participant before re-explaining the purpose and aims of the study as well as the rights of the participant, how the findings would be reported and their right to confidentiality. The researcher ensured that participants understood what participation meant and emphasised their right to withdraw from the study. Participants were asked for their sociodemographic details verbally before the interview questions (see Appendix F). Notably, the semi-structured interviewed lasted approximately forty minutes to an hour.

3.6. Data Analysis

Data analysis and data collection simultaneously occurred as the researcher recognised and noticed patterns of meaning and points of interest during the interviews. As the researcher intended to identify, analyse, report, and interpret patterns and shared meanings among the participants, reflexive thematic analysis, as described by Braun and Clarke (2021a), was used. While Braun and Clarke (2006) outline six phases of thematic analysis to ensure that researchers are guided by a coherent and logically structured analytical process, it is acknowledged that the analytic process is not linear. Instead, it is an ongoing process in which the researcher goes back and forth between the data and the themes.

Notably, the first phase of the analysis includes familiarising oneself with the data (Braun & Clarke, 2021a). During this phase, the researcher transcribed the interviews verbatim. Consequently, the researcher was fully immersed in the data, which allowed a deeper and more nuanced understanding of the data set (Braun & Clarke, 2021a). Additionally, the researcher re-read the transcripts while listening to the audio recordings to ensure the transcriptions were accurate. Furthermore, the researcher included additional notes, such as the emotional responses of the participants in the transcripts, to ensure their experience was captured as closely as possible. The researcher also kept a hand-written reflexive journal of personal responses and thoughts that influenced and shaped the way the data was interpreted.

The second phase involved the systematic process of generating initial codes (Braun & Clarke, 2021a). More specifically, the researcher read each interview transcript closely and tagged all the items, with a code label, which were potentially relevant to the research question. Braun and Clarke (2021a) argue that this process is crucial as it allows for better insight due to repeated close engagement. Additionally, the coding process ensures rigour as it is a systematic engagement with both meaning and patterns across the entire dataset.

Therefore, the development of themes will be based on a thorough and detailed analysis (Braun & Clarke, 2021a). Once each transcript was coded, the codes were summarised in a table format. When this was completed, the codes along with excerpts from the researcher's reflexive journal, was sent to the researcher's supervisor to acknowledge the subjectivity of the analysis.

Critically, the researcher adopted an inductive approach as it allowed the data to drive the analysis based on the participants' experiences. Furthermore, semantic coding was utilised, whereby patterns of meaning are identified within the explicit, overt meanings of the data (Braun & Clarke, 2021a). Subsequently, the analysis progressed from a descriptive account to an interpretive account of the participants' experiences, as the researcher attempted to theorise the importance of the identified patterns as well as their broader meanings and implications (Braun & Clarke, 2006; Patton, 2014). Notably, an experiential and realist framework was followed as it allowed the researcher to capture and explore the participants' experiences through the way it was reflected in their language during the interview (Braun & Clarke, 2021a).

Generating initial themes was the third phase, which included engaging with the codes to explore potential patterns of meaning and to develop candidate themes (Braun & Clarke, 2021a). Thus, codes across the data set were clustered into broader patterns of meaning that could answer the research questions. Notably, a thematic map was created to facilitate this process. Critically, this allowed for the thinking of potential themes, how they may be related, and the meaningful story the analysis is developing (Braun & Clarke, 2021a). Closely linked is phase four due to the recursive nature of thematic analysis. In this phase, the coded data extracts and the whole dataset were re-engaged to explore and further develop patterns and ensure the richness of the current themes (Braun & Clarke, 2021a). In this way, the researcher could avoid developing topic summaries, whereby a broad overview of what

participants expressed was summarised and included. Instead, the researcher could explore and rework the themes to ensure they centre around a particular idea that answers the research questions (Braun & Clarke, 2021a). Also interlinked is phase five, whereby themes are defined, refined, and named.

The sixth and final phase is the writing of the thematic analysis report. Braun and Clarke (2021a) highlight that writing is a vital aspect of the analysis as the analysis is still being shaped as it is written. While it is advocated that the literature review should be written after the analysis so that a more appropriate review and argument can be developed based on the analysis (Braun & Clarke, 2021a), it should be noted that an early and simplified literature review was written for the research proposal. However, Braun and Clarke (2021a) argue that literature should be engaged throughout the research process. Thus, the researcher engaged with the available literature during the process but only began writing the literature review towards the end of the analysis.

3.7 Qualitative Rigour

While some positivist-orientated researchers may question the quality of qualitative research due to the lack of objectivity and measures of reliability and validity (Braun & Clarke, 2021a; Shenton, 2004), it is argued that qualitative researchers use the term 'trustworthiness' as a form of quality criteria (Korstjens & Moser, 2018). Notably, trustworthiness may be discussed in terms of credibility, transferability, dependability, and confirmability. Critically, trustworthiness ensures the rigour of the qualitative research (Korstjens & Moser, 2018).

Credibility, which explores the congruency between reality and the research findings, was ensured as participants had the right to withdraw from the study, thus, they were genuinely willing to participate and were more likely to offer data more freely and honestly (Shenton, 2004). In addition, a form of member-checking was utilised to ensure credibility, as

the researcher frequently reflected on the participants' experiences and emotions during the interview to confirm that the provided interpretation was accurate (Shenton, 2004). Notably, this also gave the participants an opportunity to correct the researcher or expand on experiences. The researcher also used a reflexive journal, which Shenton (2004) argues helps the researcher monitor subjectivity and how themes are being constructed, thus, ensuring credibility. Finally, the researcher also had debriefing sessions with a supervisor to assist with identifying any biases or preferences (Shenton, 2004).

Transferability is concerned with whether the research findings can be applied to another context (Korstjens & Moser, 2018; Shenton, 2004). The researcher has provided a thick description of the data and the context of the data so that future researchers can understand the data, and compare instances described in this research and what they may see emerging in their studies (Korstjens & Moser, 2018).

Dependability refers to the consistency of the research finding as well as the repeatability of the research (Korstjens & Moser, 2018). While qualitative research is not static, as phenomena are constantly changing, dependability is assumed if credibility is established (Shenton, 2004). Furthermore, the process of the research has been explained in-depth to allow other researchers to repeat the study, although similar results may not be obtained.

Confirmability refers to the extent to which the research findings are based on the data and not the researcher's bias and subjectivity (Korstjens & Moser, 2018). While the researcher plays an active role in interpreting and analysing the data, confirmability was ensured as the researcher acknowledged personal beliefs and opinions, recognised the limitations of the study methods, and provided an in-depth methodological description to allow the research findings to be scrutinised (Shenton, 2004).

There is an acknowledgement of a fifth criterion which can be used to establish trustworthiness, namely authenticity (Johnson & Rasulova, 2017). Critically, the authenticity principle emphasises that the research must be transformative and emancipatory through continuous negotiation. Notably, this is achieved by ensuring that five sub-criteria are met, namely, fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity (Johnson & Rasulova, 2017). Briefly, fairness is concerned with balancing and considering competing constructions. Ontological and educative authenticity is concerned with how the participants and researcher experience the world and how constructions may change through interactions with others (Johnson & Rasulova, 2017). Together, these two dimensions seek to promote understanding and appreciation of different opinions and values. Catalytic authenticity refers to the extent to which action is facilitated by the research, and tactical authenticity refers to the extent to which participants are empowered to take action (Johnson & Rasulova, 2017).

Although authenticity aligns with the constructivist paradigm, whereby the focus is on change, and this paper aligns with the interpretivism paradigm, which focuses on understanding individual experiences, it is argued that this research incorporated fairness as well as catalytic and tactical authenticity as one caregiver, in particular, took action to create a monthly support group for the caregivers at the school. Thus, the research was empowering and facilitated some form of change.

3.8 Reflexivity

Qualitative research recognises that the researcher is an instrument and that their interpretations are shaped by personal experiences (Cresswell & Cresswell, 2018). As such, the researcher engaged in a continuous process of self-reflection to see how her particular assumptions may have shaped or limited the produced knowledge (Braun & Clarke, 2021a). Thus, reflexivity and the researcher's subjectivity must be acknowledged. Critically, a

reflexive journal containing thoughts and feelings was kept throughout the research project and some experiences were shared with the supervisor.

The researcher has always been interested in the experiences of families who have children who experience special educational needs owing to her family member's disability and related challenges. However, this interest was further piqued by the researcher's experience of working in a special educational needs school during the pandemic. Here, she was exposed to both the experiences of children and their caregivers. Notably, this played a crucial role in conceptualising the research topic.

It should be noted that during the interviews, the researcher was both an insider and an outsider, as some participants highlighted. The researcher was an insider, on the one hand, due to living with a child who experiences difficulties, and on the other hand, her hands-on experience as a teacher of such children. However, the researcher was also experienced as an outsider due to her age and not being a parent. Furthermore, the researcher's identity as a student Educational Psychologist, at the time of the interviews, appeared to make the participants feel more at ease when discussing their experiences. In particular, a few participants stated during the debriefing that it was a relief to share their story with someone who had an understanding of their experiences and the difficulties their children face.

3.9 Ethical Considerations

Qualitative researchers argue that ethics must be considered throughout the research project as qualitative processes may change as data is collected (Levitt, 2020). Therefore, the ethical considerations for this research study must be clearly outlined. First, ethical clearance was obtained from the University of the Witwatersrand's Human Research Ethics Committee – Non-Medical. Simultaneously, the researcher approached a privately registered special educational needs school to get permission to access the caregivers. Once the ethical

clearance was obtained, the school principal wrote an introductory note in a school newsletter along with the research advert.

Subsequently, caregivers responded to the school newsletter and gave consent to be contacted by the researcher. Critically, this meant that caregivers were not coerced to participate. The researcher then reached out to the caregivers and provided an informed consent form as well as the Participant Information Sheet. Notably, these documents highlighted that participation is voluntary and participants could withdraw from the study, at any time, without consequences and that there were no direct advantages or disadvantages when participating in the study. Participants were also made aware of how their data would be used and stored, as outlined by the Protection of Personal Information Act (POPI Act; South African Government Gazette, 2013). To elaborate, the data is stored in a password protected file on a password-protected laptop. Furthermore, the recordings will be destroyed 5 years after conducting the study. Once their rights to participation were explained, caregivers were asked to sign the informed consent form, which included permission to be audio- or video-recorded.

Considering that the study sought to explore the experiences of caregivers who have a child who experiences special educational needs during the pandemic, unsettling and intense emotions may arise. Thus, the contact details for telephonic and in-person psychological support were provided in the case that caregivers felt negatively affected by the study.

Before each interview, the researcher re-explained the goals and purpose of the research as well as the participant's rights and ensured they were still comfortable and willing to participate. The researcher obtained permission to record before each interview. Additionally, a discussion took place about the limits of confidentiality, as the researcher's supervisor would have access to the data. While anonymity could not be guaranteed due to the nature of the interviews, the researcher took precautions not to disclose the school's name

and used pseudonyms in the transcripts to ensure confidentiality. Participants, as well as the school, were informed that they could have a summary of the findings. Participants were also informed about the possibility of their data being used for future research, or future publication in a journal article or conference paper. Notably, this was included in both the Participation Information Sheet and the Informed Consent from. Furthermore, participants were reminded of the distress protocol should the interview evoke distressing feelings. They were given details for two organisations that provide online or face-to-face counselling.

3.10 Summary

This chapter outlined the research methods for this study. Notably, this study adopted a qualitative research design grounded within the interpretivist paradigm. A mixed purposive sampling strategy, as well as snowball sampling, was utilised. Data were collected from 12 participants through a self-developed semi-structured interview that was conducted online or face-to-face. The interviews were transcribed verbatim and analysed using reflexive thematic analysis. Measures were implemented to ensure trustworthiness, and ethical protocols were followed.

Chapter Four: Data Analysis

4.1 Introduction

This chapter presents the research findings on caregivers' experiences of caring for a child who experiences special educational needs during the COVID-19 pandemic. Additionally, this chapter includes how caregivers coped with the pandemic, their available support structures, and support needs. As mentioned, the data was analysed using reflexive thematic analysis. While various themes and subthemes were developed from the data, only information deemed salient to answering the research question was included. Thus, the researcher developed five intersecting themes and fourteen subthemes related to caregivers' experiences of caring for a child who experiences special educational needs during the pandemic. See Table 4.1 below for a summary. Notably, the presented quotes from participants have been edited for clarity. More specifically, hesitations or stuttered repetitions have been omitted for readability.

Before the interview process began, a distress protocol was developed to safeguard the well-being of the participants should they become distressed. Notably, this protocol was shared in the Participation Information Sheet and was reiterated during the initial contact with the participants. Upon reflecting on their experiences, some participants became notably distressed during the interview. While the researcher and participant reflected on the thoughts and feelings that the interview process may have evoked, the participants were reminded of the available options for counselling.

Table 4.1: Themes and subthemes

Theme	**Subtheme**
"Exhausted to the bone"	• Managing worries and anxieties around COVID-19 • Pandemic life as a balancing act • Managing the pandemic's impact on child's functioning
Twice as isolated	• Cut off from support structures • Lack of understanding as a form of isolation
Finding the light in the dark	• Enhanced connections • Personal growth • *"It takes a village"*
Soldiering on and learning to cope	• Coping through connection • Individual coping strategies • *"Crossing the bridge when we get there"*
A wish for change and advocacy	• Awareness as support need • Inclusivity and shared spaces • Advocacy and self-empowerment

4.2. "Exhausted to the bone"

Caregivers reported feeling emotionally and physically drained when caring for their child who experiences special educational needs. More specifically, caregivers found it challenging to navigate their child's anxieties, as well as their own, around COVID-19, especially with the impact of confinement and the drastic change in routine and day-to-day living. The caregivers in the study also found it challenging to balance the roles they had to adapt and adjust to, as well as balancing family dynamics, which led to higher levels of exhaustion and self-doubt and, in some cases, guilt. Over and above this, caregivers also reported concerns about the pandemic's impact on their child's functioning and behaviour.

4.2.1 Managing worries and anxiety around COVID-19

While caregivers were managing their anxieties and uncertainty about the pandemic, as Lessie explained her worry about where the next plate of food would come from or how she would find the financial means to survive for the month, some also highlighted how difficult it was to explain to their children that things had changed, when they were just as worried and confused. These fears were particularly salient in the beginning of the pandemic when information was limited but misinformation and speculations were rife, as explained by Mr T:

> *It was a bit difficult... for Miss Kay to understand some of the things during the pandemic, I think she was, everybody was anxious, you know, we were all worried and then thinking, are you going to die tomorrow because we were told if you go outside, you're going to die, you know, it was not an easy experience at all.*

Some caregivers also reported the constant battle and challenges related to their children not understanding the pandemic. In some instances, caregivers had to develop routines and firm structures so that their child who experiences special educational needs could grasp the new way of living. While children struggled to understand what the pandemic meant, they also could not understand why their caregiver could not change the situation. With this said, caregivers were often met with resistance or anger from their children, which was reported as emotionally draining, as reflected by the responses below:

> *You're continuously having to explain "No, we can't leave. We can't go, we stay home. Let's do this." No, I'm tired. I don't want to do this, you know, and stuff like that and having to kind of keep doing the same things over and over again. (Amara)*

> *They don't understand, especially him, that's the main thing ... is that he doesn't grasp that I can't do anything about the situation. So, he's like this little kid that throws a*

tantrum, but he's, you know, he's already a teenager. So that was, that's difficult [for] me, sometimes. He doesn't understand why things happen. (Dalia)

Finding the balance between making their child aware of the severity of COVID-19 without instilling fear was another reported difficulty that caregivers found mentally taxing. Caregivers also had to navigate feelings of overprotectiveness and fearfulness. With this said, caregivers experienced harrowing thoughts if they or their child contracted COVID-19. One caregiver, in particular, felt a sense of selfishness and distress around something happening to her child. Confronted with these thoughts, it took an emotional toll on the caregiver:

Lord forbid, if anything has to happen. I'd rather bury Miss Bee than she bury me because she'll never survive without me. Yes, she's got family, she's got relatives, she's got cousins, but Miss Bee will never survive without me. So, if anything happens, I always pray to God. You know, I thought yes, it will hurt me. I'll probably need therapy but somehow, I'll be able to deal with it. But she'll never survive. So, I pray that if anything happens, let her go first. (Zee)

Therefore, managing their anxieties and fears, as well as their children's concerns and difficulties adjusting to the 'new normal', was an exhausting and emotionally draining experience for the caregivers. While caregivers worldwide were concerned about their children's well-being, having a child who experiences special educational needs exacerbated feelings of fear and worry. Acknowledging the fear as well as deeply in-grained coping mechanisms, some caregivers, upon reflection, wondered how they managed to get through the pandemic. Emma wondered out loud, *"You think back on how it was, it's kind of emotional, to think... Everything that you went through*". Similarly, Dalia reflected "*The other day I thought I must rather not focus back on that time, because it's actually (pause). I don't know how we got through that time...I think for everybody it was a bad experience"*.

4.2.2 Pandemic life as a balancing act

Across the dataset, it was evident that the caregivers became overwhelmed and had difficulties managing all the responsibilities and roles they needed to adopt for their child experiencing special educational needs during the pandemic. One caregiver, Mr T, explained, *"I must be like [a] lieutenant, teacher, and a parent... and a caregiver at the same time".* Another caregiver felt exasperated and had insufficient time or energy to do everything in one day. There was a need to find time to worry about work and financial security, while performing domestic chores and caring for a child who experiences special educational needs. Over and above this, time needed to be made to connect with loved ones to ensure these different expectations did not have a detrimental effect on the marital relationship. This was highlighted by Valerie:

> *No, it's hard. And being a parent and a business owner and having no help at home. It was hard because you had to get up, clean your house, do home schooling, then carry on working, then be the snack [lady], then, like trying to keep your marriage alive. Then clean your house again, because now it's a mess again.*

In line with this idea of balancing family, some caregivers expressed uneasiness over splitting themselves between their children or, in some instances, giving the child who experiences special educational needs preference as they required more attention. This is reflected by Camilla below:

> *[Daisy] needs extra as her siblings are able bodies. She needs a little bit of extra TLC [Tender, love and care]. It's challenging because you try to juggle a normal home and not skip... in a standard family you wouldn't give preference for sibling.*

Another caregiver expressed guilt as sometimes, because the child who experiences special educational needs requires more attention and assistance, other children tend to be

'neglected'. Consequently, sometimes caregivers would engage in compensatory behaviours to repair any feelings of neglect. However, as one caregiver explained, this led to a vicious cycle of guilt, as sometimes caregivers felt they were favouring the typically developing sibling over the child experiencing special educational needs. This was reflected by Kyla:

> *It's not easy for the siblings of the special needs children because, it's stressful, they see what's happening too and it, I mean it will add stress. And he's also a little boy. So, we have to be very aware of special needs siblings to give them the attention and love and everything they deserve, because you know, we can't just neglect them. We have to realise, and... spend time with them.*

For some caregivers, successfully playing each role, such as a parent, teacher, chef, worker, and spouse, meant putting their needs last or sacrificing sleep or rest periods. Imani highlights this below. Here, it is noted that there was a continuous strain on the caregivers during the pandemic. In some cases, caregivers made use of a diary to try balance and organise time for each activity, and to ensure they had time to themselves.

> *I'd wake up at 4 am and work, do my normal work, so that by 8, I do a bit of schooling with her from 8 to about 11:30. Just concentrate on her.... And then, after 12, I'll go back to work until 5. So yeah, it was long. (Imani)*

Critically, some caregivers became concerned about whether they were good enough, especially regarding teaching. Amara expressed this doubt, *"You never really know how much stimulation you're doing. Are you doing it right?"*. Furthermore, caregivers had to learn different ways of working with and teaching their child who experiences special educational needs. Zee expressed, *"I'm not a qualified remedial schoolteacher...whenever I assist her, I tend to just do it straight-forward, forgetting that I need to explain it in the way that she best understands."* While Mr T also explained the challenges:

It was a bit difficult for her because she used to be taught by a teacher... So, for her to understand my module of teaching and the way I was teaching her...It was really a bit of a challenge for her. (Mr T)

Therefore, caregivers not only had to adopt various roles during the pandemic, but they also had to navigate complicated feelings while adjusting to their new way of living. Notably, this included a change in family dynamics and roles. In addition, caregivers had to change their expectations of their children and find a way to educate them best.

4.2.3. Managing the pandemic's impact on child's functioning

Some caregivers noted immediate changes in the child's behaviour directly related to the pandemic. More specifically, this was due to the impact of confinement. Here, it should be noted that the caregivers of ASD children described some of the distressing behaviours that their children exhibited. Notably, the caregivers found these incidents traumatic and felt they needed to be on their guard constantly, focusing on their child. One of the caregivers also found that the constant monitoring of her child during the pandemic became too much for her, and she experienced intense feelings of guilt, and as if she was a terrible mother, for wanting a break. Interestingly, the age of the child did not appear to have any impact on the behaviour as seen by the responses from two caregivers:

Joey was getting so upset the first week of the lockdown; he knocked over our fish tank on the floor, it was a small one, and luckily it was plastic, so... there wasn't glass all over the place, but the fish died, and there was water under the couch and everywhere... During one of his tantrums, his meltdowns, I think because he felt very frustrated… He tried to climb out of our upstairs bedroom windows onto the ledge. And, at one stage, my husband found him on the roof because in like literally five seconds, he would be on the roof. (Kyla)

> *He lost it, he would get angry. He would throw chairs, or I would end up black and blue… When he melts down like that, he hits me, and he picked up chairs and threw them. He broke my computer. He completely lost it. He broke tablets. He broke, yeah and no, the pandemic was hard. The pandemic was really hard. (Valerie)*

Sometimes, the anger and frustration came from trying to learn online. One of the caregivers praised the school for the seamless transition to online learning, as seen by this quote, *"They went to the extremes actually, so that the kids can have a bit of normality in terms of educational needs...They went beyond the normal stuff that made it very nice for the kids.*" (Dalia). However, despite the school's efforts to make online learning easier, the transition was still a significant obstacle because of the drastic change in routine and environment. Dalia shares her experience:

> *It was the frustration because he would just throw the tablet that it goes against the wall and stuff like that because he gets frustrated. He doesn't understand, but this is the situation we're in, and you know, you have to, learn online. You know, there's no participation in class.*

Deep concern arose for the caregivers regarding online schooling and how educational gaps might affect their child's learning and development. Imani expressed that her daughter *"digressed a whole lot"*, and she felt isolated in trying to support her daughter's development, as seen by this quote:

> *I didn't even have contacts to say, okay, now what do we do now? The only thing is that the teacher will just send, um, what is it? The class material that they will do, but for all the other, you know, therapies... there was nothing. Nothing." (Imani)*

Echoing this concern, Emma also became anxious about her son's development because *"with schooling and things like that, it's like they tend to fall behind"*. Arguably, her

anxiety was intensified, given her son's very young age. Despite recognising the masks were a necessary protective measure, Emma felt they hindered her son's therapeutic process:

> *Obviously, the therapist and him had masks on. So, that, that made everything a bit difficult, you know, the speech, especially having speech therapy and feeding therapy. You can't really see with a mask on what he should be doing with the food in his mouth or how he should be saying 'r' or 'a'. So, the masks made that a bit challenging. (Emma)*

Similarly, Olivia expressed frustration over the pandemic's impact on her son's development and the expectation that her child would adjust to online immediately, as said: *"In the beginning, I mean, nobody did the online straightaway. So, you sat with great periods [where] he wasn't receiving what was necessary, then you throw them into having to do this through technology."* In line with this idea of educational and therapeutic gaps, Zee expressed concern over her role of trying to educate and stimulate her child while working from home, *"I constantly had to find ways to keep her busy. And also remember too long without doing anything... there's regression as well"*.

Over and above hindered cognitive and physical development, concerns about children's socioemotional development arose. Considering Camilla's words, *"Socialising, challenging as it is, then lockdown made it more challenging because now you're in lockdown. You're at home. You're confined to your space"*, some caregivers wondered about the already hindered ability of their child to socialise and express themselves. Similarly, learning opportunities and ways for children to have a sense of belongingness, or to take their minds off the pandemic and reconnect with others, were taken away. Amara alluded to this, *"She missed her friends. I think that's the biggest one. She missed her friends. She missed her teachers. She missed like activities...So it's the social side of things that she really missed"*.

Additionally, some caregivers felt that the educational system and structures had let them down, and as a result, this affected their child's functioning and development. "*She didn't have any form of school in 2020, and then she went back in September; it was one week on, one week off. So literally just two weeks [of] going to school, which obviously disrupted everything"* (Imani). Others felt the school itself could have done more to assist with their child's development by empowering the caregiver. Notably, some parents also reflected upon their privilege. The caregiver below summarised the frustration towards the educational structures and more broadly, her position of privilege and access to resources:

> *The work that they sent, I think was more just to keep him busy, not to educate. I could have sat on YouTube and looked at YouTube links of ABCs...You could have sent something functional that will enable me to educate my child instead of letting him sit lost for how many months, actually years. I mean, not all parents had the resources I may have had, not all parents may have had the time that I had. And that angers me, because not everybody has what they need to do best for their children. So, enable us. (Olivia).*

Inarguably, manging these feelings and different roles as well as the uncertainty about their child's functioning and development and their changes in behaviour, parents inevitably felt emotionally and mentally drained during the pandemic. To highlight this, Imani described her experience during the pandemic as being *"exhausted to the bone"*.

4.3 Twice as isolated

As the caregivers discussed and reflected upon their experiences and challenges during the pandemic, an underlying theme of being isolated and somewhat excluded from society became prominent. In particular, caregivers of children who experience special educational needs felt isolated from their support structures due to restricted travel and lack

of access to other services. In some cases, caregivers felt neglected by the government, as the government seemingly ignored the needs, difficulties, and experiences of caregivers with children who experience special educational needs, especially with the imposed lockdown. Furthermore, the lack of understanding from society was isolating in and of itself. Some caregivers felt that this lack of understanding and awareness of what caregivers and children who experience special educational needs go through exacerbated the challenges that caregivers already face.

4.3.1 Cut off from support structures

With the commencement of the COVID-19 lockdown and subsequent restrictions, access to support or relief structures was limited. Consequently, at times, caregivers were left feeling disconnected and, to an extent, unsupported. With particular reference to Amara's words, *"seeing people, you know, and because it helps to talk with different adults (laughs), sometimes it just helps. You know, just getting your mind off things. That helps*", she felt that not being able to go out and connect with others, or different people, was a challenging aspect of the pandemic.

In some cases, caregivers were left with a sense of being stranded as they could not reach out for physical support from their families. In essence, they were left to support themselves as the distance and restrictions limited their access to the support, they felt they needed and would have assisted in navigating all the challenges they experienced. This is reflected by the responses below:

> *It was a little bit stressful, some people, you know, it affected them badly, but it was nothing compared to us with having a special needs child in lockdown with no support because we don't have any family around here. We couldn't visit people, so we couldn't get in the car, that would've been another big help, is us to get in a car and drive to [KwaZulu-Natal] where my family is, where there's more space. (Kyla)*

> *I think the closing of the borders was also a bit of an issue. Um. My husband's family stays very far. So, we didn't really have a support system other than ourselves. So, closing the borders made it difficult for support. (Emma)*

Even in some cases, support structures, such as family, lived nearby but were still out of reach due to the intense travel restrictions and the law against leaving the house. Thus, when a caregiver required extra support or needed some relief from all the challenges, the support was inaccessible. Valerie summarises this, *"Usually... [we] would just go drop OJ off at my mother-in-law. We can't do that. We weren't allowed to, you know?"*. Mrs M also alluded to requiring some relief during the pandemic, as pre-pandemic and during the less intense stages of the pandemic, *"They would go to my mother's house, it's a bigger place, and visit her so that they get some, you know, some relief"*. In this way, the child could get relief from confinement, and the caregiver could also rest.

The notion of being neglected or forgotten by the government also arose as some caregivers felt that the government did not consider the needs of the children or how such a drastic change may affect the child's functioning and behaviour. Additionally, the government did not consider how the pandemic would affect the child’s learning abilities, especially in the case of children who experience special educational needs. The government did not “cater” for all the different needs, instead, they imposed a general lockdown. Valerie explains this lack of support, *“were there formal structures to help people with special needs children? No. Nothing”*. Even within the education system, some caregivers felt as if their concerns and anxieties were disregarded, as explained by a caregiver below:

> *I personally feel the simplest thing that could have come from the school considering your child is attending a special needs school was that level of support. Where if you asked a question or raise the concern, it was almost brushed aside and the pandemic was blamed for something or the other, or no answers could be given. (Olivia)*

Notably, Kyla echoed this feeling, *"there's no support. There's no emotional support…I think at the school they should have some counselling sessions or something… But then, often the questions I ask, nobody has an answer for them"*. Camilla further echoed the lack of support, as a whole, by emphasising, *"I need more support as a parent"* and elaborated that some of the current support that is available *"weren't able to offer us what we needed*". Contextually, for some caregivers, the feelings of loneliness due to unmet expectations and support needs arose from the discourse around public and private schooling and the additional costs of having a child who experiences special educational needs. Thus, some caregivers felt let down when considering the resources available at the schools.

4.3.2 Lack of understanding as a form of isolation

As caregivers reflected on their parenting experiences during the pandemic and what made parenting difficult, many caregivers reported feelings of loneliness, hopelessness, ostracism, and anger. Notably, these feelings arose due to the way children who experience special educational needs, and their caregivers were treated during the pandemic. Many caregivers expressed that the lack of understanding from others' made parenting very difficult and, in some cases, affected their mental well-being. Furthermore, with the lack of understanding, caregivers felt isolated because it seemed as if no one could empathise with what the caregiver, and child, were going through. Critically, caregivers expressed that the lack of understanding and knowledge of their children's differences has always been a challenge. However, the pandemic appeared to highlight and exacerbate the hostile attitudes and misunderstandings that others have towards children who are different in one way or the other.

With this said, upon reflection, Camilla acknowledged how lonely the pandemic was as whole, but also being a caregiver of a child who experiences special educational needs, despite having access to a good support system:

Now that I'm putting it out there, but.... it's just when you're going through it; you literally feel alone... Considering your support system is friends and family, and your friends are great, but they don't necessarily know exactly what you're going through.

Following a similar thought, some caregivers expressed that despite the best intentions of others, they still felt misunderstood and as if they were alone when dealing with the challenges their children experienced. Critically, caregivers felt particularly disappointed and hurt by people who were supposed to understand, such as family and teachers. Furthermore, when caregivers attempted to explain the special educational need experienced by their child, people were viewed as simply "not caring" or they did not have "sympathy". Additionally, some caregivers reported that unless an individual has a child who experiences special educational needs, they will never truly understand what the caregivers undergo daily. Notably, this commonly reported feeling amongst the caregivers continued and perpetuated the feelings of isolation as seen below:

A lot of the staff... are not married, and they don't have children. So, they firstly don't know what it's like to be a parent, and secondly, they don't even know what it's like to have a special needs child. They are very good at the job, but to live with it all day... They're young people that don't even have children. They don't even have special needs children, and they're working with them all day...I get the feeling that the staff there, and I'm saying this in a nice way because they're very good. They don't understand actually what us as parents, all the parents at that school go through. It's hectic. (Kyla)

I can even see it with my husband's family. They all have kids that's fine, normal functioning and if we go somewhere and Isaac starts getting his frustration, anger issues. You know, it really irritates them, and they will yell at him and tell him to stop

making a noise, and then it makes you as a parent feel cross with that person, because those people are supposed to understand, you know, but they don't because they don't, they're not in the same situation and they don't understand the background. Even though you've told them they still don't, they don't get it. And yeah, it makes things difficult. (Emma)

Alarmingly, during the pandemic, some caregivers were ostracised and victimised because of the measures they had to take to alleviate feelings of distress within their children. Some caregivers reported being photographed and reported to the police for violating lockdown restrictions, as they had taken their children outside for a walk to release pent-up energy. *"People were taking photos of [Joey]... every day there were complaints"* (Kyla). Valerie reported a similar experience, *"they, like, report on everything they see. And they were gonna report us [to the police] for walking"* (Valerie). Caregivers had to overcome additional obstacles to prove that their child experienced a special educational need to get further support. However, after jumping over hurdles to obtain the relevant documentation, others did not care or show empathy. Despite medical certification and professional recommendations, Kyla explained that the family was *"threatened with eviction"* for disobeying rules.

Another incident, which highlights the hostility towards children who are different and their caregivers, was one in which Kyla was taken to court and had a restraining order against her. After her neighbour was *"screaming…like a psychotic woman"* at Joey when he ran into her front garden, Kyla tried to explain that Joey is autistic, however, the woman did not care and felt that she was being threatened by the family. Thus, caregivers felt high levels of distress as they did not know how else to help their child, while also trying to accommodate the lack of understanding from others. The lack of compassion and understanding made caregivers feel alone in dealing with children and their anxiety.

Arguably, caregivers felt the pandemic isolated them two-fold. On the one hand, access to vital support and relief structures was limited, and caregivers were left to support themselves. On the other hand, caregivers had the additional challenge of contending with other individuals' lack of understanding and compassion. Both of these experiences meant that caregivers felt disconnected and misunderstood by others, which affected their mental and emotional well-being. While some caregivers did not share direct experiences of hostile attitudes or incidents, many reported a deep desire for more understanding from people. Notably, that would make parenting their child much more manageable and less distressing, especially during the pandemic.

4.4 Finding the light in the dark

While having some distance from the strict COVID-19 lockdown and being able to reflect on caregiving experiences, many caregivers acknowledged that the pandemic was not always grim and full of despair and challenges. Instead, caregivers reflected on and shared their positive experiences during the pandemic. Despite trying to maintain and balance all the different roles and responsibilities, caregivers felt that there were more opportunities to bond and develop their connections with their children. In particular, the child and caregiver could get to know and understand each other. In some cases, the pandemic led to personal growth as caregivers had moments where they learnt more about themselves and, in some instances, acknowledged hidden traits and capabilities. Over and above this, caregivers learnt to lean on their support structures.

4.4.1. Enhanced Connections

Bonding and connecting became the central focus of the caregivers' reflections. In particular, caregivers expressed that the pandemic and being restricted to the house, or being allowed to work from home, meant spending more time with their children. With increased time, the relationship between the child and the caregiver appeared to be strengthened, as

well as more opportunities for the families to bond. Thus, caregivers could learn more about their children and better understand them as well as feel closer to them. Mrs M summarises this in a comment that relationships *"actually grew because we spent most of the time together"*.

Some caregivers expressed gratitude or thankfulness that the pandemic appeared to slow things down, despite the increase in work. Dalia explains, *"That was the good thing is that we had enough time, and there was no rush. We couldn't go anywhere. So, that was a special time for me with the kids*". In line with the notion of time, some caregivers realised how much their work and other responsibilities took away from spending time with their children. Olivia, while highlighting the benefits of working from home, commented, *"The greatest outcome of lockdown was realising there's so much time wasted in between going to work and going to school that you got to spend valuable time with your children"*. Dalia further highlights this point:

> *It was actually a nice time for me to spend time with the kids, that I don't normally have the time to do. And we sometimes actually talk about it, and the kids say, especially Dante, he says he misses that time when we were like, you know, spending so much time together.*

Some caregivers also found joy and excitement as they reconnected with their children due to the pandemic. In essence, relationships were revived as every day mundane tasks fell away, and the beauty of parenthood was rediscovered:

> *Just getting to know him, like watching him jumping on the trampoline and in the pool and being able to swim with him in the middle of the day and watching him grow up a bit. Like these last two years have been awesome, just to watch him grow up every day. And just to see him as a person. (Valerie)*

You don't realize just how much you miss out on living, what you would deem the normal life, which is no longer normal, but your 9 to 5 job, Grey goes to school, you come home, you do homework, you cook, you clean. But during lockdown, it enabled all these little moments to happen. The simple things in life where you could sit outside together and build puzzles or have a swim or those little things that you never got to do, or you overlooked. (Olivia)

Keeping with the revival of the relationship analogy, caregivers had to learn to be with their children and get to know them again. Although fewer preoccupations meant more bonding time, caregivers and children also had to learn to adjust to each other and their way of behaving. Mr T explains this, "*I'll be at work doing my own things, and now we are here altogether... Remember, [Miss Kay was] always at school. So, how then do I adjust to her behaviour?"*. In line with this, Olivia stated, *"I got to learn and understand more about my child and what he requires and how"*. Thus, strengthening the relationship took place through a process of learning. Lessie, in particular, commented that her relationship with her daughter was *"actually quite nice because we got to grow to know each other"*. While Zee also emphasised, *"Because we're spending so much time together, we learned to understand each other better."*

Notably, these changes in learning to understand one another positively impacted the caregiver-child relationship and the family unit. Siblings were also able to develop their bonds, as Emma explains, *"[Isaac] was the only friend that she could have, they had to bond, you know, it made them a bit closer together"*. Thus, families also learnt to bond and reconnect with each other. This was expressed by Imani below:

We got to learn how to spend time together. Like really sit down and have lunch together, just bond. We used to go, like, every Saturday we'll take a walk around the

> *block, or we will go hiking. It's just really encouraged us just to do things together as a family.*

Therefore, due to the effects of the pandemic and the constant proximity of families, caregivers were given the opportunity to bond with their child who experiences special educational needs and essentially watch their development unfold. Furthermore, considering Valerie's comment, *"It's the difficulties... nobody bonds when you just having a good time all the time...You bond through the tough stuff*", family resilience and adaptation were evident amongst the caregivers. Emma, while reflecting on her marital relationship and learning to bond and work together, joked, *"there was a lot of times that you wanted to kill each other (laughs) but you managed to work it out"*. Thus, finding positive experiences and learning to be flexible allowed for stronger relationships.

4.4.2 Personal Growth

During the pandemic, caregivers found that connecting with others and facing challenges provided opportunities for growth. Thus, while caregivers were learning to understand their children better and strengthen their bonds, caregivers also found that through this relationship, they could learn more about themselves. Some caregivers reported developing new qualities, such as having patience and being more creative and compassionate. Caregivers also relied on their sense of humour and acknowledged this quality as a way of coping.

While parenting was challenging, the pandemic highlighted the strengths of the caregivers and, at times, led to positive emotions and eradicated feelings of self-doubt or worry. Amara summarises this experience:

> *The days are different. Seasons are different. One moment, I feel like, oh my gosh, I've got this, you know, I've got this... and obviously, it makes you Supermom because*

you're like, aw. Because she brings out the best in me, I won't lie as well. So, there's obviously qualities that I've learned about myself because of having to be with her. (Amara)

Similarly, some caregivers felt that they learnt more about themselves by being with their child who experiences special educational needs. Notably, this was expressed simply by Zee, *"You learn different things as well, also as a parent"* and Camilla, *"It's taught me a lot especially in lockdown, it's taught me a lot as a parent"*. In some cases, caregivers reflected on their newly developed qualities:

Trying to learn to have patience. I don't think I'm [a] very patient person, as it is. This did teach me a lot of patience. I think I've run out of it by now (laughs), but those simple things, yes, we take them for granted, and you look back now, it was a blessing in disguise. Because it taught me more about Grey, taught me more about myself. (Olivia)

Others humorously reflected on their resourcefulness during the pandemic and felt accomplished, as seen below:

You can't just throw in the towel. So, having to think and be creative because I am a creative, and so what can I do next? If this doesn't work? What can I do? And that takes your mind off the problems as well. It helps because you're using your strengths and you're also developing your weaknesses you know, in a time like that. So, you actually kind of learning who you truly are as well... Honestly, if you look back at the pandemic, you're like how did I get through life with UIF? (laughs). So, I can actually save (laughs). Things like that. (Amara)

> *I would make OJ swim. And then I'd say Rosary and run around my pool all at the same time. So, I was exercising, spending time with OJ and praying. And I was like, bam, I'm doing three things at once (laughs). (Valerie)*

Despite the hardships and emotional turmoil caregivers experienced during the pandemic, their resilience and ability to reflect highlighted that they are resourceful and capable. Others cherished their time with their children during the pandemic as it allowed the caregiver to recognise and utilise their innate abilities while learning more about themselves and developing new skills and qualities. Thus, in the face of darkness and gloom, caregivers could highlight positive personal experiences and find the light in a dark situation.

4.4.3 "It takes a village"

Many of the caregivers expressed an immense amount of gratitude towards their support structures. Caregivers felt most supported by their families, and some wondered where they would be if they did not have access to that support during the COVID-19 pandemic. Critically, caregivers found that family played a crucial role in supporting them, as the family had the knowledge and could understand their child. The family unit also provided caregivers with a sense of relief, as caregivers could get a "breather" from their parenting responsibilities. Similarly, some caregivers felt that the schoolteachers provided support in the form of relief during the pandemic. Notably, having and maintaining close relationships with friends as well as professionals also supported the caregivers. Critically, support systems created a sense of belonginess and provide reassurances that caregivers are not alone or being left unseen. As Olivia states, *"raising a special needs child, takes an army, or as they would say, it takes a village to raise a child"*.

Perceived support was akin to a lifeline during the pandemic as some caregivers wondered what life would have been like without their families. *"If it wasn't for [my] mom, where else would I be? Yeah, I'm just grateful that door was open at that time"* (Lessie).

Similarly, Olivia trailed off, thinking, *"If not for my family... I don't know"*. Another lifeline included professionals, such as a nanny or an au pair. Kyla expressed, "*If I didn't have that support, I would've... I don't know what I would've done, just me"*. In some instances, caregivers had no other support besides the au pair: *"We don't really have other help [except] our au pair"* (Emma).

Sometimes, the relationship with a spouse was a protective factor, especially if they were *"hands-on"* and the caregivers could *"take shifts"*. Imani felt that the assistance she received from her husband, and her mother, let her know *"That I'm not alone, you know, [I'm] not facing this thing by myself"*. Valerie shared a similar sentiment: *"We relied on our strong marriage to help each other"*. It became vital for caregivers to communicate with each other effectively, and as Emma states, *"We have to be a good team"*. Notably, effective communication and teamwork allowed spouses to manage their anxieties while also trying to alleviate potential burnout and exhaustion.

Considering that family members had a good understanding of the child who experiences special educational needs, many caregivers felt that this support system was vital and beneficial. Caregivers could lean on their families for support or additional assistance without worrying excessively about their child who experiences special educational needs. Critically, the families were supportive as they provided relief to the caregiver, especially as caregivers began to feel overwhelmed and, to an extent, began to feel the onset of burnout. Mr T explains, *"They would support me... they would take the kids, you know, some of the time"*. As Mrs M alludes, sometimes caregivers and their children *"need some time away"*. Others utilised their support structures in a similar manner. Valerie acknowledged, *"If we do want a night off or something like that, yeah...It is useful to just be able to drop him off at the mother-in-law or take him to my parents' house, you know?"*. Families provided a much-needed time out for the caregivers as explained by Dalia:

When I need time out.... I know my parents are there to take care of him, and you know, they understand his condition. And they know how to interact with him. So that makes me worry less. So, I know this is a useful replacement for me. So, I don't have to be stuck at home the whole time and look after him.

Additionally, families served as protective factors as they assisted in caring for the child. In some cases, it was physical as the *"extra hands...[provided] a lot of support."* (Amara) or, in some cases, provided the caregivers' child with additional stimulation; *"my sister did a really cool thing where she did a live story every day for parents with small kids and... she's a speech therapist, and it was really cool."* (Valerie). However, in other instances, the family stepped in when the caregiver knowingly or unknowingly was reaching burnout, or the family felt the caregiver needed to rest, as seen in the quote below:

They are my people, and... they assist when I don't realize that I need the assistance. Like, there's always somebody to jump in and be like, hey, take a break or we've done this and this and this or don't worry about this. (Olivia)

From this aspect, families contributed to safeguarding many of the caregivers' well-being. While acknowledging the supportive frame that families provided, some caregivers felt that their friends also significantly impacted their coping ability, during the pandemic, due to the support they received. Sometimes, validation and reassurances from their friends kept caregivers motivated and feeling acknowledged. A simple *"you're doing a great job"* (Camilla) helped navigate potential feelings of inadequacy and uncertainty. Amara further highlighted this:

Obviously, friends [who] understand, and they know your child is...different. So, like good close relationships really play a big part... and when people know you're trying,

> *and they actually give a compliment to say, "oh my gosh you're actually doing a great job." You know, that really helps.*

Over and above the validation, caregivers appreciated non-judgemental spaces to vent and talk about their experiences. Some caregivers felt their friends, especially those who understood their child, were *"safe places... a haven"* (Amara). Friendships were another space where caregivers could not hide or deny their feelings and were encouraged to engage in conversations or self-care. To elaborate, Imani explains, *"I've got friends who always...they can tell when you're having a bad time...They're always there to help. To see us through it"*. Furthermore, caregivers felt supported when friends checked in on them and to *"touch base"* (Zee). Thus, friends were a crucial support structure available to the caregivers during the pandemic and acted as protective factors.

In line with the idea of being checked in on and the desire to not feel alone, some caregivers reported that the specific schoolteachers were a helpful support structure. Although it was not a direct support to the caregivers, the phone calls created a sense of normality and calmness in the children. Notably, this eased the anxiety within the child, as there was a connection to something familiar, and the caregivers felt slightly less burdened by trying to maintain normality and provide reassurances that things would be fine. Mrs M explained her experience:

> *During the pandemic, they would do WhatsApp calls to check up on her. How is the situation at home? Is she becoming stressed? It helped a lot...Even just a WhatsApp to check "How's the child" and they even ask, "Can I do a WhatsApp call now to speak to her?" Just to make them, you know, feel at ease. To let them know that "we still [in] the pandemic...You know what? We still gonna come back to school. You mustn't stress a lot", and it helped 'cause they would be happy to see the faces of their teachers.*

Thus, caregivers feel best supported when their support structures make them feel like they are not alone, isolated, forgotten or neglected. The various support systems available to the caregivers created a sense of belonging and acknowledged the caregivers' experiences and challenges. Arguably, with the caregivers constantly focused on their child and their needs, it was a relief to the caregivers to feel as if someone else was caring for them and to have some of their parenting responsibilities eased for a short period. Upon reflection, caregivers realised the crucial role that their friends and family had during the pandemic.

4.5. Soldiering on and learning to cope

As a way to cope, many caregivers searched beyond themselves and their immediate environment to find a sense of hope and to feel like part of something bigger. More specifically, some caregivers relied on their faith to cope, while others found ways to cope by connecting and being part of a shared experience. In other instances, ways of coping were more concrete in that caregivers reached out to family, friends, and professionals. Caregivers also utilised external means of coping, which included exercising, medication or developing routines and schedules. However, some caregivers had ineffective or no coping mechanisms, and their focus was on survival and making it through each day.

4.5.1 Coping through connection

Some caregivers highlighted the importance of faith and religion in times of adversity. In particular, caregivers felt they could muster the strength and courage to cope by connecting to God or a higher being. By drawing on their faith, caregivers remained hopeful about the pandemic and their ability to cope. Emma states, *"I would just say, pray a lot, believe, and don't give up hope"*. While other caregivers found solace in knowing that things happen for a reason, as expressed in the quote, *"God also only gives you what you can handle"* (Camilla). Furthermore, another caregiver expressed that she felt moments of strength during the pandemic due to her strong faith: *"Having a strong faith helped me. I had*

God's peace, even though it was extremely stressful... I feel strong because of Christ, and he does give me his strength and peace… It helped me a lot" (Kyla). Thus, connecting with religion was a coping strategy many caregivers employed.

Other caregivers wanted to be a part of something bigger than themselves and craved shared connections. To elaborate, caregivers felt that to cope with the challenges imposed by COVID-19, they needed to write as a form of expression and share these thoughts widely. In contrast, other caregivers felt the need to hear different voices and stories as a way to cope. However, in both instances, having an underlying sense of community and shared experience was how the caregivers coped. While mentioning coping strategies and her blog, Valerie said, *"I write, and I think that was just helpful for me"*. Dalia, while reflecting on a new coping strategy utilised explicitly for the pandemic, stated:

> *I would just put on the radio and listen to the stories and whatever the people [said]... I don't listen to the radio so much. So, that was actually, for me, something that was out of the ordinary that I did to cope with this because... Just to hear other people's voices, and I don't know. Maybe I felt like I'm part of somebody or something. I don't know.*

Staying connected with friends and family was a crucial coping strategy for many caregivers. There was a need to be proactive about coping with the stress of COVID-19 and caring for a child who experiences special educational needs. This proactiveness and being intentional about reaching out and connecting enhanced caregivers coping abilities as they held onto their hopefulness. Amara summarises this:

> *Keeping in touch with people, honestly, I think that's the biggest one. And kind of having to plan like, what next? What else can be done? 'Cause just sitting there makes you feel like you're so unproductive, and you've kind of like given up on life.*

Other caregivers expressed similar sentiments by ensuring they were *"constantly on calls with colleagues or friends"* (Zee). Furthermore, some caregivers expressed gratitude for the school having an open-door policy. Notably, this meant caregivers could connect with the school principal and "vent". Therefore, a crucial coping strategy caregivers utilised during the pandemic involved finding a connection. The connection may have been related to a sense of faith, community, or to other individuals.

4.5.2 Individual coping strategies

Some caregivers focused on expelling pent-up stress by finding a physical outlet for stress, such as exercise. *"The only way I'm seriously coping is just letting it out with exercise"* (Imani). Generally, exercise was also seen as a form of self-care and stress relief as caregivers could distract themselves or get a much-needed change in environment. Emma highlights this, *"[We] ride a bicycle, we jog, or you know, just get out of the house"*. Interestingly, exercise also appeared to be coping strategy caregivers encouraged for their children, as seen by Mr T's statement; *"[A] thing that assisted a lot, was when we were allowed to... go jog. We would go jogging with her"*.

Medication was also a helpful coping strategy for caregivers, as it appeared to lower anxiety levels and help deal with their frustrations. Olivia joked, *"Every now and then, you may need a happy pill"*. Despite the prescription of antidepressants near the start of the pandemic, Valerie stated, *"I think they've helped"*. Another caregiver felt that medication helped her cope better when dealing with her son:

> *I got an antidepressant... Actually, a chill pill, it's not an antidepressant. It's nothing hectic. And that made such a difference. So actually, now I can cope better with, with Dante, with his condition because sometimes I really get frustrated because I don't understand him really, where he's coming from...in some situations. (Dalia)*

Developing a schedule was another strategy that caregivers used to cope for themselves and their children. Logically, if children felt less anxious due to the schedule creating a sense of routine and normality, then caregivers had less anxiety to manage and more time for themselves. Amara summarises the benefits of schedules and routines, *"I'm able to focus on other things. And I'm actually able to relax*". Imani also highlighted scheduling as a coping strategy:

> *The only thing for me was just to get a routine going. Because she needs a lot of structure...That was the main strategy for me. Let's just get the structure, let's just, you know, try focusing. This is what we're gonna do after this... That was the only way I was able to cope.*

The schedules also assisted caregivers in managing daily tasks and ensuring they received some "me-time." Valerie explained her use of a diary to keep herself accountable, especially in terms of remaining mentally, emotionally, and physically healthy while keeping to boundaries and time. This is seen in her explanation, *"Then I'm stopping, and I'm doing the Zumba, and that's my time... You just try and carve out time for yourself"*. Thus, routines and schedules were considered helpful coping strategies during the pandemic.

4.5.3 "Crossing that bridge when we get there"

Some caregivers felt it was difficult to cope with the challenges during the pandemic. More specifically, caregivers had difficulties identifying their coping strategies or recognised that they had not found *"nice coping strategies"* (Imani). Sometimes, caregivers had no tangible coping strategies and dealt with stress as it came. Mr T reported this experience as *"crossing the bridge when we get there... It was that type of a situation because you couldn't plan"*. Some caregivers used distraction as a form of coping, as seen by Emma, who

stated, *"It [helped] me to have kept on working...Because it takes my mind off [things]. Not to overthink situations... If I don't have time to overthink, it also helps me a lot."*

Other caregivers found that self-isolating was the only way to cope with their children and the pandemic. Regarding coping mechanisms, Kyla said, *"I didn't really have any... If I do need a break, I would just close my bedroom door"*. However, this was deemed ineffective as Kyla felt *"like a prisoner"* in her own home, and *"[Joey] will have a bit of a tantrum because he can't come in"*. Thus, in some cases, ineffective coping mechanisms resulted in feelings of hopelessness and a sense of needing to keep one foot in front of the other. Imani summarises this, *"I don't know, but somehow, we soldier on, we survive. We do what we have to do"*.

During the pandemic, caregivers engaged in coping strategies that fostered a sense of hope and community, specifically by developing and maintaining connections with others. Another coping strategy caregivers utilised was to exercise, take medication, or develop schedules and routines for themselves and their children. Alarmingly, some caregivers reported not coping during the pandemic as they had ineffective or almost non-existent coping strategies. Critically, this led to feelings of exhaustion and hopelessness.

4.6 A wish for change and advocacy

There was a deep desire for more understanding and a wish for change in society's view of children who experience special educational needs and their caregivers. Many caregivers expressed that a form of support they need and would like centres around awareness, tolerance, compassion and understanding of the various special educational needs categories. Prejudices and discrimination often made parenting during the pandemic significantly more complicated and impacted many of the caregivers' well-being. Thus, caregivers also expressed the need for more inclusivity and opportunities for a shared, non-judgemental, and empathic space where caregivers can feel better supported by others who

understand. Upon reflecting on their parenting experiences during the COVID-19 pandemic, many caregivers felt the urge to advocate for themselves as well as other children who experience special educational needs and their caregivers.

4.6.1 Awareness as a support need

While reflecting on their experiences, caregivers expressed that the pandemic and parenting, in general, would be less complicated if others understood special educational needs. The perceptions, lack of knowledge, and lack of understanding unnecessarily complicate and exacerbate the already difficult feelings that caregivers experience. With that said, caregivers expressed sadness, anger, and frustration by the way their children are treated and viewed within society. Exasperatedly, one caregiver exclaimed, *"Just some understanding. Just some understanding!"* (Valerie), which would be an ideal form of support. Some caregivers reported experiences about how everyday tasks are made challenging due to others' prejudices and discriminatory attitudes. This can be seen in both Olivia's and Emma's experiences below:

> *We've had instances where you're walking in the shop. They see my child's physical disability, and naturally, they speak to him like he's dumb. But he's bright. He's going to give it back. So good luck for trying. But if you had a bit more understanding and a bit more awareness of differences, you wouldn't be doing that, which would make us, as special needs parents, feel a little bit more comfortable or not want to go all mama bear out on you in the shop. (Olivia)*

> *If you're going to a shop and things are a bit challenging, or it's not a good day, and your son is maybe being difficult today because he's having an overload of input... People start judging and thinking that your kid's naughty. (Emma)*

While these experiences are not directly related to the pandemic, caregivers felt strongly about awareness campaigns and finding ways to educate people. In this way, some of the emotional burdens, such as fear of social exclusion, overprotectiveness, hopelessness, anger, and anxiety, could be alleviated for the caregivers. Interestingly, Dalia felt that the social isolation during the pandemic was beneficial, to an extent, as she discussed people's lack of understanding as stressful:

> *"I'm worried [about] how they are going to treat my child and what they think. I know we shouldn't worry what people think about, but I mean, especially his sister, she's very concerned... She always says, "Mommy, people don't know that Dante is different". So, she's really concerned on behalf of her brother, but luckily, he doesn't realize that people think funny".*

Multiple caregivers expressed that *"there needs to be a lot more awareness and education in [South Africa] about special needs"* (Kyla). Emma suggested an awareness campaign *"to get the word out there [about] how different learners react to different situations... To get the message out there. Carrying awareness and giving people information. Maybe understanding will be better"*. Olivia shared a similar thought, *"a bit more awareness. That being different is okay. I may look different, but it doesn't mean I cannot achieve things in life"*. Zee also suggested *"more workshops for people"* to educate broader society about special educational needs, mainly because *"there's still a lot of people that are in denial about their kids' developmental delays and challenges"*. Arguably, this denial and disapproval of differences perpetuate stigma and discrimination. Additionally, misconceptions about particular conditions on social media also increase parenting stress and perpetuate the idea of children with differences, either not being enough, or are exceptionally gifted. Caregivers have the additional burden of trying to navigate this discourse. Thus,

awareness and education are critical support needs for caregivers of children who experience special educational needs.

4.6.2 Inclusivity and shared spaces

Notions around inclusivity and being in a shared space with others who understand and can relate to the caregivers' experiences were considered prominent support needs. Some caregivers alluded to inclusivity as a way to alleviate their anxieties around their children and social stigma. More specifically, caregivers felt that the need for categories isolated their children and perpetuated stigma. Camilla suggested social activities in which organisations group "normal kids" and "special needs kids" together so they can learn from each other. Olivia more overtly expressed:

> *I'm not comfortable for you to put my child in a box, be it with your diagnosis, with his differences, or for who he is. People are [different], they need to learn to accept that not everybody's the same. There are differences, and hopefully, somebody out there one day can create this awareness and get rid of the stigma.*

Therefore, inclusivity was seen as a form of support for caregivers of children who experience special educational needs. More specifically, inclusivity ensures that caregivers and their children can be a part of society without fear of being ostracised or judged.

As seen throughout this paper, sometimes, being a caregiver to a child who experiences special educational needs can feel isolating and lonely. Thus, some caregivers desire a non-judgemental space to discuss parenting and life. Zee summarises this, *"it would be nice to have a place where you can just go and vent without people judging and without people thinking you're a bad mother"*. Connecting with others by sharing experiences and thinking together about their children can provide a supportive network for caregivers and

protect against feelings of loneliness or inadequacy. Emma highlights the impact that a shared space with others could have:

> *A lot of parents sometimes think that they're alone in this thing and there's no one else going through the same [thing]. If you can just know, one person [that's] at least going through the same as you... It will give you a bit of more courage and confidence to not give up.*

There appeared to be an underlying sense of 'struggling quietly' and being unseen. Kyla shared her account, "*Parents need a lot of support, but nobody knows about it because they just drop their children, go to work, pick them up, and they just have to get on with it on their own"*. While Emma adds, "I *think out there, [there's] some people that's feeling a bit hopeless, and they shouldn't"*. With this in mind, a shared space would allow caregivers to discuss their experiences and feel a sense of belonging, acceptance, and hope.

4.6.3 Advocacy and self-empowerment

Interestingly, while speaking from a perspective of privilege, caregivers expressed their need to support and advocate for themselves and others. Arguably, caregivers may have been tired of feelings of powerlessness and neglect by the various structures. Subsequently, this frustration led them to act on their desires and fulfil their support needs. In other words, the caregivers reflected on their support needs and wanted to assist those, in a less privileged position, in the same way. Notably, this ties in with the idea of self-empowerment as some caregivers realised, they needed to be proactive and create the change they wanted to see.

Considering the immediate judgements and assumptions made about the functioning and capabilities of children who experience special educational needs, Amara expressed:

> *A bit more needs to be done for people with disabilities. Because... It's almost like a weakness that actually can be turned into a strength. It's just that some people's*

weaknesses show a bit more than other peoples. And then with our kids, it's like the look, they're like, "Oh, she looks a bit different", and things like that. If it's a physical disability, "Oh my gosh. They can't do this. They can't do that." But there's a lot more that can be done.

While considering the costs of caring for a child with special educational needs, some caregivers expressed their concern about other caregivers who do not have the financial means to access appropriate schooling and therapeutic support. Kyla overtly states her concern and frustration for such caregivers:

Who looks after all the special needs children in this country, if the parents are working and the children… There's no schools for them. I find that's the problem. I think there's 1000s and 1000s of autistic children, special needs, maybe Cerebral Palsy and Down syndrome, who is sitting at home every day and not getting an education - which is every child's right to an education. Because there's no schools and they can't afford private schools, and the state doesn't help, there's waiting lists for state special schools...I really believe in this country; there needs to be a lot more [action].

During the interview process, some caregivers became more reflective about their support needs and the changes they want to see. Some parents are proactively attempting to change societal stereotypes and attitudes by "normalising" differences. Valerie advocates for this:

I think it is just more normalizing it…I know that sounds ridiculous, but it's the same way we normalize homosexuality. Like it's not a big thing, now, if you're gay. They've normalised it. They just write about it and had it in movies and people read blogs

> *about it and so then it just became a thing… I think that's what we need to do by special needs. We just need to normalise it.*

Other caregivers felt that the questions in the interview opened their minds and probed thoughts about what support they still needed. One particular caregiver had a moment of realisation and empowerment when sharing her disappointment around the lack of emotional support and support groups for the caregivers. She decided she would try to start her own support group at the school.

4.7 Summary

In this chapter, there was an exploration of the subjective experiences of caregivers who care for children who experience special educational needs. Notably, from the data, the researcher developed five intersecting themes and fourteen subthemes. The themes were inductive, semantic, and experiential, which aligns with the methodology described in the previous chapter. Critically, some caregivers while sharing and reflecting on their experiences became notably distressed. In these instances, the caregivers were reminded of the distress protocol in which they could attend counselling sessions.

Chapter Five: Discussion and Conclusion

5.1 Introduction

This chapter discusses the research findings in relation to the research questions and current literature. In addition, the discussion will consider the theoretical framework used in this study as described in Chapter Two. The research study's limitations, applicability and relevance will be discussed, as well as the implications and recommendations for future research. Concluding remarks in relation to this research investigation will be provided.

5.2 Discussion of findings

This exploratory qualitative study explored the experiences of caregivers of children who experience special educational needs during the COVID-19 pandemic in South Africa. For this study, caregivers could reflect on the last two years of pandemic living, including the initial lockdown and more recent lockdowns and the easing of restrictions, as well as returning or adjusting to the 'new normal'. The findings reveal that the pandemic exacerbated underlying challenges as caregivers experienced high levels of mental exhaustion when trying to manage the worries and anxieties around the pandemic while balancing responsibilities and navigating the pandemic's impact on their child's functioning and behaviour. Caregivers had diminished support as limited access to support networks as well as the lack of understanding from various communities and systems, led to increased feelings of isolation.

Despite the challenges these caregivers experienced, some reported positive experiences, such as enhanced connections with their children and family and personal growth. In addition, the caregivers recognised and appreciated the value of the support structures available during the pandemic. Often coping meant connecting with others to gain a sense of hope, while other caregivers used exercise and medication to cope. Alarmingly, some caregivers reported ineffective coping mechanisms and had difficulties finding ways to

destress, and their feelings of hopelessness increased. In light of this, caregivers identified a need and a wish for change and advocacy. In particular, caregivers identified creating awareness as a support need as well as inclusivity and shared spaces as a form of combating isolation and misunderstandings. Additionally, a need for empowerment arose, which included self-empowerment and advocating for other caregivers of children who experience special educational needs.

Caregivers shared the significant emotional impact of the pandemic on them as they attempted to explain and mitigate their children's anxieties and concerns about the pandemic while balancing various roles and responsibilities. While navigating new responsibilities, caregivers expressed heightened levels of distress when realising that the pandemic may have hindered their child's development. This is particularly evident in the lack of access to educational and therapeutic services. Subsequently, some caregivers took on more responsibilities, despite being overburdened, to ensure that no regression in their children's abilities or functioning occurred. Furthermore, caregivers of children who experience special educational needs also experienced high levels of distress, especially at the start of the pandemic, as their children acted out, sometimes violently, as they did not understand the sudden change in their lives. Notably, these findings align with the current literature, as they highlight the higher stress levels of caregivers of children who experience special educational needs (Evans et al., 2020; Marchetti et al., 2020; Tokatly-Latzer et al., 2020), especially during the pandemic.

While caregivers attempted to manage their work and other responsibilities, they were also concerned with being sensitive to their children's needs. Thus, consistent with the literature, caregivers often put the needs of their children first (Jackson & Andipatin, 2019; Russell et al., 2020; Shum et al., 2023) due to concerns about regression and hindered development. However, this led to increased feelings of exhaustion among caregivers.

Notably, the exhaustion is further compounded by the existing demands of the child and their complex needs. More specifically, Marchetti and colleagues (2020) explain that children who experience developmental difficulties are, in essence, chronic stressors for caregivers, as the caregivers constantly need to monitor and meet the needs of their child. Consequently, the caregiver may experience parental burnout. Furthermore, Weaver and Swank (2021) explain that caregivers are at an increased risk for burnout as caregivers' roles and responsibilities increased while caregiver support and resources decreased during the pandemic. Thus, it is unsurprising that caregivers in this study reported feelings of exhaustion, as they continuously had to care for their children, as relief structures, such as the school and family, were mainly unavailable.

With the closure of the schools, feelings of inadequacy were heightened as caregivers became concerned about their capabilities to support their child who experiences special educational needs. Some caregivers questioned their abilities and felt pressure to be the best parent. Over and above this, some caregivers had difficulties managing the change in their child's behaviour due to the pandemic. Notably, this experience of caregivers aligns with previous research as the disruption in routine and lack of access to therapeutic services results in frustration and acting-out behaviours (Jiao et al., 2020; Lee et al., 2020). Nonetheless, the pressure to be the best caregiver, navigate various roles, and mitigate challenges, results in diminished self-esteem and self-fulfilment (Weaver & Swank, 2021) and increased feelings of powerlessness (Dreyer, 2015; Tokatly-Latzer et al., 2020). Hence, many caregivers in this study expressed their need for reassurance and validation in relation to their experiences and parenting during the pandemic.

Critically, the family unit often provides a supportive network for caregivers as they provide reassurance, comfort, and assistance (Weeland et al., 2021). However, with the pandemic and restrictions on travel, some caregivers were isolated from their support, leading

to further exhaustion and isolation. Interestingly, some caregivers felt anger towards entities in the macrosystem, as many felt the government had neglected caregivers and failed to consider them and their children during the pandemic, especially in terms of limiting their access to supportive networks. Similarly, some caregivers felt abandoned by the educational system, as they had to take on teaching responsibilities and incur further costs. To an extent, this aligns with the criticism of Broadbent and colleagues (2020) regarding the South African government's lack of consideration for the local context. Furthermore, past literature on pandemics, indicates that the needs of children and their families must be considered to ensure that that families do not experience long-term trauma from the pandemic or public health response strategies (Sprang & Silman, 2013). Nonetheless, caregivers of children who experience special educational needs felt isolated and abandoned during the COVID-19 pandemic which exacerbated underlying challenges.

Despite the acknowledgement that the pandemic and caregiver stress have pervasive effects on family dysfunction (Bate et al., 2021; Russell et al., 2020; Weeland et al., 2021), many caregivers reported strengthened family relationships, which is equally consistent with the literature (Cluver et al., 2020; Evans et al., 2020; Weaver & Swank, 2021). More specifically, caregivers were provided with opportunities to spend more time with their children and bond and learn more about them, while sibling relationships also improved. This finding is consistent with the other qualitative literature (Gelir & Duzen, 2021; Shum et al., 2023; Tokatly-Latzer et al., 2020). Notably, this served as a protective factor for the caregivers. As such, caregivers coped with the stressors of the pandemic by connecting with others and finding solace in religious beliefs, which is evident in the literature (Gayatri & Irawaty, 2021). Other coping strategies included medication and exercise. In some cases, exercising was done as a family, which enhanced bonding while reducing stress. Critically, these moments, as Evans and colleagues (2020) highlight in their qualitative research, assist

families to reframe the negative experiences of the pandemic into an opportunity to appreciate and develop tolerance and patience.

In line with the notion of developing new qualities, many caregivers reported personal growth during the pandemic. Some caregivers reported learning patience and developing their strengths, which gave them hope and courage to keep moving forward. Crucially, Morelli and colleagues (2020) highlighted the need for caregivers to be supported to improve their strengths and to feel that they can manage their caregiving role. Furthermore, the literature emphasises that caregiver stress or perceived self-efficacy has a significant impact on child and overall family well-being as it can mitigate disaster outcomes (Bate et al., 2021; Morelli et al., 2020; Russell et al., 2020; Spinelli et al., 2020; Tokatly-Latzer et al., 2020; Weaver & Swank, 2021). Thus, it is crucial for caregivers to be empowered or feel a sense of control over their lives and their caregiving.

Unexpectedly, the findings indicate that caregivers found the lack of societal understanding about special educational needs to be one of the most challenging aspects of the pandemic. Caregivers experienced the lack of understanding as isolating, and in some instances, it created frustration and a sense of hopelessness due to others' discrimination and prejudices. Notably, this is somewhat inconsistent with the research findings, as Wang and colleagues (2020) state that communities may serve as valuable resources in managing difficult experiences. However, considering societal views of 'difference' and disability within the Southern African context, this aspect should not have been surprising, as research clearly outlines predominant community attitudes towards difference (Malapela et al., 2020; Ndlovu, 2016; Reddy et al., 2019; Taderera & Hall, 2017). Many caregivers reported that while the fear of social exclusion and hostile attitudes towards differences were everyday experiences as a caregiver of a child who experiences special educational needs, during the pandemic, it heightened their already complicated feelings and increased stress and fears of

ostracism. Caregivers who had children on the autism spectrum were especially vulnerable to punitive attitudes and actions, as often they were reported to the police for breaking COVID-19 restrictions as a way to ease their child's anxiety. One caregiver was threatened with eviction for disobeying community rules despite following the outlined procedures. While not a South African-based study, this may explain the findings of Toseeb and Asbury (2022), in which experiences of anxiety remained stable in caregivers of children with autism over time but eased in other special educational needs categories.

Regardless, many caregivers reported that awareness and acceptance are crucial support needs, as prejudices and discriminatory attitudes unnecessarily complicate and exacerbate the already challenging aspects of caring for a child who experiences special educational needs. Hence, interventions are inadequate if they are done at the individual level. Caregivers and their children will still be subjected to punitive attitudes in society, perpetuating stigma and resulting in caregiver distress and increasing feelings of helplessness. Thus, interventions should look at personal and environmental factors (Masquillier et al., 2021). Interestingly, and along these lines, many caregivers requested that more awareness campaigns be created to normalise special educational needs, as, at present, it is viewed as a debilitating condition and something to be pitied. Masquillier and colleagues (2021) posit that various layers must be considered to eliminate the stigma.

Furthermore, in line with the literature, caregivers need to feel self-empowered and parental self-empowerment interventions are required (Dreyer et al., 2015; Jackson & Andipatin, 2019; Reddy et al., 2019). Acknowledging the scarcity of support groups available for caregivers of children who experience special education needs and a preliminary discussion of support needs with the principal at one of the schools, a support group was discussed. Additionally, a participant requested that the school start a support group so caregivers could have a safe and non-judgmental space to discuss their challenges and joyful

moments. Parental support groups have also been found to build confidence, assist skill development, and provide a support network for caregivers (Ainscow, 2020). Some caregivers, with the hopes of inclusion being the key to understanding, suggested that social groups be created with typically developing children and those who experience special educational needs, as this, will lead to a just and non-discriminatory society (Ainscow, 2020). Additionally, some caregivers reported that, from their position of privilege, in terms of accessing educational and other therapeutic services, they felt the need to advocate for other caregivers of children who experience special educational needs. In essence, a sense of community with underlying principles of solidarity and social justice was considered crucial to caregivers, as they were operating from a position of empowerment rather than helplessness. Despite South Africa's progressive legislation (DBE, 2001) regarding inclusive education and fostering acceptance, caregivers expressed the need for more to be done by the government to change societal attitudes.

5.3 An integration of the findings with the theoretical framework

At the centre of the bioecological model is the process dimension which relates to proximal processes, or interactions, that occur within families, schools, peer groups and communities (Donald et al., 2020). Critically, this dimension explores the close, face-to-face interactions occurring between the person and context over time (Smit et al., 2020), which are fundamental in shaping development and well-being (Bronfenbrenner & Morris, 2006). Notably, the proximal processes are influenced by the person dimension, context, and time factors, although the individual can also influence these dimensions (Donald et al., 2020; Smit et al., 2020).

Undoubtedly, the sudden change brought by the COVID-19 pandemic, a nonnormative event, disrupted many proximal processes as caregivers could no longer connect with other individuals in close proximity. Although time could not be incorporated as

put forth by the theory, it is vital to note that the interviews dealt with time retrospectively. Thus, while the concept of micro-time is difficult to assess, both generally and in the format of an interview, the researcher could gain a sense of meso-time or the frequency of interactions (Navarro et al., 2022). In this study, the caregivers reported experiences of frequent positive interactions that enhanced relationships and, in some instances, family harmony. Therefore, facilitating and maintaining the well-being of the caregiver and child. However, due to the continuous interaction with the child and managing their needs, some interactions were more negative and led to higher levels of distress and anxiety, thus, negatively impacting the child and caregiver.

The pandemic also disrupted the context dimension. Decisions made in the macrosystem, such as the implementation of strict containment measures, impacted the well-being of caregivers, as the effect was felt within their microsystems (Donald et al., 2020). More specifically, the containment measures disrupted the daily activities of families, such as going to work or school. In essence, there was a discontinuity of interactions and activities. Additionally, the lockdown measures led to financial instability for some caregivers, which increased their stress and, subsequently, their proximal processes. Furthermore, broader societal views which included discrimination and intolerance, also heightened the stress levels caregivers experienced and further complicated parenting.

Critically, some caregivers' person factors also influenced how they experienced and reflected upon the pandemic. As such, some caregivers had more social and material resources available compared to others, which was a protective factor against parental burnout (Smit et al., 2020). Individual personalities also played a protective role in mitigating against burnout, as caregivers actively sought-out support and attempted to engage in help-seeking behaviours. However, as previously stated interventions targeted at the individual

level are not as effective or sustainable long-term. Instead, interventions should be explored at the all the levels of the system.

5.4 Implications of the Research Study

The findings of this study provide insights into the experiences of caregivers of children who experience special educational needs during the pandemic. It was noted that caregivers often feel isolated due to society's lack of understanding or lack of compassion towards children who experience special educational needs. Thus, awareness campaigns or finding ways to combat misconceptions and discriminatory attitudes must be developed. Despite the difficulties with the implementation of inclusive education in South Africa (Engelbrecht et al., 2015; Smit et al., 2020), this policy may be a potential avenue to foster understanding and acceptance (Van Mieghem et al., 2020), more broadly.

Furthermore, there is a need for more spaces, potentially in the form of support groups, in which caregivers are provided with an opportunity to share experiences and feel understood. Caregivers of children who experience special educational needs, need a space in which they can choose the direction of the conversation, and not be given advice or be told how to 'fix' their child. In their study evaluating support groups, Jackson and colleagues (2018) highlighted that parents wanted support groups to be a space where they could feel understood while also gathering information, sharing ideas and developing connections. Notably, there were some conflicting thoughts about whether a professional should be included in the support group. In particular, the inclusion of a professional may be useful as they could provide psychoeducation. However, some felt that there was a risk of the professional adopting a 'lecturing' stance (Jackson et al., 2018).

Nonetheless, in some instances, support groups were criticised for increasing feelings of loneliness among parents, as the condition their child experiences was either considered rare or not severe enough (Jackson et al., 2018). Additionally, support groups were

sometimes experienced as sources of depression and frustration, and in some cases, parents felt demoralised and hopeless (Jackson et al., 2018). Thus, when developing a support group, it becomes critical to ensure that the group setting will foster a sense of empowerment and belonging instead of a space filled with comparisons, guilt, and self-judgement (Jackson et al., 2018). Notably, this is consistent with the research findings from Dreyer (2015), Jackson and Andipatin (2019), Mitchell and Holdt (2014), as well as Reddy and colleagues (2018), in which self-empowerment is essential.

Additionally, some caregivers became concerned for other caregivers who do not have the financial means to care for a child who experiences special educational needs. Caregivers of such children incur extra costs to ensure their child gets adequate support and can develop optimally. The financial implications of having a child who requires extra support, especially in the limited, yet unequally resourced context of South Africa, has been well documented (Mitchell & Holdt, 2014; Reddy et al., 2019; Taderera & Hall, 2017). Thus, there was a wish for advocacy and for the government to do more in providing quality education and making vital therapeutic services more accessible to children who experience special educational needs. In the current study, many caregivers felt forced into private education as they reported that the government does not recognise the needs and unique strengths of children who experience special educational needs. Some participants expressed concerns about families in less privileged positions. Thus, not only is there a need to lobby for better quality special educational needs schools, especially in lower socioeconomic settings, but there was a wish for more consideration on behalf of the government when implementing disaster management responses. This was especially salient when caregivers reflected on their support needs during the pandemic.

As Cluver and colleagues (2020) have noted, "COVID-19 is not the first virus to threaten humanity, and it will not be the last" (p.1), indicating that a discussion surrounding

potential ideas or responses to future pandemics or crises is warranted. While the South African government was applauded for their swift and proactive response to the pandemic, some have argued that the response was not contextually relevant or considerate of the various vulnerable groups (Broadbent et al., 2020). Arguably, responses to pandemics or crises have not fully considered how relational functioning within families and communities may be disrupted by such containment measures. Consequently, families may experience long-term trauma either from the experience of the pandemic itself, or due to such measures, as the lack of family engagement and connection to others diminishes both individual and family resilience (Spring & Silman, 2013; Weeland et al., 2020). Thus, future pandemic planning needs to consider the psychological importance of relationships as well as the needs of children and their families more holistically. Although it may be challenging to implement in the face of a crisis, it may be beneficial to develop a disaster plan which incorporates the importance of keeping families together.

Acknowledging the necessity of connection and social support in mitigating the negative consequences of a pandemic or crisis-related isolation, future educational psychologists or counsellors should activate resources or support structures for caregivers to feel connected with others. Notably, the literature on the value of support networks for caregivers of children who experience special educational needs is well documented (Jackson & Andipatin, 2019; Mitchell & Holdt, 2014; Tokatly-Latzer et al., 2020). While psychological interventions can be moved to online platforms, this may not be an accessible option for all South Africans, considering costs and the digital divide.

Nonetheless, during the pandemic, a community-based organisation in Johannesburg developed a social media platform that provided psychosocial support to caregivers and provided weekly psychoeducational content (UbubeleTrust, 2021). Critically, research has shown that in South Africa, social media is a powerful tool that can reach millions of people

and can be used positively to protect the well-being of individuals (Kubheka et al., 2020). Thus, in future pandemics, groups of psychologists or counsellors can use this model to share information and provide brief psychosocial support to caregivers during a dedicated timeslot. While it is essential to keep accessibility and the digital divide in mind, Kubheka and colleagues (2020) report that the costs of data and airtime were the main obstacles individuals had when trying to access social media. Thus, various stakeholders should be engaged during times of crisis to make such services more accessible and affordable.

The use of Bronfenbrenner and Morris' (2006) bioecological model, and dimensions of the Process-Person-Context-Time model, was beneficial in understanding the complex experiences of caregivers who parent a child that experiences special educational needs. While the person characteristics of each caregiver had a role in how they experienced and coped with the changes brought by the pandemic, it became evident that interactions with others and the various systems, over time, impacted the well-being of the caregivers.

While the current study did not follow the stringent PPCT research model, due to it not being longitudinal (Navarro et al., 2022) because of practical constraints, it did, however, draw on the principles of bioecological theory to understand development and well-being. Furthermore, Bronfenbrenner and Morris (2006) do not explicitly discuss qualitative research in relation to the operationalisation of the PPCT model. Thus, a major implication of this research study is the contribution it may have towards the discussions surrounding the use of theory and the PPCT model in qualitative research practices.

5.5 Strengths and Limitations

A significant strength of this research study was the use of the semi-structured individual interview, as it allowed for the exploration and analysis of rich data. Additionally, the individual interviews allowed the researcher to engage more thoroughly and go in-depth with each participant, allowing the researcher to explore the emotions of the caregivers

parenting a child who experiences special educational needs. Another strength was the researchers' prolonged exposure to the context of special educational needs, which allowed the researcher to be more familiar with the experiences of caregivers of children who experience educational needs. Furthermore, this research contributes to the limited knowledge surrounding the experiences of South African caregivers, in the context of the COVID-19 pandemic, who parent a child that experiences special educational needs. Another strength of this exploratory study was the inclusion of all special educational needs categories, instead of focusing on a specific category. Thus, a diverse range of parenting experiences of children with different abilities and functioning could be explored. The timeframe also allowed caregivers to reflect on their overall pandemic experience. Additionally, this study may be helpful in advocating for better services for caregivers of children who experience special educational needs and contribute knowledge on how to handle future pandemics.

It is equally as vital to acknowledge the various limitations of this study. Firstly, given the difficulties of getting a diagnosis in South Africa, not all participants' children had received an 'official' diagnosis from a healthcare professional. However, their child was placed in a special educational needs school as they could not cope with mainstream or remedial schooling. Secondly, while the study attempted to obtain a diverse sample, there were primarily mothers in this sample, and caregivers came from mainly the middle-income socioeconomic class. In addition, many of the caregivers had children who were seen by other healthcare professionals for therapeutic intervention, which may imply that these caregivers were more resilient and understanding of their child's condition compared to caregivers with limited access to healthcare services, education, and therapeutic interventions. Furthermore, these findings are limited to an urban setting in Johannesburg which is only partially representative of the nation of South Africa. However, it is noted that

generalisability is not the goal of reflexive thematic analysis (Braun & Clarke, 2021a). Instead, the researcher has tried to ensure transferability in which the research has been contextualised so that others may judge whether the analysis can be transferred to their context or setting (Braun & Clarke, 2021a).

5.6 Recommendations for future research

Considering the limitations, future research should be expanded to include a broader range of experiences of parents, or caregivers, from different socio-economic and socio-cultural settings within the diverse South African context. Similarly, given the mixed literature on fathers' parenting experiences during the pandemic, and potential burnout, it may be beneficial to conduct further research with this specific group of individuals. In this way, future research can provide a better understanding of various caregivers' experiences during the pandemic, how they coped, and their support needs. Furthermore, future researchers may uncover the experiences of those with limited access to special educational needs schools and vital therapeutic interventions. Notably, this further exploration and understanding of experiences from a broad range of South Africans, may also contribute to future pandemic or crises planning that is contextually relevant.

5.7 Conclusion

To conclude, the COVID-19 pandemic had a significant impact on South African caregivers and their children who experience special educational needs. Parenting a child who experiences special educational needs is a challenging and daunting task, due to an array of complicated feelings and requires an extensive support network. Notably, these challenges were exacerbated during the pandemic.

Through reflexive thematic analysis, as outlined by Braun and Clarke (2021a), the current research study developed five intersecting themes. The first theme highlighted the high levels of exhaustion caregivers experienced due to their attempts to manage their

anxieties and their child's worries. Furthermore, caregivers were overextended due to the multiple roles and increased responsibilities during the pandemic. In addition, caregivers also had deep concerns about the pandemic's impact on their child's development, functioning, and behaviour. Furthermore, these aroused feelings of inadequacy and self-doubt among the caregivers.

The second theme highlighted the isolation that caregivers tend to undergo when they have a child who experiences special educational needs. Caregivers tend to feel twice as isolated, as during the pandemic as access to vital support networks was limited. Caregivers also felt isolated due to society's lack of understanding of special educational needs, which complicated the parenting experiences and stress levels of the caregivers. This subtheme was an unexpected development, however, given the prejudicial attitudes towards 'difference' in South Africa, this finding is consistent with local literature. Many caregivers identified awareness campaigns, inclusivity, and shared spaces, as well as a need for advocacy and self-empowerment, as support needs.

Strengthened relationships between family members and friends was seen as the light in the dark of the pandemic. Notably, caregivers found that with increased time, they learnt to adjust to their child and learn to understand them better. Additionally, spousal and sibling relationships also improved as a result, as individuals were forced to work as a team and bond. Aligning with this, many caregivers reported coping strategies which involved connection, either to other individuals or through their faith. Some caregivers felt that the only way to cope with the pandemic was to feel connected to a broader community. Hence, some caregivers reported the need for more support groups, with others who understand their experiences. Other caregivers used medication and exercise to cope, while some had ineffective or almost non-existent coping strategies, and felt they just needed to soldier on.

With these experiences in mind, the African proverb "it takes a village to raise a child" is especially fitting in the context of caregivers with children who experience special educational needs. To elaborate, caregivers require extensive support, from family, friends, community members, and professionals, when raising a child who experiences special educational needs. In future, the needs of caregivers and their children should be taken into account when imposing a lockdown to reduce the spread of diseases. Furthermore, more needs to be done in the way of awareness, to develop acceptance and understanding of the various special educational needs categories, as prejudices and discriminatory attitudes heighten feelings of distress in children and their caregivers.

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Appendices

Appendix A: Permission Letter

Dear [redacted]

My name is Jenna Fernandes, and I am conducting research at the University of the Witwatersrand in partial fulfilment of the requirements to obtain a Master's degree in Educational Psychology. My research aims to explore the experiences of caregivers of children who experience special education needs during the COVID-19 Pandemic. This research will help to better understand the experiences of caregivers of children who experience special education needs, which may inform practice, and help better support, such individuals.

I am requesting permission to please be allowed to approach the parents, or caregivers, of children attending the school at a school meeting, to request them to participate in my research, should they be interested. I am also requesting that you please advertise my research study in your school newsletter along with the Participation Information Sheet, which gives the details of my research study as well as my contact details and those of my supervisor.

Participation will entail face-to-face interviews, or online interviews, with approximately 12 caregivers, depending on their preferences. I will obtain permission from the participants to audio-record or, if online video-record, the interviews. The interviews should be approximately an hour long. The caregivers who show interest in participating in the study will be contacted to set up a date, time and venue where the interviews will be conducted. I'd also like to ask for your permission to use the school as a potential venue for the interviews, as it may be more convenient for the caregivers. National guidelines, as well as the school guidelines, will be followed in terms of COVID-19 safety protocols.

Furthermore, participation in my research study is completely voluntary and will not advantage or disadvantage the parents in any way if they choose to participate in the interviews. There are also no direct benefits or foreseeable risks for participating in the study. No identifying information, such as names, will be asked for and although the identity will be known to me as the interviewer, this will be kept strictly confidential, and will not be disclosed to anyone else. Any information that could directly identify the caregivers will be removed from the transcript of the interview. Participants will be able to obtain feedback on the study in the form of a summary of general results. Participants will also be asked for permission to store their data as a password-protected file and to use this for future research, or future publication in a journal article or conference paper.

Umthombo Building – 2nd Floor, Room U211, Braamfontein East Campus, Private Bag 3, WITS 2050
T +27 11 717 4503/33 | E psych.SHCD@wits.ac.za | www.wits.ac.za/shcd/psychology/

If you are happy for the caregivers from your school to participate in this study, please sign the consent slip at the end of this letter. If you have any questions or concerns, please feel free to contact me or my supervisor as per the details below. Any queries regarding ethical issues can also be directed to: The University of the Witwatersrand Human Research Ethics Committee (non-medical): 011-717-1408; Shaun.Schoeman@wits.ac.za.

Yours sincerely,

Jenna Fernandes (Researcher)

Email: 1616073@students.wits.ac.za

Cell: XXX XXX XXXX

Professor Zaytoon Amod (Supervisor)

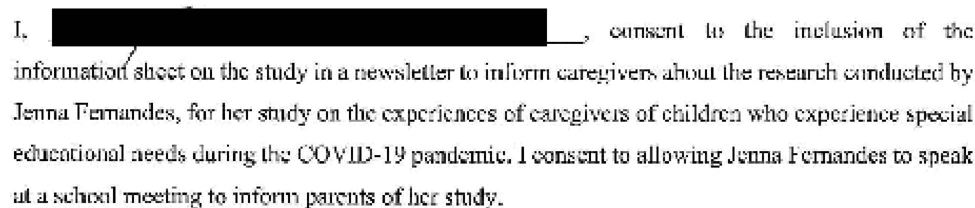
Email: Zaytoon.Amod@wits.ac.za

Tel: 011 717 8326

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT
PSYCHOLOGY

Permission Letter

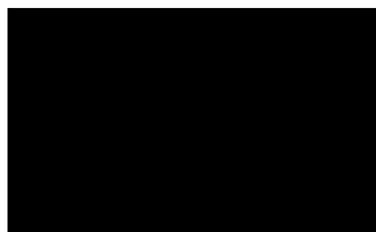


I, ____________________, consent to the inclusion of the information sheet on the study in a newsletter to inform caregivers about the research conducted by Jenna Fernandes, for her study on the experiences of caregivers of children who experience special educational needs during the COVID-19 pandemic. I consent to allowing Jenna Fernandes to speak at a school meeting to inform parents of her study.

Signed:

Dates: 04/05/2022

School Stamp



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Appendix B: Ethical Clearance

SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT ETHICS COMMITTEE
CONSTITUTED UNDER THE UNIVERSITY HUMAN RESEARCH ETHICS COMMITTEE (NON-MEDICAL)

CLEARANCE CERTIFICATE: **PROTOCOL NUMBER: MEDPSYC/22/01**

PROJECT TITLE: COVID-19 and children experiencing special education needs: Caregivers' experiences, coping strategies and support needs

INVESTIGATOR Fernandes Jenna (1616073)

SCHOOL/DEPARTMENT OF INVESTIGATOR SHCD/Psychology

DATE CONSIDERED 26 April 2022

DECISION OF THE COMMITTEE Approved unconditionally

RISK LEVEL Low Risk

EXPIRY DATE 31 December 2024

ISSUE DATE OF CERTIFICATE 14 June 2022 **CHAIRPERSON** __Z. AMOD__________
(Prof. Zaytoon Amod)

cc: Prof. Zaytoon Amod (Supervisor)

DECLARATION OF INVESTIGATOR

To be completed in duplicate and **ONE COPY** returned to the Chairperson of the School/Department ethics committee.

I fully understand the conditions under which I am are authorized to carry out the abovementioned research and I guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee.

________________________ **Signature** **Date** _____/_____/_____

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES

Appendix C: Short Poster

COVID-19 and children experiencing special education needs: Caregivers' experiences, coping strategies and support needs

Raising a child who experiences special education needs is a unique experience for each caregiver and family, especially in light of the COVID-19 pandemic. Caregivers can share valuable insight into the realities of what it is like to raise a child who experiences special educational needs during the pandemic.

If you are a caregiver of a child who experiences special education needs, researchers at the University of the Witwatersrand are looking to hear your experiences.

To take part in the study you need to:

1. Be a parent/caregiver of a child who experiences special educational needs
2. Have a child who is diagnosed with special education needs
3. Be willing to share your experiences

Understanding your experiences of raising a child who experiences special educational needs during the pandemic, could further assist in the exploration of how to support caregivers and children who experience special education needs more holistically.

If you are interested in sharing your journey with us or have any questions, please contact:

Jenna Fernandes (Researcher)
Email: 1616073@students.wits.ac.za
Cell: XXX XXX XXXX

Professor Zaytoon Amod (Supervisor)
Email: Zaytoon.Amod@wits.ac.za
Tel: 011 717 8326

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Appendix D: Participation Information Sheet

Dear Sir/Madam,

Project title: COVID-19 and children experiencing special education needs: Caregivers' experiences, coping strategies and support needs.

Good day,

I am currently completing my Masters in Educational Psychology at the University of the Witwatersrand. As part of this degree, I am conducting a qualitative research project through individual interviews with caregivers of children who experience special education needs. This project aims to gain insight into the caregivers' experiences of raising a child who experiences special education needs during the COVID-19 pandemic, the ways in which they coped and the type of support they had and might still require. It is important to gain insights from caregivers of children who experience special education needs as this information can be used to inform and better support caregivers, provide insight to assist mental health care workers, and further the development of programmes and support services for families.

I would like to formally invite you to take part in my research study. This will involve you taking part in an interview with me to discuss your experiences around the topic mentioned above. The interview will last for approximately 45-60 minutes, and it will be conducted at a place and time that is most convenient for you. Participation in the research is completely voluntary. Taking part in the interview will not advantage or disadvantage you or others in any way and there are no perceived risks in participation. You are not obliged to answer all the interview questions. You have the right to withdraw from this study at any time without any consequences. Should the questions make you feel emotional or cause any distress, you will be provided with access to free telephonic counselling through the South African Depression and Anxiety Group (SADAG). Alternatively, face-to-face counselling can be sought at the Johannesburg Parent and Child Counselling Centre (JPCCC):

SADAG Details:	JPCC Details:
Tel: 011 234 4837	Tel: 011 484 1734
WhatsApp: 076 882 2775	Email: gaby@jpccc.org.za

For analysis purposes and with your consent, the interview will be audio-recorded or video-recorded, if online. Only my supervisor and I will have access to these tapes which will be safely stored and protected. Once the information of the interview has been transcribed verbatim, the

tapes and transcripts will be password protected and stored on a password-protected laptop. Notably, this data will be destroyed 5 years after the research has been conducted.

Care will be taken to protect your identity and the nature of your contribution. To ensure your anonymity, pseudonyms will be used so that you are not identified. Additionally, the name of the school will also not be shared in my research report. Only the researcher will have access to this information. Confidentiality will be maintained by not disclosing any of your personal information in my results or the final research report. Although direct quotes from the interview will be used in the final report, I will ensure there are no distinct identifying factors that can be linked to you.

Once the study has been completed, in March 2023, you may request a summary of the study and the findings if you wish. This can be emailed to you by either myself or my supervisor. Our contact details are provided at the end of this letter.

Before the interview takes place, I will ask you to read through and understand the consent forms. For online interviews, the consent form will be emailed to you, and you can email a signed copy back. These forms will confirm that you understand what is required of you and the confidentiality of the study. If you have any questions or concerns about the study or wish to report any problems you have experienced related to the study, please feel free to contact me or my supervisor. Any queries regarding ethical issues can also be directed to: The University of the Witwatersrand Human Research Ethics Committee (non-medical): 011-717-1408; Shaun.Schoeman@wits.ac.za.

Best wishes,

Jenna Fernandes (Researcher)

Email: 1616073@students.wits.ac.za

Cell: XXX XXX XXXX

Professor Zaytoon Amod (Supervisor)

Email: Zaytoon.Amod@wits.ac.za

Tel: 011 717 8326

Appendix E: Informed Consent

Informed Consent Form

I, ____, agree to participate and be interviewed, either face-to-face or on an online platform, and audio- or video-recorded respectively, for the research project of Jenna Fernandes on caregivers' experiences of raising a child who experiences special education needs during the COVID-19 pandemic.

I agree to and understand that (please tick ✓ each box provided to indicate agreement)

☐ My participation in this study is completely voluntary and I will not be advantaged or disadvantaged in any way by choosing to participate or not.

☐ I may elect to not answer any specific questions asked if I do not wish to do so.

☐ There are no foreseeable risks or benefits associated with participation in this study.

☐ My identity will be kept strictly confidential, and any information that may directly identify me will be removed from the interview transcript. If I am referred to it will be using a pseudonym.

☐ A copy of my interview transcript, with all information that may directly identify me removed, will be stored safely and permanently, and may be used for future research and if the research is published in a journal article or conference paper.

☐ I can withdraw from the interview at any time and can at any time request that my response not be included in the study.

☐ I will be asked for permission to audio-record or, if online video-record, my interview as per the conditions outlined below.

☐ The recording will be stored in a secure location with restricted access (either a locked cupboard or password-protected computer) and will only be accessible to the researcher and her supervisor.

☐ The recording will be transcribed by the researcher and any information that could directly identify me will be removed.

☐ Once the analysis of the data and write-up is complete, the audio recording, or video recording, of the interview will be stored as a password-protected file and on a password-

protected laptop. The transcript, with all information that could directly identify me removed, will be stored safely and permanently, and may be used in future research and if the research is published in a journal article or conference paper.

☐ Direct Quotes from my interview, with any information that could directly identify me removed, may be cited in the research report or other write-ups of the research. If I am referred to it will be using a pseudonym.

I do hereby consent to be interviewed, either online or face-to-face for the research project	Yes	No
I do hereby consent to be interviewed for the research project and for my interview to be audio recorded, or video recorded	Yes	No

Signed: ___________________________ (signature of participant)

Date: _____________________________

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Appendix F: Interview Schedule

SEMI-STRUCTURED INTERVIEW SCHEDULE

Part 1: Demographic Information

This information is for research purposes only and will be kept strictly confidential.

Participant's Pseudonym: ______________________________

Child's Pseudonym: ______________________________

Information about your child.

1. Gender: Male ☐ Female ☐
2. Age: ________
3. Nature of child's special education needs:

   ____

   ____

   (Diagnosis received, specific learning difficulty, mental difficulties, behavioural difficulties, emotional difficulties, sensory difficulties, physical disabilities)
4. How did you learn about your child's diagnosis?

   ____

   ____

   (Psychologist, psychological assessment, or other methods)
5. When was your child diagnosed as experiencing special education needs?

   ____
6. How long has your child been at his or her current school?

   ____
7. What type of school did your child previously attend?

   ____
8. How many siblings does your child have?

   ____

Information about the caregiver.

1. Gender: Male ☐ Female ☐ Non-binary ☐
2. Age Range: 20-29 ☐ 30-39 ☐ 40-49 ☐ 50-59 ☐ 60+ ☐

3. Marital status: Single ☐ Married ☐ Divorced ☐ Widowed ☐

4. Race: Black ☐ Coloured ☐ Indian ☐ White ☐
   Other: ________________

5. What is your highest qualification?

   ____

6. What is your occupation?

   ____

Part 2: Interview Questions

The following questions will be asked during the interviews with participants.
All the main questions are in bold while probing questions are phrased as sub-questions.

1. **What are some of the experiences that you have had with caring for a child who experiences special educational needs during the pandemic?**
   - Could you share if there are some positive experiences that you have encountered in relation to your child's learning and functioning during the pandemic?
   - Please describe some of the more difficult experiences that you have encountered during the pandemic that may have affected your child's learning and functioning.

2. **Can you explain what are the factors that contributed to the challenges that you experienced in relation to your child during the pandemic?**
   [This question will be asked if applicable, depending on the participant's response to Question 1]

3. **Could you describe the strategies that you have used to cope with the demands of meeting the special education needs of your child during the pandemic?**
   - What personal coping strategies have you employed to cope with these demands?
   (For example, liaising with the teacher or principal, using a home support programme, drawing support from other parents, family support, online professional support, social media)
   - How do you cope with these demands now?

4. **What are some of the current support structures that are available to you, as a caregiver with a child who experiences special education needs?**

   - What makes these structures useful to you and how do they support you?

5. **What type of support, if any, would you have liked to receive since the start of the pandemic?**

   - Share if there is any support that you still need.

6. **Please feel free to add any other comments that you would like to add regarding the topic of raising a child who experiences special education needs during the COVID-19 pandemic.**

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