RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

TOGETHERNESS, CARE AND EXCLUSION: ADOLESCENTS' EXPERIENCES OF LIVING WITH A DISABLED SIBLING IN A SOUTH AFRICAN CONTEXT

A thesis submitted in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY
IN PSYCHOLOGY

at

RHODES UNIVERSITY

by

TAMMY FOOTE

Supervisor: Professor Lisa Saville Young
February 2024

DECLARATION

I declare that this thesis hereby submitted by me for the degree of PhD in Psychology at Rhodes University has not been submitted to any other university and is my own original work. Each significant contribution to, and quotation in, this thesis from the work, or works of other people has been attributed and has been cited and referenced.

Signature: ______ ____________________

Date: ____7 February 2024_____________________

ABSTRACT

The importance of the sibling relationship in an individual's life has been established, and various aspects of siblingship have been studied. Recently researchers have begun to explore what it means to be a sibling and how siblingship is embodied. Where disability is present in the siblingship, however, there is very little literature, particularly in the Global South.

This cross-cultural, cross-language, Interpretative Phenomenological study explores how *isiXhosa* speaking adolescent non-disabled people, living in a socio-economically disadvantaged context in South Africa, experience their lives in relation to their disabled sibling. Through the use of semi-structured interviews and photo-production with 9 isi-xhosa speaking adolescents from a disadvantaged socio-economic context in South Africa, three master themes emerged. Firstly, non-disabled siblings (NDSs) experienced togetherness in their relationships with their disabled brothers/sisters. In their experiences of togetherness, where reciprocity was prominent, they felt a sense of we-ness. In these instances, disability did not play a central role in their relationships. Secondly, NDSs living in disadvantaged socio-economic contexts experienced care in different ways. Some experienced wanting to care and some experienced having to care for their disabled brother or sister. Where care was voluntary it was experienced as an act of love, contributing to their self-esteem or a family value. Where care was experienced as obligatory, NDSs felt lonely and unsupported, and this contributed to ambivalent feelings toward their disabled sibling. Finally, NDSs experienced themselves as outsiders. Experiences of being an outsider sometimes occurred because of their socio-economic status, and sometimes because of experienced stigma related to their sibling's disability. In both instances this contributed to feelings of inadequacy and exclusion. To overcome these feelings, NDSs focused on becoming successful, wealthy or famous.

These findings have important implications in terms of how NDSs may be supported. Furthermore, this study has important methodological implications for using Interpretative Phenomenological Analysis in a cross-cultural, cross-language context.

ACKNOWLEDGEMENTS

I would firstly like to acknowledge the nine adolescents who gave of their time and hearts for this study, I see you, I hear you and I thank you!

Thank you also to APD for all your assistance as gatekeepers, because of you my hard-to-reach population became accessible.

To Professor Lisa Saville Young, my supervisor, your knowledge, guidance, understanding, patience, humour and motivation have been invaluable. Thank you for your ongoing willingness to supervise this research amidst the changes that have occurred in both our lives over the years.

I am eternally grateful to Zuki Gubevu, my interpreter, friend, *sisi,* I think we could write a book on the adventures of my data collection process! Thank you for enduring grandad's temperamental car, the many Friday night break downs, you have a knack for turning what could feel like a disastrous situation into fun. More importantly however, thank you for your very precious time and investment in this project. For all your generous contributions, cultural insights and interpersonal finesse, this project is largely what it is, because of you.

I would like to express my gratitude to Jaqueline Gamble, thank you for tackling this thesis with your editorial prowess (and being gentle about my self-acknowledged limitations).

To my little family, Rob and Kai, thank you for your understanding and support while I have been so intensely preoccupied with this mammoth task for so very long. Thank you for trying to play ping-pong quietly, for the snacks and for tolerating my very audible groans of frustration, "the distress call of the PhD student", you have been the best team I could have hoped for.

Finally, to Kim, what an honour it is being your "Tammy-sister", thank you for loving me like you do, your big heart inspires me every day.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

ABBREVIATIONS AND ACRONYMS

American Psychological Association	APA
Association for Persons with Physical Disabilities	APD
Autistic Spectrum Disorder	ASD
Childhood Disability Studies	CDS
Confirmatory Factor Analysis	CFA
Critical Disability Studies	CDS
Down Syndrome	DS
Group Experiential Theme	GET
Interpretative Phenomenological Analysis	IPA
Nonprofit Organisation	NPO
Non-Disabled Sibling	NDS
Social Auxillary Worker	SAW
Socio-Economic Status	SES
United Kingdom	UK
United Nations	UN
World Health Organization	WHO

CHAPTER ONE

INTRODUCTION

1.1 Sibling Relationships and Disability

This study explores the experiences of non-disabled adolescents, living in disadvantaged socio-economic contexts, in relation to their disabled siblings. Siblings typically remain connected to one another from birth until death (Lanthier & Campbell, 2011). Where the relationship may change across the lifespan, the intensity and longevity of this unique relationship means that it plays a central role across a number of life areas. The study of siblingship has largely had a psychological and sociological focus (Meltzer, 2015). Woodrow (2007) has succinctly noted that, in early psychological literature,

> the sibling is usually seen primarily as a rival for the mother's attention and affection (Freud), as an opponent to be overcome (Adler), or as a substitute attachment figure and "care-giving other" (Bowlby) largely as a result of "failed dependency" and deficient early "holding" (Winnicott, 1960/1990) experiences in the mother-infant relationship. (p. 15)

Subsequent psychological research has shifted focus to the developmental outcomes of siblingship, indicating that siblings influence the development of their brothers and sisters in various ways (McHale et al., 2012). It has been argued that structural factors of the relationship, such as the number of siblings, age, birth order and gender composition, will impact on a young person's psychological well-being and social adjustment (Howe et al., 2018; Lawson & Mace, 2010). Sociological research has documented the impact of siblings on the operation of families as social and socialising systems (McHale et al., 2012). In essence, it has been recognised across widely differing cultures that young people learn a significant amount from their siblings, about being responsible and being in the world, through day-to-day interactions, shared jokes, playing tricks on and arguing with each other (Brody & Murry, 2001; Rabain-Jamin et al., 2003).

Conflict and rivalry have been documented as being a normal part of the sibling relationship and will determine how much time siblings spend together (Noller, 2005). Edwards et al. (2006) note that siblings often provide support to each other that other family members may not be able to provide, and siblingship contributes holistically to one's self-identity. Further, Guan and Fulgini (2016) note that siblings are often major sources of companionship and intimacy during transitions to adulthood.

There is also a slowly growing body of literature which has considered how siblingship is enacted and how various phenomenon are embodied[1] within the sibling relationship. For example, Zukow (1989) has considered the extent to which siblings embody the role of socialising agent in various cultures. Edwards et al. (2006) have argued that siblings demonstrate how they embody gender through "talking" and "doing activities together".

Furthermore, how siblings assign meaning to their relationships has become a focal point within the literature. Edwards et al. (2006) have argued that being a sibling is a subjective experience and will therefore have different meanings for all young people. Ethnicity, social class, gender, age and birth order are all factors that will contribute to how siblings interact and make meaning of their relationships, as well as who they are as individuals in relation to others and their environment (Edwards et al., 2006).

In addition to biographical and contextual factors, frequently occurring circumstances such as a brother/sister having a chronic illness or disability may also contribute to how siblingship is subjectively experienced (Knecht, Hellmers & Metzing, 2015). The prevalence of disabled children in the world (10.1% of young people aged 1 to 17 years according to UNICEF) is notably high, and

---

[1] An embodied perspective purports that all bodies tell stories about the context in which they exist and cannot be understood as existing in isolation. The stories bodies tell reflect what people think, feel and say, and often bodies offer insight into aspects of a person's life world that they are unable or unwilling to disclose (Krieger, 2005).

therefore not uncommon, however, the way in which disability contributes to meaning-making between young siblings is largely unknown. To this extent, the current study aims to understand, through their subjectivities, how non-disabled siblings make meaning of their siblings' embodied disability, and thereby respond to the aforementioned gap in sibling literature.

That, however, is not to say that NDSs have been ignored by scholars. Research on NDSs dates back to the early 20th century and was born of institutionalisation and deinstitutionalisation where, for a period in history, disabled children were institutionalised (Meltzer & Kramer, 2016). When institutionalisation was dismantled, many families had to adjust anew to having disabled children living at home. Research focussed on the assumed challenges experienced by families of disabled children living at home. Specifically, it was determined that the presence of a disabled child at home would place significant demands on parental capacity, and NDSs would be the victims of neglect, isolation, trauma, stigma and shame (Castles, 2004; Jones, 2004). Much of the previous research that has considered disability within the sibling relationship has taken place in the Global North and has focused on the impact of having a disabled brother/sister on a young person's psychological well-being, developmental, behavioural and relational outcomes. The current research aims to further elaborate on what is known about NDSs living in socio-economically disadvantaged contexts in the Global South, by exploring how they experience their lives in relation to their disabled siblings.

Several important components, which comprise the overall topic, require defining. Given my emphasis on **non-disabled** siblings (NDSs) in relation to their **disabled** brothers/sisters, providing a definition of "disability" is imperative. This research, however, also explores **adolescents' sibling relationships**, and the context in which their experiences occur, which, in this case, is **socio-economically disadvantaged.** The socio-economically disadvantaged context I have chosen to focus on is in a semi-rural location, populated by ***AmaXhosa*** (people from the Xhosa **culture**) in South Africa, from the **Global South**. In this chapter, I describe the focus and aims of the study, thereafter, defining each of the bolded terms above, which are key concepts in this study. It is important to recognise that each bolded term interacts or intersects with the others; they do not occur in isolation. The experiences I aim to understand are made up of experiences and understandings of disability, adolescence as a developmental stage, sibling relationships, socio-economic context and culture.

1.2 Focus and Aims of the Study

This study investigates the experiences of adolescent NDSs living in disadvantaged socio-economic contexts. I have located this research within the field of Childhood Disability Studies (CDS), a sub-field of Disability Studies. Disability Studies is described as an:

> interdisciplinary field of inquiry that includes representation from the social sciences, the humanities, and the medical, rehabilitation, and education professions … and may be understood as the theoretical and research arm of the disability rights movement that has aimed to challenge how society thinks about disabled people. (Berger & Wilbers, 2021, p. 3)

In turn, CDS have largely assumed the same stance as broader Disability Studies, however, several important inclusions have been made by critical enquirers, these being important to note. One particular factor that has significantly impacted research and theorising on disabled children is the argument for disregarding notions that conceptualise children as passive participants and objects of welfare, urging for the inclusion of children's voices in research (Colver, 2005; Watson, 2012). It has additionally been highlighted that many of the perspectives of childhood disability (drawn from broader disability perspectives) were conceptualised for adults and may therefore ignore important discrepancies between adult and childhood experiences and fail to account for the rapid changes that occur within childhood development (Watson, 2012).

Within the field of CDS, I am assuming a psychological viewpoint. I have already briefly noted some of psychology's contributions to the study of NDSs, where the focus has predominantly been to measure the impact of having a disabled brother/sister on a young person, highlighting the gap in the literature pertaining to adolescents' experiences of being a NDS. It is my intention to explore how adolescents think and feel about being a NDS within their daily lives, or what their lived experiences of having a disabled brother or sister are. The emphasis on lived experience and hearing the subjective accounts of NDSs lends itself to a phenomenological approach. Phenomenological approaches have previously been utilised both in psychology (Langridge, 2007; Smith, 1996) and other related disciplines, such as psychoanalysis (Stolorow & Atwood, 1984) and sociology (Giddens, 1976). By assuming a psychological view, with a phenomenological approach, I aim to contribute first-hand, subjective accounts from adolescents about their experiences of being a NDS in the Global South. Methods that employ first-hand interviews, like the current study, enable the researcher to obtain a youth-centred perspective, as opposed to relying on adult perspectives to understand young people (Cheney, 2011; Cortis et al., 2009; Montgomery, 2009). However, the method employed required adaptation for appropriate use with young people, while also appreciating that the participants are not first language English speakers and are from a different cultural background to the researcher. In this respect, the study contributes to thinking about using Interpretative Phenomenological Analysis (IPA) in cross-cultural, cross-language[2] studies that include youth.

Given the particularity of the sample, from the outset it was evident that my research would not make claims that can be conflated to group level, or general laws about human behaviour (Smith et al., 2009). Rather, by obtaining small scale in-depth insights in relation to a broader context of knowledge, it aims to give "a human face to statistical data" (Visagie, 2015, p. 6). The knowledge gained from this research contributes to a more comprehensive representation of the lives of adolescent NDSs living in socio-economically disadvantaged contexts in the Global South, and thus to better understand their needs.

---

[2] The term "cross-language" research is utilised to describe research that uses a translator or interpreter, where the researcher and participants may speak different languages (Temple, 2002). Cross-cultural research, refers to research in which the researchers and participants are members of distinct cultural communities (Miklavcic and LeBlanc 2014)

1.3 Defining Disability within Disability Studies

The predominant 20th century view of disability from a medicalised perspective, which came to be known as the medical model, framed disability as the “physiological, psychological, and functional pathologies originating in the bodies of individuals” (Longmore, 2003, p. 1). Although, the intention of those assuming a medicalised view of disability was arguably to provide care, the emphasis on fixing, curing and remedying implied a clear distinction between “normal” people and “abnormal” people (those unable to participate in normal activities) (Beauchamp-Pryor, 2011; Thomas, 2002; Watermeyer & Swartz, 2008).

The exclusion of disabled people from work and society during the era of industrialisation only served to reinforce normal/abnormal framing of disabled people, where they were increasingly seen as a social problem (Beauchamp-Pryor, 2011, 2013). During the 1960s and 1970s, disabled academics and activists in Britain began to challenge the medical model’s perspective of disability. These academics and activists argued that disability was not simply about impairments, but also social exclusion (Watermeyer & Swartz, 2008; Thomas, 2002). Later, in the early 1980s, Mike Oliver formally presented the Social Model of disability (Oliver, 1990; Roulstone et al., 2012). The Social Model’s definition stated that disability was “the loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on an equal level with others due to physical and social barriers” (Finkelstein & French, 1993, p. 27).

For a time, both the medical and social models continued to be largely dominant (Oliver, 2018; Symeonidou & Beauchamp-Pryor, 2013). More recently, however, researchers have come to acknowledge that disability should be considered as a multidimensional phenomenon (Martiny, 2015). The social relational model, for example, contributed the perspective that “people are disabled both by social barriers and by their bodies” (Shakespeare & Watson, 2001, p. 17), and disability is rooted in unequal social relationships, like racism[3] or sexism (gender-based discrimination) that in turn manifest as a “barrier to being” (Thomas, 1999). The social-relational model defines disability as “a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing” (Thomas, 1999, p. 60). That is, it should be recognised that impairments may cause a certain amount of limitation, however, this does not in itself constitute a “disability” (Thomas, 2010). In turn, Thomas (2004) conceptualises disability as the relationship between people who are socially constructed as being different to the norm (because of a bodily/cognitive impairment) and people who embody normality. The UN Convention on the Rights of People with Disabilities (CRPD) (2007) defines disability as “long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder full and effective participation in society on an equal basis with others” (p. 5). It is evident from this definition, largely in accordance with Thomas’ (1999) social relational model of disability, that disability is no longer seen merely as a medical diagnosis, but increasingly encompasses functional, social, psychological and environmental aspects that include a person’s ability to access and interact with their community.

Defining disability continues to be an ongoing debate in disability scholarship (Draper, 2018; Flink, 2019; Shakespeare, 2006). Specifically, there is a concern regarding whether or not to use “person-first” or “identity-first” language to describe people experiencing impairments. Whereas person-first terminology (“persons with disabilities”) forefronts personhood, disability-first (“disabled person”) terminology is said to locate a person as disabled by society. Some disability advocates contest that person-first language is unrealistic and unhelpful given individuals cannot be separated from their disability (Collier, 2012). Based on this argument, it has been suggested that disability

---

[3] According to Omi and Winant, (2020) race has historically been a term used to define biological differences between people, which include physical features (such as skin colour). The social sciences have, however, rejected biological notions in favour of a socio-historical construction that categorises individuals based on shared social practices. The authors, however, purport an understanding of race as “an unstable and *decentred* complex of social meanings constantly being transformed by political struggle” (Omi & Winant, 2020, p. 15, original emphasis).

scholars employ identity-first language. It is however, recommended that identity-first language take place alongside person-first constructions of disability in order to “address the concerns of disability groups while promoting human dignity and maintaining scientific and professional rigour” (Dunn & Andrews, 2015, p. 255). Furthermore, using identity-first language, such as “disabled people”, has been said “to highlight disability as an affirmative identity, not something to be ashamed of, that identifies the common cause of a particular political constituency” (Berger & Wilbers, 2021, p. 5). Use of the term disability has in itself been considered problematic, in that it groups people with little in common, other than that they may function differently to those labelled as normal (Shakespeare, 1998). Dalvit (2022) highlights how this is problematic by relating it to the term “non-White” used in Apartheid South Africa. He emphasises:

> Such an issue does not seem to arise in the nine official indigenous South African languages, spoken by the vast majority of the population. In isiXhosa, for example, the term for disability (*isidalwa*) could loosely be translated as “he/she who is created” and people with disabilities (*abantu abakubazekileyo*) as a term, does not have any immediate semantic association with ability. Nevertheless, the definition of disability in the South African institutional context reflects Western conceptions. (p. 304)

In my choice of terminology for this thesis, I acknowledge that use of the term “disability” presupposes divergency from the norm, while simultaneously denying other important attributes that make up a person’s lived experience. I am, however, left with the challenge of providing a way to refer to a very particular phenomenon that will be examined in this research. For this reason, and because a consideration of social, political and environmental contexts is important for this study, I continue to use the term “disability” from the social model’s perspective. That is, from a disability-first perspective, which emphasises that a person is always circumscribed by society, and people are regarded as being disabled through discriminatory societal practices (Lourens & Swartz, 2016). I use the terms “disabled people”, “disabled siblings” and “non-disabled sibling” (NDS).

While I will be using the term disability as it is understood from a social perspective of disability, I recognise what Smith et al. (2009) refer to as “social constructionism’s [in]ability to deliver an adequate account of the body, that is one that recognizes its experiential, social and political primacy” (p. 198). I am particularly interested in the experience of disability, or more specifically, NDSs’ experiences of their sibling’s disability, that is, “how they live with their [sibling’s] body/mind, and how their experience of their [sibling’s] body/mind informs how they talk or communicate, act or interact, and in how they build and express relations with others” (Meltzer, 2017, p. 1017). In essence, I am referring to the embodiment and enactment of disability. Embodiment and enactment are concepts that originally stem from phenomenological theory (Merleau-Ponty, 1945, as cited in Meltzer, 2017). Assuming a perspective that views disability as embodied and enacted allows me to prioritise the lived experience of disability, which does not reduce the understanding of disability as referring only to functional impairment but recognises the experience of functional impairment as it transpires between people who live in a dynamic context comprising of their physical and cultural worlds (Meltzer, 2017; Smith et al., 2009).

While providing an account of how I refer to disability throughout this research, this is an IPA study, where the emphasis is on the participant’s subjective accounts of their lived experience. Therefore, respect is given (where appropriate) to various self-ascriptions irrespective of whether they are shaped by biology or society (Lourens, 2015). To this extent, when discussing the participants’ experiences of their sibling’s embodied disability, I will use the terms and phrases chosen by them as these are reflective of how they understand and make meaning of disability.

1.4 Disability Studies in the Global South

According to Martins (2020), a singular, universally agreed upon definition of the terms “Global South” and “Global North” does not exist, however, the term “Global South” generally refers to a "broad grouping of countries and people that experience economic marginalisation within the global system and have elements of a shared history of colonisation and exploitation.… The global North refers to countries and people traditionally referred to as 'the West'" (p. 151). Global South is a term given to the largest portion of the world's population (the majority world), to nations who are economically impoverished, largely due to colonialism, capitalism and war (Shome, 2019). It is therefore not necessarily a geographic reference to one part of a hemispheric split. In fact, many counties in the Global South are in the northern hemisphere, e.g., India and the northern parts of Africa. The Global North include countries who advance capitalism and hold geopolitical power (Shome, 2019); as such, the Global South exists and is maintained by the rich Global North (Goodley et al., 2012)

Meekosha (2008) highlights that while the Global North holds power over the Global South in terms of economy and resources, the provocation of violence and war from the Global North on the South, in battles over the control of resources (mineral and oil, for example), is seldom considered. This is, however, an important issue in conversations about disability, where much disability in the Global South "is produced" either directly or indirectly by said violent provocations from the Global North (Meekosha, 2008, p. 2).

Distinctions between the Global North and South do not, however, refer only to imbalances in wealth, power, population size and an exploitative history, but have increasingly become the standard vocabulary of academics and activists in an attempt to re-orient knowledge production, validate knowledge and practices from the Global South, and give voice to those previously marginalised (Müller, 2020). This recent shift in academic focus is important in challenging what Meekosha (2008) refers to as "the northerness of disability theory" where scholars from the Global North have tended to claim universal relevance of their knowledge generation, while "excluding" and "erasing" studies from the Global South (p. 4). The exclusion of perspectives of disability from the Global South, and Africa in particular, is problematic when we consider that the majority of disabled people in the world reside in the Global South, and 20% of the population in Africa are disabled (Nyangweso, 2018; Swartz & Marchetti-Mercer, 2018).

Where perspectives of disability, primarily stemming from the Global North, make general claims about disability, the difficult realities of disabled people in Africa are ignored (Connell, 2011). In addition, Connell (2011) emphasises that many of the key debates that have occurred are irrelevant to people whose primary focus is on survival (although poverty is also prevalent in the Global North and many people in the Global South are not financially constrained), due to lack of basic material resources and access to necessary amenities. Finally, excluding African perspectives from the body of global knowledge means that theories, that are frequently applied universally, cannot adequately build on, or be formulated from knowledge systems originating in the Global South. To this degree, research from Africa and the Global South (such as the current study) are important in that they contribute to the decolonisation of knowledge.

Researchers have critiqued the tendency to depict Africa as primitive, superstitious and abusive toward disabled people (Swartz & Marchetti-Mercer, 2018) or as all caring and all accepting of disabled people (Swartz & Marchetti-Mercer, 2018). Results of these perceptions may inhibit active efforts to challenge the possible presence of stigmatisation and perpetuate an oppressive stance to disabled people in Africa. There has been an argument (Grech, 2009, 2011, 2015) for relevant and applicable approaches with which to conceptualise disability in the Global South. A relevant approach to disability in Africa should include African epistemologies and consider the social and cultural legacy of (including but not limited to) urbanisation, colonialism and Apartheid (in South Africa) that have contributed to current conceptualisations and experiences of disability (Berghs, 2017; Grech, 2012; Livingston, 2006; Meekosha, 2011; Ned, 2022; Nyangweso, 2018; Sefotho, 2021). By utilising a phenomenological approach in this research, the participants' perspectives on their lived experiences (which may be informed by South Africa's social and cultural legacy) are fore fronted.

The negation of collectivist belief systems in the conceptualisation of disability models that have historically been applied to Africa, has also received the prominent criticism and consideration of several scholars (Berghs, 2017; Chataika et al., 2015; Livingston, 2008). For example, research conducted in Africa should consider the principles of *Ubuntu*[4], which is an African world view that emphasises shared collective humanness and responsibility, purporting the belief "I am, because we are" (Mbiti, 1990). It centralises human dignity and participation within family and community (Chataika & McKenzie, 2013). According to Berghs (2017), an *ubuntu* perspective of disability purports that:

> Impairment becomes cognitive, sensory, mental, physical and spiritual diversity that can have a multitude of shared meanings that society, as human collective, constantly make together. Ubuntu can change over time and recognises the difference of experiences of diversity of humanness as positive and negative, which are part of our shared humanity. (p. 2)

Berghs (2017) impresses that through the space provided by *ubuntu,* discourses aimed at dismantling oppressive colonialist and disabling practices and legacies can be achieved. This phenomenological study shares similar aims as those purported by *ubuntu* in that it recognises that participants may have diverse experiences of disability that change over time, and the meaning they have attached to their experiences can be collectively created with others in their specific context. A phenomenological approach also acknowledges the importance of highlighting subjectivity when understanding an individual's experiences, and emphasis on subjective accounts is also a prominent aspect of CDS, discussed in the next section.

---

[4] [4] *Ubuntu* is an African world view that emphasises shared collective humanness and responsibility, purporting the belief, "*I am, because we are*" (Mbiti, 1990).

1.5 Childhood Disability Studies (CDS)

Drawing from Disability Studies, CDS aims to shift the focus from a Eurocentric, medical discourse that views disabled children as having, or being, problems, to having childhoods (Curran & Runswick-Cole, 2014). It is, however, argued that CDS be a distinct approach in its efforts to prioritise the voices and experiences of children, to take into consideration that disabled children's lived experiences are more than those concerned with disability and inequality, while challenging the conceptualisation of disabled children, in a global context, as being other than normal. This means thinking differently about their relationships with their families, caregivers and communities and taking into consideration the various cultural practices to which they adhere:

> Disabled children's childhood studies are written by disabled children and young people, disabled scholars and activists reflecting on their childhoods, as well as parents/carers of disabled children, allies and academics listening directly to disabled children and young people's voices. (Curran & Runswick-Cole, 2014, p. 2)

To this extent, the current phenomenological research (by a NDS) adds the voices of adolescent NDSs on their subjective experiences of their brother/sister's embodied disability and how this is enacted through their relationships in their daily lives together. The voices of NDSs are of importance in that they too live with disability on a day-to-day basis, however, there is an acknowledgment that their experiences may be different to those of their brothers/sisters in that embodied disability is experienced within their relationship with their disabled sibling.

Curran and Runswick-Cole (2014) further emphasise that, just as Childhood Disability draws from childhood studies and disability studies, it can similarly contribute to both fields, by adding the voices and experiences of disabled children. CDS can be useful in how all children's lives (disabled and non-disabled) are considered. I contend that the voices of adolescent NDSs, who are in essence young people living with disability, can similarly contribute to knowledge on childhood disability, by adding their own, unique sense of what embodied disability means to them.

It is noted that in the literature about disabled children, where siblings are mentioned, this usually refers to siblings of disabled children, however, it is rarely considered that disabled children contribute as siblings to their non-disabled brothers' and sister's lives (Curran & Runswick-Cole, 2014). While the current research follows suit to some extent in that its focus is on the experiences of NDSs, by using a phenomenological approach to understanding NDSs' life worlds in relation to their disabled brothers/sisters, space is created for participants to discuss how they experience their disabled brothers/sisters as contributing to their lives, as siblings. As such, in addition to contributing to Childhood and Disability studies, this research can contribute to sibling studies by adding the voices of adolescent NDSs' experiences of their sibling's embodied disability and how this contributes to how they do siblingship together.

Curran and Runswick-Cole (2014) state that children's embodied disability in the Global North has historically contributed to concerns about disabled children's futures, however, it is anticipated that a non-disabled child should "achieve autonomy as a disembodied intellectual or to be a body perfect performer" (p. 23). In essence, this distinct difference in what is expected of young people, where disability is either present or not, firstly, perpetuates the perspective of disabled children as passive and vulnerable, and secondly, sets up a very specific trajectory of possible experienced expectation and pressure of success for young NDSs without taking their particular circumstances into consideration. The fact that evidence on the experiences of young NDSs is predominantly from the Global North means that there is no clear sense of whether these problematic, opposing expectations of young people living with disability is prevalent in the Global South, or what this may mean for young NDSs who might be limited in other ways, for example, by their socio-economic status (SES). CDS, however, critically challenges assumptions pertaining to the opposing perspectives on vulnerable disabled children versus active, entrepreneurial non-disabled children in recognising that all childhood experiences may be unique, and the presence of disability does not foretell what childhood experience will look like (Curran & Runswick-Cole, 2014).

Chataika and McKenzie (2013) acknowledge the importance of critical enquiry and perspectives of Childhood Disability from the Global North that encourage the participation of disabled children in society (Watson, 2012). It is, however, emphasised that the voices of children living with disability in the Global South are excluded, and their experiences are not framed within African epistemologies (Chataika & McKenzie, 2013). For example, in thinking about interpersonal experiences of children living with disability, including NDSs, recognising the foreign nature of the nuclear family and considering the broad, extended family as it prevails in many African contexts, is imperative (Chataika & McKenzie, 2013; Peters & Chimedza, 2000). Chataika and McKenzie (2013) highlight that the *ubuntu* principles of care and interdependence act in opposition to prevailing discourses pertaining to autonomy and individual human rights in the Global North. This directly impacts on the experiences of NDSs who may assume particular roles in their disabled sibling's lives, (for example, certain caregiving tasks) that are considered normative from a collectivist perspective but vary from assumptions pertaining to care in the Global North.

Chataika and McKenzie (2013) therefore argue for an African Childhood Disability perspective that is family centred, acknowledges the impact of colonisation on familial structures and how this effects the disabled child and their relatives (including siblings), and considers how the principles of *ubuntu* frame the needs and values in the Global South and how these might be different elsewhere in the world. To this extent, the current study pays heed to this call from Chataika and McKenzie (2013) in its aim to obtain first-hand, subjective accounts of young *isiXhosa* NDSs' experiences in relation to their disabled brother/sister. It is acknowledged that their experiences cannot be separated from their cultural values and their context, which is socio-economically disadvantaged (because of the impact of Apartheid and colonialism) and are therefore unique. The phenomenological emphasis in this research, however, dictates that while the aforementioned considerations are made, I am not imposing any theoretical leaning, but rather allowing the participants own meaning-making about their experiences to be brought to light.

1.6 The Poverty–Disability Nexus

The relationship between disability and poverty, how disability and poverty are bound together, mutually reinforcing one another, has become known as the poverty–disability nexus (World Health Organization and World Bank 2011, as cited in Grech, 2016). It has been noted that disabled people in poorly resourced areas are more disadvantaged than non-disabled people (Groce et al., 2011). Furthermore, disability is more prevalent among socio-economically disadvantaged South African populations (Ataguba et al., 2011). Arguments state that poverty largely increases vulnerability (Grech, 2011; Groce et al., 2011; Mitra et al., 2013; Vladeck, 2007), or may contribute to disablement due to a lack of access to education, healthcare, employment, income, social support and community involvement (Graham et al., 2020). Inadequate access to the aforementioned provisions in socio-economically disadvantaged contexts frequently results in family members of disabled people assuming responsibility for their needs (Hunt & Watermeyer, 2017). In some instances, this may become the NDS's responsibility.

In turn, disability has been said to contribute to poverty, due to a lack of employment as a result of discriminatory exclusion, lack of education and the impairment (Groce et al., 2011). Disability may require healthcare, rehabilitation and supported assistance which incur costs that families are unable to sustain (Grut et al., 2011; Yeo & Moore, 2003). These are important contextual factors to note when considering NDSs living in disadvantaged socio-economic contexts who, firstly, may live in households where various members have to navigate the financial challenges that are incurred due to their sibling's disability, and secondly, they may have fewer educational or life opportunities due to lack of funding or having to assume more caregiving responsibilities, where primary caregivers have to prioritise obtaining financial income.

While existing literature demonstrates that poverty may influence the health, productivity, physical environment, emotional well-being and relational interaction of families of children with disability (Park et al., 2002), there is minimal research addressing the experiences of NDSs in disadvantaged socio-economic contexts, though there are notable exceptions (Lobato et al., 2005; Manor-Binyami & Abu-Ajaj, 2012). It is argued that this is due to groups with diverging characteristics, who are difficult to access, having been considered by researchers as being hard-to-reach populations (Brackertz, 2007; Meltzer, 2015). Barriers to access have been listed as age, race, ethnicity, value structure, language, political affiliation, geographic location, religion, criminality and socio-economic factors that may render people vulnerable in society (Sadler et al., 2010; Sydor, 2013; Wahoush, 2009). By focussing on the experiences of young, isiXhosa speaking NDSs living in a socio-economically disadvantaged context, this study has accessed what may be deemed a hard-to-reach sample and aims to offer further insight into what it is like for young people living with disability and socio-economic disadvantage. As was highlighted, age may act as a barrier to research on young or adolescent populations, thus adolescent NDSs' voices are often excluded from the literature on disability. In addition, adolescence is often considered tricky, both regarding attempts to define it (Sawyer et al., 2018) and in the actual experience thereof (Dahl et al., 2018). In the next section I provide a description of how the term "adolescence" will be applied in this study, and how siblingship and disability have been understood in relation to adolescence.

1.7 Sibling Relationships and Disability in Adolescence

Sawyer et al. (2018) emphasise the arbitrary nature of age definitions that are informed by culture and context, noting that adolescence is largely defined as the onset of puberty. Puberty marks a new developmental phase associated with physiological changes, neurocognitive maturation and role transition into adulthood. From an experiential perspective, it has also been termed a "dynamic maturational period" (Dahl et al., 2018, p. 441) during which culturally embodied knowledge and skills that are associated with increased levels of social, emotional and regulatory capacities are acquired

(Dahl et al., 2018; Sawyer et al., 2018). While Sawyer et al. (2018) argue that the ages 10–24 years might be deemed a better fit for the concept of adolescence in our current context, it is noted that puberty characteristically begins at 10 years for girls and 12 years for boys, and although difficult to define an endpoint, the more widely accepted conclusion is 19 years (Dahl et al., 2018).

Research employing a developmental perspective in the Global North indicates that adolescence is a period in which socio-emotional and relationship patterns are determined (McHale et al., 2016), and the nature of the sibling relationship is linked to diverse psychological, behavioural and social outcomes for adolescents (Kim et al., 2007). Other research has indicated that the impact of sibling interaction on adolescents varies between nuclear and non-nuclear families, where adolescents from nuclear families benefitted less, psychologically and emotionally, from sibling interactions than those from non-nuclear families (Wikle & Hoagland, 2020).

In adolescence, siblings also reported positive impacts such as increased tolerance and a better understanding of disability and diversity (Petalas et al., 2012). On the other hand, some negative experiences included higher levels of anxiety or guilt (Opperman & Alant, 2003; Shivers & Dykens, 2017), feelings of embarrassment, and isolation (Barr & McLeod, 2010).

Pavlopoulou and Dimitriou (2019) argue that research on adolescent NDS from the Global North has tended to prioritise adjustment-related outcomes, is largely categorical (describing their experiences as positive or negative) and has often failed to include other important developmental factors such as environmental settings. It has however been emphasised that it is important to consider adolescents' subjectivities and experiences of being a sibling to a disabled person, to better understand their development of self and social identity, and how they navigate various developmental challenges (Pavlopoulou & Dimitriou, 2019).

Developmental Studies from the Global North that have aimed to understand adolescents have largely focused on identity formation and individuation (which include a separation from family values and need for peer acceptance) (Shapiro & Margolin, 2014). Crosnoe and Johnson (2011) argue that a desire for personal identity, close relationship with peers and group affiliation are primary objectives in adolescence. In contexts like South Africa, that has itself undergone significant change due to colonisation/decolonisation, Apartheid and globalisation, social expectations are continuously evolving and identity formation for adolescents may be complex:

> Black South African adolescents' social development occurs in the context of a history of legitimised power relationships; of which racial membership is a factor alongside gender, social class and socioeconomic status. (Arndt & Naude, 2016, p. 268)

An African worldview emphasises the importance of social maturation in an individual's development (Nsamenang, 2006). The acquisition of knowledge occurs through participation in the cultural and economic life of the family and society at various life stages. McKenzie and Chataika (2018) have noted that within the African worldview, a sense of self is attained in relation to and enacting one's social roles, highlighting the principles of *ubuntu*. This highlights the importance of familial, social and community connection for African adolescents. Despite the emphasis of family and community within the African worldview, there is a paucity of literature pertaining to how siblingship contributes to adolescent outcomes in the Global South. Only three studies on young NDSs in South Africa were located. Findings indicated (Mophosho et al., 2009) that NDSs were accepting of, and displayed positive attitudes toward, participating with their disabled brother/sister (Hansen et al., 2016), and that their attitudes toward their sibling became more positive as they reached adolescence (Hansen et al., 2016; van der Merwe et al., 2017). In addition, they were frequently required to help their disabled sibling with day-to-day functions, such as eating (Mophosho et al., 2009), and at times NDSs felt frustrated at other people's lack of consideration toward their sibling. While these findings are valuable, participants in these studies were required to be proficient English speakers and belong to a middle SES population (Mophosho et al., 2009). Furthermore, the cultural background of the participants was not explicit. To my knowledge, there are no studies that assume a cross-cultural, cross-language approach to the study of NDSs' experiences in a socio-economically disadvantaged context in South Africa. In order to respond to this gap in the literature, I have utilised IPA as a theoretical and methodological approach, in conjunction with Photo-production, to bring the voices of young isiXhosa speaking NDSs' experiences to light. I provide a description of IPA as a theoretical approach next.

1.8 Theoretical Approach of the Study

This thesis takes an Interpretative Phenomenological approach, where IPA provides a means to explore how individuals make sense of their experiences (Smith et al., 2009).

IPA is a form of phenomenological study, where the primary aims are to understand and make meaning (through interpretation) of experiences (Smith et al., 2009). Our meaning-making process occurs within a particular context and is always in relation to, shared or overlapping with something else. Moreover, IPA draws from Merleau-Ponty's (2013) philosophy of our embodied experience of a phenomenon and how that leads to our own individual perspective of a particular experience (Smith et al., 2009). Another important aspect of IPA is its hermeneutic leanings, a philosophy that argues that we cannot know something without being aware of how our presence in the process facilitates how we come to know it. In other words, the researcher is implicated in the meaning-making of the participants' experiences.

IPA is also idiographic, in that, unlike other approaches to research, it is interested in individual experiences and does not aim to make claims that can be conflated to group level or general laws about human behaviour (Smith et al., 2009). In this case, each participant's meaning-making is important in its own right.

Following from the contextual background provided above and IPA's particular theoretical approach, this study has a very specific scope. It is interested in how adolescent NDSs experience their lives in relation to their disabled brother/sister. It is interested in how they make meaning of their experiences and how various intersecting factors, including their developmental stage, culture and

SES, contribute to their meaning-making. More specifically, it is interested in what these experiences look like in a particular socio-economically disadvantaged context in the Global South.

1.9 Context of the Study

1.9.1 Describing the geographical location

An important objective of this research is my intention to respond to the call for further research on NDSs in the Global South (Meekosha, 2008; Meltzer, 2015). This study takes place in a semi-rural location called Joza Location in Makhanda (formally Grahamstown) in the Eastern Cape Province of South Africa. Before describing Joza Location, a brief understanding of the South African context is necessary.

Despite being one of the wealthiest countries in Africa, with an abundant supply of natural resources and modern infrastructure, South Africa's political legacy of Apartheid has resulted in an ongoing imbalance in the distribution of wealth (Cramm et al., 2013). Cramm et al. (2013) argue that the socio-political underpinnings of healthcare, education and employment continue to offer a dire forecast for many, especially those families living with disability. It has been argued that subsequent misappropriation of public resources and corruption linked to Jacob Zuma's presidency have fuelled challenges related to social inequality, unemployment and unequal access to public services, disproportionately affecting the majority black population (Cook, 2020). Fengu and Khamalo (2020) report that during the 2018-2019 financial year in South Africa, municipalities lost thirty-two billion rand due to corruption. Infrastructural impacts include crumbling roads, disrupted waste collection, illegal dumping, neglected public spaces, water rationing and frequent (often multiple times throughout a day) electricity cuts across the country.

The dismantling of Apartheid in the early 1990s promised an optimistic future for many young, previously oppressed, South Africans, especially with regards to improved education and employment opportunities (Leibbrandt et al., 2009). Yet, in spite of the concerted efforts by many, including the National Youth Congress, to improve the quality of education for young, black, South Africans, a notable disparity between the quality of education offered to the affluent minority and the socio-economically disadvantaged majority prevails (Spaull, 2013). Spaull (2013) contends that intergenerational perpetuation of poverty, where the young inherit the social positioning of their caregivers, is sustained by the inferior education offered to many. Furthermore, while formal racial segregation was abolished over two decades ago, many of the schools originally set up for black children in the Apartheid era, remain racially homogenous and socio-economically disadvantaged, while those schools set up for white children, although now somewhat more racially diverse, continue to serve the more affluent sector (Spaull, 2013). This has been explained as being due to the ongoing impact of spatial segregation policies during Apartheid, where black children were forced to live in areas remotely situated in relation to the Central Business District and suburbs. For many black children in South Africa, affluent schools continue to be geographically and financially inaccessible (Spaull, 2013; Yamauchi, 2011).

In South Africa, only about 35% of children live with both biological parents, a similar percentage live only with their mother. Less than half of families conform to the "nuclear norm", and there are often more than three generations living in one household. Grandmothers frequently assume the role of primary caregiver in the absence of the children's parents (Budlender & Lund, 2011).

The Eastern Cape is the most socio-economically disadvantaged province in South Africa. It has a population of 6.5 million people, approximately 80% of whom are isiXhosa speaking (Webb, 2012). It has significantly elevated unemployment rates and low education levels (Statistics South Africa, 2015). According to Nomsenge (2019), the school attrition rates in Makhanda-East are notably higher than the national average, indicating that a significant number of young people do not complete their schooling career with the necessary qualifications for tertiary education or employment/economic opportunities. The education system continues to be a space of language discrimination and exclusion for many young people in Joza Location, where, despite students being mostly isiXhosa speaking, classes and examinations continue to be in English. As a result of the high unemployment levels, 41%

of households in the Eastern Cape of South Africa receive government social grants[5] (Mutumbi et al., 2021).

Makhanda's spatial layout continues to be representative of colonial and Apartheid inequalities. With a clear juxtaposition between the east and west of the city, the more affluent west includes three of the most expensive schools in the country (Vorster, 2016), an established university and the High Court. Many residents of Makhanda struggle for basic services, however this is especially prevalent in the east, where most do not have access to healthcare and many continue to live in informal shack dwellings without sanitation (Pentz, 2021).

1.9.2 Defining the socio-economic context

The American Psychological Association (APA) define "socio-economic status" (SES) as:

> the position of an individual or group on the socioeconomic scale, which is determined by a combination of social and economic factors such as income, amount and kind of education, type and prestige of occupation, place of residence, and—in some societies or parts of society—ethnic origin or religious background. Examinations of socioeconomic status often reveal inequities in access to resources, as well as issues related to privilege, power, and control. (Adapted from the APA Dictionary of Psychology, 2023, para. 1)

In this study, socio-economic disadvantage is understood as being a notable inequality in SES, which may contribute towards poorer health and mental health, lower life expectancy, poorer skills and education attainment, lower paid work, increased likelihood of being victim to crime and feelings of unsafety, increased likelihood of living in less than adequate housing, and poorer access to transport

---

[5] Social grants are defined as income received by members of vulnerable groups from funds which they did not contribute towards (Leibbrandt et al., 2010). There are several types of grants, including childhood grants (R100 or $5.2 US per child per month, where the child must be below seven years old); and care dependency grants, eligible to carers of children who are severely disabled and require full-time home care (R1415 or $75 U.S. per year). Other grants include the disability grant (R107 or $5.59 US per month) available on a permanent or temporary (6–12 months) basis to people deemed unfit to work as a result of functional impairment and who do not have sufficient other means of support (Satumba et al., 2017).

and services. As such, socio-economic disadvantage may have enduring impacts on many areas of an individual's life (Mills, 2021).

1.9.3 Orienting the reader to the Xhosa culture

This is both a cross-language and cross-cultural study, as I am White, English speaking, and South African born, while the participants for this study are Black, isiXhosa[6] speaking, South African born. Psychological research on the relationship between cultural identity and language purports that language is important in defining cultural identity and facilitating a sense of belonging to a particular group, where this sense of belonging is a significant aspect in the development of self-concept (Tajfel & Turner, 2004). Language can be used to assert in-group identification and contributes to positive social identity (Giles & Ogay, 2007). A fundamental element of the Xhosa culture is its oral tradition, where an oral tradition is considered the cultural transmission that occurs verbally between generations (or testimonies are orally delivered by speech or song and may take the form of folktales, proverbs, ballads, songs, or chants) (Finnegan, 1970; Mazaleni, 2022). "Culture refers to collective conventions, values and practices indigenous to specific groups" (Theron et al., 2011, p. 801), and language may be considered the medium through which it is expressed. To properly understand the lived experiences of participants (which are embedded in their culture), in this study it was important to create space for them to do so in isiXhosa. Where there is a language barrier between qualitative researchers and their participants, interpreters or translators are employed (Temple & Young, 2004). To ensure trustworthiness in this research I used an interpreter during both recruitment and data collection.

IsiXhosa speaking people are the second largest language group in South Africa. The AmaXhosa lived on the mountain slopes of the Eastern Cape, primarily herding cattle until the 18th century, and were the first indigenous South Africans to encounter European settlers. The Xhosa culture has endured significant pressure from exposure to Western influence, particularly during the

---

[6] IsiXhosa refers to the Xhosa language. IsiXhosa is a dialect of the Nguni language, spoken mostly in the Eastern Cape and Western Cape of South Africa. AmaXhosa refers to people of the Xhosa culture (Mazaleni, 2022).

industrialisation and urbanisation of South Africa, where many AmaXhosa had to migrate to cities because of the demand for low-wage labour. Urban migration fractured traditional family structures that were founded on the collectivist ideals of *ubuntu*, and many of the cultural values and practices became difficult to uphold. For example, traditionally, family roles were determined by patriarchal principles which positioned men as the breadwinner and women as nurturer and carers, however, as men migrate to cities to earn an income, grandmothers or single mothers are often required to financially support their families (Ramphele, 2002).

AmaXhosa traditionally hold ancestral beliefs, asserting that the ancestors mediate between the living and the dead. Many cultural practices are determined by a drive to please ancestors who are believed to punish people for not adhering to customs (Pentz, 2021).

Culture is, however, not static, and acculturation, or the extent to which people absorb new traditions, discard older practices, or adapt to accommodate different ones is inevitable in a globalising world (Stead, 2004). An example of this is the incorporation of Christian beliefs into a traditional ancestral focussed belief system, a result of the arrival of missionaries during colonialism (Rice, 2015). Irrespective of notable changes that have occurred in South Africa over time, many centuries-old Xhosa values and practices prevail and are important to mention to appropriately contextualise this study. For example, cultural values such as patriarchy, respect for elders, and belief in witchcraft remain widespread throughout the Eastern Cape (Rice, 2015).

AmaXhosa adhere to the principles of *ubuntu* which feeds into childrearing practices, property arrangement and social obligations (Rice, 2015). Kinship or clan membership may determine an isiXhosa speaking person’s identity. The common use of the terms “*bhuti*” (brother) and “*sisi*” (sister) to refer to community or clan members is indicative of the value placed on connectedness and mutual support from others, where each member of a community fulfils a valuable role (Rice, 2015). In a study including Xhosa adolescents (Albien & Naidoo, 2016), participants described cultural values as including dignity, honesty, integrity, hard work, wanting respect and being respected, as well as being influenced by and influencing other people, pooling resources and giving back to the community. While the principles of *ubuntu* continue to be largely honoured, Western, individualistic values, that are more competitive and egocentric, are increasingly absorbed by youth, and risk disrupting overall cohesiveness within the culture (Ramphele, 2012 as cited in Theron et al., 2016).

Despite increasing urbanisation, many traditional Xhosa practices continue, such as *ulwaluko*, an initiation or rite of passage ceremony which includes circumcision and a period of solitude, to mark the transition from boyhood to manhood (Mfecane, 2016). *Lobola* (bride price), whereby a young man offers payment to the father of the potential bride (previously in the form of cows) (Mtuze 2004) is also widely practiced by the AmaXhosa. This study's focus is on experiences of sibling disability in youth, thus an understanding pertaining to Xhosa beliefs around disability is important.

1.10 Locating myself as the Researcher

A fundamental element of IPA is its hermeneutic (interpretive) grounding. As the researcher, my task (among others) was to interpret the thick descriptions of the various experiences participants relayed. Interpretations, however, are informed both by what is intended by the participant and by the researcher's own previous experiences, understandings and knowledge. Thus, being mindful of how my experiences and knowledge might create potential bias was imperative to ensure the trustworthiness of the overall results, as Rose (1985) confirmed, "There is no neutrality. There is only greater or less awareness of one's biases" (p 77). Reflexivity is thus a critical component of IPA, and consistent efforts were made throughout the research process to consistently adhere to reflexive practices (Willig, 2001).

In locating myself withing this study, I do so with awareness of the conversations around insider epistemology in qualitative research. In an article on insider-outsider researcher positioning, Dwyer and Buckle (2009) challenge the dichotomous thinking around these stances within research. The authors suggest that a dialectical approach that acknowledges the fluidity of group membership be assumed. This approach emphasises that between the binaries of insider-outsider positioning, there is a “space between” where both similarities and differences between the researcher and researched are acknowledged. As such, I have approached the task of locating my voice, bearing the “space between” in mind, yet similarly, with open eyes, assuming I knew nothing of the participant’s world in order to reveal the essence of their understandings (Dwyer & Buckle, 2009).

While I have completed this doctoral study as a practicing Clinical Psychologist, this research question has arisen from both my personal and professional experiences. As the only sibling to a younger sister with an intellectual impairment, I am acutely aware of how my experiences in relation to her have shaped my own life world. These experiences have allowed me to approach with empathy the meanings the participants in this study offered. However, I am also aware of how differing contextualisation, cultural background and SES separate me from the participants’ unique experiences. I am a middle aged, white, South African woman, currently living and working in New Zealand. My life as an adolescent NDS, from a middle-income background in South Africa, was undeniably different to that of my participants, for an infinite amount of socio-political and socio-economic reasons. Yet, on reflection, and when hearing the participants’ stories, there were a plethora of similarities. As such, my positioning could be considered from both an insider and outsider perspective.

As an insider, during interviews with my participants, I often wanted to exclaim, “Yes, yes, I know what you mean, it’s like [insert assumed understanding]!” I, however, had to catch myself on many occasions, to challenge my assumption that simply because I had overlapping experiences with the participants, they would attach the same meaning to their experiences as I did. As an outsider, I frequently found myself grappling with guilt. Guilt because I knew that after the interview, we would all be returning to very different living conditions. Guilt because, despite having no recollection or direct/intentional involvement with the Apartheid system, I am white. While irrational, I fear that being a white South African somehow, de facto, may create an assumption about me that associates me with the systems of Apartheid. Lastly, I felt guilty about daring to write about a culture that is not mine, and in being in every sense an outsider, I feared getting it wrong. In these instances, my interpreter, Zuki Gubevu, who has become a dear friend was invaluable. She constantly reminded me of the value my research could offer in terms of giving the participants, who are often overlooked or unheard, a voice. On the many occasions we had to drive to Joza Location to meet parents (for consent), pick up cameras or interview participants (times where I was very obviously the only white person for as far as the eye could see), she had the uncanny ability to make me feel like her *sisi* (sister) and, as a result, I felt welcomed into a community that was not mine. Finally, her contributions during our reflective process, particularly pertaining to Xhosa practices and beliefs, provided an important depth to the participants' experiences. This suggests the value of being aware of our outsider status so that we might find means to bridge possible gaps in the meaning-making process.

1.11 Outline of the Thesis

In Chapter Two, I provide a critical review of the previous research on NDSs, noting how this has been largely divided by studies that have aimed to measure the impact of disability on young NDSs' psycho-emotional well-being, behaviour, relationships with their disabled brother/sister, and other family members, as well as caregiving experiences. I also discuss factors that influence the impact of disability on NDSs. I then consider the limitations of approaches that primarily aim to measure the impact of disability on NDSs. In the second part of the chapter, I discuss the qualitative research that has aimed to understand and provide thick descriptions of the experiences of NDSs, primarily with a relational focus, and highlight the gap in the literature pertaining to the experiences of NDSs in the Global South.

In Chapter Three, I discuss in detail, the dominant theoretical approaches that have been applied to the study of disability, including the medical model, the social models, psychoanalytic and the critical approaches considering their orientations and associated definitions. In doing so I demonstrate their inapplicability to my particular research question and in turn argue for Critical Realism as the most appropriate approach to respond to my particular research question.

In Chapter Four, I orient the reader to the methodology, or the way in which knowledge is constructed (Tebes, 2005) in this particular study. I provide an in-depth description of the theoretical underpinnings of IPA, including phenomenology, hermeneutics and idiography and how each of these theoretical underpinnings make IPA the most appropriate approach for exploring the subjective, lived experiences of adolescent, Xhosa, NDS. I also describe the practical element of IPA that guided this study.

Chapter Five details my application of IPA as a method. I describe how nine adolescent isiXhosa speaking NDSs participated in this study and how I accommodated for the fact that this research study took place with a hard-to-reach population. I describe the research design and the data collection, which included the use of semi-structured interviews and photographs. I then detail my analytic process. I discuss my inclusion of an interpreter and professional transcriber and how their inclusion aided in overcoming any possible language barriers.

In Chapter Six, the first findings chapter, I present the first of three Group Experiential Themes (GETs). The first GET is related to adolescent's experiences of togetherness with their disabled sibling. It was noted in the first sub-theme that participants often described experiences of reciprocal love, which offered them a sense of we-ness. We-ness was experienced in playful moments (the second sub-theme) and ordinary moments of togetherness (the third sub-theme). The fourth sub-theme noted how participants also experience togetherness as difficult and, in this case, we-ness is less prominent. Throughout the presentation of the themes, verbatim extracts from the participants' original transcripts are presented to support my interpretations.

In Chapter Seven, the second findings chapter, the GET pertaining to NDSs' experiences of care is presented. In this chapter I note how participants described experiencing either wanting to, or having to care for their disabled sibling. The various sub-themes include participants' experience of care as voluntary and an act of love, experiences of care as obligatory and lonely, and care as difficult and requiring sacrifice.

In Chapter Eight, the final findings chapter, I present the GET related to participants' experience of being an outsider. Participants in this study reported feeling like an outsider, often because of their SES and sometimes because of stigma related to their sibling's disability. They emphasised how they attempted to overcome experiences of exclusion by striving for material wealth, fame and success to receive approval from others.

In Chapter Nine, I remind the reader of my research aims and key objectives. I then discuss the various themes that emerged from the data in relation to existing literature previously reviewed in my thesis. As recommended by Smith et al. (2009), in the instances where new insights emerged from my findings, new literature was incorporated. I then consider the various strengths and limitations of this study.

Finally, in Chapter Ten, I conclude this thesis with a summary of the key points of this study. I consider the various practical implications, noting how this research can be valuable in helping to address the specific needs of isiXhosa NDSs in disadvantaged socio-economic contexts. I then consider the theoretical implications of using a phenomenological approach in the study of adolescent NDSs in the Global South. I also reflect on the methodological implications, highlighting the effectiveness and future possibilities of using IPA in conjunction with photo-production with young, participants, as well as the use of an interpreter in cross-language, cross-cultural IPA. Finally, I provide a justification of why I consider this research to be of significance.

1.12 Summary

In this chapter I have introduced the study and highlighted the importance and value of the sibling relationship when one sibling has a disability. I have discussed how developing an understanding of sibling experiences provides a sense of how they ascribe meaning to their relationships. It was, however, noted that there is very little research on how adolescents ascribe meaning to their sibling relationship when their brother or sister is disabled. I have located this research in CDS, with a psychological view, utilising IPA as a theoretical and methodological approach. Positioning this research in CDS stipulates that young people’s voices should be brought to light and the use of IPA allows me to get thick, detailed, subjective accounts of how adolescents make meaning of their particular experiences of their sibling’s embodied disability while taking their particular context into consideration. I have noted that previous psychological studies on NDSs have largely occurred in the Global North, emphasising how this study responds to the call for research in the Global South, and have therefore paid particular heed to the participants’ contextual factors, including socio-economic context and culture. Finally, I have located myself as a white, English-speaking, middle aged NDS who grew up and lived in South Africa.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

I begin this review by considering the dominant body of work that has prioritised measuring and quantifying the effect of disability on NDSs. This includes the degree and nature of the psychological and emotional impact the presence of a disabled person has on their brothers and sisters. I then review research that has focused on measuring the impact of disability on NDSs' relationships with their disabled siblings, family and peers. Through studies measuring the psycho-emotional and relational impact of disability on NDSs, researchers have emphasised caregiving as a major relational facet. Research focus has therefore included efforts to understand how caring for their disabled sibling may correlate with psycho-emotional and relational outcomes; this work is also reviewed in this chapter. It is noted that these studies have led researchers to recognise that NDSs' psychological, emotional and relational outcomes are not informed solely by the presence of a disabled brother/sister, but by a myriad of additional factors. These include birth order, gender, type/degree of disability, available social support and knowledge of disability.

I then consider the more recent, developing literature that has aimed to make sense of NDSs' experiences from a subjective perspective. I first review the studies that have considered NDSs' psycho-emotional, relational and caregiving experiences, followed by a review of studies that have transcended these particular domains and considered other experiential themes, such as school and day-to-day experiences. Finally, I look at the important studies that have considered NDSs' experiences from contexts outside of the dominant Global North.

Through my evaluation of this particular body of work, I argue for the importance of approaching the study of NDSs from diverse perspectives that additionally allow for NDSs' subjective accounts of their experiences to be included, thereby adding a greater sense of meaning to what is known. I additionally show how overgeneralising ignores subtle differences between experience and argue for research that considers NDSs' individual perspectives as necessary to understand their unique experiences. Furthermore, I demonstrate how the tendency to compare NDSs' experiences with a control group sets their experiences up as "not normal". This then may not accurately reflect how NDSs feel about their life world's, their day-to-day relational experiences with their siblings. Finally, through this review, I aim to demonstrate that when the study of NDSs is approached with the intention of examining very specific foci, such as the impact of disability, or caregiving, without considering the complex interplay of intersecting factors, such as context, culture and family constellation, important nuances in experience are omitted and non-normative framing is reinforced.

2.2 Literature Quantifying NDSs' Experiences

The majority of research on NDSs has focussed on measuring the impact of the presence of a disabled sibling on NDSs' psychology, emotions, behaviours and relationships by comparing these to siblings where no disability is present. Each of these focus areas will be explored in turn.

2.2.1 Measurement of the psychological impact of disability on NDSs

The majority of research on NDSs has been situated within the psychological discipline, framed by a medical perspective which views disability as the negative impact of a physical/cognitive condition located within an individual (Oliver & Barnes, 2012; Shakespeare, 2013). As such, a great deal of research has aimed to measure the negative impact a disabled sibling will have on a young person's psychological well-being in comparison to those who do not have disabled siblings. In order to measure psychological impact, researchers have frequently used diagnostic measures to determine the presence of psychiatric symptoms in NDSs (such as anxiety and depression), or scale measures to determine the rate of psychiatric symptoms (Shivers et al., 2019). In their meta-analysis on the functioning of NDSs (which included findings on behaviour problems, psychiatric symptoms, social functioning, family functioning, relationship outcomes, beliefs, coping and adjustment) Shivers et al.

(2019) noted that most of the data were collected through questionnaire measures. An example of the various measures used to measure the psychological impact of disability on NDSs are presented below in a table adapted from Shivers et al. (2019).

Table 2.1

Measures Assessing the Psychological Impact of Disability on NDSs

Psychological Construct included	Types of measures used
Anxiety, generalised anxiety, separation anxiety, social anxiety, panic, obsessive-compulsive disorder, depression, negative mood, negative self- esteem, ineffectiveness, interpersonal problems, functional problems, emotional problems.	Children's Depression Inventory-2; Revised Child Anxiety and Depression Scale; clinician report; Kiddie Schedule for Affective Disorders and Schizophrenia (K-SADS); International Classification of Diseases (ICD-10/ ICD-9); Beck Depression Inventory; BASC-2; Revised Children's Manifest Anxiety Scale; Stress Appraisal Measure; Depression, Anxiety, and Stress Scale (DASS); Hospital Anxiety and Depression scale.

Note. Table adapted from Shivers et al. (2019, p. 179).

Results of these studies have indicated increased negative outcomes in psychological functioning, including anxiety (Shivers et al., 2019), and a higher rate of depressive symptomology (Lovell & Wetherell, 2016) in NDSs in comparison to siblings who do not have a disabled brother/sister. Other research, however, suggests that the presence of a disabled sibling does not negatively impact on NDSs' psychological functioning and adjustment in comparison to those siblings where neither is disabled (Hallett et al., 2013; O'Neill & Murray, 2016; Shivers et al., 2013; Shivers et al., 2019; Walton & Ingersoll, 2015). Furthermore, researchers have reported positive findings such as increased resilience (Macks & Reeve, 2007; Meadan et al., 2010; Neely-Barnes & Graff, 2011;

Rossiter & Sharpe, 2001), as well as higher levels of compassion and empathy (Bellin et al., 2009; Jones et al., 2006).

Thus, it has been recognised that attempts to measure the psychological impact of disability on NDSs, have frequently produced findings that are largely inconsistent and inconclusive. It is suggested that these inconsistencies are informed by the research methods and approaches utilised. For example, contradictory findings may be explained by conflicting responses between parents and NDSs' self-reports (Barrack-Levy et al., 2010; Hastings & Petalas, 2014). Research has indicated that where parents reported that the presence of a disabled sibling fostered positive attributes, such as responsibility and helpfulness in the NDS, the NDS's self-reports suggested that these attributes possibly elevated their emotional distress (Barrack-Levy et al., 2010). It has also been recognised that parents/caregivers, particularly mothers (Griffith et al., 2014), are more likely to overreport on the negative impact a disabled child may have on the NDS's psycho-emotional well-being (Hastings & Petalas, 2014). This suggests the importance of obtaining first-hand, subjective accounts for accurate data.

2.2.2 Measuring the impact of disability on NDSs' behaviour

In addition to quantifying the psychological impact the presence of a disabled brother/sister has on a NDS, researchers have attempted to measure NDSs' behaviour. Shivers et al. (2019) acknowledge that in the research measuring the impact of disability on NDSs, the line between *behaviour problems* and *psychiatric symptoms*, especially pertaining to children, is frequently blurred and lacking in precision, and they make their distinction by considering what measure has been utilised to determine the impact.

While some research indicates that NDSs may display maladaptive or impaired behaviours (Fleary & Heffer, 2013; Goudie et al., 2013; Griffith et al., 2014), other research has shown that the presence of a disabled brother/sister does not have a significant negative effect on a NDS's behaviour (Hayden et al., 2019; Howlin et al., 2015; Shivers et al., 2013; Walton & Ingersoll, 2015). Rather, NDSs have been reported to present with greater prosocial behaviours, including an elevated sense of responsibility, a protective inclination (Bellin & Rice, 2009; Orm et al., 2022; Perenc et al., 2015), maturity (Fleary & Heffer, 2013), and patience and understanding. An earlier review (Mandleco & Webb, 2015) that considered NDSs with Autistic Spectrum Disorder (ASD) or Down Syndrome (DS) brothers/sisters in comparison to a normative sample, also reported positive findings pertaining to NDSs's behaviour. NDSs with DS brothers/sisters demonstrated more caring and kindness (Cuskelly & Gunn, 2006), helpful attitudes (Skotko & Levine, 2006; Skotko et al., 2011), patience and acceptance (Graff et al., 2012) and higher levels of involvement in their brother/sister's lives, than NDSs with brothers/sisters with ASD or no disability. Further studies have noted that prosocial behaviours are often informed by modelling between siblings, that is, sibling interactions often include teaching and caregiving where siblings learn how to behave from one another, however, the presence of a disability, especially where an older sibling is disabled, may impede the acquisition of certain social behaviours for the other sibling (Hughes et al., 2018).

Shivers et al. (2019), however, emphasise the importance of recognising that "not all behaviour problems are created equal" (p. 174). For example, some behaviour problems are considered as internalised behaviour, such as worrying or withdrawal, while others are considered as externalising behaviours, such as aggressive and delinquent behaviour. The measures predominantly utilised to determine where/when/if behaviour problems exist, look at behaviour problems in their totality or split behavioural problems into internalising behaviour and externalising behaviour, which, according to Shivers et al. (2019), "washes out more subtle differences for specific types of behavior problems" (p. 174). While measuring behavioural problems is useful in that it acknowledges the behavioural impact of having a disabled sibling, it does not provide any detail on what this means for the NDS. We do not have a sense of what their worries entail or what makes them feel angry and become aggressive.

Furthermore, simply noting the presence of internalising or externalising behaviour, and generalising these findings to all NDSs, does not accommodate for the subtle differences that may occur between NDSs' experiences of worry, or anger and frustration. In order to capture subtle differences between NDSs’ psychological, emotional and behavioural responses to having a disabled sibling, research approaches that focus on their individual accounts is required. By aiming to understand NDSs as unique individuals, further meaning can be added to existing, generalised findings.

2.2.3 Measuring the impact of disability on NDSs’ relationships with their disabled sibling

Given the value placed on siblingship in a person’s development (Edwards et al., 2006), as noted in the introduction of this thesis, researchers have additionally been motivated to understand how the presence of disability may impact on sibling relational experiences. As in the case of quantitative studies on psychological impact, there is significant variability in research that has measured the impact of disability on siblingship (Taylor et al., 2016). Some research has claimed more negative outcomes pertaining to social and relational functioning (Shivers et al., 2019). For example, relationships between siblings where disability is present have been reported to lack closeness (Taylor & Hodapp, 2012) and warmth (Doody et al., 2010). Findings have additionally indicated less reciprocity and higher degrees of conflict (Love et al., 2012). In contrast, other findings have highlighted the strengths or positive aspects within siblingship where disability is present, in that they are more rewarding than sibling relationships without disability (Burke, Fish, & Lawton, 2015).

Rivers and Stoneman (2003) noted discrepancies between findings on relational quality when parental reports and self-reports were compared. In this case, NDSs expressed satisfaction with their relationship with their sibling, while their parents’ reports were less positive. Conversely, other research (Ohannesian et al., 2014) has found that adolescents viewed their relationships more negatively than parental reports indicated. The contradictions and variances of these findings have been linked to different sample characteristics, methods of data collection and the tendency to discount the changing dynamics within relationships (Latta et al., 2014). This again reinforces the need for alternative methods that focus on obtaining first-hand, subjective accounts of NDSs’ relational experiences.

This research, often utilising control groups, essentially measures the impact disability has on the relationship, highlighting the differences and non-normative aspects of the relationship in comparison to sibling relationships without disability (Alderfer et al., 2010; Knecht et al., 2015; Meltzer, 2015). In so doing, what is potentially missed is that any relational difficulties NDSs may experience with their disabled brother/sisters, be they informed by disability or not, may simply be incorporated into their everyday interpersonal dynamic together and not experienced as other than normal (Meltzer, 2015). NDSs, like siblings without disabled siblings, may experiences frustrations, rivalry, envy, joy, playfulness, comradery, and so forth with their disabled siblings, despite or because of the presence of disability, these experiences being a part of siblingship.

When comparative approaches are employed, and one group is measured against another, such as NDSs and control groups (siblings who do not have a disabled brother/sister, who are generally considered the norm), findings indicate how one group's relational outcomes are more/less positive than the other. Meltzer (2015) notes that focussing on the positives and negatives has been a prevalent tendency in research that aims to measure the impact of disability on NDSs and their relationships, referring to this trend as "dualistic framing". Dualistic framing denies space for more nuanced aspects of the relationship between siblings, where disability is present, and excludes the possibility of more neutral relational experiences being explored. Whereas an approach that aims to understand the range of relational experiences that occur between siblings in the context of disability, not only allows for more nuanced findings but acknowledges that the presence of disability in a sibling relationship might alternatively be viewed as a part of their everyday experiences (Meltzer, 2015). The gap in this literature has occurred due to the emphasis on comparing siblingship where disability is present to those without disability, as opposed to trying to understand the nature of relationship itself.

2.2.4 Measuring the impact of caregiving on NDSs

Research on siblingship where disability is present has also focussed on the caregiving role of the NDS. This focus has been informed by NDSs commonly assuming the caring role when parents or primary caregivers are no longer able to support a disabled person, should care be required (Hodapp & Urbano, 2007).

The Edinburgh Young Carers (2024) defines a “young carer” as:

> somebody who cares for or is affected by someone else at home – usually a parent or sibling – who suffers from physical or mental ill health, or who has substance misuse issues. Edinburgh Young Carers works with young people aged 5 to 25 years old. (para. 1)

It has been argued that this definition requires further expansion to accommodate for the fact that many young carers, particularly those in socio-economically disadvantaged contexts, where there is a lack of state-provided welfare, are additionally required to engage in income generation (Joseph et al., 2020).

The term “parentification” has also been utilised to describe the role children/youth assume in their familial context (Earley & Cushway, 2002). Parentification is a term that was initially utilised to describe caregiving provided by children to their disabled or chronically ill parents (parent-focussed parentification) (Beffell & Nuttall, 2020). It is, however, increasingly utilised to describe the care provided by young people for their chronically[7] ill or disabled siblings (sibling-focussed parentification). It has been noted that, in some contexts, NDSs will be providers of both (Nuttall et al., 2018; Tomeny et al., 2017).

Research conducted on NDSs has confirmed that caregiving responsibilities are frequently reported (Nuttall et al., 2018; Tomeny et al., 2017; Ward, 2016). It has been noted that the caring role may include assisting in domestic duties, such as preparing meals or household cleaning, acting as an advocate for their disabled brother or sister, and providing emotional support (Burke, Arnold, & Owen, 2015; Burke et al., 2012). Findings from studies on NDSs in disadvantaged socio-economic contexts

---

[7] Due to the fairly limited availability of sibling caregiving, research on siblings caring for chronically ill brothers/sister was also considered. While I acknowledge that disability and chronic illness cannot be equated, there is a possibility that the duration and type of care provided to a disabled or chronically ill sibling may overlap.

in the Global North have noted that less available financial resources often lead to greater household and caretaking responsibilities, which may in turn limit personal time and reduce social opportunities (Barak-Levy et al., 2010; Macks & Reeve, 2007; Dyke et al., 2009).

In addition to defining NDSs' caring responsibilities, researchers have also sought to understand the psychological and social outcomes for NDSs who assume caring roles. Outcomes-related research on NDSs in caregiving roles has also been comparative, and dualistically framed. That is, researchers have categorised caregiving outcomes as either positive or negative. Positive outcomes include NDSs presenting higher levels of empathy (Meadan et al., 2010), and increased closeness or enhancement of the sibling relationship through their caregiving role (Floyd et al., 2016; Orm et al., 2022; Tomeny et al., 2017). Other researchers have suggested that young carers may integrate their caring role into their identity and progress into adulthood taking on carer roles (Earley & Cushway, 2002). NDS carers have acknowledged feelings of frustration and a perceived lack of independence (Bellin & Kovacs, 2006), and in a review of the literature, higher absenteeism at school has been noted (Gan et al., 2017).

Differences in gender pertaining to care has been reported, with sisters providing higher levels of support than brothers (Orsmond & Seltzer, 2000). Using the Confirmatory Factor Analysis (CFA) measure, Floyd et al. (2016) noted that there was greater conflict in sibling relationships where brothers/sisters were involved in caregiving and lived together, however, conflict was reduced when siblings no longer co-resided.

Further, studies that have considered the impact of caregiving on adult NDSs have suggested differences between *anticipated* care (where a NDS may expect to care for their disabled sibling in the future) and *current provision* of care (the active engagement of caregiving) (Burke, Fish, & Lawton, 2015). NDSs' experiences of anticipated caregiving responsibilities may be influenced by the type of disability, where a disability with higher need provision may elicit greater concern for the NDS (Burke, Fish, & Lawton, 2015).

Furthermore, where there is an expectation of future caregiving, survey results (Burke et al., 2012) noted that female NDSs, who were emotionally and physically closer to their disabled brother or sister, were more likely to anticipate caregiving responsibilities than young male NDSs. Those currently providing care reported difficulties trying to make sense of and access service delivery systems, whereas those anticipating caregiving experienced anxiety about thinking and planning for the future, worrying about how caring for their disabled brother/sister would impact on their marriages, careers and where they would live (Hodapp et al., 2017).

Meltzer (2017) provides a valuable critique of the above literature measuring the impact of caregiving on NDSs. She states that while adding value, previous research on NDS carers is "largely instrumental or descriptive of expectation, behaviour and impact" (p. 1016), and has tended to utilise quantitative comparative methods. As such, they again measure the effects of care on NDSs' and their relationships, while neglecting to provide understanding of the relational experience itself. Meltzer (2015) highlights that it is common practice for most siblings, where disability is not present, to at least provide some care for one another, yet when disability is a factor, sibling care risks becoming pathologised and again is framed as non-normative. Similarly, caregiving between siblings in non-Western cultures is considered normative (Kao, 2012; Paul et al., 2022). Joseph et al. (2020) have argued that the level and degree to which caring exists may vary in complex ways. Research that aims to understand young carer experiences therefore needs to accommodate for the nuances in experience.

2.2.5 Factors that influence the impact of disability on NDSs

Researchers have become increasingly aware that the presence of a disabled sibling alone may not determine the degree of psychological or relational impact on a NDS. Rather, there are additional informing factors – this review focuses specifically on studies that have explored the impact of birth order, gender, type and degree of disability on NDSs. Efforts have therefore been made to measure how these various predisposing factors inform the psychological and relational impact.

2.2.5.1 Birth order

It has been noted that where the disabled sibling is the first born, their younger NDS is likely to exhibit problematic behaviour, this being considered as being due to social learning effects (Tomeny et al., 2014; Tudor & Lerner, 2015). Koukouriki et al. (2021) suggest that being born after a disabled child possibly increases risk for NDSs' psychological and social outcomes because they receive less parental care, given parents' attention is focused on the older disabled child.

Some argue that birth order may influence the degree of positivity NDSs feel toward their disabled brother/sister (Bitsika et al., 2015; Hastings, 2003). Older or first born NDSs have been noted to experience higher rates of positive psychological outcomes than later born NDSs (Hastings, 2003; Koukopuriki et al., 2021). The positive outcomes have been explained as being informed by the first born or an older sibling having a greater ability to understand and cope with the disability (Glasberg, 2000; van der Merwe, 2017). An alternative understanding is that siblings who were born before their disabled brother/sister will have had different life experiences to those born after, and as such, this may factor into how disability impacts on their emotional and behavioural adjustment (Petalas et al., 2009). In a population-based study on the behavioural and emotional adjustment of older siblings of disabled children (utilising several scale measures), results indicated marginally elevated peer and conduct problems compared to a normative sample. When other contributory factors were considered, such as, socio-economic disadvantage, living in a single parent household, having a disabled sibling with elevated behavioural problems, or having a primary carer with elevated psychological distress, the results were negligible (Hayden et al., 2019). This is an important study in that it emphasised the need for research that considers how various intersecting factors can contribute to the impact of disability on NDSs. Koukouriki et al. (2021) therefore concluded that, while considering birth order to be important in its significance to overall family dynamics, the research findings on how it impacts on NDSs' psychological well-being is limited and inconsistent.

2.2.5.2 Age

In addition to birth order, age has also been considered as a factor that may influence the impact of disability on a young NDS. Research on how or if age influences the impact of having a disabled brother/sister is varied.

It has been noted that older NDSs may present with elevated conduct problems because they assume more caregiving responsibilities (Hayden et al., 2019). Whereas other studies have concluded that younger NDSs may be more vulnerable to psychological and emotional impact (Koukouriki et al., 2021; Petalas et al., 2009; Tomeny et al., 2014; Verté et al., 2003). Specifically, they may present with higher levels of externalising problems than older siblings and more psychological difficulties than a normative sample (Hastings, 2003; Tudor & Lerner, 2014). Based on parental reports, Cuskelly and Gunn (2006) reported that increased externalising behaviour was likely to occur in sibling dyads (where disability was present) when children were similar in age. This finding was supported by Rossieter and Sharpe (2001), who integrated the quantitative literature on NDSs, and noted that the negative effects of having a disabled sister are more immediate (evident in younger NDSs), while positive effects present as the NDS gets older. This is attributed to older children, with increased maturity, being better able to understand their disabled sibling's diagnosis (Glasberg, 2000).

2.2.5.3 Gender

Gender has also been frequently identified as a factor influencing the impact of disability on NDSs and their experiences. Some authors have argued that gender has greater impact on the quality of the sibling relationship where disability is present, than age or birth order (Taylor & Hodapp, 2012; Tomeny et al., 2016). For example, Orsmond and Seltzer (2007) reported that sisters are more likely to take on a caring role then brothers. Sisters have also been reported as having closer relationships with disabled brother/sister (Taylor et al., 2016). These findings, however, contradict previous research that indicated that there was more warmth between siblings (where disability was present) in same sex dyads (Begum & Blacher, 2011). Additional contradictory findings argue that there is no clear indication that gender as a factor within the sibling relationship where disability is present, has any impact on NDSs (Petalas et al., 2012). Rather, it has been argued that the interplay between age and gender is more likely to predispose NDSs to psychological and relational impact.

It is therefore evident that attempts to ascertain *if* gender impacts on NDSs' experiences has produced variable findings. To better understand the complex manner in which various informing factors, such as age and gender, may influence experiences, it may be important to ask NDSs' *what being a brother/sister means to them* where they are able to make sense of their experiences and discern what meaning they attach to their unique experiences within their specific context. Meltzer (2015) has emphasised that intersecting factors such as gender and culture do not exist discretely, but overlap with one another, creating contextualised experiences of disability (Goodley, 2011) and relationships (Collins, 2006). In reference to NDSs, Meltzer (2015) argues that "in their enactment of their sibling relationships, these multitude of overlapping influences may then *together* influence their relations with their brothers and sisters" (p. 77, original emphasis).

2.2.5.4 Social support

Authors have further emphasised that NDSs' positive or negative experiences might be better attributed to various social and contextual factors, such as socio-economic challenges. For example, where NDSs live in disadvantaged socio-economic contexts, they may have less access to social services or formal support, and family financial strain may place greater demands on the NDS to help with care (Taylor & Hoddap, 2012). Hayden et al. (2019) hypothesise that growing up with a disabled sibling may indirectly affect a NDS's adjustment, albeit marginally, by directly increasing other risks, such as increasing familial financial demands or parental stress.

Another factor that has been considered is parental mental health and involvement (Hayden et al., 2019). There has been a noted correlation between maternal psychological distress and sibling adjustment (Petalas et al., 2012; Quintero & McIntyre, 2010), and between the behavioural and emotional problems of children with ID and their siblings' psychological adjustment (Hastings, 2007).

A family systems perspective on outcomes for siblings of children with disability (Kovshoff et al., 2017) suggests that the well-being of other family members is also likely to affect sibling psychological adjustment. Orm et al. (2022) additionally noted that NDSs' psychological difficulties strongly correlated with the level of communication between them and their mothers. Laghi et al. (2023) reported where NDSs received adequate support, fewer behavioural problems were reported. It is therefore apparent that while having a disabled sibling may to some degree impact on NDSs' psychological well-being, and this may be direct or indirect impact, there are a multitude of additional factors related to social support.

2.2.5.5 Type and degree of disability

Researchers have also recognised that the type or degree of disability a young person's sibling has may impact differently on their psychological state and relationships (Cuskelly & Gunn, 2006; Skotko & Levine, 2006, 2011), For example, studies utilising a comparative approach have examined the variances between the presence of a sibling with ASD and DS on the psychological impact on NDSs (Kaminskey & Dewey, 2002; Pollard et al., 2013). Through this research it has been deduced that in instances where the disability type or severity informs what might be considered "atypical or disruptive behaviour", or when violent behaviour or communication difficulties are present as a result of the disability, the psychological impact on NDSs has been reported as being greater (Bendrix & Sivberg, 2007; Hastings, 2003; Mascha & Boucher, 2006; Stalker & Connors, 2004; Taylor et al., 2016). In addition, where a disabled sibling has ASD, NDSs may display less prosocial behaviour, whereas there is no difference in the levels of prosocial behaviour in NDSs when their brother/sister presents with physical disabilities or has no disability (Orm et al., 2022). This suggests that when a disabled sibling has potentially higher emotional needs, there may be greater demands on NDSs and their families, and NDSs may experience more psychological impact.

Furthermore, it is reported that where disabled siblings have ASD, there is more frequent inter-sibling conflict, possibly due to some children with ASD displaying unpredictable and volatile behaviours (Orm et al., 2022). It has additionally been noted that where a disabled brother/sister has greater functioning abilities, there is a positive correlation in the relational quality with their NDS (Taylor & Hodapp, 2012).

Related to this, researchers have reported that when NDSs have an adequate understanding or knowledge of the disability, the severity or type of disability may have less of an impact on their relationships with their disabled brother/sister (Mandleco & Webb, 2015). However, the capacity to fully comprehend the disability may be age dependent (Angell et al., 2012) or related to cultural context (Sage & Jegatheesan, 2010; Viswanathan et al., 2022).

As such, it has been noted that the type or severity of the disability may independently be insufficient indicators of negative or positive effect, but, as in the case with other vulnerability factors, act in conjunction with age, gender, birth order, understanding of the disability and context (Petalas, Hastings, Nash, Lloyd, & Dowey, 2009). Therefore, how NDSs experience their life worlds in relation to their disabled brother/sister will be determined by a complex interaction of informing factors that may vary between each individual. It is therefore highly probable that NDSs' experiences are unlikely to be generalisable and require idiographic consideration. Therefore, using a one size fits all approach to create generalisable claims ignores the complexity and nuance of each NDS's unique experience. While recognising that each of these factors may possibly inform NDSs' experiences, and should therefore be taken into consideration, to obtain less conflicting and more meaningful data, recognising NDSs' individuality from the outset seems imperative.

2.2.6 Limitations of measuring and quantifying NDSs' experiences

Research measuring the impact of the presence of a disabled brother/sister on NDSs' psycho-emotional well-being and relationships is valuable for informing service providers where risk or protective factors can be identified. It is emphasised, however, that individual, first-hand accounts of how NDSs' feel about having a disabled brother/sister are necessary to accurately respond to their specific needs and offer appropriate support when or should this be required (Meltzer, 2015).

Furthermore, studies that have largely included predefined objectives, such as aiming to measure psychological or relational impact or the degree to which caregiving roles impact on psychological and relational experiences, deny NDSs the space to discuss the complexity of their experiences and therefore do not allow for a deeper understanding of their experiences that transcend these categories. Furthermore, research that has been guided by the medical model has tended to frame the presence of disability as an anomaly, where NDSs are viewed as being different or abnormal in comparison to siblings where disability is absent. For example, where the non-normative aspects of disability have historically been seen as burdensome or problematic, research has set out to look for evidence of sibling burden. In so doing, researchers may overlook the dynamisms and everchanging qualities of NDSs' experiences and the societies in which they exist. Willig (2001) cautions that fervent efforts to focus on generalising data in fixed themes is problematic as it assumes a single and fixed reality for all and ignores the fact that what is observed and described in research is selective. There is a need for more research that is designed to allow NDSs to discuss their experiences, fore fronting issues and concerns that are important to them, in order to challenge the assumption of a fixed reality.

It is also important to note that most of the research I have reviewed in the sections above has occurred in the Global North and may not be true for NDSs living in non-Western cultures. As such, there is a risk of data becoming outdated with findings potentially being largely inapplicable to the majority world. Meltzer and Kramer (2016) have argued that sibling disability research has often excluded other important areas of focus, such as "exploring common experiences between siblings or the social and political forces shaping their experiences" (p. 17).

Saxena and Adamsons (2013) note that despite the growing body of knowledge pertaining to NDSs, there remains little understanding of their needs and challenges and how best they might be supported. Further, much of the current literature on psychological impact is descriptive and atheoretical. Stoneman (2005), cited in Saxena and Adamson (2013), states:

> There has been a dramatic increase in the size of the sibling disability literature. Our conceptual frameworks and research methods, however, have tended to stay the same. Continuing to ask the same questions in the same way holds little promise for advancing our future understanding. (p. 343)

It is therefore important to reposition ourselves in relation to sibling disability studies, stepping from the somewhat disconnected, objective viewpoint into the proverbial shoes of NDSs, and aim to establish what it feels like to be a NDS, how being a NDS is experienced and what kind of meaning they attach to their experiences of being a sibling (Stoneman, 2005). In the following section I note that researchers have begun to do this by utilising qualitative methodologies.

2.3 Qualitative Literature Investigating NDSs' Experiences

> I found research that says that siblings of people with disabilities are less well-adjusted and are more likely to experience severe behavioural problems than children without a sibling with a disability; that siblings of children with severe emotional disturbances tend to feel overlooked or ignored, suffer from a disproportionately lower share of parental attention, and a disproportionately higher share of parental expectations; and experience "survivor's" guilt for their better health. Other researchers have found, however, that siblings of children with disabilities are more well-adjusted than other siblings—many show more maturity, responsibility, altruism, tolerance, self-confidence, and independence. I relate to all of those findings. (Davis & Salkin, 2005, p. 208)

This extract from an autoethnographic study on the experience of being a NDS eloquently captures how a young NDS might feel all, some or none of these various categorical, comparative findings at any given point in their life. By focussing on predetermined psychological and relational vulnerabilities, there has been little exploration of the meanings attached to the experience of being a

NDS, or how NDSs enact their siblings' embodied disability. Therefore, while we have information on the degree to which disability impacts on the psychological and relational experiences of NDSs, this remains a narrow focus (Pavlopoulou & Dimitriou, 2019). There is still relatively limited information on what the day-to-day relational experiences feel like for NDSs, on what being a NDS means to them. Increasingly, qualitative research with a focus on understanding NDSs' subjective experiences is responding to this gap. In the next section I will review the literature that is concerned with understanding NDSs' experiences from a qualitative perspective.

2.3.1 Thick descriptions of relational experiences

The move toward experiential research has demonstrated that NDSs' might experience a wide range of experiences and that their experiences are more complex and less dualistic than previous recognised (Bendrix & Sivberg, 2007). There is an increasing shift away from describing experience as only positive or negative, to exploring mixed or ambivalent feelings instead (Gan et al., 2016). It is additionally noted that there is greater focus on relational experiences, which are captured in greater detail, and more nuance in NDSs' experiences in relation to their disabled sibling are identified. In this section I review the literature that considers how NDSs experience their relationships with their disabled sibling, their family and their peers.

2.3.1.1 Experiences of the sibling relationship where one sibling is disabled

Meltzer (2015) has highlighted that "disability becomes meaningful through the everyday encounters and interactions that people share" (p. 53). Research that explores how siblings (where one sibling is disabled) interact with one another, and experience their relationships, is important in that it provides insight into how they make meaning of their sibling's embodied disability. Assuming a binary approach when studying the relationships between siblings where one is disabled has, however, proved to be limiting in terms of capturing details that adequately reflect the ways in which NDSs *do* their relationships.

Qualitative researchers (Gorjy et al., 2017; Meltzer, 2015; Pavlopoulou & Dimitriou, 2019, 2020; Riosa, 2023) have, however, responded to the gap in the literature that captures the details of siblingship (where one sibling is disabled) by providing thick descriptions of their experiences. Through these studies it has become evident that NDSs' experiences in relation to their disabled sibling are nuanced. For example, NDSs express divergent attitudes toward their relationships with their disabled brother/sisters (Petalas et al., 2009), acknowledging strong bonds, despite challenges. Some NDSs report feeling pride and affection toward their disabled sibling while simultaneously feeling self-conscious about their disabled sibling in public (Correia & Seabra-Santos, 2022). A study on adolescent, non-disabled sisters from lower and middle-class backgrounds in the United Kingdom (UK), has identified that NDSs may experience "a myriad of feelings" in relation to their disabled sibling (Pavalopoulou & Dimitri, 2019, p. 15) and that "joyful experiences appeared to coexist with frustration" (Pavlopoulou & Dimitriou, 2019, p. 24). For example, NDSs have acknowledged that while having a disabled sibling increased their sense of empathy and understanding of disability, as well as their willingness to cope with being a NDS, they also felt upset, embarrassment, and socially isolated at times (Watson et al., 2021).

What is noted in these findings is the complexity within their experience and the sense of ambivalence they describe, as opposed to only positive or negative experiences. NDSs address the experience of their sibling's disability within their relationships and acknowledge that it can be experienced as being simultaneously valuable and challenging. For example, some NDSs have reported that when their disabled brothers/sisters present with more severe symptoms, a unique sibling bond may be developed:

> I absolutely love my brother so much. I do think it's different than other families. I think the fact that he's nonverbal and has autism, I've had to make an effort to have a relationship more than one would with a neurotypical sibling. I felt like … it was a greater bond. [NT Sibling] (Iannuzzi et al., 2022, p. 2434)

The complexity of the relationship between siblings where one sibling is disabled is as such, increasingly recognised.

As opposed to measuring the impact of disability on siblingship, qualitative researchers have explored *how* siblings spend time together and what it is like to spend time with their disabled siblings. In a IPA study conducted in Canada, NDSs reported that there were times where they felt close, meaningful bonds with their disabled brothers/sisters, as well as times when they felt connecting to their siblings was difficult. Often NDSs indicated that just physical closeness without necessarily planning activities was valuable for fostering close connections (Riosa, 2023). This finding was supported by an IPA study on NDSs in Greece, where non-disabled sisters described their lived experiences with their disabled siblings. NDSs reported enjoying the silence they share with their disabled siblings, where they could feel a sense of togetherness or their connection to one another without having to do anything specific (Pavlopoulou & Dimitriou, 2020). The researchers (Pavlopoulou & Dimitriou, 2020) were able to capture and detail some of the more nuanced, day-to-day interactions that occurred within the sibling relationships. For example, participants reported painting, cycling and singing together, and how through these activities they felt increased love for their disabled sibling. They also acknowledged that managing their brother's/sister's disability was difficult at times, for example they felt guilty about how they had to control challenging behaviour, or sometimes experienced their disabled sibling's tantrums as a form of rejection.

In NDSs' descriptions of their more corporeal interactions with their disabled siblings, the way in which their sibling's embodied disability is experienced and how they made meaning of it, was made evident. For example, some NDSs reported finding everyday outings like going to the supermarket or playground difficult when their disabled brother/sister displayed volatile behaviour due to their frustrations (Pavlopoulou & Dimitriou, 2019). They describe challenges doing their schoolwork due to their sibling's disruptive and distracting behaviour. One participant stated, "It is hard to do your homework in the evening when your brother creates madness all over the place" (Pavloupouou & Dimitriou, 2020, p. 15). Through their descriptions of these experiences, some of the struggles they experience because of their relationships with their disabled brothers/sisters is noted.

NDSs' descriptions of ambivalent experiences, such as simultaneously wanting to be close to their disabled brother/sister and do things together, but also wanting to be able to pursue peer relations and have alone time (Pavlopoulou & Dimitrou, 2019), echo those experiences that occur in a siblingship where neither is disabled. These findings are important in that they challenge previous assumptions about the non-normative nature of siblingship where disability is present and highlight the complexity of NDSs' experience of disability.

Similarly, in her research, Meltzer (2015) highlights that disability can be pivotal for creating space where normative sibling interactions may occur, such as how they talk, bicker or joke with one another:

> Siblings experience disability in everyday relations that have a very commonplace and often normative character: the presence of disability is experienced in a moment of chat, in a brief hand game or tickling, in silent support, argument or banter or in wonder at the thoughts or feelings of one's brother or sister. (p. 151)

In other qualitative research, NDSs have specifically described their relationship with their brother/sister as "normal", but also personally acknowledge the distinctiveness of their situation and how this has informed who they are (Gorjy et al., 2017; Meltzer, 2015). For example, in her study on the relational experiences between siblings with and without disability, Meltzer (2015) emphasises that disability may have a formative role in sibling dynamics, for example, it may inform why and how some interactions happen or how NDSs enact their relationships with their sibling.

Meltzer (2015) elaborates that disability may constitute, create or contribute to the relational experiences between siblings. Where disability contributes to how siblings experience their relationships with one another, it occurs as one of several influencing factors. An example of this is where one NDS spoke about planning her disability accessible wedding. Meltzer (2015) argues that it is likely she would plan a wedding anyway, however, **how** she plans to execute her wedding is partly influenced by her brother's disability. Where disability creates their experiences, NDSs may make choices that are due to their sibling's disability (i.e., deciding to take a university paper on disability because they are largely responsible for caring for the disabled sibling). Where disability constitutes their relational experiences, the experience is expressed through disability and would potentially not occur if disability was not present within the relationship. To this extent, how disability is experienced by various NDSs is based on how they perceive its presence in their relationships with their disabled brother/sister. These findings emphasise the value of qualitative methods that prioritise obtaining first-hand subjective accounts of NDSs experiences in developing an understanding of what disability means for NDSs.

In other qualitative studies, NDSs indicated the way in which their sibling's disability contributed to how they made sense of themselves and their relationships with their brother/sister. NDSs emphasised that the experience of "difference" was prominent in their relationships with their disabled brother/sister and that having a disabled sibling made them feel unique (Gorjy et al., 2017). NDSs experienced their brother/sister as being different to others, emphasising that there were things their disabled siblings could do that others couldn't, and things they couldn't do that others could (such as the way they communicated with one another) (Gorjy et al., 2017). It is important to note that while NDSs described experiencing their relationships with their sibling as different to their relationship with others, they also emphasised that they experienced this difference as being normal for them, and not something they would readily change (Gorjy et al., 2017).

Approaching the study of NDSs' relationships with a focus on their experiences has highlighted the interconnectedness of disability and relational experiences. This allows for a different understanding of disability, where it is no longer simply viewed as impacting on relational experiences, but rather, disability contributes to how siblingship is experienced, and experiences of disability are also informed by relational interactions.

There are increasing efforts to understand relational experiences between siblings (where disability is present), that challenge normative assumptions. Through thick descriptions of NDSs' experiences, researchers have increasingly managed to capture the nuance of the relational dynamic between siblings. However, it is noted that the research reviewed above has focussed on NDSs' experiences of their relationships with their disabled brothers/sisters in the Global North, in contexts where Western cultural values are prevalent. It cannot be assumed that NDSs from non-Western cultures, where beliefs and perceptions of disability and family may vary, will share these experiences.

2.3.1.2 Experiences of family relationships by NDSs

Researchers from the Global North have also considered how being a NDS contributes to the experience other familial relationships.

NDSs described various aspects of their family experiences, including levels of closeness (Mandleco &Webb, 2015), how they perceived their families as both unique and normal (Riosa et al., 2023), how they experienced varying degrees of differential parental attention (Bachraz & Grace, 2009; Mandleco & Webb, 2015) and different kinds of parental pressure (Pavolopoulou & Dimitrou, 2019).

Pavlopoulou and Dimitriou (2019) emphasised that often NDSs described their relationships with their parents through rich descriptions of everyday home routines (however these were not made explicit by the authors). It was also noted that they highlighted "specific events in which their autistic sibling was starring – often displaying behaviour that was unsafe" (2019, p. 17). In so doing the authors indicated that a common experience for them was the sense of frustration they felt in their parent's efforts to "normalise" autistic behaviours, which often led to conflict (Pavlopoulou & Dimitriou, 2019). This is an interesting finding in that it suggests that at times NDSs are more accepting of their sibling's behaviour then their parents may be, or that they, at minimum, may have differing expectations of their siblings. This highlights the value and importance of exploring siblingship in studies on disability, where meanings ascribed to a child's disability by siblings may vary from those of parents.

In a later study by the same researchers (Pavlopoulou & Dimitriou, 2020) NDSs' in Greece described the importance of their relationship with their cousins. Some of the participants described their cousins as their best friends, noting that they provided both support and valuable company. While this was not elaborated on in detail by the authors, it may be speculated that cousins of a similar age may be better able to engage in shared activities that disabled siblings might not be able to because of their disability. To this extent, NDSs may establish ways to have their needs for companionship met by other family members (where they are not always able to be met by their disabled siblings).

These thick descriptions of NDSs' experiences with their parents and cousins provide further detail on how NDSs negotiate their relationships with their disabled brothers/sisters. It is, however, again relevant to note that because most of this research has been conducted with NDSs from families that adhere to a more Western family structure (where the nuclear family model is prominent), familial experiences may differ where families adhere to familism or collectivist cultural values.

Park et al. (2021) recently conducted a phenomenological study on the experiences of Korean adolescents with younger disabled siblings. In this research the participants described their ambivalent experiences with their parents, feeling compassion for their parents while also seeking their approval (Park et al., 2021). Park et al. (2021) noted how NDSs indicated that they may not express the need for parental companionship or support as they perceive their parents to be focussed on their disabled brother/sister. Instead, they tended to minimise their own needs or tried to be good or undemanding to gain their parent's approval (Park et al., 2021). NDSs reported that at other times, they would fake illness to get their parents' attention, but would then feel guilty for adding to their parents' challenges (Park et al., 2021). This research by Park et al. (2021) is valuable in that it provides thick descriptions of NDSs' experiences and contributes to the overall literature on NDSs. It also adds to the minimal body of knowledge on the experiences of adolescent NDSs from a non-Western culture, however, the authors were not explicit about Korean family values or structure in the study. To this extent it is difficult to establish whether the intersecting factor of culture contributed to how participants experienced their familial relationships.

2.3.1.3 Experiences of relationships with peers

The importance of peer interactions during adolescence was noted in the introductory chapter of this thesis (see section 1.7). It is therefore important to understand how having a disabled brother/sister contributes to NDSs' peer relationships and how these relationships might contribute to how they make sense of their sibling's embodied disability.

A notable theme in the literature from the Global North was NDSs' experiences of perceived judgment, and difficulty navigating their peers' lack of understanding in relation to their sibling's disability. Some NDSs' reported that they rarely shared information about their disabled sibling with peers as they did not think their friends would understand, and this was difficult for them (Iannuzzi et al., 2022). Other NDSs stated that, at times they felt embarrassed about their disabled brother's/sister's behaviour in front of their peers, indicating that they had, at times adjusted social interactions to avoid having to navigate their sibling's behaviour when with friends (Hastings & Petalas, 2014; Pavlopoulou & Dimitriou, 2019; Petalas et al., 2013). For example, some NDSs reported no longer being able to have birthday parties at home or inviting friends to their homes due to a brother/sister with ASD's previous behaviour (Gorjy et al., 2017).

Some NDSs also reported that they felt their peers lacked empathy or demonstrated negative attitudes toward their disabled brother/sister (Leedham et al., 2020; Petalas et al., 2009, 2012), and sometimes making friendships was difficult to navigate (Leedham et al., 2020). NDSs, however, reported that school was fun because they got to be with their friends (Pavlopoulou et al., 2022). Leedham et al. (2020) noted that in instances where NDSs' had friends who also had disabled brothers/sisters, they experienced these relationships as valuable.

The limited research from the Global South indicated that young NDSs from South Africa found their friends to be accepting of their brother's/sister's disability (Mophosho et al., 2009), however, no further details on peer relationships were noted by the authors. Research from India indicated that some NDSs experienced the support provided by friends (particularly the older sibling who is seeking coping strategies outside of their family context), valuable in mitigating experiences of social stigma (Viswanathan et al., 2022). It is evident however, that while qualitative researchers have contributed valuable information on the complexity and nuance of NDSs' relationships with their peers, there is an overall paucity of knowledge on NDSs' social experiences.

2.3.2 Caregiving experiences

It is argued that care is embodied and enacted on a daily basis between siblings (Meltzer, 2015). Where some care is considered normative in sibling relationships, irrespective of the presence of the disability, it is important to further understand how young people experience caregiving when disability is present (Meltzer, 2015, 2017). To this extent, qualitative research has elaborated on quantitative findings on the impact of caregiving on NDSs.

Qualitative studies have indicated that young NDSs may take various caregiving roles, or caregiving may look different for different NDSs. For example, they may be involved in their disabled brother's/sister's education, helping with homework, acting as entertainers, providing childcare, and assisting with mobility and medical or sleep routines (Pavlopoulou & Dimitriou, 2019). In addition, some NDSs feel it is their responsibility to advocate on behalf of their non-disabled brother/sister to create understanding and acceptance (Pavlopoulou & Dimitriou, 2020).

In her study on young adult NDSs in Australia, Meltzer (2015) describes how disability-related care at times contributed to participants feelings that their siblingship did not feel the way they thought it ought to. Specifically, she emphasises that where NDSs provide care because of their sibling's disability, it at times "undermined the extent to which they feel like siblings" (Meltzer, 2015, p. 187). In these instances, NDSs reported finding ways of resisting certain kinds of disability-related care, or care that did not feel normative in their relationships by putting certain boundaries in place, to protect their siblingship. To this extent they were able to assume agency in terms of how caregiving contributed to their sibling experiences.

While qualitative findings have provided more detailed and nuanced findings pertaining to NDSs’ experiences of caring for their disabled sibling, there is a significant gap in the literature pertaining to young carers in the Global South where SES and cultural values may differ from those in Westernised contexts (Hamilton & Adamson, 2013). Lane et al. (2015) state that as most black, South African children (83.9%) engage in chores at home (Statistics South Africa, 2011), current understanding of young care, most of which has been developed in Westernised settings, may be irrelevant. There is a notable difference in what might be considered care as opposed to a chore in non-Western contexts; for example, young carers in rural sub-Saharan Africa may be responsible for fetching water due to indoor plumbing being uncommon in many of the informal houses in South Africa. It is noted (Cluver et al., 2012; Evans & Becker, 2009), however, that most recent research on young carers in the Global South has been based on global constructs of childhood, such as the United Nations (UN) Convention’s model of child rights. Therefore, findings pertaining to young carers in the Global South, conducted by researchers in the Global North, have indicated largely negative outcomes or view sibling caregiving practices in the Global South as non-normative (Evans & Becker, 2009).

Cultural values that underpin family practices in many of the populations in South Africa, for example (Albien & Naidoo, 2016; Chataika & McKenzie, 2013), suggest that some young carers may not perceive their caring responsibilities as constraints or non-normative (Lane et al., 2015). For instance, in many African cultures, caring is considered gendered, where girls and women are viewed as natural nurturers and therefore assume more caring roles (Evans, 2010; Evans & Thomas, 2009). In these instances, care is viewed as a moral obligation based on love and familial reciprocity, or what is culturally known as an intergenerational contract (Evans, 2010). This emphasises the importance of being culturally aware when engaging in research on young NDSs engaging in care.

Where qualitative studies on NDSs' experiences of care have been situated in the Global North, researchers have developed insights into how participants think and feel about anticipated care. Some young carers revealed that they did not perceive their future caring constraints as impacting on their current planning (Graff et al., 2012), (Hamilton & Adamson, 2013), nor did they think their caring responsibilities would impact on their intentions to attend university (Hamilton & Adamson, 2013). Other NDSs anticipating caregiving responsibilities did acknowledge worrying about future caregiving (Iannuzi, 2021) as they had witnessed their parents' struggles (Pavlopoulou & Dimitriou, 2019) and feared being unable to meet their disabled brother's/sister's needs (Coyle et al., 2014). It was, however, noted that these concerns could be mitigated when there was adequate future planning available (Coyle et al., 2014). It is important to note that in these instances, the NDSs were not from socio-economically disadvantaged contexts, where being able to go to university might be assumed as a given, or financial restrictions don't impede the possibility of future planning.

Evans (2010) emphasises that the socio-cultural expectations of care in sub-Saharan Africa are also heavily informed by healthcare systems that are overburdened, and the unaffordability of medical treatment, and may therefore be contextually necessary. As such, Evans (2010) notes:

> Geographies of children and youth have demonstrated that children often make significant contributions to the household's productive and reproductive work in the global South, challenging universal models of childhood as a period in which children are cared for within the family home and their time is spent predominantly in full-time education and recreation in preparation for a productive adult life. (p. 5)

Research from the Global North has also considered how parental expectations contribute to how NDSs experience care. Young NDSs reported that while they experienced acceptance, empathy and compassion for their disabled brother/sister, they felt expectations from others, particularly from parents, to care for their sibling as being stressful, especially when thinking about their futures. For example, Pavlopoulou and Dimitriou (2019) noted that when parents' expectations required that NDSs had to take responsibility for certain care-related activities, they were more likely to consider their roles as carers as atypical. However, when NDSs felt that they had agency or were voluntarily involved, they saw their contributions as a means to demonstrate feelings of kindness and love or as normal (Pavlopoulou & Dimitriou, 2019). Similar findings were provided by Petalas et al. (2013), who noted that adolescent NDSs had varied perceptions of responsibility, where some saw their responsibilities as typical to other sibling relationships, while others reported a pronounced sense of duty. In essence, when NDSs experienced agency and value in their caring role, they were less likely to experience care as burdensome (Beffell & Nuttall, 2020; Jurkovic et al., 2005; Pavlopoulou & Dimitriou, 2019). There is a question, however, in cases of significant socio-economic disadvantage, where young NDSs may not have agency in their caring role, about how care then contributes to experiences of siblingship and disability. There is as such a gap in the literature pertaining to NDSs' caregiving experiences in the Global South, particularly in disadvantaged socio-economic contexts, that takes the specific cultural values that NDSs align with into consideration. Given that the current study takes place in a socio-economically disadvantaged context in the Global South, it is important to establish what is currently known about NDSs where socio-economic context and culture have contributed to their experiences. I will consider this literature next.

2.3.3 Qualitative research on NDSs' experiences that has emphasised socio-economic and cultural context

My review of the literature to this point has highlighted the overall need for research that considers how young NDSs from non-Western cultures and disadvantaged socio-economic contexts experience their sibling's embodied disability. Meltzer (2015) emphasises the importance of considering various intersecting factors that may contribute to how disability is experienced by NDSs when she states:

> The relational presence and role of disability is not divorced from social and temporal context … this multifaceted and contextualized role of disability means that, for example, ecological (e.g. family context, policy, services), intersectional (e.g. cultural background) and temporal (e.g. young adult experiences of life stage and generation) influences are relationally formative for siblings and mediate how disability's formative presence and influence appears within the sibling relationship. (p. 237)

In this section I review the few qualitative studies that have paid heed to how socio-economic disadvantage and cultural (where it is non-Western) factors contribute to young NDSs' experiences in relation to their disabled sibling.

2.3.3.1 The role of socio-economic contexts in NDSs' experiences

Socio-economic disadvantage is often listed as an intersecting contextual variable contributing to how disability may impact on NDSs. There is, however, marginal research that has detailed the experiences of NDSs living in disadvantaged socio-economic contexts.

Studies from the Global North on the experiences of young NDSs, that have specially noted socio-economic disadvantage, have included Latino[8] children in America (Kao et al., 2012), and a comparative study between a European American NDS and an Asian American NDS (Sage & Jegatheesan, 2010). Research on young Latino NDSs indicated that living in a socio-economically disadvantaged context contributed to their interpersonal experiences, self-concept and family experiences (Kao et al., 2012). NDSs expressed feeling disappointment at having limited time with peers as they were expected to help with caring for their sibling due to limited resources. Latino NDSs acknowledged that they were frequently absent from school because of their responsibilities at home and with their sibling. Furthermore, low income, and poor housing and living conditions meant that

---

[8] Latinos living in the United States experience disproportionate rates of poverty, low educational and occupational achievement, poor healthcare, and chronic childhood illness and disability relative to non-Latinos (Vazquez-García et al., 1995; Hajat et al., 2000; U.S. Bureau of the Census, 2000 as cited in Lobato et al., 2005).

these siblings experienced a heightened level of psychological and emotional vulnerability (Kao et al., 2012). While these findings are important in that they provide some insight into how SES contributes to Latino NDSs' experiences, SES was only briefly acknowledged in the study and very little detail was provided on what these experiences meant to them.

Sage and Jegatheesan (2010) outlined what the dissonance between their two participants' SES looked like. For example, they noted that the European American participant from a more affluent context "lived in a large home with many toys", the family "had access to many services" for the disabled child; and the "children could play inside or outside in open spaces with a large variety of toys" (p. 100). The socio-economically disadvantaged, Asian American participant, on the other hand, "had few resources at their disposal, lived in a small apartment with a limited number of toys", had limited access to services for the disabled sibling and the "children could not play actively given the apartment guidelines on noise level" (Sage & Jegatheeson, 2010, p. 100). Findings from this research indicated significant variances in the two NDS's experiences, however, because the emphasis of the research was on culture, the authors did not specifically indicate how these differing socio-economic contexts contributed to their participants' experiences. Some inferences could, however, be made. For example, for the more affluent NDS, emphasis on having fun with his brother was a primary theme, where they frequently played video games or basketball together, with no caring responsibilities expected of him. The more socio-economically disadvantaged sibling's parents were noted as being a blue-collar worker and a stay-at-home mother who were both busy and seldom had time for their sons. The NDS experienced ambivalence with regards to his relationship with his brother and they rarely played together, sometimes this was because they could not make any noise because they might upset their neighbours, moreover there was an expectation from their parents that he be a role model to his younger, disabled brother. These findings seem to suggest that socio-economic factors, such as having more access to services (and therefore more parental engagement and support), toys, play time and space to play, may have contributed to how the NDSs were able to engage with their disabled sibling.

We cannot assume that research on NDSs in socio-economically disadvantaged contexts in the Global North is generalisable to that in the Global South. There is a complicated relationship between disability and poverty in the Global South, born out of colonisation, notably restricted resources, and because disadvantaged populations make up the majority rather than the minority (Hunt & Watermeyer, 2017).

Research on the experiences of young NDSs living in disadvantaged socio-economic contexts in the Global South included NDSs from Albania and India. Research on the perceptions and experiences of adolescent NDSs in Albania[9] (Dervishaliaj & Murati, 2014), noted that due to financial restraint, NDSs', particularly sisters', commitment to assuming care-giving roles in Albania were notably elevated. NDSs did not, however, report experiencing their care-giving role as burdensome, largely because of the support they experienced from other family members (Dervishaliaj & Murati, 2014).

NDSs in India acknowledged a general lack of knowledge about disability in their communities which often contributed to experiences of stigma and social exclusion, this being attributed by the researchers to the lack of educational and social services available in disadvantaged socio-economic contexts in India (No further details were provided in either of the studies, indicating a significant gap in the literature pertaining to the experiences of NDSs living in disadvantaged socio-economic contexts, particularly in the Global South where there is a greater prevalence of childhood disability).

Eide and Ingstad (2013) emphasise that while efforts to understand poverty and disability as a global phenomenon are valuable, attention should be given to how variances in contexts, which will differ significantly in the Global South and Global North, frame the experiences of disability. The current study therefore responds to a call for research that considers the interconnectedness of experiences of disability and poverty, by exploring young NDSs in a disadvantaged socio-economic

---

[9] Albania, one of the poorest countries in Europe; according to open data Albania, an average of 20% of its population have lived in absolute poverty in the last twenty years (see https://ndiqparate.al/?p=17298&lang=en).

context in South Africa. In so doing, however, there is also a need to consider additional contextual factors that may inform their experiences, such as culture.

2.3.3.2 The role of cultural context in NDSs' experiences

Where culture is understood to encompass race, ethnicity, religion, language and SES, Lee et al. (2021) argue that the experiences of NDSs from non-Western cultures have been largely underrepresented. Yet, research has indicated that cultural and religious beliefs contribute significantly to how family members experience, cope with, interpret and understand disability, practices and roles and responsibilities of the NDS in their disabled brother's/sister's life (Sage & Jegatheesan, 2010; Tsai et al., 2016). In the case of families with a child with disabilities, cultural factors can affect the ways that families seek help, and approach treatments and resources, and can influence parental coping patterns and child-rearing (Tsai et al., 2016). Further research on the experience of NDSs from culturally diverse backgrounds is required to create relevant and appropriate support services (Kao et al., 2012). Only a few qualitative studies that detailed how specific cultural beliefs and values (other than those from Western cultures) contributed to NDSs' experiences in relation to their disabled brother/sister, and most were located and conducted in the Global North.

Kao et al.'s (2012) research on Latino NDSs noted how the cultural value of familism (cultural construct that prioritises family over the individual, characterised by interdependence and duty to family) was emphasised. As such, NDSs reported being actively involved in their disabled brother's/sister's life, in terms of providing help and supervision. Kao et al. (2012) noted that this was consistent with Latino values where sibling relationships are considered to be of high importance within the family. In this study, parents indicated that they were open about discussing their child's disability with their NDS, in their efforts to socialise the NDS towards the cultural value of family support and obligation. NDSs, however, reported ambivalence pertaining to care responsibilities.

Sage and Jegatheean (2010), who studied the experiences of one European American NDS in comparison to one Asian American (Vietnamese) NDS, described how the Vietnamese NDS was expected to adhere to specific cultural role expectations. This included being a role model and making personal sacrifices which he explained made him feel angry and frustrated, because of the differential parental treatment, but nevertheless was obligated to wear a smile when with his brother because his mother had taught him to do so. As a result, he did not want to play with his brother.

Paul et al. (2022) conducted a phenomenological study on the experiences of NDSs from Latin America, Africa and Asia Pacific. This research, while focussing on the benefits and challenges of having a disabled sibling, and their support needs, did not cite many details of the various cultural norms or practices. It was noted that all participants acknowledged the collectivist aspects of their cultures, and therefore had many responsibilities in the household. This was found particularly in Asia Pacific, where siblings felt conflicted and had difficulty articulating their own needs, in a culture in which it is common for extended family to live together and for siblings to assume responsibility for each other, and for siblings to assume a caregiving role throughout their life span. Similar findings were reported by Visawanathan (2022) amongst siblings in India where cultural expectations focussed on the pursual of collective goals, result in NDSs not reporting their own needs.

Tsai et al. (2018) conducted comparative research on the experiences of NDSs and their mothers from the UK and Taiwan. In their study, the authors (Tsai et al., 2018) noted that filial piety (obedience and respect for one’s parents) is considered a virtue in Chinese culture and this contributes to Taiwanese parents having high expectations of NDSs’ caregiving obligations within the family, and NDSs feeling undervalued at times.

Viswanathan (2022) reported that NDSs from India reported feeling that they had insufficient knowledge pertaining to their disabled sibling’s impairment, contributing to unrealistic expectations for the future and hopes for a cure where this was not possible. Bhattashali et al. (2018) indicated that disability is considered a taboo by many in India who ascribe to the caste system. In Indian societies, socio-religious beliefs and practices have an immense impact on the family. As such, a child’s disability can affect all family members. Furthermore, disabled people are seldom included in community settings, and have very limited access to schools and employment opportunities.

Taiwanese NDSs and their mothers reported feeling stressed and embarrassed about other people's opinions of their disabled child, as such mothers taught the NDSs not to discuss their brother's/sister's disability with others. Stigma pertaining to disability is common in Asian cultures, where the causes of disability are considered to be due to individual wrongdoing (for example, where a mother has not adhered to specific cultural dietary stipulations) or due to divine punishment (Jegatheesan et al., 2010; Tsai et al., 2018). As a result of perceived stigma, NDSs and their mothers are reported to experience guilt and shame and are reluctant to talk about disability or seek out help. These findings were similar to those of Sage and Jegatheesan (2010) who noted the belief about karma and retribution informing a child's diagnosis, and how this contributed to the way parents shared information about their disabled child's diagnosis with his NDS.

Cultural and religious beliefs that hold the aetiology of disability to be the result of punishment from God, deities, ancestors, curses, witchcraft or ill fortune are based on what is typically referred to as the moral model of disability (also referred to as the spiritual, religious or traditional model, depending on its particular cultural orientation) and is one of the oldest ways of understanding disability (Henderson & Bryan, 2004; Visagie, 2015). Goodley (2011) acknowledges that even though it is possibly considered the most oppressive perspective, due to adherent's tendency to shun, ostracise or hide disabled people, as they are seen as defective (and representative of sin), it continues to be prevalent throughout the world. The ongoing prevalence of the moral model can be understood in its embeddedness in cultural lore and religious indoctrination that it is a sin to challenge this lore (Goodley, 2011).

Research conducted in Thailand (Rukwong, 2008), Zimbabwe (Munsaka & Charnley, 2013) and Uganda (Mulumba et al., 2014) noted that disabled individuals who were members of communities ascribing to the moral model frequently reported being ostracised. There continues to be reports of disabled people being denied access, executed due to false beliefs, and hunted for magic potions (Ojok & Musenze, 2019). These spiritual perspectives of disability restrict disabled people in Ghana (and many other countries where the moral model is dominant) from entering education, government or traditional stations (Opoku et al., 2022). As such, many disabled people are forced to revert to illegal begging, perpetually intertwined in the yoke of poverty (Kassah, 2008; Opoku et al., 2022).

A study in Ghana (Opoku et al., 2017) noted that, to avoid stigmatisation, disabled children are at times hidden, locked in a room in the house by their families, so that they cannot be seen by the community or extended family. In these instances, NDSs, as relatives, may bear the same associations of being cursed or belonging to a sinful family. Furthermore, in most instances, there is little opportunity for relational development between them and their disabled brother or sister (Areya, 2022; Opoku et al., 2022).

Similarly, in a study by Paul et al. (2022), African NDSs reported that many people in their families and communities held beliefs stemming from the moral model that resulted in stigmatisation and segregation of their disabled brother/sister. One participant in this study reported how sad he felt when others in his community compared his brother to a “mad creature” (Paul et al., 2022, p. 680). It was also reported by African participants that because of their families’ cultural beliefs about disability, there would seldom be investment in their disabled brother’s/sister’s education. This has been supported by Opoku et al. (2022) who noted that African families adhering to beliefs based on the moral model commonly fear stigmatisation due to negative traditional/spiritual interpretation, frequently resulting in a reluctance to invest in disabled children’s education or providing adult support in obtaining employment. African NDSs in Paul et al.’s (2022) study reported that they personally had to endure unwanted stares from the community when with their disabled brother/sister. Similar findings were noted in India where young NDSs reported discrimination from their peers because of their sibling’s disability, where families were assigned blame for the disability due to past life/karmic behaviour (Bhattashali et al., 2018) resulting in limited social interactions and feelings of isolation (Dervishaliaj & Murati, 2014).

The research discussed above provides valuable insight into how cultural beliefs and practices contribute to the experiences of NDSs in non-Western cultures. Only one of the studies included NDSs from Africa. It included eight male participants between the ages of eight and 25 years from different countries, including Botswana, Kenya, Mauritius, South Africa, Swaziland, Tanzania, Uganda and Zimbabwe; specificities pertaining to race and ethnicity of the participants were not included. The interviews were conducted in English; however, it was not specified whether this was their first language or their levels of language competency. The current study aims to build on the finding from Paul et al. (2022) by adding the voices of nine isiXhosa speaking non-disabled brothers and sisters about their experiences. This work is important in informing theory in this field (McHale et al., 2016) but also to ensure that recommendations for health and education are culturally appropriate (Tsai et al., 2016). It is argued that further understanding of NDSs from various cultural backgrounds is valuable for developing more culturally responsive interventions.

2.4 Summary

In this review I have critically described the body of literature that has measured and categorised NDSs' experiences. While this research adds value in that it identifies risks pertaining to the psychological and relational impact of having a disabled brother/sister on NDSs, further studies are required that incorporate NDSs' subjective, first-hand accounts in order to obtain more specific, nuanced and meaningful data.

I have emphasised that there has historically been a tendency to focus on psychological or relational experiences that compare NDSs' experiences with siblings where disability is not present or categorise their experiences as positive or negative. Meltzer (2015) states that comparative studies, as opposed to viewing disability as an entity that contributes to normative psycho-emotional development, set up any experiences that occur in the context of disability as non-normative. There is therefore a need for research that adopts an approach and method that is able to incorporate the complexity and nuance of NDSs' day-to-day experiences, while not being comparative. In addition, research that has primarily set out to examine psychological, emotional or relational outcomes, or the specific contributing factors to various outcomes, seeing each element as being distinct, risk omission of the complex interplay between each element. That is, relational and psycho-emotional experiences both inform and are informed by one another, and both are informed by the context in which the NDS exists. While qualitative studies have increasingly captured these important overlaps between experience and context, research from multi-cultural contexts and hard-to-reach populations, particularly disadvantaged socio-economic contexts in the Global South, are largely absent.

Based on the identified critiques and gaps in the previous research, this study specifically aims to obtain detailed, first-hand accounts of adolescent Xhosa NDSs' relational experiences with their disabled brothers/sisters. Furthermore, I aim to challenge previously assumed stances that have measured or compared NDSs' experiences and framed NDSs' experiences as being other than normal. Finally, it is my intention to add the voices of adolescent Xhosa NDSs living in socio-economically disadvantaged contexts to the existing research on NDSs' experiences. In the following chapter I will discuss the various theoretical approaches researchers have employed to understand NDSs.

CHAPTER THREE

THEORETICAL PERSPECTIVES OF SIBLING DISABILITY

3.1 Introduction

In this chapter I review the different theoretical perspectives that have been used to study sibling relationships and disability, given that one's perspective of disability will influence how research on disability is approached and the kinds of questions one asks. Through a review of the various dominant theoretical perspective on disability, I will argue for the appropriateness of a critical realist perspective to meet my research aims and answer my specific research questions.

First, I consider the medical model in which disability is perceived as an abnormality located in the individual. Disability is seen as contributing to individual differences that require a cure. Scholars employing the medical model perceive NDSs as atypical, and as such aim to measure the degree to which the presence of a disabled sibling separates them from the norm. I then discuss the Social Model, a perspective assumed by activists and scholars who argue that disability is imposed on an individual by society, through oppression which limits a disabled person's experiences. This is followed by a review of the Social Relational model in which disability is seen as being rooted in social interactions. Next, I discuss the psychoanalytic perspective of disability, proponents of which assert that disability is an intrapsychic experience that influences an individual's actions in response to disability. Critical Disability Studies (CDS), an interdisciplinary approach that scholars have employed to challenge assumptions of normativity, is then reviewed. I follow this with a discussion on Phenomenology, which offers a means to understanding subjective experiences of disability. Finally, Critical Realist perspectives, which offer an approach to understanding the everyday experiences of disability and IPA, my theoretical perspective of choice for this research, are presented.

3.2 The Medical Model

The Bio-Medical or "Medical model" of disability is a way of viewing disability as the negative impact of a physical/cognitive condition that is located within an individual (Oliver & Barnes, 2012; Shakespeare, 2013). Disability is seen as a "personal tragedy" that the disabled individual has to overcome; it is therefore considered as an individualising perspective. From the Medical Model's perspective, disabled people, who do not fit into society's perceptions of normal, are seen as requiring curing, either medical or psychological. As Goodley et al. (2017) have aptly stated:

> When disability is defined as a problem and when that problem is located in an individual's body or mind, then there is only really one way we can go with disability and that is pathologisation. (p. 491)

Approaches to the study of NDSs primarily aimed at measuring how and to what extent non-disabled siblings were affected by the presence of a disabled brother/sister, and how they differed from siblings where no disability was present (as discussed in Chapter Two). Like their disabled brother/sisters, NDSs became viewed as individual, personal tragedies, who, by virtue of having a disabled brother/sister, were seen as different and abnormal, given their predisposition to psychological and relational impact (Meltzer & Kramer, 2016). Where disability has been viewed through an individualising lens, it has been perceived as a physical and social burden and focus has been on the physical, psychological and economic cost for siblings.

Campbell (2008) has argued that the medical perspective has played a significant role in invalidating disabled bodies, which are considered abnormal, or as Michalko (2002) stated, the "body-gone-wrong" (p. 120). Where the body was seen as being "wrong" it was deemed to be in need of rehabilitation or cure. The task of identifying and curing perceived abnormalities due to disability was assigned to non-disabled, medical professionals or therapists, rendering those in their care as "patients", dependent on expert advice and having little agency (Lourens, 2015; Oliver & Barnes, 2012). The medical model thereby enforced a hierarchical social dynamic that gave privileged individuals say over how disabled individuals and their families should live their lives. This included whether they had to be separated from society (institutionalised or sent to special schools), perpetuating a cycle of "dependency and exclusion" (Rieser, 2006, p. 135). Lourens (2015) emphasises that "the medicalisation of disability furthermore separated people with disabilities from mainstream society, since it constructed them as deviant from socially constructed norms" (p. 22).

The medical model, imposed during colonialism, not only problematised individuals, and reinforced power imbalances between "experts" and "patients", but strengthened racial structures in colonised contexts. Swartz and Marchetti-Mercer (2018) note that this is a legacy that continues in South Africa, where racial inequalities, social injustices and poverty (products of colonisation and Apartheid) are persistent. While subsequent disability rights policies have been written into constitution, it is recognised that in South Africa, as in many other countries, legislation sluggishly trails behind more recent approaches to disability that have challenged the medical model. This means that services and healthcare for disabled people continue to be based on the medical model which impacts family members who live with and care for them, including NDSs (Mji et al., 2011; Visagie, 2015). For example, Visagie (2015) points out that in some countries, like South Africa, obtaining a diagnosis is necessary to get access to support services that are specific to disabled people, such as a Disability Grant, or healthcare and occupational accommodations. In this instance, defining disability in a specific way is purpose driven in that it attempts to establish equity, however, a tension is established in that, despite South African policies purporting advocacy for a less individualising approach to disability, that takes environmental factors into account, it continues to focus on individual impairments and diagnoses thereof that are determined by medical experts (Visagie, 2015).

Where an expert role is assumed by someone who does not share the experiences of a person living with disability, their subjective experiences and, therefore vital information about those experiences, may be ignored. Furthermore, when subjective experiences are not considered, change (as in cure, remedy, rehabilitation), should it be required, cannot be made where it is most wanted/needed, as identified by those requiring it. For example, application of the medical model fails to consider the broad, extended family and collectivist values that prevail in many African (and other collectivist) cultures (Chataika & McKenzie, 2013). Understanding social and cultural structures is imperative when conceptualising childhood disability, as these familial values will directly inform the expectations, participation and experiences of those living with disability, including NDSs. Chataika and McKenzie (2013) point out, however, that during colonisation, the introduction of capitalism and urbanisation resulted in the dismantling of the extended family for many, resulting in less support in families with a disabled child. The impact thereof was that disabled children in colonised countries were perceived as problematic and, like many children in the Global North, were institutionalised by missionaries. These practices largely informed and/or compounded the stigmatisation of disability.

In essence, what proponents of the medical model have ignored is that disabled people and their families may not want to be pathologised, cured or changed, wanting instead to be accepted and included as they are (Visagie, 2015). Zaks (2023) eloquently notes that, the

> core aim of the medical model since the 1800s has been to sort people into abnormal and normal categories, with abnormal status denied access to societal resources, curtailing life opportunities, and stripping the individual of power and agency. (p. 5)

The medical model has, as such, been identified as a problematic approach given its tendency to be individualising, non-normative, exclusionary and lacking in subjective perspectives.

Shakespeare (2008) has, however, cautioned that high standard medical intervention should be accessible for anyone living with disability, and in many cases is imperative for managing impairment. As such, intervention should not be criticised, however, the hierarchical manner in which it is disseminated, where those without impairment dictate how best to cure, ease the suffering, normalise or improve the lives of disabled people, should be challenged (Shakespeare, 2008). Furthermore, facilitating inclusion and acceptance, without disabled people and their families being required to alter themselves, requires that change occur socially and contextually.

The medical model's perspective, conceptualising disabled people as problemed bodies by virtue of their inability to participate in society's view of "normal" life, in a "normal" way, resulted in many becoming dependent on medical input, lacking in personal agency and being socially excluded (Beauchamp-Pryor, 2011). The 1960s and 1970s saw disabled activists and scholars in the UK speaking out about their experiences of oppression and exclusion, and from these outcries, a new social perspective of disability was conceptualised. Formalised in the early 1980s (Oliver, 1981), the Social Model saw disability as being better understood by the limitations placed on disabled people by society, and not solely about impairments.

3.3 The Social Model

Early proponents of the Social Model argued that disability was not a tragedy, suffered by individuals, but the result of societies' inability to appropriately respond to the needs of people with impairments (Zaks, 2023). Disability was therefore seen as the result of social oppression and societal barriers (Goodley & Runswick-Cole, 2013). Adherents of the social model of disability acknowledge bodily impairments, but purport that disability should not be seen as a biological deficit, but as the result of unequal access to societal systems, stigmatisation and the socio-economic causes of oppression (Goodley, 2011; Goodley & Runswick-Cole, 2013; Oliver, 2018; Symeonidou & Beauchamp-Pryor, 2013). Society, according to the social model, has disabled people with impairments by limiting educational, occupational and leisure experiences, and in so doing has segregated and excluded disabled people (Oliver, 2013).

Assuming a social perspective challenges the notion that disability lies within the individual but is instead a social problem. It has therefore been recognised as a crucial step in de-individualising disability. By de-individualising disability, focus is shifted from fixing the individual's problemed body to identifying inadequacies in service provision, infrastructure, education and employment accessibility, and how these inform challenging experiences both for siblings with and without disabilities (Arnold et al., 2012; Meltzer & Kramer, 2016; Taylor & Hodapp, 2012).

As such, proponents of the social model of disability view disability as a social issue linked to the spread of capitalist society in which the emergence of capitalist commodity production and exchange has resulted in certain variations of social embodiment being repressed (Curran & Runswick-Cole, 2014; Thomas, 2007).

For example, it has been documented that many NDSs will at some stage across their life course assume some form of care for their disabled brother/sister (Harland & Cuskelly, 2000; Seltzer et al., 2005). Care provided by NDSs may be instrumental, physical or emotional (Seltzer et al., 2005). Where disabled people are socially and economically excluded from society, this may create additional responsibility for the NDS (Tozer et al., 2013). In arguing against oppression and exclusion, and more opportunity for participation, social model supporters aimed to establish more autonomy and independence for disabled people. In so doing, this would alleviate some of the care required by NDSs.

Due to its focus on challenging the oppressive, socio-economic exclusion of disabled people, the British social model is also commonly referred to as the "materialist model" (Thomas, 1999). Viewing disability through a less medicalised and more materialist perspective has been argued as being important in a socio-economic climate where welfare services are shrinking and the importance of economic participation is emphasised (Meltzer & Kramer, 2016). For example, in many countries, workforce-leave policies have not permitted sibling carers to take authorised family leave. This has particularly impacted on those NDSs in disadvantaged socio-economic contexts who assume low-paid roles with little flexibility. This has been reported as restricting NDSs from being able to adequately care for or spend time with their disabled brother/sister (Meltzer & Kramer, 2016).

Meltzer and Kramer (2016) note that:

> By stepping back from individualized approaches, it is possible to examine the economic policy considerations that shape the lives of siblings. (p. 17)

While the social model, in challenging individualising perspectives of disability, has been a useful political tool for exposing societal oppression, it has not been without criticism (Shakespeare, 2015; Visagie, 2015). Shakespeare (2015) argues that the challenges disabled people and their families face are not only related to oppression. Although impairments are acknowledged in the social model, overemphasis of societal oppression risks detracting from the possible pain or suffering, the "harsh realities" of living with an impairment (Goodley & Runswick-Cole, 2011). Separating impairment from disability arguably creates yet another binary understanding of disability (Goodley & Runswick-Cole, 2011; Shakespeare, 2013). The implications of this for NDSs include minimising the real, day-to-day challenges that may occur, due possibly to bodily pain their brother or sister may endure because of their impairment, and the need for medical intervention. Lourens (2015) reinforces the viewpoint that those approaches focussing on the oppressive attitudes of others are oversimplistic and cannot change how a person physically and psychologically experiences their impairment. There have consequently been arguments for an approach to disability that allows for a continuum of experience and takes the person, including their internal and social experiences, into account (Watermeyer, 2012).

The social model has also been criticised for conceptualising disabled children as a homogenous group, ignoring the possible differences in their experiences as a result of ethnicity, gender, nature of impairment and socio-economic context (Watson, 2012). Meekosha (2008) emphasises that the conversations pertaining to human rights and independent living for disabled people have not considered people in the Global South, where, for many, their primary concern is with survival. According to Meekosha (2008), "In this context, concepts of disability and impairment seem hopelessly inadequate, and the concept of social suffering may be more appropriate" (p. 5).

While its primary focus has been to de-individualise disability, as a Western construct, the social model has prioritised independence and autonomy, self-sufficiency and determination centred on the individual (Grech, 2012). It has, therefore, been further criticised, in that it loses applicability when applied to collectivist cultures, such as many of those in Africa, where people adhere to the principles of *ubuntu* and interdependence is an important value (Chataika & McKenzie, 2013).

3.4 The Social Relational Model

The social model's focus on the societal barriers that cause disability has been acknowledged as being valuable in challenging individualising perspectives of disability, however, the lack of emphasis on the body, the reality of the effect of impairment on a disabled person's life, has been recognised as being problematic. In response, some disability scholars argued that "people are disabled both by social barriers and by their bodies" (Shakespeare & Watson, 2001, p. 17). These scholars devised the social relational model, where Thomas (1999) subsequently suggests the following definition of disability:

> Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing. (p. 60)

That is, it was recognised that impairments may cause a certain amount of limitation, however, disability is rooted in oppressive, unequal social relationships, such as racism or sexism. These in turn manifest as a barrier "to being" within the life of the disabled person (Thomas, 1999, 2010).

These barriers "to being" are the result of two factors; "psycho-emotional disablism" caused by the unaccepting attitude of others and "impairment effects" (such as physical discomfort or restrictions in activity) which are in turn caused by the experience of living with a disability. Watermeyer and Swartz (2008) elaborate on the psycho-emotional aspects of disability, highlighting how distorted personal and psychic boundaries between disabled and non-disabled people serve to further entrench oppressive dynamics and barriers to being in the world. The authors argue that distorted personal and psychic boundaries, as the result of skewed socialisation processes and inaccessible resources are central to the lived experiences of disabled people and ultimately contribute to internalised disablism. Contributory factors to psycho-emotional disablism include downplaying one's disability to make others feel at ease, colluding with inappropriate helping responses from the non-disabled, or allowing for boundary confusion to occur when assistance is required due to limited available resources (Watermeyer & Swartz, 2008). Following this, it could be argued that NDSs contribute to psycho-disablism themselves, by playing down their sibling's disability in their relationships with other people, or taking on more responsibility than necessary, which may undermine or devalue their sibling's autonomy.

Reeve (2014) argues that psycho-emotional disablism acts at an inner, personal level, but occurs because of stigmatisation. NDSs have frequently reported incidents of bullying and felt discrimination, which may be linked to Burke's (2010) thinking that NDSs experience disability by association (Scavarda, 2023; Stalker & Connors, 2004). Disability by association, according to Burke (2010), entails discriminatory experiences of NDSs because of their disabled sibling's difference, which may then be internalised as oppressive or empowering when challenged or overcome. Scavarda (2023) has equated psycho-emotional disablism with the idea of "felt stigma", or the internalisation of shame and worry about experiencing enacted stigma, and the consequential rejection and discrimination that may occur. Scavarda (2023) states that "Siblings are in an intermediate position between their family and the social context that considers disability a form of abnormality, and they strive to find a balance between them. They often push the boundaries of normalcy to include their brother's or sister's characteristics – of which disability is only one" (p. 5). It is stressed, however, that the concept of disability by association is not intended to reflect all NDSs' experiences but is useful when trying to understand relational interactions that contribute to the lived experiences of NDSs, such as psycho-emotional disablism (Scavarda, 2023).

The social relational model offers value in that it provides an understanding of how impairments are experienced and impact overall engagement with life (Thomas, 2010; Watson, 2012). When applied to the study of NDSs it provides a way of conceptualising NDSs' experiences in both micro- and macro-relational contexts. For example, a relational perspective provides a means of developing an understanding of NDSs' experiences within their sibling, family and peer relationships, as well as community and contextual engagement, and may therefore be more applicable to collectivist cultures. When aiming to understand the subjective experiences of NDSs, a possible limitation of the Social Relational Model may be its tendency to presuppose that everyone ascribes to its particular perspective of disability, in viewing disability through a specific theoretical lens, there is a risk that those experiences of disability that exist outside of a social relational conceptualisation may be missed.

3.5 Psychoanalytic Perspectives

Proponents of the psychoanalytic perspective of disability recognise contributions of the various socially informed models of disability, however, they argue that when the focus is primarily on social experience, internal experiences such as thoughts and feelings may be ignored. For an all-encompassing understanding of disability experiences, approaches to disability should be extended to consider the effect on the internal experiences of the disabled person (Watermeyer & Swartz, 2008). Watermeyer (2009) defines the psychoanalytic perspective of disability as:

> A means to begin to interrogate the phenomena of the intrapsychic world, toward developing an understanding of how these processes in turn profoundly influence and shape collective action within society. In the case of disability, psychoanalysis directs our attention at the unconscious meanings with which bodily difference is imbued, and beyond, toward and analysis of how universal anxieties regarding these evocations manifest in oppressive social formations. (p. 61)

As with the socio-relational model, a psychoanalytic approach to disability draws on Thomas' (1999) concept of psycho-emotional disablism and recognises that, if psycho-emotional experiences of disability are not considered, there is a risk of losing subjectivity, given that a significant part of the disabled person, their internal experiences, become obscured (Thomas, 1999; Watermeyer, 2009; Watermeyer & Swartz, 2008).

By ignoring the psycho-emotional experiences of disabled people, oppressive forces are perpetuated. For example, Watermeyer and Swartz (2008) state that when no space for conversations pertaining to the psychological experience of impairment is created for disabled people or their families, they may experience shame and feel required to subjugate their needs.

Normalising talk and disclosure about impairment experience is essential to challenge non-disabled people's discomfort, which at times causes those with impairments to disguise how they feel. As a result of the discomfort pertaining to impairment experienced by a non-disabled society, disabled people may feel obligated to shield others from their discomfort. In turn, they may begin to interpret their emotional experiences as dangerous and unacceptable to others. In essence, a significant part of the disabled person's self must be hidden, leading to feelings of inauthenticity and invisibility. An example of this in relation to NDSs was noted by Scavarda (2023), where adult NDSs retrospectively acknowledged how, when young, they were rarely able to talk to their parents about their sibling's disability which was the cause of anxiety for all family members, and which in turn was not spoken about. Furthermore, this added to their experience of embarrassment about their sibling's disability when they were with their peers.

To navigate feelings of discomfort, the psychoanalytic approach to disability recognises the range of strategies both disabled and non-disabled people might employ in their interpersonal relationships. For example, non-disabled people may collude with a disabled person's subjugatory behaviour, a suppression of personal experiences of psychological difficulty and needs, as described above (Watermeyer & Swartz, 2008). As a result, a disabled person's capacity to accept the shameful parts of self and become more integrated or self-compassionate, which are psychoanalytically considered to be important psychological processes, are impeded.

Furthermore, where society ignores a disabled person's subjective experience, they may, due to their own discomfort, feel the urge to fix what they perceive to be lack or incapacity. To ease the discomfort displayed by non-disabled people, a disabled person may accept and be grateful for assistance that has not been requested. When non-disabled people are unable to remedy or right the perceived wrong in a disabled person's experience, their discomfort may result in their experiencing feelings of helplessness and withdrawing from, rejecting or blaming disabled people (Watermeyer & Swartz, 2008).

Psychoanalysis offers value as an approach to disability in that the NDS's subjective experiences are conceptualised as being on a continuum, and dichotomous thinking is challenged. By way of example, in an application of psychoanalysis to disability, Watermeyer (2006, 2009) considers how defence mechanisms, such as dissociating from pain and vulnerability, assists individuals in maintaining psychic equilibrium in response to disability.

Watermeyer (2009) suggests how a psychoanalytic perspective offers an in-depth means of shedding light on how disability dichotomies may be reified in sibling experiences. For example, parents may, in their anxiety pertaining to their disabled child's capacity to cope, project a sense of vulnerability or neediness onto them. Whereas they might project independence, strength and possibly maturity onto the NDS. Each child may consequently internalise these parental projections and the NDS may consequently experience guilt and feel to be the undeserving survivor or needing to meet parental expectations.

Advocates of the psychoanalytic perspective have further argued the importance of considering the bi-directionality of relational dynamic where disability is present (Watermeyer & Swartz, 2008). Specifically, it has been emphasised that there is a risk when disability is viewed only as the result of social oppression, where disabled people and their families (including NDSs) are seen as passive participants. This may perpetuate thinking of disabled people and NDSs as victims (Watermeyer & Swartz, 2008).

To challenge being perceived as tragic, disabled people may engage in compensatory behaviours. That is, they may feel the need to demonstrate their capabilities through extreme resilience or achievement, thus perpetuating the individualising, tragic/overcoming dichotomy. Alternatively, disabled people may attempt to disguise their levels of impairment to ease the discomfort experienced by non-disabled people, and in so doing thwart the possibility of being known or seen in a real or authentic way.

While psychoanalysis proves to be a valuable perspective in terms of developing an in-depth understanding of NDSs' internal experiences in relation to their disabled sibling, there is a risk that those applying psychoanalysis, who are considered specialists, are in danger of reverting to a top-down or expert approach (Saville Young, 2009). Long (2002) has argued that researchers assuming such an expert stance can obscure what is actually being said by participants, thereby losing the reality of their experience, which is imperative for this particular research. Furthermore, it has been argued that being overly invested in an individual's internal experiences again risks excluding society's role in disabling practices, reverting to medicalised perspectives (Barnes & Mercer, 2004).

3.6 Critical Disability Studies

Critical Disability Studies destabilises ableist constructs that hold "perfect, species typical" bodies as the corporeal standard, and as such, distance disabled people from the so-called norm (Campbell, 2001). By offering new ways of theorising disability that emphasise the value of human variation, CDS aims to positively recognise previously considered minority identities. In a move to claim recognition in a previously socially oppressive context, disabled people are said to embody "the deconstruction of ableism and the celebration of difference" (Loja et al., 2013, p. 191).

Shildrick (2009) describes CDS as a transdisciplinary approach (overlapping with other disciplines, including feminism, race, queer, post-structuralism, post-colonialism) that aims to challenge conventional meanings that are associated with disability. It encourages us to re-think the relations between disabled and non-disabled people, while recognising that normative assumptions are embedded in our conscious and unconscious conceptions of the world.

In response to previous perspectives of disability, CDS scholars encourage us to challenge conceptualisations of disability such as, good/bad (moral perspective), normal/abnormal (medical perspective), disability/impairment (social perspectives), and relational/personal (social relational perspective). Goodley et al. (2019) state that in doing so, CDS "troubles dominant notions of what it means to be human" and "celebrates the disruptive potential of disability to trouble these dominant notions (p. 972). For example, Goodley and Runswick-Cole (2013) describe how a CDS approach to understanding the "leaking, lacking and excessive bodies of disabled children" views their bodies as differently embodied, providing "opportunities for emancipation" from being viewed as non-normative (p. 2).

Proponents of CDS have argued that the intention is not to erase what previous theories have contributed to the field of disability studies, but instead to challenge established perspectives, while simultaneously incorporating other critical ideas (Goodley, 2016). For example, while the Social Model has received notable critiques for it dualising tendencies, Meekosha and Shuttleworth (2009) emphasise:

> We believe that it is not a question of including the social model as one of a number of separate tools in our analysis, but rather of incorporating a more complex conceptual understanding of disability oppression in our work that nevertheless still employs key ideas about disability that saw the light of day with the ascendance of the social model. (p. 50)

In remaining open to various social, political and psychological perspectives, CDS adherents aim to create ongoing, self-reflexive discourse, pertaining to disability studies, that enables a more complex, nuanced understanding of what it means to live with disability (Goodley et al., 2019). For example, various authors (Goodley, 2007; Goodley & Runswick-Cole, 2011; Hodge & Runswick-Cole, 2013) have noted that CDS takes a critical perspective on the familial experiences (including siblings) of disabled children, to determine how various family members challenge "professional and/or public coding's in order to create their own meanings" (Meltzer, 2015, p. 50) of embodied disability.

CDS has been recognised as valuable in that it has provided space for gaining understanding of similarities as opposed to differences that exist between disabled and non-disabled people. CDS directly responds to previous trends that have aimed to discern what makes siblings who have disabled brothers/sisters different in relation to those sibling dyads where disability is not present.

Several scholars influenced by CDS have noted the dominance of theoretical perspectives on childhood disability from well-resourced contexts, largely in the Global North (Chataika & McKenzie, 2013; Meekosha & Shuttleworth, 2009; Mgwili & Watermeyer, 2006; Mji et al., 2011; Moodley & Graham, 2015; Schneider, 2009; Swartz, 2014; Watermeyer, 2012). There has been an argument (Grech, 2009, 2011, 2015) for relevant and applicable models with which to conceptualise disability in the Global South and emphasise the social and cultural legacy of (including but not limited to) urbanisation, colonialism and Apartheid (in South Africa) (Berghs, 2017; Grech, 2012; Livingston, 2006; Meekosha, 2011; Ned, 2022; Nyangweso, 2018; Sefotho, 2021). CDS does this by questioning and interrogating the dominant perspectives of disability originating largely in the Global North (Titchkosky, 2000).

Grech (2013) emphasises the importance of paying attention to the spatial, social, cultural and economic dimensions when analysing the experiences of disabled children. He argues that assuming any unified model, particularly when premised on constructs from the Global North, is problematic when considering young people in a global context (Grech, 2013). Several CDS scholars have subsequently argued for a Southern Theory, or for CDS to be decolonised (Ghai, 2012; Meekosha, 2008, 2011; Meekosha & Soldatic, 2011). Ghai (2012) contends that "overbearing and sweeping theories" stemming from the Global North fail to acknowledge the complex interplay between disabled bodies and cultural, religious, and medical practices that contribute to meanings of disability in the Global South (p. 273). A decolonising or Southern approach to disability recognises the influence of the violence of colonisation on the prevalence of disability in the Global South and has argued for a recognition of the intersectionality of disability, race and gender (Hollinsworth, 2013).

It has been argued by CDS scholars, that in addition to considering cultural diversity within disability studies, when thinking and theorising about disability, the importance of acknowledging the body in everyday life is imperative (Turner, 2001). Zola (1991) emphasizes bringing "bodies back in" validates impaired bodies within disability discourse (as cited in Loja et al., 2013). Debate about the body and impairment is re-emerging within the dis-ability[10] movement (for example, Shakespeare, 1992; French, 1993). The movement has been recovering this lost corporeal space, and as Hughes and Paterson (2006) emphasise, "disability is experienced in, on and through the body, just as impairment is experienced in terms of the personal and cultural narratives that help to constitute its meaning' (p. 101).

CDS has however been criticised (Watson, 2012). Specifically, it has been emphasised that while CDS offers a platform to challenge various conceptual aspects of disability, denying simple categories does not necessarily lead to change, such as the active challenging of discriminatory and exclusionary practices (Vehmas & Watson, 2014). In addition, CDS has been criticized in that it does not consider the practical everyday aspects living with disability entails (Vehmas & Watson, 2014).

3.7 The Critical Realist Perspective

In my review of the previous theoretical approaches to disability, I have thus far recognised how proponents of the medical model construe disability as an abnormality situated within the individual, thereby positioning NDSs' experiences as problematic. I have discussed the social model's value in de-individualising disability, however, I have also noted that adherents of the social model presuppose that NDSs' experiences will be predominantly socially informed. Similarly, a social relational approach assumes that all NDSs' experiences will be informed by interactions with others. With this assumption, NDSs' who may have experiences of disability that deviate from this conceptualisation may be ignored. Furthermore, both approaches overlook the fact that NDSs' have differing social and

---

[10] Goodley (2018) argues the use of the term dis-ability illustrates the tension between the binaries of ablism and disablism that CDS aims to challenge.

relational experiences that are unique to them and alter over their life course, therefore risking homogenising their experiences. As such, I argue that an appropriate approach will be able to capture the unique subjective account of NDSs by challenging the tendency to homogenise experiences, while similarly allowing for examination of internal, relational *and* contextual experience.

Psychoanalytic approaches to disability have considered a continuum of experience, taking a person, including their internal and social experiences, into account (Watermeyer, 2012). With its strong theoretical underpinnings, there is a risk however, that a top-down, expert approach will dominate the way in which participants' meanings are understood, as opposed to allowing meaning-making to occur at an individual level. Critical Disability's capacity to challenge dualistic categories and labels is recognised as valuable in that it has provided space for gaining understanding of similarities as opposed to differences that exist between disabled and non- disabled people. CDS directly responds to previous trends that have aimed to discern what makes siblings who have disabled brothers/sisters, different/abnormal in relation to those sibling dyads where disability is not present. It has, however, been argued that in the commitment of CDS to discourse, there is a risk of becoming intertwined in ideology and theory, thereby limiting the efficacy of research, which may not allow for tangible impact; CDS thus "has no conception of the real" (Watson, 2012, p. 198). Furthermore, as with previous approaches, there is a presumption at the outset to challenge normativity.

Critical Realism in turn, offers an alternative way of conceptualising disability. The critical realist approach has been largely informed by Bhaskar and Danermark (2006), who purported that the study of disability should take into consideration the complex interplay between biological, psychological, psychosocial, emotional, socio-economic, cultural and normative factors. Critical realist proponents argued that disability exists within each of these domains simultaneously, at varying degrees, at different moments in time, whether a person has awareness of this or not. Certain domains may be forefronted at certain times, while others are not. As such there is an ongoing flux of experience. Therefore, critical realism acknowledges experiences of disability are highly nuanced.

Furthermore, each individual may have a different experience of disability based on their particular social, physical, cultural, psychological predicament, their experience will therefore be unique to them. As such critical realism cautions against viewing NDS's experiences as being homogenous.

The critical realist perspective offers a means to understanding the everyday experiences of living with disability as it is for the person living with it. There is no agenda aiming to illustrate a predetermined conceptualisation of disability. Similarly, critical realists do not view the body in a predetermined way, rather the intention is to understand how each individual experiences their own body and embodiment of various phenomena, including disability, is unique to each individual. For example, critical realist disability theorists (Shakespeare, 2006; Shakespeare & Watson, 2001, 2010; Watson, 2012) emphasise the importance of recognising the reality of living with an impairment. Watson (2012) argues:

> A critical realist agenda enables us to move beyond debates about what is disability and how it should be defined and what is or is not an impairment and what is the relationship between impairment and chronic illness and disablement. It also permits an examination of the experiential basis of impairment and an exploration of the day-to-day problems associated with living with a condition without reducing the disease to a social construction or creation. (p. 137)

Critical realists have additionally highlighted that many previous models that have been applied to childhood disability were conceptualised for adults and may therefore ignore important discrepancies between adult and childhood experiences (Watson, 2012). In addition, the critical realist perspective of childhood disability also offers value in its inclusion of contextual elements, such as socio-economic status or culture, that inform the experiences of disabled children and their families. Watson (2012) argues that a critical realist approach allows disabled children to be active participants in the research relating to their experiences, takes the heterogeneity of their experiences (social, impairment, gender and familial) into account. In addition, a critical realist approach accommodates for the rapid changes that occur within childhood development, explores the diversity of impairment experiences and is cognisant of factors related to disablement, oppression and exclusion (Watson, 2012). As such, a critical realist approach recognises the lived experiences are particular to whoever is having that experience.

In her application of the critical realist disability approach to sibling relationships, Meltzer (2015) determined that how disability is experienced within a sibling dyad is dependent on who perceives it, that is, who they are and what their positioning to disability is. Therefore, non-disabled siblings and disabled siblings may have different experiences of disability that are not static, but subject to change depending on a myriad of contextual and temporal influencing factors and do not need to be positioned as being non-normative.

My aim in this study is to develop an understanding of how participants describe, understand and make sense of their lived experiences of being a Xhosa adolescent NDS from a disadvantaged socio-economic background in relation to their disabled brother/sister. My intention is not to impose a theoretical or political agenda, pertaining to disability, onto their meaning-making, but rather to explore their experiences in light of the meanings they ascribe to them, however they understand them. In order to accomplish this aim, I argue that the Critical Realist perspective of disability is most appropriate.

3.8 Summary

In this chapter I have reviewed various dominant theoretical perspectives of disability, considering their strengths and limitations, I have noted how the medical model construes disability as being an abnormality existing within the individual, the social model presupposes that all experiences relating to disability would be informed by society and the social relational model assumes people are disabled primarily through their interactions with others. In turn I have identified how psychoanalysis risks applying a theoretically heavy, top-down approach to disability which may dominate how an individual's meaning pertaining to their experiences are understood , thereby impeding an exploration of their meaning making at an individual level. I have also described how CDS, while acknowledging previously marginalized minority groups (recognizing how disability intersects with race and gender for example), challenges categorical conceptualisations of disability, it has been criticised for becoming intertwined in ideology and losing touch with real, everyday experiences of disability (Watson, 2012).

I have argued that approaches with specific agendas and theories used to challenge previous, problematic constructs (such as inaccessibility, oppression) tend to lose focus of the actual experiences of the participants and result in creating homogenous perspectives. Furthermore, many of the studies pertaining to childhood disability to date have been approached through theoretical lenses that have stemmed from affluent contexts in the Global North and have ideologies that are not applicable to Xhosa adolescents from disadvantaged socio-economic backgrounds in the Global South. I have therefore argued that locating my research broadly within a critical realist perspective is aligned with the aims of the current study in that it offers a means to understanding the everyday experiences of living with disability as it is for the person living with it. In the following chapter, I present Interpretative Phenomenological Analysis, which has its roots in critical realism as my methodology of choice.

CHAPTER FOUR

METHODOLOGY

4.1 Introduction

In my review of the literature on NDSs, I have noted that while there have been increasing efforts to gain understanding of young NDSs' experiences and meaning-making, there is still relatively little research that has explored the experiences of NDSs in disadvantaged socio-economic contexts. Thus, an understanding of their lived experiences and the meanings they have attached to their experiences has been largely neglected. Furthermore, through a review of the theoretical approaches utilised in previous studies, I have argued for locating this research within a critical realist perspective to emphasise the subjective, nuanced, day-to-day experiences of NDSs, particularly those in hard-to-reach contexts as they occur for each individual. In the following chapter I provide a detailed discussion of Interpretative Phenomenological Analysis (IPA), a critical experiential approach, with a primary interest in meaning, subjectivity and experience, demonstrating its methodological applicability for this study.

IPA, is an epistemological framework and methodology, introduced by Johnathan Smith in 1996, in an effort to develop a different, yet parallel approach to experimental (or positivist) and experiential (or interpretivist) methodologies in psychological research (Shineborne, 2011). IPA is epistemologically rooted in critical realism (Bhaskar, 1978) and the social cognition paradigm (Fiske & Taylor, 1991) and has phenomenology, hermeneutics and idiography as its theoretical underpinnings (Smith, 2007). The following chapter provides a detailed description of each of these theoretical underpinnings and how disability, specifically NDS is considered within each.

4.2 Phenomenology

Phenomenology is a philosophical movement, which emphasises the value of insight into personal experiences in an attempt to understand human phenomena, as opposed to scientific, individualistic approaches that focus on causality (Shinebourne & Smith, 2010). Phenomenology offers space to understand subjectivity, in that it prioritises how individuals experience and make meaning of their day-to-day lives, and is as such, focused on lived experience (Smith et al., 2009).

Where Critical Disability Studies have emphasized the importance of bringing the bodily focus back in disability studies, Phenomenologists pay specific attention to how the body facilitates subjective experiences through embodiment. The term "embodiment" is used to capture the notion that conscious human beings are intertwined with their external world in intricate ways. Husserl (1927 as cited in Paterson, 2001) introduced the concepts of *Leib* and *Körper*. *Körper* conceptualises the body as an object, that is corporeal, organic, and is in constant physical interaction with material forces such as temperature or disease and is subject to the laws of physics and scientific and medical evaluation. *Leib* is a conceptualisation of an animated body as subject, or the living centre of experience, how we meaningfully perceive the world (Jensen & Moran, 2013). These experiences of body occur simultaneously, *Körper* enables meaningful experience of being (*Leib*), while our meaning-making (*Leib*) becomes embodied in our physical being (*Körper*) (Jensen & Moran, 2013).

The experience of *Leib* and *Körper* occurs within a dynamic, changing world, and therefore a person is in perpetual adjustment to its context (Jensen & Moran, 2013). This understanding is valuable in that it captures the uniqueness and nuance of each person's experience within their specific context. Embodied experience also incorporates temporality, the fact that people's physicality continuously changes through time, from birth to death and this occurs within a particular context and moment in history. Embodied experience includes both our intentional interaction with the world around us, and our day-to-day habitual practices. Furthermore, we can continue to have experiences of an object that are not immediate or tangible through memories or fantasies. Importantly our embodied experiences occur in relation to others. Through our interaction with others, or intersubjective experiences, we co-create embodied experience (Jensen & Moran, 2013).

Applied to the experience of disability, an impaired body object (*Körper*) and disabled social subject (*Leib*) become intertwined. The meanings we construct through our physical experiences are simultaneously enacted on a day-to-day basis by our bodies. Where the body is understood as both object and subject, a phenomenological approach is able to uncover socially oppressive structures, while simultaneously understanding personally lived experiences (Paterson & Hughes, 1999). Paterson (2012) explains that a phenomenological approach to disability recognises that, "Unlike the non-impaired body, which is customarily 'unaware' of itself until it is confronted by pain or discomfort, the impaired body can also be stunned into its own recognition by the disablism that permeates everyday life" (p. 608). This experience occurs precisely because the social world has been created both for and by non-impaired bodies, where the impaired body is considered a misfit (Garland-Thompson, 2011), referred to by Hughes and Paterson (1999) as dys-appearance. Dys-appearance is a form of everyday felt oppression for disabled people in the felt mutual interaction between their bodies and the social world.

Hughes and Paterson (1999) propose that impairment may be seen as social, and disability seen as embodied, thereby enabling a "sociology of impairment" and "embodied disability" (Hughes & Paterson, 1997). The authors (Hughes & Paterson, 1999) therefore suggest that a phenomenological approach to disability would highlight the fact that the impaired body is situated biologically, historically and culturally.

Embodied disability, according to Titchkosky (2000), is demonstrated in day-to-day narratives and behaviour in relation to disability and will therefore infiltrate into our everyday discussion and interactions with those around us. Making sense of disability, according to Titchkosky (2000), occurs between people and not just within the individual, through everyday, taken-for-granted conversations and enactments of disability. The everyday enactment of disability thus becomes a shared experience through which meaning is made for all the participants. The young sibling of a disabled person may in turn, through shared meaning and enactment, incorporate embodied disability into their identity (Titchkosky, 2000). Titchkosky (2000) additionally highlights that "people make relations with what has made them" (p. 198). From this it might be inferred that a young person's day-to-day experiences with their disabled sibling will be incorporated into their selfhood and may inform how they go on to interact with others. Therefore, embodiment informs how relationships between siblings (where one sibling is disabled) are enacted. Through a phenomenological application of embodiment to disability, disability informs relational experiences and relational experiences will inform disability experiences (Meltzer, 2015). Where the physical and social experiences of the body are perceived as being so intimately interwoven, the risk of polarising the body is mitigated. A phenomenological approach is therefore invaluable for studying disability as a phenomenon, when the intention is to understand how groups of people, such as NDSs, from a particular context experience disability, and how disability informs their lived experience.

4.3 Interpretative Phenomenological Analysis

There are two approaches to phenomenological inquiry, descriptive phenomenology and interpretive phenomenology. IPA incorporates both approaches. Descriptive phenomenology, developed by Edmund Husserl (1927), aims to describe lived experiences in their essence. Interpretive phenomenology aims to uncover the meanings behind what is stated at face value, while simultaneously recognising that an attempt to reveal meaning in experience is always in relation to the perspective of the researcher. In the section that follows, I will discuss the theoretical underpinnings of IPA in further detail, advocating its appropriateness for the current research on NDSs.

4.3.1 Descriptive Phenomenology

Phenomenologically, IPA draws initially from Husserlian (1859–1938) philosophy that has at its central focus a concern with individual, subjective experiences. Husserl's phenomenology is descriptive in that it aims to develop detailed accounts of a participant's experience of their "life world" as it appears to them consciously (Langridge & Ahern, 2003; Smith, 2004).

Husserl (1927) proposed that our consciousness or awareness cannot be separated from the world around us, and when we are conscious, it is always of something, whether it be internal or external (Langridge, 2007). Husserl's intention was to understand what experience was, subsequently determining that experience constituted a combination of thinking and modes of feeling, will, valuing and striving.

According to Husserl (1927), we can better understand our own reality experience when we shift our focus from acting with no awareness (our natural attitude), by lifting the assumptive veil, to a phenomenological attitude. Husserl named this process "intentionality". Intentionality focusses our consciousness to awareness of what we physically or psychologically experience or focus on. When something is of importance to us, we shift our thinking, feeling and valuing to focus on the object, and in so doing, our focus becomes part of the perception of the object. It has additionally been described as the relatedness between the object of our focus and how the object appears to us in our consciousness (Lewis & Staehler, 2010). The object therefore changes depending on how we perceive it. As such, the subject and object are seen as one entity; we can only be conscious if we are conscious of something. The concept of intentionality, because of its focus on inner experiences, has often been misinterpreted and criticised as simply being an introspective experience. However, Larkin et al. (2011) emphasise that the term "intentionality" derives from the Latin, *intendere,* which means "to stretch forth", and describes a connection between the world we live in and how "as conscious being, our experience is always of something, in its appearing in the world, and specifically for us, as uniquely embodied and situated persons" (p. 323).

Husserl (1927) urged that we should return to the “things themselves”, meaning that, when trying to understand our experiences, we should consider our actual perceptions as opposed to what we think we already know or are trying to understand, or causal explanations (Husserl, 1927, as cited in Moran, 2000). To accomplish this, Husserl proposed that we should engage in a rigorous scientific method which entails bracketing any preconceptions or assumptions so that experience is reduced to a pure phenomenon or experience (Langridge, 2007). In other words, Husserl (1927, as cited in Moran, 2000) proposed that the researcher suspend or bracket their previous knowledge in order to reflect on the phenomenon itself, evading the inclination to assign meaning (Smith et al., 2009). In this study on NDSs, where I too am a NDS, and being a sibling to a disabled sister is my taken-for granted everyday life, according to Husserl (1927), a descriptive phenomenological method would require that I suspend or bracket what I know of being a NDS in order to reflect on my participants’ experiences themselves, without assigning my own meanings to their experiences. The result of this method is that we move away from our natural attitude or taken-for granted everyday life (Smith et al., 2009) towards an examination of experience as it manifests through a phenomenological attitude (Lewis & Staehler, 2010).

Husserl’s (1927) approach subsequently came to inform the first phenomenological research methodology, “descriptive phenomenology”. Descriptive phenomenology, proposed by Giorgi (2009), places emphasis on describing phenomena or lived experiences as they appear, as opposed to explaining or interpreting them. While the key features of descriptive phenomenology are, according to Langridge (2007), the utilisation of first-hand accounts of a specific phenomenon or experience, the intention of analyses is to identify common structures pertaining to each experience, presenting results as universal essences of the phenomenon (experience) while noting individual idiosyncrasy. Phenomenological research thus aims to explicate personal experiences from the participant’s perspective in order to further develop an understanding pertaining to a specific phenomenon (Smith

& Dunworth, 2003), in this case the experiences of adolescent NDSs living in a disadvantaged socio-economic context.

4.3.2 Interpretive phenomenology (hermeneutics)

In response to Husserl's (1927) philosophy on experience, Heidegger (1962) argued that it was not possible for preconceptions to be suspended or bracketed. Given that we are contextually situated (thrown or being) in the world, all experience is interpreted through our historical, social and linguistic knowledge. Therefore, by virtue of our situatedness (being-in-the-world), we are always engaged in the interpretative act of knowledge and meaning-making and cannot assume a detached or unbiased (bracketed) position in our experience-making (Moran, 2002). To this extent, Moran (2002) indicates that irrespective of my position as a NDS, I am, in being-in the-world, first a person, thus my personhood will always act as a lens through which I experience the world (and is flavoured by being a NDS) and cannot be suspended. However, it is my role to keep returning to the phenomenon itself, in this instance my participants' experiences of being a NDS.

Returning to the Greek etymology of the term "phenomenon": "to bring into light", Heidegger (1962, cited in Smith et al., 2009) stated the purpose of phenomenology as revealing and interpreting the meaning a subject attaches to their lived experiences. Phenomenological research thus aims to explicate personal experiences from the participant's perspective in order to further develop an understanding pertaining to a specific phenomenon (Smith & Dunworth, 2003).

The process of interpretation, according to Heidegger (1962), occurs through discourse, where a subject communicates their experiences and the meanings they attach to them. That is, they disclose or reveal their interpretation of their life world, what is hidden to the researcher. "The task of interpreting is therefore to engage in the dynamic of conceal/reveal, making manifest what may lie hidden" (Shinebourne, 2011, p. 47).

Interpretation in IPA can therefore be seen as a dual process, in that, as the subject interprets and conveys their understanding of their experiences, the researcher aims to interpret and understand these conveyances. The dual process of interpretation, referred to by Heidegger as the "hermeneutic circle" (1962), postulates that all interpretation by the researcher is informed by her own prior knowledge and self-understanding (Eatough & Smith, 2017). To this extent, as my participants communicate and attempt to make meaning of their experiences of having a NDS, I aim to interpret their meanings. My interpretations will, however, be informed by the meanings I have attached to being a NDS.

Smith et al. (2009) equate the process of interpretation to detective work, where there is, as Heidegger suggests, an entity ready to "come into light". It is the researcher's task to help in the uncovering and make sense of it once it is uncovered. According to Smith (2004), one cannot access this personal world without the researcher. Smith likens the researcher to the mythological "Hermes" whose role it was to translate the messages of the gods for humans (Pietkiewicz & Smith, 2012). As such, the researcher aims to translate or interpret the meanings and understandings the participants attach to their lives, revealing the cyclical nature of the process.

Hermeneutically, IPA enables me to look beyond what the participants are simply saying about their day-to-day lived experiences in relation to their disabled sibling, interpreting the meaning they are making in relation to their experiences. Engaging in an interpretative process allows me to develop an understanding of what it is like to be a NDS living in a disadvantaged socio-economic context, both in a physical and emotional sense. In addition, I am able explore more existential aspects, such as, what it means to be a Xhosa adolescent NDS living in a disadvantaged socio-economic context. Smith (2019) emphasises that the multi-layered meaning-making process in IPA (initially descriptive and interpretative), a hallmark of good IPA research, can be both existential and experiential, and is largely particular to IPA.

Following on from Heidegger, Gadamer et al. (2013) understood our biases (or prejudices) to be an important aspect of our ability to experience. Our prejudices, according to Gadamer, are positioned withing certain "horizons" or vantage points, however, through shifts in time and context, our horizons continue to evolve (Shinebourne, 2011). Context (consisting of place, space and time) was therefore also of particular importance to Gadamer (2013). Gadamer purported that while all our experience and meaning-making occurs through our own prejudiced knowledge and perception (subjectivity), it also exists in relation to the context, our environment and others and is, as such, also intersubjective. Through intersubjectivity, or participation with others, we are able to generate understandings. We fuse our horizons of knowing about time and place and context with other horizons to create a fusion-of-horizons, a new form of understanding or meaning-making. According to Gadamer, interpretation or hermeneutic experience permits a new or different way of seeing (Gadamer, 2013).

Merleau-Ponty (2013), like Gadamer (2013), was also interested in Heidegger's concern with our interaction with context. However, Merleau-Ponty advocated that it was through our bodies that we experienced the world (embodiment). Our bodies, according to Merleau-Ponty, make the world accessible through our senses. Additionally, it is through our lived body (lived experience) that space and time are connected. According to Merleau-Ponty, a lived experience or embodied phenomenon refers to a subject as a "total being", thereby challenging the idea that our physical experiences are separate from our psychological experiences (Merleau-Ponty, 2013).

Diverging from Heidegger, however, Merleau-Ponty (2013) proposed that because of our embodied experience, we can only see or understand others if we are able to see ourselves as separate from them. Hermeneutics, according to Merleau-Ponty, therefore suggests that we cannot know another the way we know ourselves. However, we can imagine what it is like for another. Through speaking, meaning can be shared, our words and gestures creating a bridge between embodied actions.

As a result of another's experience being directly inaccessible, the researcher is required to engage in a double hermeneutic or hermeneutic circle, a fundamental element of IPA research (Smith & Osborn, 2015). The hermeneutic circle requires the researcher to enter the participant's world in an attempt to make sense of the participant's sense-making (Smith & Osborn, 2015). To do so, the IPA researcher, instead of bracketing their viewpoints as Husserl (1927) suggests, is required to reflexively engage with them. By continually interrogating interpretations, and ensuring all interpretations are firmly grounded in the data, the IPA researcher demonstrates reflexivity (Finlay, 2011). Smith (2007) suggests that instead of engaging in analysis in a linear manner, the IPA researcher moves iteratively between parts of transcripts or texts and whole texts, developing increasingly deeper levels of understanding of the phenomenon under investigation.

The interpretative element, or hermeneutic circle, of IPA can, however, be further expanded on in the consideration of the different levels of interpretation that occur (Shinebourne, 2011). According to Smith (2004), in order for me to holistically understand the lived experiences of young siblings of disabled people, two modes of hermeneutic engagement should be applied: firstly, a hermeneutic of meaning-making and empathic engagement, and secondly, a hermeneutic of suspicion and critical engagement. Interpretation is subsequently described as being a "craft or art, involving a combination of a range of skills, including intuition" (Smith et al., 2009. P. 22).

4.3.3 Idiography

Lastly, IPA is considered to be idiographic, and it is this idiographic commitment to analysis that differentiates it from other interpretative phenomenological methodologies. Unlike nomothetic methodologies that focus on generalised findings, IPA is committed to idiographic details at an individual level (Eatough & Smith, 2017). The idiographic, analytic process of singularly exploring each unique case allows the researcher to make specific statements about the participants. Through a detailed exploration, it is the intention of the IPA researcher to generate various themes, noting similarities (convergences) and differences (divergences) between the various narratives, bringing to light multiple layers of meaning which might be obscured within the data or text (Larkin et al., 2011).

Grounding the interpretative process in the data honours the participant's experience within a specific moment in time and context, simultaneously acknowledging the possible evolution thereof. This is of particular relevance to my study of adolescents' experiences in relation to their disabled siblings in disadvantaged socio-economic contexts, as it provides a space within which to position both the particular developmental phase of the participants and their current socio-cultural positioning, and how they make sense of the contribution these make to their experiential world at this point in time.

Utilizing IPA as methodology, with its roots in critical realism, is congruent with the aims of this study that aim to explore how NDS subjectively make sense of their experiences of their sibling's disability. Where a critical realist approach suggests that how we understand the experience of disability is determined by each individual's unique (idiographic) interpretation of their experience, IPA provides a platform from which their interpretations may be explored.

4.4 Summary

In this chapter I have aimed to further expand on my chosen theoretical perspective, IPA. Through a detailed discussion on the philosophical and theoretical underpinnings of IPA, phenomenology, hermeneutics and idiography, I have highlighted the particular attributes that make it an appropriate methodology for a study that aims to understand the meaning NDS adolescents ascribe to their experience of having a disabled brother/sister in a disadvantaged socio-economic context.

CHAPTER FIVE

METHOD

5.1 Introduction

Following on from my discussion on IPA as my chosen methodology (theoretical lens), in this chapter I will provide a detailed account of how IPA as a method was employed in this study. I will additionally detail how I navigated the "hard to reach" element of my sample group, given their age and specific demographic factors. As an interpreter was used in this study, specific attention is paid to how this transpired. I will then discuss the variations to the data collection I included in my research, including photo-production. The analytic process is then detailed, followed by the reflexive process and ethical considerations.

5.2 Research Aims and Questions

Through the utilisation of IPA, the overall aim of this study is to develop an understanding of the subjective experiences of young Xhosa people with disabled siblings who live in poorly resourced contexts.

The aims of this research are to:

1) Contribute to the minimal body of knowledge from the Global South regarding first-hand accounts of how young people with disabled siblings, living in disadvantaged socio-economic contexts, experience their life world in relation to their disabled sibling; and
2) Respond to the call for further studies on NDSs from hard-to-reach populations, in this case, the Xhosa culture from a semi-rural context in the Eastern Cape of South Africa.

Following from this aim, this research explores the following questions:

- How do non-disabled adolescents experience their sibling's disability?
- How/Does disability feature in their relationships with their disabled brother/sister?

The underpinning question of the research is "What are the lived experiences of Xhosa adolescent siblings of disabled people living in disadvantaged socio-economic contexts?

5.3 Utilisation of an Interpreter

As a white, English-speaking, middle-aged female, I was acutely aware of the possible linguistic, cultural and age disparities presented, and how they might limit or influence this qualitative study. Despite isiXhosa being their first language, all the participants opted for both English and isiXhosa as language preferences. It was evident in the first meeting that most were highly proficient in English. However, given their age, cultural differences and the fact that there are frequently concepts and phrases that do not immediately translate from isiXhosa to English and vice versa, I decided that utilising an interpreter would assist in developing rapport and bridging the cultural and language differences, should they arise. The role of an interpreter, according to Squires (2009), is to provide verbal translation services during an interaction between at least two people who do not speak the same language (Hole, 2007; Larson 1998).

Below, I have detailed the procedures I undertook in the utilisation of an interpreter. The importance of doing so, given the impact utilisation of an interpreter might have on the rigour of the research process and the validity of the data has been emphasised (Squires, 2009; Temple, 2002; Wallin & Ahlstrom, 2006). Wallin and Ahlstrom (2006) also argue that inclusion of the interpreter's role within a study contributes to its trustworthiness. The procedure I undertook has been adapted from Squires (2009), Temple and Edwards (2002), and Williamson et al. (2011).

5.3.1 Competence of an interpreter

Choi et al. (2012) stress the importance of using an interpreter who fully understands participants' culture and language. Furthermore, Brämberg and Dahlberg (2013) caution that in cross-language research, the presence of an interpreter can impact on the participants' spontaneity and transparency. As such, they suggest utilisation of someone who has experience in verbal translation and matches the participants' cultural orientation.

The interpreter I employed for this study is Zuki Gubevu, who was at the time employed as a social auxillary worker (SAW) for the nonprofit organisation (NPO) acting as the primary gatekeeper for the study. The NPO is made up of a Social Worker and Social Auxiliary Worker who provide care and assistance to disabled people and their families. As such, she had an established rapport with many of the families approached for the study. She was specifically selected as she is isiXhosa speaking and, like the participants, lives in Joza Location in Makhanda-East, situated in the Eastern Cape of South Africa. She therefore had a shared cultural and contextual background with the participants. It is additionally noted that we had an established relationship, as she had previously assisted me as an interpreter in a study on a similar topic while I was completing my Master's degree. I was thus confident in her competence and experience as an interpreter, and in her knowledge on disability due to her occupational role within the disability sector. Additionally, being the mother of two adolescents, one of whom is disabled, I was confident that she would make a valuable contribution in establishing trust and rapport with the participants. As such, her knowledge, research-related experience and skills, understanding of the target context, linguistic competence and personal characteristics were taken into account in my selection of her as interpreter (Squires, 2009).

In this study, a professional translator was additionally employed to translate and transcribe the recordings. The translator was fluent in both isiXhosa and English.

5.3.2 Adequate interpreter preparation

Prior to the commencement of the data collection process, the interpreter and I met to discuss the research and how the interviews would proceed. During this meeting, I provided a detailed description of the purpose and background of the study, being clear regarding the research questions. Given the interpreter's shared cultural background with the participants and the fact that she has two adolescent children, it was valuable to receive feedback from her regarding how she anticipated the participants might respond. I thus provided a platform for her to comment on any cultural topics, such as family structure and hierarchy (discussed in Chapter Four, section 5.9.2), that might be shared by interpreter and participant, that the researcher was unaware of (Adamson & Donovan, 2002). In this meeting, we additionally discussed confidentiality, given the interpreter has ongoing involvement with the families through the NPO, and she signed a confidentiality agreement. Furthermore, due to the interpreter's personal and professional responsibilities and her own lack of personal transport, various logistical factors had to be considered.

I additionally engaged in an informal training session with the interpreter during which we consolidated the underlying premises that inform the semi-structured interview (Smith & Shinebourne, 2012), further discussed below. We considered the interview schedule in depth and again clarified any concerns or concepts that might cause confusion in the translation. Finally, we considered various technical aspects, such as the use of an audio recorder (which I would be responsible for operating), including being aware of our own non-verbal responses, the interpretation style and ethical considerations (discussed in detail later in this chapter).

5.3.3 Style of interpretation

The importance of conceptual equivalence, which is the transfer of meaning from the participants' language to the study language, was also considered (Choi et al., 2012; Spivak, 2000; Squires, 2009). Conceptual equivalence is the necessity of staying as close to participants' meaning, not embellishing some points or omitting others deemed irrelevant, or feeling the need to interpret dialogues verbatim (Murray & Wayne, 2011; Williamson et al., 2011).

I discussed with the interpreter how softening and selectively interpreting responses (to make them more acceptable to the researcher) would affect the validity of the data. However, providing elaboration or additional information when necessary to clarify concepts that may be unfamiliar to the researcher would be valuable. (I discuss how I have considered the impact of elaboration on the data in Chapter Five, section 5.8.1 and 5.9.2). I emphasised the importance of our assuming a curious stance throughout the interview, being careful not to interrupt or make assumptions about what the participants might be attempting to articulate, and consistently clarifying that we had grasped their meaning (Brämberg & Dahlberg, 2013). We also discussed how we would navigate a scenario where a participant becomes non-responsive or indicates distress. This is discussed in greater detail in the ethics section in Chapter Five (section 5.11.).

5.3.4 Extent of interpreter participation/role in research

As noted above, the interpreter was made fully aware of the aim of the research and the method being used. I explained that the transcripts would be translated and transcribed, and I would then analyse these. I noted that in IPA, the emphasis would be on my interpretation of participants' meaning-making process, and her role would be to assist with interpretation where participants chose to speak in isiXhosa, bridging the cultural gap (if necessary, elaborating on any cultural themes that I might not understand) during the interview process.

While IPA has been used successfully with young people (Pavlopoulou & Dimitriou, 2019, 2020), it has been emphasised that in research with youth, developing a rapport with a parent or caregiver, where possible, is important (Barley & Bath, 2014). The interpreter in this study had already established familiarity and trust with the families through the "home visits" conducted for the NPO. Familiarisation, according to Barley and Bath (2014), includes being well versed in the norms, beliefs, rules, rituals and language associated with the young person to minimise offence and have awareness of social cues that could encourage a more natural discourse. Again, the fact that the interpreter was from the same cultural and contextual background ensured that she was aware of more discrete social nuances, and the participants were able to relate to her freely.

5.3.5 Limitations and challenges using an interpreter in IPA

The utilisation of phenomenological studies for cross-language studies has been warned against by some authors, due to its emphasis on how participants utilise language to describe their experiences, where language contributes to their identity (Squires, 2008; Temple, 2002). They argue that the act of translation interrupts the process of studying how participants utilise language to detail their experiences (Squires, 2009). I aim to demonstrate through this study that this can be accommodated for by careful inclusion of the interpreter and professional translation.

In addition, I have used a separate translating service. The translator utilised is an experienced academic translator who also shares the participants' socio-demographic characteristics, and therefore offers a triangulating element (essentially a triple layer of translation has occurred). Finally, for this study I have incorporated photo-production (discussed further below) as an additional means to obtain insight into the meaning the participants attach to their experiences of having a disabled sibling in a poorly resourced context. It is intended that the use of photographs, created by the participants, provided an additional means of communication.

While matching cultural affiliation is useful for rapport, it has also been noted that when interpreters are well-known in the community, status and influence may inhibit participants' openness (Murray & Wynne, 2001; Williamson et al., 2011). This did not appear to be a problem in the current study where interviews flowed smoothly, participants expressing eagerness and some even requesting repeated interviews. In light of this, I was conscious of how the interpreter's involvement in the NPO, an organisation that is valued by the families in their care, might influence their willingness to be involved in the study. This caused me to question a possible coercive element and the families not wanting to risk disappointing or losing the support of the NPO. It was therefore imperative that, in our interactions with the families and the participants, it was clearly indicated that their willingness or unwillingness to participate in the research would not in any way impact on the NPO's ongoing support (discussed further under ethics in section 5.11).

5.4 Sampling

The participants in this study were purposively selected to form a reasonably homogenous sample, in that they share important characteristics (in this case each participant was an isiXhosa speaking adolescent, had a disabled sibling and lived in the same socio-economically disadvantaged location in South Africa). By using a homogenous sample, it is intended that participants are representative of a particular perspective, not a specific sector of the population. In so doing, it is intended that participants may relate to the research question in a meaningful way. Furthermore, by using a homogenous sample, I am better able to discern where similarities and variabilities between their experiences may exist.

5.4.1 Inclusion criteria

In this study the participants were required to be between the ages of 12 and 20 years and were required to have a disabled sibling. Additionally, they had to fall within the bracket of being socio-economically disadvantaged. The latter was ascertained by determining (via a demographic questionnaire to be completed by the parents) (see Appendix A) whether the monthly income of the household in which the participant resides was below the national mean of R8607 per month (£373.40/US$452.80), as determined by The Living Conditions Survey (Statistics South Africa, 2015).

This purposive convenience sample was drawn from the Joza Location in Makhanda-East, situated in the Eastern Cape of South Africa, where the majority of the inhabitants identify as being of Xhosa cultural heritage. Due to the aforementioned socio-economic status of Joza Location residents (see Chapter One, section 1.9, it was considered an appropriate setting from which to draw my sample.

As the aim of this study was to develop a detailed understanding of the participants' individual experiences, a smaller sample was drawn. Smith (2007) suggests smaller sample groups to allow for "sufficient in-depth engagement with each individual case" (p. 57) in order to adequately attend to the commonalities and particularities within and between experiences (Nizza et al., 2021). For doctoral studies, a sample size of 10 to 12 participants is most appropriate (Smith & Nizza, 2002). Given the hard-to-reach nature of this particular group (due to language differences and socio-economically informed barriers such as long commutes, the reliability and cost of transport as well as their age) meant that obtaining a larger sample size might have been unachievable.

5.5 Recruitment

Participants were recruited through the local branch of a national NPO for persons with physical disabilities in Makhanda (the Association for Persons with Physical Disabilities or APD). As such, they had prior contact with families that met the criteria for the purpose of this study. My relationship with the NPO pre-dates this research as they acted as gatekeepers for my Master's research in 2015. The chairperson of the NPO was contacted via email (see Appendix B) and a meeting held, during which I presented the aims of the study and explained what the NPO's involvement would entail, including the various ethical considerations. On receiving permission from the chairperson, and once ethics approval (see Appendix C) had been granted by the university ethics committee to conduct this research, I met with staff at the NPO in order to obtain their assistance in identifying families that would likely meet the criteria for this study.

The interpreter, who had previously engaged with the families identified through her NPO involvement, was able to ascertain in her interactions with them whether they required further information about the study. Where positively indicated, the interpreter provided each with an additional information letter (translated into isiXhosa) with a tear-off slip on which they could indicate their willingness to engage and provide me with their contact details (see Appendix D). Caregivers were met with in the first instance, and with their consent, meetings were set up with the participants.

Initial meetings were held in the caregiver's homes, and on two occasions at their place of work, where this was feasible and permissible. During this meeting, with the aid of the interpreter, I introduced myself, provided details about the study, what the expectations of their child would be and then allowed for any questions. I provided each caregiver with a consent form (see Appendix E) and a demographic questionnaire to confirm that participants met the socio-economic criteria. The demographic questionnaire consisted of several questions aimed at establishing the income of each household, the occupations of the primary caregivers (and their relationship to the participant), and the number of people living in the house. The demographic questionnaire was translated into isiXhosa and clearly explained by the interpreter. The participants were provided with an information and assent form, also written and verbally translated into isiXhosa.

5.6 Participants

The initial sample was made up of 10 first language isiXhosa speaking adolescents, one of whom did not complete the second interview process due to school commitments. What follows is a brief description of each participant and their circumstances. Details about participants' circumstances, including their language preference, were obtained in initial meetings with their parent, and in their interview. Participants were also asked whether they knew their sibling's diagnosis, where they did not know, this information was obtained from their families or APD, but was kept confidential. Furthermore, on parents consenting to their child's participation, a questionnaire (see Appendix F) on which they were requested to provide such details was administered (this was provided in isiXhosa and English and discussed in isiXhosa by the interpreter). I have included this information to provide a sense of their living conditions, which despite meeting the criteria for socio-economic disadvantage, vary at times.

Table 5.1

Participant Demographic Information

<table>
<tr><th></th><th>Participant</th><th>Age</th><th>Gender</th><th>Sibling</th><th>Age (years)</th><th>Sibling diagnosis</th><th>Language preference</th></tr>
<tr><td>1</td><td>Pumla</td><td>17</td><td>F</td><td>Asa (F)</td><td>10</td><td>Spina bifida</td><td>English & Xhosa</td></tr>
<tr><td colspan="8">Lives in a small shack dwelling (no running water or internal ablution facilities) with Asa, her older sister, her grandmother and uncle. Mother is HIV positive and resides elsewhere. No contact with father. Grandmother consented.</td></tr>
<tr><td>2</td><td>Nkosi</td><td>12</td><td>M</td><td>Kwezi (M)</td><td>2</td><td>Spina bifida</td><td>English & Xhosa</td></tr>
<tr><td colspan="8">Lives with mother, aunt, grandmother and Kwezi in a small state funded house. Has no connection with father who is currently imprisoned. Mother consented.</td></tr>
<tr><td>3</td><td>Sona</td><td>16</td><td>F</td><td>Gugu (F)</td><td>32</td><td>“Intellectual disability and mild physical disability”</td><td>English and isiXhosa</td></tr>
<tr><td colspan="8">Currently lives with maternal grandmother in a state funded house. Has recently (reluctantly) relocated from father’s house (occupied by father, stepmother, paternal grandmother, uncle, cousin, older disabled sister (Gugu) and brother, due to financial reasons. Mother lives elsewhere. Father consented.</td></tr>
<tr><td>4</td><td>Luthando</td><td>12</td><td>M</td><td>Amahle (F)</td><td>15</td><td>Intellectual disability and ASD</td><td>isiXhosa</td></tr>
<tr><td colspan="8">Lives with father, Amahle, uncle, older brother and cousin. Mother recently deceased. Has stepmother (acts as caregiver) living in the same street, but not in the house. Father consented.</td></tr>
<tr><td>5</td><td>Aya “Sugar”</td><td>18</td><td>F</td><td>Nana (M)</td><td>10</td><td>“Autism”</td><td>English</td></tr>
</table>

<table>
<tr><td colspan="8">Lives with mother and father. Nana no longer lives at home, recently moving to a special needs school. Mother consented.</td></tr>
<tr><td>6</td><td>Thando</td><td>17</td><td>F</td><td>Portia (F)</td><td>7</td><td>Intellectual disability</td><td>English</td></tr>
<tr><td colspan="8">Lives with mother, stepfather, stepsister, Sisi (14) and Portia. Recently (reluctantly) relocated from maternal grandmother’s (has been primary caregiver) house due to transport costs to a new school. Stepfather consented.</td></tr>
<tr><td>7</td><td>Sizwe</td><td>14</td><td>F</td><td>Buhle (M)</td><td>3</td><td>Cerebral palsy</td><td>isiXhosa</td></tr>
<tr><td colspan="8">Lives with mother, father, older sister, Sethu (also a participant but interviewed independently) and Buhle. Mother consented.</td></tr>
<tr><td>8</td><td>Sethu</td><td>13</td><td>F</td><td>Buhle (M)</td><td>3</td><td>Cerebral palsy</td><td>English
isiXhosa</td></tr>
<tr><td colspan="8">Lives with mother, father, younger sister, Sizwe (also a participant, but interviewed independently) and Buhle. Mother consented.</td></tr>
<tr><td>9</td><td>Bhuti</td><td>18</td><td>M</td><td>Sipho (M)</td><td>24</td><td>Spina bifida</td><td>English</td></tr>
<tr><td colspan="8">Recently moved to university residence but previously lived with mother, father, older sister and Sipho. Father consented as Bhuti was 17 at the time of recruitment.</td></tr>
</table>

Key: F = Female; M = Male

5.7 Data Collection

At the commencement of each initial interview, I introduced myself and explained in English that, while ability and willingness to engage in English and isiXhosa was noted, the interpreter would be there to assist us. Participants were encouraged to converse in the language they felt most comfortable with. If they chose to speak in isiXhosa, the interpreter would translate back to me in English, and we would check in to ascertain whether they felt the translation adequately reflected what they were attempting to articulate. For consistency, all my questions and probes would be translated from English to isiXhosa. This dialogue was translated into isiXhosa. It was noted that most of the participants subsequently used English, some switched between English and isiXhosa and two spoke only isiXhosa. It was noted that this style of interpretation appeared to contribute to the rapport between the interpreter and the participants, who for the most part appeared at ease during the process.

5.7.1 Photo-production

Smith and Nizza (2022) note that there are instances when the breadth of lived experience may be challenging to communicate verbally, and that in such cases employing visual methods can assist participants in articulating and making sense of their experiences. Additionally, it has been noted that interviewing as a data collection method can further contribute to imbalances in the power dynamic between the researcher and the participants (Potter & Hepburn, 2005), where researchers inform the venue, choice of topic and the interview schedule (Kvale & Brinkmann, 2009).

The metaphor of "voice" may reproduce the very understandings that marginalise children: the voice as the property of a rational, articulate, knowledgeable individual, capable of speaking for herself (Tisdall et al., 2009). Focusing on voice privileges speech over other forms of communication, thereby risking the exclusion of young people who are not, or only moderately, able to communicate through speech (Komulainen, 2007), or choose not to talk, or laugh instead in response to a researcher's questions (Lewis, 2010; Nairn et al., 2005).

Burton et al. (2017) argue that to achieve a "participant-led understanding of concepts" (p. 377), other methods, such as the inclusion of visual stimuli, should be considered. Given the participants' ages and the cross-language and cross-cultural aspects of this research, with the challenges these aspects might present, I decided that including visual material would add richness to the data, in that it offered participants an additional way to visually demonstrate their sibling's embodiment of disability and how this is enacted in their relationships. As such, I decided to use photography, which has previously been effectively utilised with IPA (Burton et al., 2017; Williamson, 2019).

There are several ways of using photography in research, including photo-production (Collier, 1957; Harper, 2002), auto-driving (Heisley & Levy, 1991), reflexive photography (Harrington & Lindy, 1999), photo-voice (Wang & Burris, 1997) and photo-production (Reavey, 2012). In this study, I chose to utilise photo-production (Frith, 2020; Hodgettes et al., 2007). Photo-production is a method that requires participants to produce their own photographs, in relation to the phenomenon being investigated, for the purpose of the research (Reavey, 2012). Aside from the fact that photo- production has previously been successfully utilised in IPA studies (Burton et al., 2017), including with adolescents (Pavlopoulou & Dimitriou, 2020), using photographs provides a means for "tapping into and grounding participants in remembered experiences, time and space/place" (Busso, 2021, p. 46) by eliciting affective and reflective responses. Photo-elicitation methods are well suited for such purposes, providing an active means for participants to engage with their contexts and then discuss their lived experience through images (Busso, 2021).

IPA researchers, aiming to obtain an "insider perspective" on experiences, draw on Gadamer's (1975) conceptualisation of "horizons", which states that individuals sense and interpret the world through their horizon, which is made up of all their preconceptions, beliefs and past experiences. The use of photographic images evoked in the participants emotions and thoughts which expressed their horizon, the fullness of their life experience related to their disabled sibling, thus enhancing their insider perspective (Burton et al., 2017).

Incorporating visual methods has been noted as being valuable in providing space to illuminate experiences that are difficult to verbally articulate (Majumdar, 2022). Photo-production, specifically, has also proved to be effective in bridging power imbalances between the researcher and participants in populations who have previously been considered less visible, by providing agency regarding what is included in the data (Johnson & Reavey, 2022). In addition to this, photo-production can offer the researcher an opportunity to see the world through the eyes of participants (Noland, 2006) and further develop understanding of culturally contextual factors (Fleury et al., 2009).

Majumdar (2022) acknowledges that the verbal representations of emotional experiences that are created in narrative approaches can be restricted by words and are held within culturally informed parameters. Photographs, however, can offer a potent means of depicting emotional experiences that are not easily articulated through words (Reavey & Johnson, 2008). I considered this to be particularly relevant to this cross-cultural, cross-language research. The use of photographic methods (Kaplan et al., 2007; Streng et al., 2004) has proven to be useful in engaging adolescent participants in the topic and establishing trust and rapport between participants and researchers, which subsequently permits a more in-depth discovery of themes. This was at times particularly noticeable in this study, where most participants became more emotive in response to their photographs and were able to discuss details pertaining to their personal experiences that may not have been brought into the interview without their photographs. The photographs in this study were taken by the participants, who then chose the ones they wished to discuss, and as such, these were analysed by the participants, not myself. However, I then analysed their discussions pertaining to the photographs. I had initially decided not to incorporate photographs in the final report as my analytic focus was primarily on what participants said about them, therefore the transcripts were my primary concern. However, during the writing it became evident that including the photographs would provide richness to the data, as well as adding further transparency to my analytic process.

5.7.2 Interview procedure

Once both consent from caregivers and assent from participants was received, I set up the first interview with each participant. Kruger (2014) emphasises the need to be aware of contextual challenges and the participants' practical challenges when conducting research where adversity is present. Having been to the participants' homes, I was aware that there would be little privacy. As such, it was arranged that the interpreter and I would collect the participants from their home and bring them to the interview venue. To ensure confidentiality, the interviews took place in a private room at the NPO premises or in an interview room in the psychology department of the university to which I am affiliated. Despite considering the fact that both these venues may reinforce possible power imbalances, they were deemed the most appropriate options available.

At the initiation of each interview, I again reminded the participants that the interviews would be recorded and transcribed, but that their identities would be protected. I additionally reminded them that they could at any time indicate to me if they no longer wished to participate, and this would not negatively impact on them in any way. It was important at this stage, given the age of participants and the cross-language, cross cultural factors, that I explained that, unlike a job interview, this was not an evaluation, but an opportunity for me to talk about and try to understand what if felt like to be them. The translation process was also reiterated.

A face-to-face, individual, semi-structured interview is most suited to IPA as it creates space for rapport building and offers participants adequate opportunities to be heard (Reid et al., 2005; Smith & Nizza, 2022). Furthermore, the semi-structured interview permits the researcher and the participants to converse in a manner in which initial focus questions can be adapted in light of the response, offering flexibility to probe areas of interest. Edwards et al. (2006) describe how using a more flexible approach while interviewing young people enables them to choose how they wish to convey their experiences, allowing for richer data. As such, the semi-structure interview was utilised.

Prior to the interview, an interview schedule (see Appendix H) was drawn up. Key questions were structured in an open-ended way to create space for individual interpretation. Follow-up questions were oriented around more specific aspects of the participants' understanding to facilitate further disclosure. Furthermore, simple prompts were provided should the participant be unable or refuse to answer the question posed.

At the end of the first interview, the participants received training on the photo-production method. This was adapted from Wang (2006) and Laws and Mann (2004). First, I ensured the aim of the research was clear to the participants, emphasising the importance of them capturing “what it was like to be them in relation to their disabled sibling”. We explored the concept of “creating a picture to describe an experience” whereby I provided examples of pictures I had taken from previous photographic research, books and magazines that might relay emotions and suggest experiences. I highlighted the fact that this process might be different to their previous ideas of what the purpose of taking photographs was, and that it was not the intention to create “nice pictures”. A few technical considerations were addressed to ensure the clarity of their images, including the proximity of the content they wished to capture and basic lighting. It was, however, noted that this should not be their primary focus so as not to create unnecessary performance anxiety in relation to the task. I then explained that their photographs would be printed out and presented to them in the following interview, at which point they would be discussed. I also suggested that, if they had any thoughts in relation to our first interview, these could be written down and brought to the next meeting.

Due to logistical issues, it was decided that, if possible, participants would take photographs using their mobile phone, I would provide them with mobile data and they would send the photographs to me. In the case where participants did not have access to a mobile phone, they were provided with disposable cameras. In the case of the latter, several issues arose, including the case of sisters who mixed their cameras up. Additionally, trying to retrieve the disposable cameras from participants presented with ongoing logistical challenges and took longer than intended. This then delayed the printing process which meant that the second interviews occurred later than I had intended. This did not, however, seem to have any negative consequences for the process. Ultimately, four participants used disposable cameras and five participants used mobile phones. The participants took 10 pictures, which were printed and presented to them at the start of the second interview. They were then given some time to look at their pictures and choose the ones they wished to talk about. Prior to the interview a prompting schedule had been drawn up which aimed to elicit the story behind the picture.

By asking the participants for their interpretations of their photographs I was able to glean further insight into their perspectives (Grogan et al., 2018). Furthermore, through making, sharing and discussing photographs, Banks (2001) argues that the degree of intimacy between the participants, the images they have created, and the researcher is increased. It has additionally been stated that the use of photographs has the capacity to "bridge culturally distinct worlds" (Roger & Bumegren, 2019).

Participants were given copies of their pictures and were also provided with a cold drink and snack at the end of each interview before I drove them home. It is noted that while driving with the participants, I tried not to engage in topics that were relevant to the study, as this was beyond the interview context and was not being recorded. In total, each participant was interviewed twice for approximately an hour, with 18 hours of participant interviews being generated.

5.7.3 Transcription

All of the recordings, including the debriefing sessions with my interpreter, were sent to a professional transcriber and translator who was fluent in isiXhosa. Given her extensive experience in translating and transcribing, specifically from isiXhosa into English, and her depth of understanding of both languages, she recommended a transcription notation she had found most effective for the process. However, we discussed in detail what I deemed necessary for this study, given that Smith et al. (2009) have stated that there are multiple social interactions that may be included for transcription and that the transcription is therefore a form of interpretative activity. To this extent I determined that I required the transcriptions to include as much detail as possible, as such all utterances, including non-linguistic features, such as pauses, laughter and repetition were included. In these instances, the transcriber indicated the utterances by including them in brackets, and where pauses were noted, the length of each was included in brackets. Where I have included excerpts from the transcription in this thesis, I have, due to space restraints, not always included the isiXhosa transcript, but have indicated that it has been translated with underlining.

5.8 Analytic Process

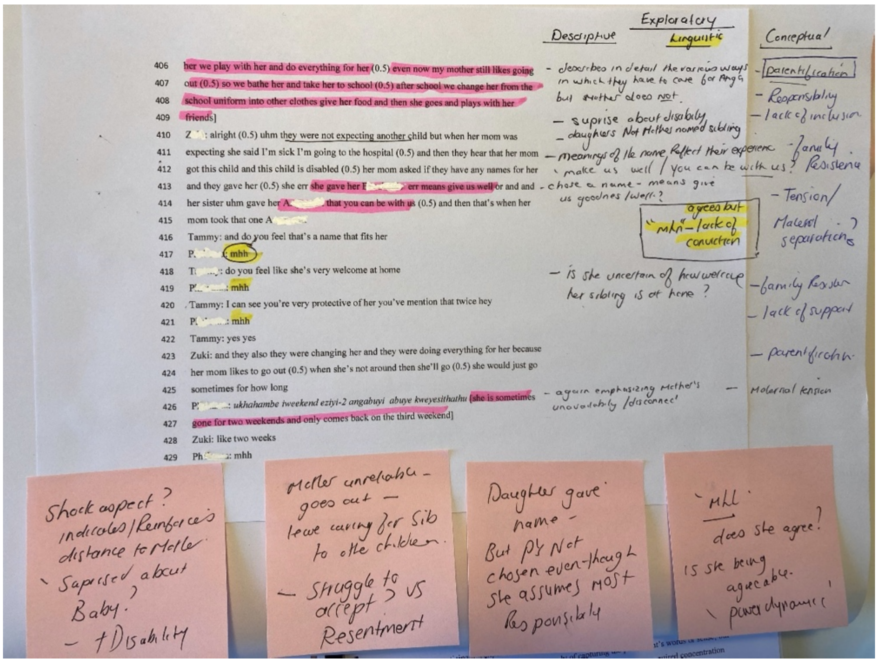
Smith et al. (2009) indicate that, while analytic methods in IPA are not necessarily prescriptive, holding sight of the focus – the participants' efforts to make sense of their experiences – is imperative. The researcher's intention is to transition from the individual to shared meaning and from description to interpretation. In so doing, the researcher demonstrates their dedication to developing an understanding of the participants' viewpoints and how they make sense and create meaning within their specific context (Smith & Nizza, 2022). Smith and Nizza (2022) additionally emphasise the importance of holding an idiographic and inductive stance so that each participant's data are viewed independently and not bound by theoretical constraints. During the analytic process, the participant's photographs were not analysed, rather, how they interpreted or made meaning of their photographs was considered. Given the warnings that IPA can be a daunting task, I stayed true to the steps provided by Smith and Nizza (2022). These include engaging in depth with the data, making exploratory notes, noting experiential statements, grouping statements and creating a table of personal themes, each of which will be discussed in further detail below.

5.8.1 Making exploratory notes

I began the analytic process by engaging with the first participant's first interview transcript. This entailed reading through the transcript while listening to the recording, capturing points of interest on post-it notes. During the second reading of the transcript, I began making exploratory notes. To do this, a margin was created on the right of the transcript and divided into three columns, titled descriptive, linguistic and conceptual respectively (Smith, 2009). In the first right-hand column (descriptive) I noted where something of notable interest was evoked. This included highlighting and noting my first impressions, identifying similarities and differences between different sections of text, magnifications and contradictions in what the participant said (Smith & Nizza, 2022). The notes in the descriptive column aimed to describe what the participant was talking about, such as objects, places, events and experiences. I then reread the transcript paying attention to the use of the participant's language, making linguistic notes. The linguistic notes captured how they were using language, such as repetition, tone or pauses, or when they switched language preference, that may indicate uncertainty, contemplation or difficulty talking about something. Additionally, during this stage, I considered the translation process, taking note of whether the interpreter's and the transcriber's translations did not match or when the interpreter may have provided additional context. Finally, I made the conceptual notes, these as their name indicates, carried a more conceptual weight. In this column a more interpretative stance was assumed. Smith et al. (2009) acknowledge that engaging in conceptual coding requires that the researcher draw on their own experiential and/or professional knowledge in an attempt to open a range of provisional meaning. The image below (Figure 1) is simply to provide an impression of a working copy of the exploratory process. As seen in Figure 1 below, the initial noting is on the pink post-it notes, the yellow highlighted text are the linguistic notes, descriptive notes are on the far left and conceptual notes on the far right.

Figure 1

Example of Exploratory Note-Taking Process



her we play with her and do everything for her (0.5) even now my mother still likes going out (0.5) so we bathe her and take her to school (0.5) after school we change her from the school uniform into other clothes give her food and then she goes and plays with her friends]
Z[redacted]: alright (0.5) uhm they were not expecting another child but when her mom was expecting she said I'm sick I'm going to the hospital (0.5) and then they hear that her mom got this child and this child is disabled (0.5) her mom asked if they have any names for her and they gave her (0.5) she err she gave her E[redacted] err means give us well or and and her sister uhm gave her A[redacted] that you can be with us (0.5) and then that's when her mom took that one A[redacted]
Tammy: and do you feel that's a name that fits her
P[redacted]: mhh
T[redacted]: do you feel like she's very welcome at home
P[redacted]: mhh
Tammy: I can see you're very protective of her you've mention that twice hey
P[redacted]: mhh
Tammy: yes yes
Zuki: and they also they were changing her and they were doing everything for her because her mom likes to go out (0.5) when she's not around then she'll go (0.5) she would just go sometimes for how long
P[redacted]: *ukhahambe iweekend eziyi-2 angabuyi abuye kweyesithathu* [she is sometimes gone for two weekends and only comes back on the third weekend]
Zuki: like two weeks
Ph[redacted]: mhh

Descriptive

Exploratory
Linguistic

Conceptual

- describes in detail the various ways in which they have to care for Anga but mother does not.
- suprise about disabily
- daughters Not Mothes named sibling
- meanings of the name Reflect their experienc
- make us well / you can be with us?
- chose a name - means give us goodnes / well?

agrees but "mhh" - lack of conuction

- is she uncertain of how welcome her sibling is at home?
- again emphasizing Mother's unavailabily / disconnect

- parentification
- Responsibiliy
- lack of inclusion
- family Resistence
- Tension / Materal separations?
- family Resistence
- lack of support
- parentification
- Maternal tension

Shock aspect? indicates / Reinforces distance to Mother
- Suprised about Baby? + Disability

Mother unreliable - goes out - leave caring for Sib to other children.
- Struggle to accept? vs Resentment

Daughter gave name - But P's Not chosen even though she assumes most Responsibily

"MHH" does she agree? is she being agreeable
- power dynamics

Figure 2
Example of Descriptive Notes

Original Transcript	Descriptive Notes
Pumela: *"…we play with her and do everything for her (0.5) even now my mother still like going out (0.5) so we bathe her and take her to school(0.5) after school we change her from the school uniform into her other clothes, give her food and then she goes and plays with her friends"*	Describes in detail the various ways in which they have to care for Asa, but emphasises mother does not. P's use of the word *everything* indicates the amount of care she feels she engages in She uses the word 'we', here, however this is inconsistent with the rest of the interview

As illustrated above, the process of recording descriptive notes acts as a face value exercise and a means to summarise the explicit meaning of what the participant has said, noting specific experiences or events, and ensures that a basic grasp of what has occurred within that part of the transcript had occurred (Smith & Nizza, 2022).

Figure 3

Example of Linguistic Notes

Original Transcript	Linguistic Notes
P: uhm [long pause] can I know, uhm *bendizobuza ubana ndim ndedwa okule research okanye sibaninzi* [I was going to ask if I am the only one who is taking part in the research or are there are many more others as well] Z: she has a question (0.5) is she the only one^0 or are there other siblings partaking T: no so, I'll hopefully, speak to eight to ten siblings (1) so there'll be a group of you uhm (.) it's an interesting question why did you ask P: cause I was shocked like (1) *ingathi ndim ndedwa* [it seems like I am the only one] Z: she thought she was the only one	*Uhm*: hesitant/unsure? *Long pause:* thinking, difficulty saying next statement *Note: switches from English to isiXhosa:* (easier to say difficult thing in isiXhosa, reverting to familiarity *Shocked*: heightened sense of amazement that others may have similar experiences, feels isolated/alone Consistent translations

I have used this annotated example of my linguistic note-taking for Pumla, as I think it demonstrates how some of the participants used isiXhosa and English interchangeably. In this case I noted when Pumla switched from English to isiXhosa, following some hesitation, and wondered if it was because she felt nervous about what she was about to ask, and whether speaking in isiXhosa gave her a sense of comfort or confidence. Furthermore, it provides a sense of how the interpretations compare to the translations. I also took note of her use of the word *shocked,* to explain how she felt when discovering there may be other siblings who share her experiences, and she wasn't alone.

As I transitioned into making conceptual notes (see Figure 4 below), I was able to assume a more interpretative stance. Smith et al. (2009) note that at this stage the researcher's focus shifts from the participant's explicit claims to what they mean within the overall context. I took heed of the warning to not be overly descriptive and attempted to mitigate this by writing single words or brief statements (Smith et al., 2009). In the extract below (see Figure 4), Pumla is conveying a feeling of being alone and unsupported by her family in caring for Asa, while simultaneously revealing some of the day-to-day challenges that stem from Asa's disability, including experiences of stigma and utilisation of a wheelchair in town.

Figure 4

Example of Conceptual Notes

Original transcript	Conceptual notes
P: *like bayandityhafisa abakwazi ukuncedisana nathi* (0.5) especially *usister wam akakwazi ukuncedisana nathi like sinosister onjena ukhubone* (0.5) *so mhlambi siya etown sikwazi ukuhamba noAnga abafuni* (0.5) *soze mna ndiqhube uAnga ntoni ntoni* [like they discourage me because they do not want to help me (0.5) especially my sister she can't even help us she is ashamed to have a sister like Asa (0.5) so if for instance we are going to town we could take Asa with us but they don't want to go with her (0.5) they say they will never wheel her and so on] Zuki: her two siblings (0.5) they don't want even to wheel Asa to take her to town, they feel ashamed and that's another thing that is hard for her (0.5) because she feels like if they can't help each other	-feels unsupported /isolated (*discourage)* -them vs me - disability evokes shame -challenges of disability -perceives families experience of stigma -caring is lonely

Including the interpreter's voice was a crucial aspect of this study, given its cross-cultural, cross-language nature. While I have attempted to remain loyal to the recommendations (Smith & Nizza, 2022) on how to approach my analysis, it is also noted by the authors that IPA is not prescriptive. As such, the slight deviation I have included, for the sake of transparency, is the creation of a step that specifically platforms the interpreter's voice. That is, on completing my exploratory notes, I listened to the recording and read the transcripts of the debriefing conversation held with the interpreter following each interview. During this process, I documented any examples where our experiences of the interview, and the participants responses, were shared or possibly differed, or where she was able to provide additional context or understanding to the participant's accounts; this was incorporated into my findings.

Figure 5

Excerpt from Original Transcript

Excerpt from Pumla's original transcript	My exploratory notes	Transcript of the reflective process with the interpreter post-interview
P: *ndikhe ndibenayo lonto* [sometimes I do feel that way] –:*andingxoli ndiye ndimxelele ukuba Anga uba ubukwazi like naye athi uba nam Phakama khange ndizenze uba mandibekule wheelchair* [<u>But I don't shout at her I just tell her that if she could walk but she also tells me that she never asked to be on a wheelchair either</u>]	-feels resentment -guilt for feeling resentment	*Z: yes and she kept mentioning that every time, if A is not here, if A was a able bodied person then I would be able to go out and be with my friend. And you're not even aware that I'm stuck*

Z: sometimes when she's angry she will say 'you know what if you could walk and then Asa would just say 'you know what I didn't make myself to be like this it's not my choice to be like this' in this chair T: okay, and what's that like for you? Z: mhh and then *iye ikuphathe njani wena lonto* [and how does that make you feel] – P: *iphinde indiphathe kabuhlungu like ngendingayithethanga kuye kuba nam zange nditsho uba ndandingalindelanga ukuba kuyawuze kufike umntana onje ngaye* [it hurts because sometimes I wish I hadn't said that to her because I never expected to have a sister like her] *ndiphinde ndicele uxolo* [I then apologise for saying it] Z: then she feels bad, she will apologise to Asa for that because she also understand that it's not her fault. It's not her choice as well but that's her condition.	-cares about sister vs caring for sister -tension between how much she cares about her sister and her feelings of resentment	*here with you because of your own challenges, your disability. And saying that and A is also that vocal person that will say, you know what, it's not my fault I didn't choose to be like this then that will strike her mind again, to apologise to her little sister, that it's not normal to us African people to apologise or to just humble yourself to any younger sisters or people younger than you. It's like you're not ok if you say I'm sorry or apologise to others who are younger.*

An example of this entailed the interpreter reinforcing my sense that Pumla experiences a tension between how much she cares for Asa and the resentment she feels at times for having to care for her, because of her disability. She had previously acknowledged not having the opportunity to be with her own friends. The interpreter links this with her current acknowledgement of resentment and simultaneous guilt for saying something hurtful to her sister when she cares about her. The extent to which she cares about Asa is demonstrated by the interpreter's explanation that Pumla's apology to her younger sister breaches traditional Xhosa cultural practice. This possibly indicates how important it is for Pumla that Asa understands she feels bad. In this case she highlights the fact that within the culture, familial hierarchies are often determined by age, to the extent that an older sibling would not apologise or subjugate themself to a younger sibling. In essence, the interpreter's reflections were utilised as a way of offering cultural context, as well as some degree of triangulation, given her deeper awareness of the participant's family dynamics, elucidating meaning from what is said, where I might have not been able to.

5.8.2 Developing personal experiential statements (PETs)

Smith and Nizza (2022) emphasise that formulating experiential statements requires the researcher to switch modes, aiming to succinctly capture the meaning of the experiences participants have relayed in each portion of the text. Similarly, statements are required to be adequately specific and detailed in order to reflect the participant's experiences. As such, one is traversing a proverbial tightrope between the parts and the whole. While looking into separate parts of the transcript, I am also required to hold the whole – all I have come to know about in the initial noting phase – in mind. In essence I am trying to make sense of the participants' sense-making. Smith et al. (2009) highlight how, at this level of analysis, the hermeneutic circle (described in Chapter Four) is clearly represented. Table 5.2 below reproduces an example of exploratory themes and experiential statements taken from P's interview in relation to her experience of fear and vulnerability. (Note, due to space constraints, I have only included the English translation.)

Table 5.2

Exploratory Themes and Experiential Statements

Experiential Statement (Emerging theme)	**Original transcript**	**Exploratory theme**
P experiences vulnerability due to contextual, socio-economic informed factors Experiences disability as contributing to vulnerability Experiences a sense of care and responsibility for Asa Cares about Asa’s needs Experiences of socio-economic disadvantage	P: like *so* [where I stay there are a lot of criminals and the street lights are not working so that makes me scared even worse because recently () she (Asa) can’t do anything for herself] P: [I think that she would be fine if she were to get the help that she needs (0.5) but if she doesn’t get help I don’t know how she will continue to live in that condition but I hope to finish my studies (0.5) I will finish my studies and get a job and then help her to become whatever she wants to be] T: and if you get a job what would you do for (0.5) what would you change for her P: [she wishes to have that electric wheelchair that comes with a light so that would be the first thing I would get her] T: does she have a wheelchair now, P: mhh T: but it’s not the electric one P: mhh Tammy: is it quite hard? For – P: [yes because she can’t push herself in other places most of the time we have to push her even in the yard when she has to go to the toilet she struggles (0.5) so we have to assist her]	Indicates prevalence of crime, causes vulnerability Infrastructural challenges due to socio-economic factors contribute to contextual and disability stressors Feels motivated to protect Asa Wants to help Asa Prevalence of socio-

contributing to challenges associated with Asa's disability	T: is the bathroom outside P: yes	economic disadvantage makes navigating disability challenging

5.8.3. Developing experiential themes

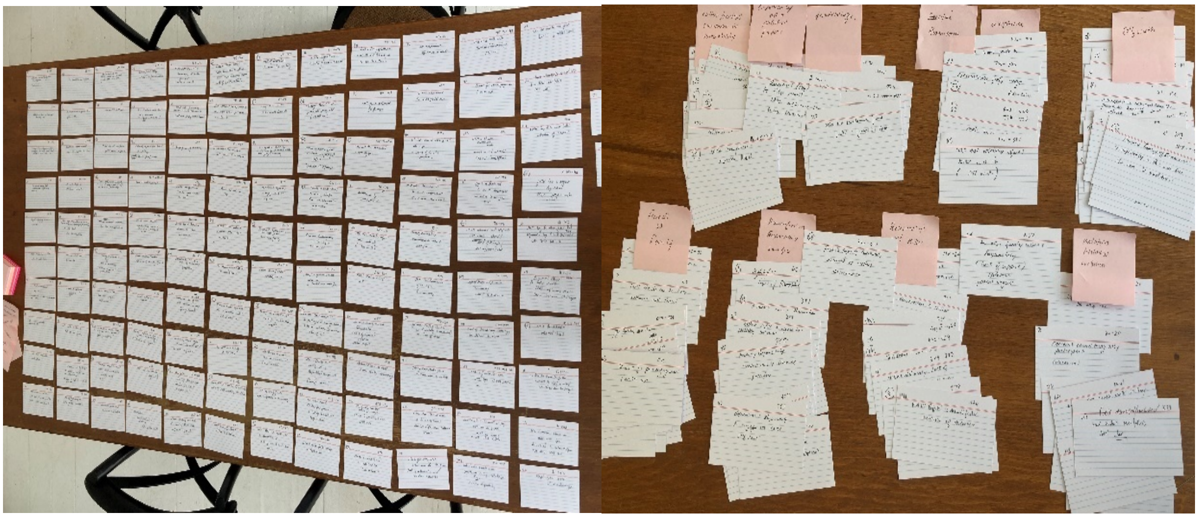
Smith and Nizza (2022) describe this part of the process as "distilling, synthesizing and identifying a structure" (p. 43). The objective now is to take the extended list of experiential statements (I created 121 experiential statements for this transcript) and link them to one another, forming clusters or groups to create subordinate/experiential themes. In doing so, Smith et al. (2009) urge the researcher to be mindful of polarisation, contextualisation, numerations and function in creating subordinate themes (Smith, 2009)/experiential themes (Smith & Nizza, 2022).

Polarisation refers to oppositional relationships that may exist between themes but act as a bridge between the two. In this case the researcher might look for juxtapositions or contradictions, where themes converge or diverge. Contextual themes may include time/place, culture and socio-economic factors. Additionally, a researcher might consider numeration, the frequency with which a theme occurs, which may indicate its level of importance. Finally, the functionality of the themes within a transcript can be considered, what it says about the meaning the participant attempts to convey. Again, it is emphasised that the way in which a researcher should go about creating subordinate themes is not prescriptive, however, useful guidelines have been provided and have been applied and demonstrated below (Smith & Nizza, 2022; Smith et al., 2009).

After developing all the experiential statements for the transcript, I wrote them onto individual cards with the line number to which they referred. I then laid these out on a table and began to arrange and link them to one another, forming groups according to the meaning they represented.

Figure 6

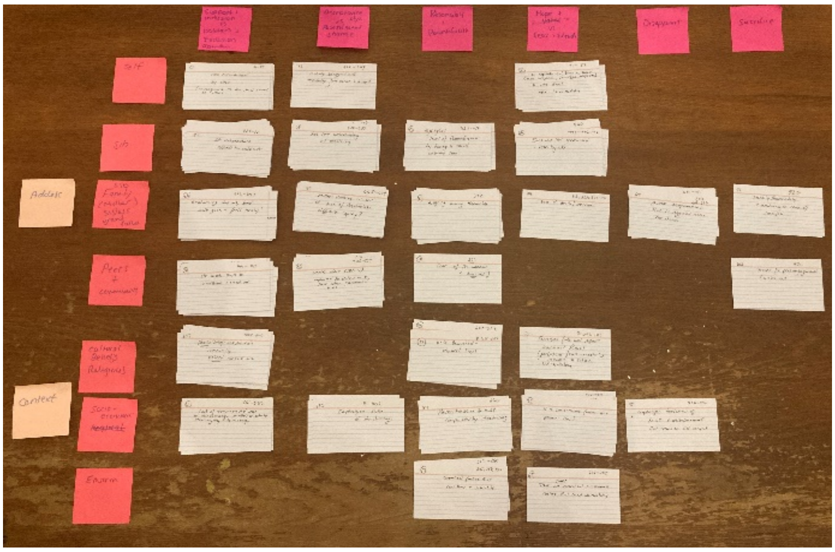
Photographs of the Process of grouping Experiential Statements



It was necessary to repeat this process several times before patterns that made sense began to emerge. I noticed that when I was able to hold my research question in mind, themes related to the participant's emotional experiences became increasingly evident. I then employed a subsumption process (Smith, 2009) whereby I created super-ordinate/experiential themes from experiential statements and brought together related experiential statements. Until this point, I was still navigating more than 40 super-ordinate/experiential themes. I then began to identify several divergent relationships between some of the themes. For example, Pumla's experiences of Asa's disability presented with challenges, but she also experienced disability as contributing to their bond. As such, several directly opposing emotional experiences could be drawn together to create one theme, "Experiences of *disability as complicated/nuanced*".

Figure 7

Photograph of Experiential Statements Grouped into Cross-Cutting Relational Experiences and Contextual Experiences



Through this process, the 121 initial experiential statements were clustered into three higher order themes. I created a table representing each of the emergent themes and relevant experiential statements. Once I had created a table for each of the three of Pumla's experiential themes, I could blend the tables with relative ease to create a single table which presented a more concise, simplified account of the themes, where only the most representative experiential statement remained, in order to make the (later) cross-case analysis between participants simpler.

5.8.4 The cross-case analysis (looking for patterns across cases)

Following the development of experiential themes for each participant, Smith et al. (2009) recommend moving to the next participant's account and repeating the process. Finally, I engaged in a cross-case analysis. The purpose of this process is to bring together shared experiences that indicate a connection between each case (Smith & Nizza, 2022). Finally, I created a table (see Table 5.3 below) of group experiential themes that would guide the write up.

Table 5.3

Group Experiential Themes

Table of Group Experiential Themes for adolescents with disabled brothers/sisters living in disadvantaged socio-economic contexts (in the Global South)		
Group Experiential Theme 1: Adolescent's experiences of togetherness		
1a. Non-disabled adolescents experiencing their sibling relationship as playful and reciprocal		
Bhuti	*(Laughs) It reminds me of all the fun times we have together and /pause/ ja, how playful we are, cause he's quite a lot older than me, I think he's like 4 or 5 years older than me, but like, the way we are playful you would never tell the difference*	P39:968-970
Pumla	*[laughs] she likes to (0.5) we like to laugh and joke around when we are together,*	P26:604-621
Luthando	*(Amahle loves playing, she loves jumping up and down the bed and playing with us)*	P20, 468-471
1b. NDS adolescents experiencing togetherness as ordinary		
Bhuti	*B okay, so it' early in the morning and we're cleaning our room*	P34:833-843
Luthando	*(sometimes when A is bored and I am also bored, we hang out together)*	P14:314-321
Pumla	*(chuckles) [for instance she always asks me what I did at school and so I show her and she also shows me what they did at school too and sometimes she asks me to help her (0.5) so I help her (0.5) she likes asking for help with her Xhosa homework (0.5) and then she asks me if I don't have homework and I tell her no I did get one this is what we did]*	P22:514-527

1c NDS adolescents experiencing relational reciprocity		
Luthando	*L: (I feel loved)*	
Pumla	*P: (I don't know but she no longer even tells me that she has homework when she gets home, she just puts her bag down and changes her clothes)*	P43:736-756
Group Experiential Theme 2: Non-disabled adolescents' experiences of care as voluntary or obligatory		
Group Experiential Theme 3: Non-disabled adolescents' experience difference and isolation due to daily difficulties that are informed by socio-economic disadvantage and/ or disability		

5.8.5 The writing up process

As per Smith et al.'s (2009) recommendation, to maintain the momentum of my analytic process I moved straight onto writing up my findings and quickly discovered (as it also suggested by Smith et al., 2009) that this was in actual fact an extension of the analytic process. Moving themes from a somewhat abstract space into a format that would make sense to someone else required a significant amount of honing in, in that, at times, concepts or ideas required much more development or reordering. This required an immense amount of back and forth between my supervisor and me, in order to ensure my interpretations made sense, but more importantly so that I was challenged to push myself beyond mere descriptions, into a more interpretative stance. It was during the writing up process that I referred back to any photographs that were referenced in the experiential themes as I found looking at the images the participants had created (and were making meaning from), assisted me in making my own interpretations by providing additional, more nuanced context. A particular challenge

I experienced was appropriately naming my themes, which required several attempts and only fell into place when I realised (with my supervisor's urging) that I could approach this creatively.

5.9 The Reflexive Process

Saville Young (2016) notes the importance of reflexivity in qualitative research, due to its primary role in facilitating meaning-making. She acknowledges that a qualitative researcher recognises their subjective stance in their work, and that their subjectivity is in itself a valuable research tool. Additionally, however, she highlights the importance of researchers being transparent in how they employ reflexive practices and in ensuring that their reflexive approach is coherent with their paradigmatic orientation.

Given the underlying hermeneutic principles and interpretative stance of IPA, appropriate, ongoing engagement in a reflective process throughout the research is imperative (Smith et al., 2009). As noted in the methodology chapter, hermeneutic awareness requires that before I try to make meaning of my participants' meaning-making process, I need to be conscious of the meanings I attach to my take-for-granted experience of the world. In this study, being aware of the meanings I have attached to being a NDS seemed paramount. What does being a NDS mean to me? Throughout my engagement with this research, this was a question that I had to engage with and acknowledge, and at times found it challenging to respond to. In my dedication to transparency, I lay some of my own meaning-making process out for the reader.

5.9.1 "Being special"

"Being special". This is a loaded term for me in many ways. When my sister was born, for some reason, other people, teachers, family friends, extended family, all continuously seemed to reiterate to me that "she was special". Maybe for some this was an attempt to console me, for what? For having a sister I loved, but in their eyes might not have been the sister I wanted? To feel better about themselves for having such a positive view on something they may have previously perceived as

negative? To emphasise that her differences (her disability) were what set her apart and made her unique? I will never know. I do know, however, what this meant to me at the time. Despite how much I loved her, she was more special than me. I didn't quite put my figure on this until much later in life when trying to come up with a title for a Master's thesis (of a similar theme to the current one). I blurted out to my supervisor that I could call it "I'm special too!" Acknowledging this now makes me cringe at my lack of personal (and academic) insight at the time. It also does something else; it draws my attention to how much needing to be special has been a part of my life narrative. I would argue, however, that irrespective of whether or not I had a disabled sister, I would have probably wanted to be special in one way or another. As a clinical psychologist I recognise that this is largely a shared, inherent human trait. I feel this speaks to Meltzer's (2015) view that disability can have many roles in a relationship between siblings. It can create, contribute or constitute our relational experiences. This is perhaps an example of where it contributed to my experiences. Part of being a NDS means recognising how my sister's embodied disability has contributed to my need to feel special.

There are endless examples of how disability has featured in various ways throughout my life. I never wanted to have "a big white wedding", but my sister has always loved big white weddings. We have watched many romantic comedies together, featuring a bride or a wedding. Long ago I told her that because I wasn't going to be looking like a meringue at my wedding, she could do the honours. This holds weight in itself, somehow; we had both realised that she might not have her own wedding or be able to wear a wedding dress. I acknowledge this is an example of my enacting my sister's embodied disability, letting her wear a wedding dress at my wedding. The truth is I eloped, and a part of me has felt bad about this for the last twenty years. I would not want to change how I got married, but I wish I could change the fact that I was unable to give her the moment she dreamt of her whole life. Being a NDS has meant shared moments of watching movies and thinking about our futures and dreams together. For me it has also meant feeling guilty about the experiences my sister would never have, that I would. It has meant feeling responsible for her happiness at times.

Was I her carer? At times, yes. Shortly after she was born, in a fierce attempt to challenge the very dire prognosis she had been given, my mother went to the UK to learn the Glen Doman programme designed (for children with Down Syndrome) to hone various muscles, senses and so forth. While she was gone, 8-year-old me did the mothering, the feeding, dressing, bathing, playing and putting her to sleep. On my mother's return, she would not let anyone other than myself put her to sleep. One year when we had gone to spend Christmas with extended family and I was staying with cousins, I got fetched at midnight to come and put her to sleep because no one else had succeeded; that was the year I discovered who Father Christmas really was. Being a NDS has meant my childhood did look different to that of my friends and cousins, and at times required caring and sacrifice, but it wasn't different for me, it just was. It has meant a lifelong recognition that "normal" is not generalisable. It looks different for everyone.

These are not meant as sad or tragic stories. These are just some of the meanings I have attached to being a non-disabled sister. I have loved, resented, protected, envied, valued, missed her throughout my life, depending on the situation. How I have felt about her disability has shifted accordingly to whatever was happening at the time. How I have enacted her embodied disability has never been static, that is, how I have lived, acted, talked in my role as a NDS, in relation to my sister's disability, has changed as we have aged, as the situations and places we have lived in changed. To this extent I see how our experiences are temporally and contextually embedded. Importantly, what I acknowledge is this is a part of my meaning-making process. From the outset I am aware that the participants will have their own unique meanings, however, this is the lens through which I have interpreted their meaning-making experiences.

The IPA researcher's primary goal is to make sense, through their own subjective perspective, of lived social phenomena. Engaging in IPA as a method therefore required that, from the conception of this study, I was cognisant that interpretations made were grounded in the participants' lived experiences, while similarly recognising that they are formulated through my own lens. I needed to be alert to when there was notable difference between my lens and the participants from a cultural, socio-economic and age perspective. Furthermore, making continuous efforts to demonstrate how I arrived at my interpretations by engaging in an ongoing reflexive process was crucial for transparency and trustworthiness.

As I considered each of the various perspectives to disability, I became aware that while they were not necessarily perspectives I have held throughout my life, there have been times where they have been embedded in my experiences. For example, I remember how implications of the medical model set up my first experiences of being a NDS:

I was seven years old when my sister was born; she was a twin, the other did not survive birth, both were diagnosed with Down Syndrome. The doctors told my mother that they "could find a place" for my sister. I don't know how or why I was aware of this, but I remember the horror I felt at the thought of my two, new, baby siblings suddenly becoming none. I'm not sure whether it was because she survived a traumatic birth or if it was because "they" tried to take her away, but having her in our lives felt a gift, and being the best big sister I could was a job I was determined to take very seriously from then on.

I would like to follow this with, "that was then, and this is now, and things have changed", but I still find myself navigating the implications of the medical perspective.

I am and have been my sister's legal guardian since I was 18 years old. It was a thing I knew when was younger, but it has gained meaning with age. I currently live in New Zealand, while my mother and sister live in South Africa. Should my mother die before my sister does, which is highly probable given my sister's good health, she would optimally come and live with us in New Zealand, where we have set up a home, where I have set up a practice and my son and husband have their lives. However, at this stage that is impossible. Currently, NZ immigration laws will not permit this because *she is disabled (she is in perfect health – but she is disabled). The reasoning is that she may become a burden to the state health system. She is being denied a visa because of a medical definition of who she is.*

Yet, like many South Africans living with disability, there have been innumerable occasions throughout my sister's life when we have had to provide some bureaucratic office or another with documentation to prove she is disabled. My mother, as a self-employed, single parent required the financial assistance offered by the government disability grant, applications for special needs schooling, tourist visa applications, etc. Having a piece of paper that defined her by virtue of her disability diagnosis was important. To this extent we have been reliant on medical input to allow her to have some of the opportunities that she has.

The moral model in contemporary society has been largely implicated with traditional, indigenous belief systems, however, reviewing the literature reminded me of a pivotal moment in my adolescence.

As a high school student, living in a small South African town we had recently relocated to (and were therefore isolated from any extended family), navigating the challenges (emotional and financial) of living with an alcoholic father, and struggling to make sense of my life in relation to that of my peers, I found myself in what felt at the times like existential turmoil. I wanted answers to lots of "why" questions, and the only thing available to me was a local bible group. I do not come from a religious family and so much of what was said to me was new, I didn't feel I had the knowledge or authority to challenge or question anything. On one occasion, however, the pastor that led the bible group came to me and told me that God had spoken to him while he was praying, and that the reason my sister was disabled was because of the sins of my father (not forefathers mind you). Apparently, I needed to break soul ties. I didn't break soul ties; I didn't go back to bible group.

Reviewing the socio-relational model and psychoanalytic perspectives on psycho-emotional disablism also elicited memories.

As a young NDS in the early 1990s, with my own "fear of rejection" (Watermeyer, 2009, p. 98), I would pretend not to hear the use of demeaning language associated with disabled people, frequently used as playground insults. For a long time, when anyone did anything that warranted teasing or jibing, "Don't be a retard!" was commonly used. There was even a time when, "You're acting Down Syndrome" was common, or "spastic". In instances where my peers would recognise their offensive behaviour and the hurt it caused me, I would rush to placate and excuse their behaviour to put them at ease, or to subsequently avoid feelings of pity. Nonetheless, I would be left feeling as though having an intellectually disabled sister meant others felt as though they had to be careful what they said around me. My perception was that I had inadvertently created a discomfort for others, making me difficult to have around.

Thus, I exemplify the various perspectives of disability which have directly influenced my experience of being a NDS. My experiences could not be captured or understood through the application of a single theoretical approach – they would not have the same meaning. I share my experiences not only to emphasize the argument made by critical realists who acknowledge that utilization of specific theoretical perspectives will implicate different experiences, but also to reinforce my argument for the use of IPA as an approach to understanding my participants' experiences as they have come to understand them, irrespective of the perspective of disability that may have informed their experience. Finally, these experiences are important to reflect on, to remind myself that they are mine, the meanings I have attached to them are mine, and while some of the experiences may be similar to those of my participants, they may have different meanings. What is important here is exploring their meaning-making process.

Willig (2013) emphasises that “the knowledge produced by IPA is reflexive in so far as it acknowledges its dependence upon the researcher’s own standpoint” (p. 69). This encapsulates the iterative, double hermeneutic nature of IPA, whereby the process entails both the participants’ meaning-making and the researcher’s efforts to make sense of their meanings. Given the integral role of the researcher’s involvement in knowledge production within IPA, it would stand that, for the sake of ensuring rigour, there are clear accounts of how the researcher arrives at her insights.

Engward and Goldspink (2020) state that engaging explicitly and reflexively with the data is complex and time-consuming, frequently rendering the researcher frustrated. Similarly, if not carefully and tentatively approached, the reflexive process can become “an infinite regress of excessive self-analysis at the expense of focusing on the research participants” (Finlay, 2002, p. 532). As such, to keep from floating adrift, the researcher is urged to anchor herself to the data and adopt clear methodological means for tracking the reflexive process – transparently tracking one’s thought process in relation to the data can contribute to rigour. Throughout my analytic process, anchoring myself in the data, my transcripts, methodically abiding to the recommended analytic steps, documenting each stage through notes and photographs which were shared with my supervisor, was crucial.

The tension between providing transparent accounts of my own working and insights, while fore fronting the participants’ experiences, was navigated by adopting various strategies. The first of these included keeping a research journal. Smith (2009, 2011) emphasises the importance of transparency in IPA, whereby the researcher clearly demonstrates the various steps taken to arrive at interpretations. Maintaining a journal can contribute to a research audit trail, by evidencing transparency.

It has been noted that when engaging in a reflexive journaling process, there are dual processes to consider – personal reflexivity and epistemological reflexivity (Willig, 2008). According to Willig (2008), a personal reflexive process entails consideration of how our own positionality may have informed the study and, in turn, how the research may elicit change within the researcher. In this instance, how my thoughts and insights pertaining to my own experiences of having a disabled sibling, my cultural affiliations, age and socio-economic context, positioned me in the research in relation to the phenomena under scrutiny, were considered. To this extent my reflexive journal has been used throughout this study, and in my analytic process.

Epistemological reflexivity, however, asks the researcher to consider how the research question has allowed for or impeded what knowledge is created, whether the research design has been appropriate in the acquisition of data and how/if the research could have been approached in an alternative way (Willig, 2008).

In addition to maintaining a journal throughout the study, Engward and Goldspink (2020) acknowledge that despite active efforts to be transparently reflexive, prolonged engagement in an in-depth analysis can still result in blind spots. As such, the importance of an ongoing supervisorial dialogue that can assist in teasing out the obscured and expose the researcher's thought processes is emphasised (Engward & Goldspink, 2020). This assists in highlighting the aspects of the interpretation that belong to the researcher, and what belongs to the participants, thereby supporting rigour. Despite the fact that I conducted the analytic and writing aspects of this study in New Zealand, while my supervisor was in the process of immigrating from South Africa to Australia, we were able to regularly engage via videocall and ongoing emails. At this point it is important to acknowledge that for us both, our status as emigrants might add to our lenses an awareness of how our insider-outsider status, by virtue of changed location, positions us further as outsiders (while acknowledging our heritage as white South Africans). I have, throughout my research, in addition to my reflexive journal, maintained separate notebooks in which I have recorded notes from my meetings with my supervisor. These notebooks reflect our many conversations over the years, elaborations on feedback, recommended changes, recommended reading, questions, queries, ever-changing timelines and trajectories and evidence of how our own lives have changed. Maintaining a reflexive journal and supervisory notebook proved valuable, by creating a space for me to reflexively discern which of my insights belonged to me and what was embedded in the data, as well as by creating an audit trail of my thinking process.

5.9.2 Interpreter's role in the reflexive process

While this study's primary aim is to develop an understanding of the meaning the participants attach to their lived experiences (informed by a context separate from my own), I cannot ignore the fact that without the utilisation of an interpreter this knowledge might be closed off to me. Emphasising the interpreter's role in the reflexive process is therefore also imperative to cross-cultural/cross-language research (Temple & Edwards, 2002). Caretta (2015) stresses the critical positioning the interpreter holds, being at once translator, gatekeeper and cultural broker, yet questions the absence of the interpreter's voice in cross-cultural, cross-language studies, aside from brief acknowledgement or anecdotal gratitude. Furthermore, it is noted that the lack of inclusion of the interpreter's voice denies the researcher further space to consider her own positionality and ethnocentricity within her reflexive process (Temple, 2002). While this is commonly included in a technical manner, by implicitly naming differences in perspective and identity between researcher and interpreter, it is seldom considered reflexively (Temple & Edwards, 2002). An example of this includes (as I have done above) providing evidence of the interpreter-participant match from a demographic or characteristic perspective. A more reflexive account, however, challenges the assumption that interpretations will necessarily be superior, simply because of the characteristic matches between the interpreter and the researched (Temple & Edwards, 2002). Instead, we are urged to consider how the interpreter forges her own identity within the research, which may create a border between the participants and herself and may in turn impact on knowledge production. In this case, my interpreter's age, her role as a mother of adolescents and her position within the NPO could have created identity borders between her and participants. Additionally, while it could not go unnoticed that for the most part, she was representative of the participant's demographic status, she was simultaneously acting as an assistant to me, a white woman, from the university. Her role in this case may have been seen from the participants' (and my own) perspective as the expert in interpretation. In addition, the interpreter had her own individual experience of this positioning in that while she acknowledged her role as interpreter, there were times where she questioned her capacity in this role.

After each interview the interpreter and I engaged in a debriefing session. These sessions were also recorded and transcribed, and the information was considered in the analysis and formed an integral part of the reflexivity process. I have considered the instances where the interpreter's experiences of the interviews significantly reinforced, differed greatly from, or contributed to my own, by adding cultural understanding, I have provided examples of this by including excerpts of the transcripts of our reflective sessions in the findings. Where possible, we attempted to do the reflection sessions shortly after the interview. Aside from reflecting on the participant's responses to the questions, the debriefing sessions also created a platform for us to consider our own technical and emotional responses, that is our own subjective stance, to the interview, be it the actual content or the process itself. An example of this was when the interpreter reflected to me about her own anxieties around whether she was adequately capturing what the participant was trying to say, given that she too was bilingual.

I have included an excerpt from the transcript of my reflective/debriefing session with the interpreter (following the first interview with Pumla) below, in which it is apparent how the interpreter formulates her identity in relation to the process.

Z*: ...not really, I think for me that, I wanted to keep on translating. But also, because I'm here now err with just us in that room, maybe she thought that it's ok that, uhm I do that. For me , I wished that she can express herself with her English. But I think because I was there, she was like, ok I can ask Ms Z to translate to Tammy. But now that translation… I started to think, umm I wonder if it was ok with her, although maybe she will think that it was ok because she will express herself and keep talking in isiXhosa and then I will translate to you. I worried because I don't know if uhm I captured the way* *that she's feeling, the way that she wants to express that. because as I am translating, and she's sitting here , she can hear and understand easily, and so maybe she thinks, "but I didn't mean this."*

T: ok so you were worried about your ability to interpret her feelings?

Z: mhh yes that's why, but also I was thinking that because I could see that she was comfortable that I'm there you know…

T: yes that's what I thought, she seemed very comfortable with you…

Z: yes she was comfortable with me, but I was like, oh, I kept on thinking, I wonder if I'm translating it right…

T: oh so it was more your insecurities?

Z: yes, that is it ok to say, because sometimes its not easy to know what is going on in her mind, is it, is it accurate?

In this extract it is evident that the interpreter is reflecting on her own ability to relay the participant's meaning. She also considers that while Pumla is proficient in English she tended to revert back to isiXhosa at times, possibly because this made her feel more comfortable and was available to her because of the interpreter's presence. Additionally, as a result of her proficient English, the interpreter was aware that Pumla was able to gauge the accuracy of her interpretations, which created a degree of anxiety in her own proficiency.

Temple and Edwards (2002) have documented how one may approach the interpreter as a "key informant' whereby they are included in a reflexive evaluation/interview (such as our post-interview reflection/debriefing sessions) pertaining to their positioning in relation to the research topic and participants, their own lived experiences, and own values. I have documented (Chapter Five, section 5.8.1) how I engaged in this reflexive evaluation process with my interpreter prior to initiating the data collection process. This information (the additional layer of subjectivity) has also informed my analytic process, by providing an additional perspective or step, that could influence my interpretations.

I have slightly extended the idiographic procedure by adding space to consider the interpreter's voice within my own initial responses. Smith and Nizza (2022) recommend that the IPA researcher is guided by specific steps (tabulated below). By adding an additional step for reflexive purposes, the process stipulated by Smith and Nizza (2022) is marginally expanded on. Following the creation of my exploratory notes and prior to developing experiential themes, I listened to the recording of the debriefing session with the interpreter and read the accompanying transcript. While doing so, I made efforts to capture anything noteworthy (reinforcement of concepts, exploratory notes, differing in understanding or cultural contributions). I was then able to utilise this information while formulating experiential themes. In essence, the additional perspective provided by the interpreter allowed me to engage more deeply with the data, while simultaneously holding onto my own positionality.

The amended step-by-step process is presented in Table 5.4.

Table 5.4

Amended Idiographic Process

Reading and creating exploratory notes	Reading and creating exploratory notes, (taking heed of discrepancies or embellishments in translation during the development of linguistic notes).
	Engaging with the interpreter's voice by listening to recordings of our reflexive sessions in relation to the interview.
Formulating experiential statements	Formulating experiential statements.
Finding connections and clustering experiential statements	Finding connections and clustering experiential statements.

Compiling the table of personal experiential themes	Compiling the table of personal experiential themes.
Cross case-analysis	Cross case-analysis.
Writing up the study	Writing up the study.

The interpreter in this study did more than interpret language, in fact she rarely had to, because most of the participants opted to talk in English. There were times where interpretation was necessary, and I noted that when reading her interpretation against the formal, professional translation, that occasional, albeit minor discrepancies occurred. On closer reading I realised that the interpreter in these instances was providing a more colloquial, somewhat interpretative interpretation as opposed to mostly verbatim translations provided by the professional translator. This did not necessarily impact on the interview in any way. Her role also included bridging a cultural gap. Her presence, her familiarity, obviously put the participants at ease. She did not offer cultural insights or explanations during interviews but did so in our reflective sessions following each interview, so as not to break the flow of the discussions. These insights were especially valuable during the analytic process where I was able to listen to our recordings of the session and read the transcripts to make more in-depth interpretations that took the participants' cultural affiliations into account. The drawback of this, however, was that I received these insights in a drip feed fashion, so what I knew when interviewing the first participants and what I knew at the end of the interview process about Xhosa culture was vastly different.

5.10 Credibility and Recognisability

Validity and reliability are integral aspects of scientific research in order to ensure the credibility and trustworthiness of work produced. Particular attention should be paid to the demonstration of this in qualitative studies where the subjectivity of the researcher could potentially affect the interpretation of the data (Brink, 1993). According to Brink (1993) however, the very nature of qualitative research does not lend itself to the statistical tactics employed in quantitative research.

Applying criteria traditionally purported by quantitative research, such as generalisability, objectivity, and reliability to qualitative research is not legitimate; akin to "Catholic questions directed to a Methodist audience" (Lincoln & Guba, 2000, p. 175). The concepts of reliability, validity and generalisability have thus been more appropriately named and defined for qualitative studies. Reliability is commonly substituted by the concept of credibility. By making one's research credible, one is ensuring they are believable through provision of evidence that is both supportive and challenging of one's claims, acknowledging the possibility of various interpretations of data and framing one's analysis tentatively (Bryman, 2016). Generalisability is replaced by the concept of transferability. By ensuring research is transferable, the researcher aims to produce a study that can be applied to similar populations and contexts. This is achieved by providing thick descriptions of one's method and subjects (Bryman, 2016).

Saville Young (2016) describes various concepts that can be utilised in order to ensure quality in qualitative research, namely, coherence, reflexivity, rigour and richness.

Saville Young (2016) describes coherence, which contributes to the recognisability in qualitative research, as the utilisation of the most appropriate method and approach for the research. This includes ensuring the method matches the research question and the aims of the research, making the research coherent and understandable to the audience. To ensure the appropriate choice of method it is imperative to have an understanding of the paradigm through which you are working as this will inform the focus of the research and the manner in which it is executed (Saville Young, 2016). According to Saville Young (2016), qualitative researchers grasp thoroughly the subjective role of the research, however, approaches to how it is applied and demonstrated vary, therefore transparency with regards to reflexivity is imperative. I have provided a thorough explanation of how I approached the matter of reflexivity throughout my research above.

Saville Young (2016) describes rigour in qualitative research as being akin to being provided with an infinitely detailed map of how one arrived at one's final destination. Throughout my research I have tried to apply rigour by providing thick descriptions of each process, keeping detailed notes and a journal and maintaining evidence of tables constructed through the analytic procedure to ensure interpretations stemmed from the data. Saville Young (2016) also emphasises that interpretations should be checked for credibility in a way that is appropriate to the methodology employed. I tried to ensure credibility through a transparent audit trail and multiple readings of the transcripts.

Finally, good quality research is described as being "rich in its description and interpretation of data" (Saville Young, 2016, p. 8). By providing clear examples of themes, identified in my analysis, and clearly demonstrating the links between themes, I have attempted to create a study that tells a story that will resonate with the reader (Saville Young, 2016).

In addition to ensuring credibility and transferability, I also considered four key recommendations made by Nizza et al. (2021) that are aimed at establishing good quality IPA. The first is to construct a compelling, unfolding narrative. I have aimed to achieve this by ensuring that the story held in my analysis is coherent across themes and within the themes. To achieve this within themes, I have organised my themes into sub-themes and chosen specific participant quotes and my interpretations thereof to lead the reader through the story. To obtain coherence across themes, I have ensured that each of the three GET, "Experiences of togetherness", "Care" and "Being an outsider" speaks clearly to the others. Each of my GETs are interrelated in that they all tell the story of the participants' experiences of being a NDS.

Secondly, it is recommended that vigorous experiential and/or existential accounts are developed (Nizza et al., 2021). To achieve this, it was important that I focussed on the meanings my participants were conveying about their experiences. This was at times challenging for me and required ongoing urging from my supervisor to engage with more than what was being said by the participants, in other words, with what the existential consequences of their experiences held in terms of their sense of self.

It is subsequently recommended that IPA researchers engage in close analytic reading of the participant's words. Through a thorough analysis and interpretation of the participant's quotes, concentrating both on what was immediately being said, but also what each quote meant in the participant's overall context, I aimed to "reveal the deeper significance of the particular relationship between the participant and the experience" (Nizza et al., 2021, p. 376).

Finally, it was important to attend to the convergences and divergences between the participants' experiences, to show where their experiences were the same or different, but also to indicate representation, prevalence and variability in my analytic process.

5.11 Ethical Considerations

5.11.1 Informed consent

Consideration of informed consent when including youth in research raises several arguments. Developmentally, there are stages where, given the cognitive and social capacity of the young person, they could be considered able to make independent decisions pertaining to informed consent (Cocks, 2006). However, Cocks (2006) highlights that it is frequently recommended that informed consent be provided by a responsible caregiver, while assent is obtained from the child. In the case of adolescents, however, where there is a drive toward individuation, there is the possibility that the acquisition of parental consent could elicit a sense of being undermined or negated for the participant, negatively impacting on the data collection process by hindering rapport between the researcher and participant. As such, when meeting with the participants initially, it was emphasised that assenting to participate was voluntary and they could decide at any stage if they no longer wanted to participate.

Despite these debates, the South African Children's Act 38 of 2005 (as amended by Act 41 of 2007) (Republic of South Africa, 2007) and the National Health Act 61 of 2003) (Republic of South

Africa, 2004) has legislated specific requirements. These state that any non-therapeutic research with a person under the age of 18 years requires assent or consent, where clear understanding is deemed possible from the participant. In addition to this, the primary caregiver or guardian is required to provide consent. Furthermore, consent must be obtained from a legally appointed committee accredited to approve research involving minors (e.g., certain university ethics committees) or the Minister of Health. I have therefore actively complied with legislature by obtaining consent from a legal guardian or caregiver (see Appendix E), assent from the participants (see Appendix G) and ethics approval from the Rhodes University Psychology Department's Research Projects and Ethics Review Committee, as well as the Rhodes University's Ethical Standards Committee (see Appendix C).

It is essential to pay careful attention to how child participants are informed about the research. Given the cross-language, cross cultural aspect of this study, all information letters disseminated were translated into isiXhosa. I also took into consideration, the possibility of various literacy levels. As such, these were disseminated in person, read with the recipients and clearly explained in the first language of the guardian or participant by the interpreter. In the case of both the consent and assent form, recipients were required to indicate through tick or signature that they understood. At this stage, it was also imperative to highlight any potential risks. It was explained to each participant that interviews may include sensitive information. They could advise if there was something they did not wish to discuss and if they experienced any distress they did not have to continue with the interview. The option to withdraw at any stage was carefully explained.

I was continuously mindful of the fact that in the case of cross-cultural studies there may be cultural factors that predispose a young participant to positively respond to an adult, despite their own lack of willingness or inclination (Clacherty & Donald, 2007). As such, it was reiterated at every encounter with the participants, by myself and the interpreter, that they could withdraw at any point with no repercussion. Furthermore, at the end of each interview, the participants were debriefed and offered the opportunity to discuss any distressing thoughts or feelings that may have arisen during the interview with a professional psychologist at the Rhodes Psychology Clinic should they so wish. An example of this occurred when one of the participants acknowledged that she had experienced suicidal ideation in the past. When this occurred, we paused the interview process and established with her whether she wanted to discuss this matter with a psychologist (detailing what this would entail and that I would facilitate this should she wish to proceed).

5.11.2 Confidentiality and anonymity

During the consenting and assenting procedures, it was emphasised that the data collected would be used solely for research purposes. Throughout the study, the identities of all persons would be protected through utilisation of pseudonyms, and specific identifying data adjusted.

Anonymity is a form of confidentiality that involves keeping the identity of the participant's secret. The researcher in qualitative research is engaged in a balancing act, on the one hand trying to protect the identities of the participants and on the other maintaining transparency and integrity of the data (Kritzinger et al., 2015). In this research the primary researcher, the supervisor and the interpreter were privy to the identities of the participants, however pseudonyms have been used throughout the research.

In addition to consent related to participation in the interview, the participants would be required to photograph their lives in relation to their disabled sibling within a community. There was, as such, a high possibility of other people being included in the pictures. For this reason, participants received guidance on the ethics on photographing other people. They were given various ideas on how people could be photographed without their faces being viewed. Additionally, they were required to request permission from the people they photographed (providing an explanation on the purpose of the photograph) and obtain written consent to photograph them. To support and simplify this process for them, pocket photo consent cards were created and translated into isiXhosa (see Appendix J), with tick boxes for quick and easy utilisation to issue to the people in their pictures. It was emphasised that their pictures of others could not be included without an accompanying consent card. Furthermore, I have, (as emphasized to participants and their caregivers) blurred any identifying data, including faces in the photographs that have been included in this report.

In addition to protecting the identities of the participants and their subjects, other members of the research team (for example, the interpreter), were required to sign confidentiality agreements. Finally, the audio recordings of the interviews were deleted on the completion of the research and were password protected throughout the duration of the research. Transcripts have been stored in a password protected file.

5.12 Summary

In this chapter I have provided a description of the method I have utilised to best respond to the research question: “What are the lived experiences of Xhosa adolescent siblings of disabled people living in disadvantaged socio-economic contexts in semi-rural South Africa?”. I have detailed how I approached the sampling, recruitment and data collection, given the “hard to reach” nature of my sample. In particular, I have given attention to describing the use of an interpreter to accommodate for the fact that the data collected may not have been accessible to me without her assistance. Finally, given that the participants might be considered vulnerable due to their age, I presented my approach to reflexivity, and the ways in which I ensured quality and transparency within the study. Finally, I have explained the various ethical aspects considered.

CHAPTER SIX

FINDINGS: ADOLESCENT NON-DISABLED SIBLINGS' LIVED EXPERIENCES OF TOGETHERNESS

6.1 Introduction

The first noted theme in this study was the sense of togetherness participants experienced in their relationships with their disabled siblings. Some participants described reciprocal love which they experienced prominently in their sense of togetherness with their disabled brother/sister. Reciprocity was also experienced in playful moments and ordinary moments. In these instances, disability was experienced as periphery. Participants also described difficult interactions with their sibling, where disability was fore fronted and the relationships were experienced as being more one-sided. Here togetherness was experienced as difficult.

6.2 Reciprocal Love and Togetherness

Some of the siblings in this study emphasised experiences of reciprocal love in their sense of togetherness with their disabled siblings. They described feeling love for their disabled brother/sister and also feeling loved by their brother/sister. Their experiences of reciprocal love suggested a sense of mutual togetherness.

Bhuti (18 years old) had recently left his family home to live in university residence. When asked how he felt about his older, disabled brother Sipho, Bhuti stated that he "cares about" him (p 12; 280), however, since his move to university, they were not able to spend as much time together. I then asked how he felt about their relationship. He described how he is aware of Sipho's efforts to be together when he comes home to visit:

(Extract 1)

B: Ja, I think, like it's special, ja, so, cause the way we are interacting, like when I'm back now, he always wants to talk to me and we're always together. So, I think he is making the most of me being there, cause when I'm away he won't be able to. (Bhuti, p41:1017-1038)

Bhuti describes their relationship as "s*pecial*", indicating that it means a lot to him. He then highlights his sense that Sipho "*always wants to talk to [him]*" too and that he "*is making the most*" of his visit, indicating an experience of reciprocal love. Furthermore, his emphasis on the fact that they are "*always together*" suggests he experiences a mutual willingness to be together, and that wanting to be together is experienced by them both. In this extract Bhuti describes how togetherness is embodied in his relationship with his disabled brother through their talking.

Luthando (12 years old) also describes a sense of reciprocal love he experiences in his relationship with his older, disabled sister Amahle. He chooses to talk about a photograph he took of her, sitting and playing in their living room. He had earlier in the interview stated "*[he] loves her*" (Luthando, p24:553-568) when asked about his motivation to look after her, making his feelings evident. When he chose this photograph, I asked him how looking at it made him feel.

Photograph 1

(Extract 2)

L: (I feel loved)

Z: (You are loved?...Who loves you?)

L: (by) Amahle (Luthando, p10: 219-224)

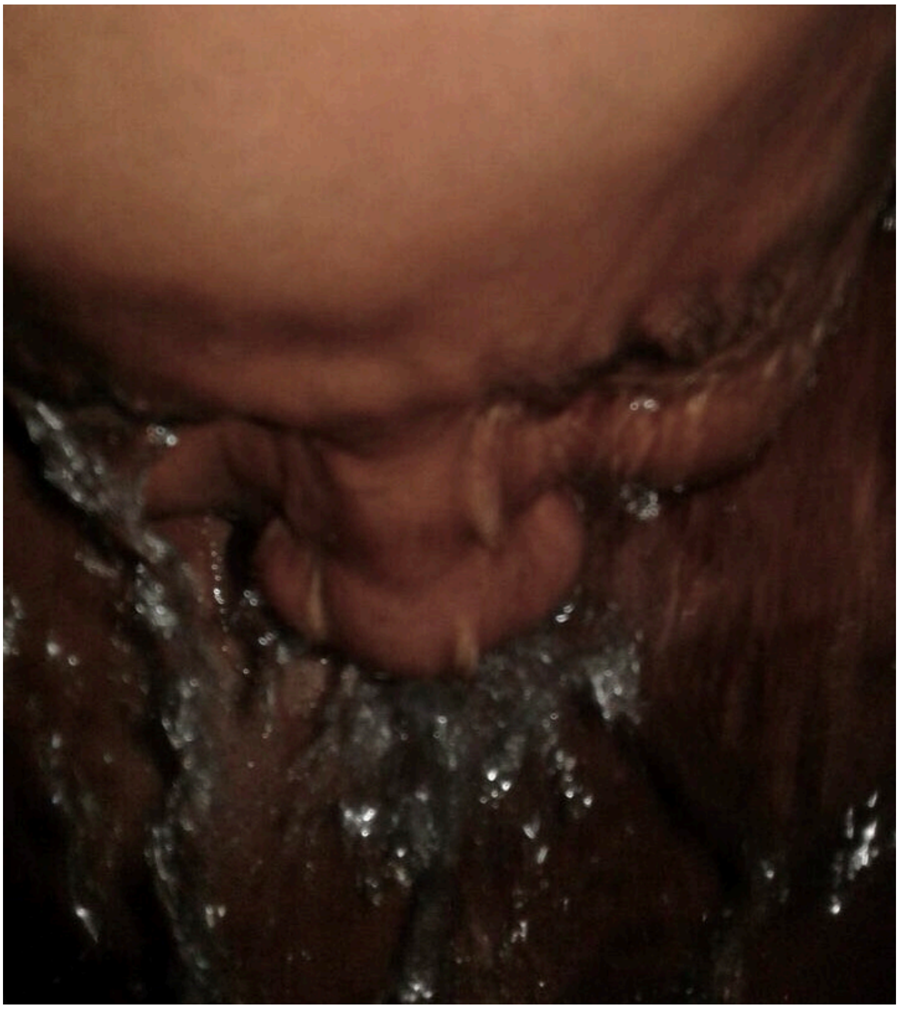
Luthando responds with certainty to my question on how he feels when looking at his photograph of his sister, that "*[he] feels loved*". There is a sense that just seeing Amahle elicits a sense of feeling loved. He is seemingly confident about their mutual love for one another although Amahle is unable to communicate verbally. His earlier acknowledgement of his feelings of love for her and the lack of doubt in the reciprocity he experiences suggests to me that he experiences a sense of mutual togetherness in his relationship with Amahle.

Where both participants describe experiences of reciprocal love and a sense of mutual togetherness is inferred, I noted in these moments, disability is not experienced as central.

6.3 Play and Reciprocity

At times disability was embodied and enacted in experienced togetherness through play and "*all the fun times [had] together*". NDSs experienced moments of togetherness as playful and special, during which feelings of mutual reciprocity were notably pronounced. The siblings in this study enjoyed playing pranks on one another, laughing at and teasing passers-by, and jumping on the bed together. Participants also experienced mutual togetherness and a sense of reciprocity in playful moments. In the playful interactions they described, a sense of mutual we-ness was experienced. In reflecting on a photograph he had taken of an amusing prank he had played on his older brother, Sipho, Bhuti muses about the many times they have engaged in these jocular, brotherly interchanges. In this prank, Bhuti had convinced Sipho that a specific requirement of taking photographs for this research was that he had to pour water on his head:

> *I told him no like we have to do this photo shoot where I pour water over your head and he was like 'what' and I'm like serious and that's what happened, [chuckles] ja he went along with it, uhm ja, I just poured water over his head.* (Bhuti, p39:981-985)



Photograph 2

(Extract 3)

B: (Laughs) It reminds me of all the fun times we have together and /pause/ ja, how playful we are, cause he's quite a lot older than me, I think he's like 4 or 5 years older than me, but like, the way we are playful you would never tell the difference. (Bhuti, p39:968-970)

In this extract, Bhuti happily reminisces about the "fun" and "playful" moments he has shared with Sipho, his older disabled brother. Having fun together and being playful are described as regular experiences within their togetherness. Bhuti emphasises that, despite his awareness of their age gap, he does not feel different to Sipho. He seems to suggest that they share a mutual willingness to engage playfully with one another. Buthi's frequent use of the word "we" suggests that he experiences these playful exchanges as reciprocal, that they are both willing participants, something he appears to deem valuable in their relationship. The we-ness Bhuti emphasises in their playful interactions highlights his sense of experienced togetherness.

Photograph 3

When looking at a photograph, Pumla (16 years old) has taken of her younger sister, Asa, she reflects on their enacted togetherness and highlights the playful moments they share. The sisters live together in an informal dwelling, and being in a wheelchair, Asa's lack of mobility means that outside of school, they spend the majority of their time together at home:

(Extract 4)

P: [laughs] <u>she likes to (0.5) we like to laugh and joke around when we are together, with Asa, laughing at people who are walking down the road, she always calls me, and tell me there is so and so (0.5)</u>

> *Z: Asa would just go 'Pumla come and see' and then Asa and her would just laugh about the manner (people) are walking ..., so they will be laughing and having fun together.* (Pumla, p26:604-621)

Pumla describes how she and her disabled sister, Asa, like to laugh and joke about the strangers passing by their home. This activity suggests Pumla experiences her and her sister as being in alignment or as a team. By laughing at others at the same things and sharing jokes, a sense of we-ness is created.

Pumla highlights that when they are engaged in this activity together, her sister "*always calls*" her to share in her fun. She, like Bhuti, emphasises her sibling as seeking her out, and the value she places on the reciprocity in their relationship – demonstrated by her changing "she" to we", when describing their activity. This seems to suggest that she values Asa's consistent desire to include her in her fun, making it a prominent aspect of their experience and contributing to a felt sense of togetherness. In this instance, it is evident how Asa's embodied disability, being in a wheelchair, has contributed to how they enact their playful togetherness in shared moments at home.

After the interview, in our reflection sessions, the interpreter, Zuki, commented on this particular description provided by Pumla and noted, "*yes and when she described how they laugh together about that man who is walking funny, Pumla is forgetting about her loneliness and it is Asa, she is the one who is making her happy*" (Zuki, p6, 112-115).

I found this statement by Zuki valuable in that it reinforced my sense that Pumla was communicating the togetherness and reciprocity she experienced with Asa.

Similarly, when asked to describe his sister, Luthando's first response was to describe her playfulness:

(Extract 5)

L: <u>(Amahle loves playing, she loves jumping up and down the bed and playing with us)</u>

> *Z: she is very playful, they are playing together, jumping on the bed and these things* (Luthando, p20:468-471)

Like the other participants, Luthando highlights the playful activities his sister likes to engage in, that make having fun together possible. His response suggests the value he places on their playful interactions. His use of the word "loves" in plural, suggests that this is something that happens regularly, and the predictability of these interactions possibly form a part of the togetherness he experiences. Additionally, he, like the other participants, feels that she enjoys playing with him too, indicating an experienced sense of reciprocity in the fun they have. Furthermore, by Luthando stating what Amahle "*loves*" to do, he demonstrates that even though she is unable to speak how her disability is embodied, the nature of their experienced togetherness has made it possible for him to understand her wants and needs.

In reflecting on their relationships with their disabled brother/sister, the participants described fun and playful moments. Bhuti, Pumla and Luthando each emphasise their sibling's willingness to engage in playful interactions, suggesting they experience a sense of reciprocity contributing to a sense of we-ness where disability is not necessarily central.

6.4 Ordinary Togetherness

The NDSs also described how experiencing togetherness was enacted through ordinary moments, where they shared quieter interactions of companionship engaging in mundane, day-to-day tasks together. These included "*just sitting together*" in moments of boredom or "*doing homework together*" or "*Cleaning [their] room*".

While ordinary, these moments still held meaning for the NDSs. One participant described how he and his non-verbal, intellectually disabled sister like "*hanging out*" where they can just be "*bored*" together. In this instance, in his sister's embodiment of her disability, she provides a space for them to be together, where there is no expectation of either of them to do or be more. While ordinary, his decisions to take and discuss the photograph are indicative of the value he places on the moment.

Another participant described doing homework together with her disabled sibling, highlighting the turn-taking aspect of this interaction, helping one another, again highlighting a sense of mutual reciprocity in their experience of ordinary togetherness. In their descriptions of ordinary togetherness, NDSs indicated that they experienced these interactions as something they both wanted to do together. For example, one participant stated about her disabled sister, "*she likes asking for help with her Xhosa homework, and then she asks me*", emphasising a sense of mutual we-ness.

Where togetherness was enacted through ordinary moments, the importance of shared spaces was also noted. For example, "being bored" together was more meaningful because it occurred on the verandah where they "*always*" hang out. Similarly, NDSs' emphasis on cleaning their "*shared*" bedroom suggested having a clearly demarcated space for them to share moments and be together was important.

In addition to the playful interactions participants described in their relationships with their disabled siblings, there were also moments of ordinary togetherness, quieter moments of shared companionship.

Luthando chose to discuss a photograph that he specifically requested his non-disabled brother take of him and Amahle, his disabled sister, sitting together in a seemingly regular moment of shared boredom. I asked him to describe what was happening in the photograph.

Photograph 4

(Extract 6)

L: *(<u>it's just me and Amahle hanging out together)</u>*

T: and where is that?

L: *<u>(on the veranda)</u>*

[…]

T: And what do you like about this moment?

L: *<u>(we're just hanging out together)</u>*

Z: just him and her sitting together

L: *<u>(sometimes when A is bored and I am also bored, we hang out together)</u>*

Z: sometimes if they feel bored, they always sit together

T: okay, and why did you want this picture taken?

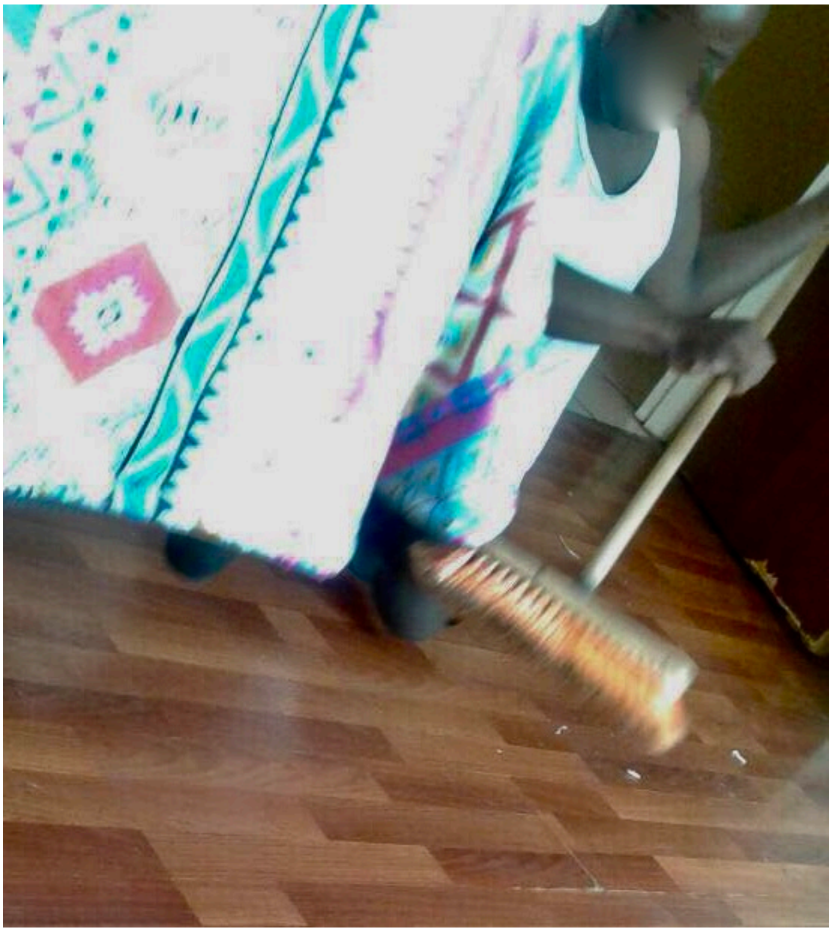
L: <u>(because that's where we like to sit when we are bored)</u>

Z: because it's the time where they always uhm, it's those moment that want to be captured, that when they bored or think about something they go and sit together, him and her (Luthando, p14:314-321)

Luthando notes that in the picture, "*it is just*" he and Amahle "*hanging together*". His use of the word "just" seems to capture the sense that within their relationship they share and experience ordinary moments of togetherness. Zuki's interpretation reinforced my sense that he was trying to emphasise the simplicity of this moment of togetherness, "*just him and her sitting together*". While there is simplicity in his experience of them "*just hanging out together*", its significance is demonstrated by it not being a spontaneous photograph. Luthando's need to replicate the moment suggests that it was something he wanted to capture as not only was it demonstrative of a seemingly ordinary, but regular moment of boredom, it also captures a sense of their everyday, mutual willingness to be together that is not framed by his sister's disability.

The sense of connection he experiences with his sister seems again, to be further extended by his capacity to interpret his sister's desires and emotional state, "*that's where* ***we*** *like to sit when* ***we*** *are bored*", despite her inability to express this verbally to him. It also seems important to Luthando to demonstrate that they have their own place to be together, again something he seems to value. "*Hanging out*" in their place seemingly reinforces a sense of unity, albeit an ordinary moment.

Similarly, Bhuti provides evidence of seemingly ordinary day-to-day, shared interactions with his brother, Sipho. Bhuti captured and chose to discuss a photograph of him and Sipho cleaning their shared bedroom.



Photograph 5

(Extract 7)

B: okay, so it's early in the morning and we're cleaning our room

T: cleaning?

B: Ja, cleaning our room, it's me and my brother's room

T: Okay, that is the room you share?

B: ja, and uhmm, and there's like music playing, cracking jokes, and we're cleaning (Bhuti, p34:833-843)

Bhuti recalls the moment he photographically captured Sipho. Although a seemingly ordinary activity that they engage in together, there is emphasis on the fact that it is their shared bedroom, "*me* *and my brother's room*". Like Luthando, he demonstrates a space that is theirs, where they can share moments of ordinary togetherness, and an experience of we-ness is suggested.

Furthermore, Bhuti provides further context, "*music playing, cracking jokes*", my sense was that in so doing, he wanted to highlight that while ordinary, they similarly make the most of, and find moments of shared togetherness in these everyday relational interactions, such as cleaning.

Sethu (13 years old) also describes how regular trips to the local library provide moments of being together with her little, disabled brother, Buhle. She talks about a photograph she had taken of the library:

> *S: (This is the library that I love going to because there is also a children's section and so I have my own library card. Even the books I take from the library are for Buhle, I don't take any books for myself. I love him, I take him there sometimes because they also have toys. So, I love taking him there every day, from Monday to Friday.)*
>
> (Sethu, p27:759-767)

Sethu describes her regular excursions to the library with Buhle. She states, she takes "*him there every day, from Monday to Friday*", indicating that this is an activity that occurs frequently, and is not particularly novel. Although it is an everyday, ordinary interaction, she experiences it as valuable in that she "*loves taking him there*". My sense was that she valued the regularity of this ordinary moment because of the togetherness she experienced with Buhle. She also emphasises that she experiences a sense of generosity toward Buhle in this activity, in her reiteration "*even the books [she] takes are for Buhle*" and that she doesn't "*take any books for (herself)*". While being an ordinary activity, Sethu also experiences it as an opportunity to demonstrate love.

Pumla also talks about ordinary togetherness with Asa, which included helping one another with their homework:

(Extract 8)

P: (chuckles) [for instance she always asks me what I did at school and so I show her and she also shows me what they did at school too and sometimes she asks me to help her (0.5) so I help her (0.5) she likes asking for help with her Xhosa homework (0.5) and then she asks me if I don't have homework and I tell her no, I did get one this is what we did]

(Pumla, p22:514-527)

Pumla describes how she and her younger disabled sister, Asa, spend their afternoons in ordinary togetherness doing homework. She emphasises that Asa "*always*" asks her about her day at school and for her assistance with her homework. This, as in the case of other participants' experiences, suggests the regularity of their shared, ordinary interaction. She describes how they are both curious and interested in one another's day at school and what their homework is. As such, there appears to be a methodical turn-taking, thereby suggesting that the mutuality of this interaction is important to her, as it possibly contributes to her experience of togetherness. There is also a sense of experienced equality which contributes to the mutuality emphasised in these moments of ordinary togetherness. Furthermore, I interpreted Pumla's emphasis on Asa requesting her assistance as her obtaining a sense of validation and purpose in these interactions. As such, while she describes a moment of ordinary togetherness, she, like the other participants, also thinks of these moments fondly, and experiences them as enjoyable.

Participants described moments of ordinary togetherness with their disabled sibling. They emphasised the fact that these interactions were largely routine, reinforcing that they were both regular in content and frequency. This also highlighted their disabled sibling's willingness to engage in these moments, suggesting they experienced a sense of mutuality, and while ordinary, these moments of togetherness were experienced as valuable.

6.5 Togetherness as Difficult

Participants described situations where togetherness was reported as being more difficult.

Thando (17 years old) has been looking after her younger sister, Portia, since she was a baby, however, she has only recently started living with her (and their mother and stepfamily). I asked her to describe her relationship with Portia. She relayed day-to-day interactions which consisted largely of having to be with Portia, because other family members were not available, or willing to do so. She also emphasised challenges she experienced with Portia's behaviour which made being together difficult:

(Extract 9)

Th: (With Portia (laugh) it's [her relationship] alright (continue laughing) because we hang out together most of the time, whenever I would get home in the afternoons from school, I would be with her. Sisi (non-disabled stepsister) would go and play, my grandfather wouldn't be there, my mother and father would also be at work, so it's fine, but she's so naughty.)

T: Okay, okay so you've always been very close to her?

Th: Maybe … (She makes a lot of noise; she causes a mess and even tears my schoolbooks.)

T: Okay?

Th: It's very frustrating. Yoh!

[...]

T: Does that happen a lot?

Th: Yes

T: Ja (yes) okay, and then how do you feel when that happens?

Thando: (Yoh! That irritates me a lot.)

(Thando, p20:570-583)

Thando initially describes her relationship with Portia as "*alright*", and how they are often together, as they "*hang out together all the time*". As such, I initially interpreted her response, with her emphasis on how often they spend time together, as her way of describing a willingness to be together. This was especially in light of how differently she had described her relationship with her non-disabled stepsister, Sisi, which was irrefutably difficult, "*my relationship with Sisi isn't that great, we clash all the time, we never just sit and chat*" (Thando, p16, 440). However, she responds to my request for clarification on their closeness by indicating a sense of ambiguity, in her response of "*maybe*". She does not outrightly refute my suggestion of closeness, but quickly explains why she does not necessarily feel close, in her description of difficult interactions with Portia because of her behaviour. She specifically names Portia's "*naughtiness, noisiness and messiness*" as hard to manage. Thando's description of Portia's tendency to tear her schoolbooks while she is trying to do her homework highlights the frustration she experiences within their togetherness at times. There is the sense that as a result of Portia's behaviour, there are many instances where she is unable to achieve tasks that are important to her, making Portia's disability something that requires regular endurance, and togetherness is experienced as difficult. It is also noted that Thando does not explicitly link Portia's challenging behaviour to her disability. Her initial ambiguity in her description of their relationship may be explained in the same vein, that there is a degree of impression management in play, where Thando does not want to infer that she experiences Portia's disability as difficult because of how Zuki or I may perceive this.

There is also a sense that because her interactions with Portia are expected of her, because her other sister "*would go and play, [her] grandfather wouldn't be there, [her]mother and father would also be at work*", their togetherness is determined by necessity. It seems that Thando feels that, unlike other members of her family, she has no choice in whether she spends time with Portia or not. Her experienced lack of choice possibly contributes to feelings of resentment that play out in relationship with Portia, contributing to her experiences of togetherness as being difficult.

Difficult moments of togetherness are also described by Aya (17 years old), who similarly, frequently feels frustrated with her younger, disabled brother's behaviour:

(Extract 10)

A: And there are so many times, like there was this time, we were at the Spaza shop and we were buying chips, we love NikNaks. So, buying 5 packets and then this guy comes, and he buys four 50 cent cigarettes; the shop owner puts them on the counter. So, Ande, I'm not really watching what he's doing, he was just standing there and then he took those cigarettes and broke them. So, I had to hustle another R2 to buy another four cigarettes for that guy, because I don't even know, my gosh, that was the worst, he was so angry and I was so angry with Ande.

(Aya, p14:388-413)

Aya describes taking Ande to the local corner store to buy chips. While not watching what he was doing or minding him, he destroyed another customer's purchases. She relays how she consequently had to resolve the situation, despite not having any money, and in so doing has to take responsibility for Ande's behaviour at her own expense, causing her to feel anger toward Ande. There is a sense that, like Portia tearing Thando's books, Ande's behaviour is costly to Aya. Their experiences of togetherness seem to consist more of required giving, and less reciprocity. Like Thando who spends most afternoons with Portia, Aya indicates that this is a scenario she has experienced "*many times*" when spending time with Ande. By emphasising the frequency of these challenging interactions, their experiences of frustration are noted. Experiences of togetherness for these particular participants include having to spend time with, and take responsibility for their disabled siblings, who often demonstrate challenging behaviour, and there is a noted absence of we-ness.

Sizwe (14 years old) also describes a complex and frustrating interaction with her little brother, Buhle, when I asked her to describe her relationship with him:

(Extract 11)

S: (He likes crying or just to sit quietly, and I would say, 'no man, why are you so quiet, say something,' but then he would keep quiet. And then when I am annoyed because he is crying a lot, I will say, 'hey can you be quiet,' when he is quiet, I will then say, 'no man say something,' and when he is crying, I will say, 'no man be quiet.')

(Sizwe, p5:135-149)

Sizwe expresses how being with Buhle is confusing and frustrating at times. She describes wanting him to be able to talk to her, when he is quiet (and unable to talk because of his disability, although she is not explicit about this) and then feeling "annoyed" when he is crying and wanting him to be quiet. She describes experiencing a sense of ambivalence about their relationship. Her ambivalence might be understood by her inability to understand his needs and emotions, wanting him to be different to how he is, or the fact that, like the other participants, there is no sense of we-ness experienced in their togetherness. Although, like the other participants, she is not explicit that her difficulty being with him is because of his disability, by highlighting his inability to speak, my sense was that she was trying to allude to this.

Sona (16 years old) also describes finding it difficult to be together with her older, disabled sister, Gugu:

(Extract 12)

T: and what are some of the things you like to do together

S: uhm, nothing

T: you don't like doing things together or you just don't do things together?

S: we don't do things

T: okay, I wonder why that is?

S: she is older, and we cannot do things that uhm…

T: Would you like to do things with her?

S: sometimes

T: what would you like to do with her?

S: maybe she could take me shopping and take me to places that are nice

T: is it because she is older than you that she doesn't do these things?

S: yes, and it's because she cannot

T: she cannot?

S: she has grant money but it is not enough

T: it's because she doesn't have enough money to do nice things with you?

S: yes, I can do these things with my cousin sister, with her it is fun

T: so, if Gugu had more money would you like to do those things with her?

S: hmmm, no, it's better with my cousin (Sona, p15:402-421)

I initially interpreted Sona's response of "*uhm nothing*" to my question about what she and Gugu liked to do together as her reluctance to participate, possibly due to nerves, or discomfort in the interview. I also wondered if perhaps there may have been a lack of understanding, given that she had resisted speaking in isiXhosa or utilising Zuki's presence as an interpreter. I was hence prompted to seek clarification, however, Sona initially asserted that she and Gugu did not spend time together. I was aware that she had recently, reluctantly moved out of her family home to live with her maternal grandmother (where she had lived with Gugu), due to financial reasons and a lack of space, and wondered if it was physical distance that prevented their time together, although I was reluctant to lead her response in any way.

Sona then alternates between providing several reasons for their inability to spend time together, including Gugu being too old, and not having enough money to do the things she likes with her, and simply stating that "*she cannot*". Sona seemed to struggle, however, to be explicit as to why

Gugu could not spend time with her, although she emphasised this twice. This, however, was something she would like to do "*sometimes*". She acknowledges that their age difference partially contributes to their inability to do things together, as does Gugu's lack of money, but mostly it is because "*she cannot*". Although not explicit, Sona appears to ultimately suggest that this is because Gugu is unable, possibly because of her disability. In addition, it is noted that for Sona, even if Gugu was financially able to do the nice things with her that she wants to do, she would prefer not to, choosing her cousin instead. I was then aware that my initial uncertainty about whether she didn't do things with Gugu or didn't want to do things was because Sona experienced both. They don't do things together because she doesn't want to, possibly because Gugu is unable to spend time with her the way Sona wishes she could, Sona experiences her togetherness with Gugu as lacking in we-ness, and as such Sona has these particular sisterly relational needs met in her relationship with her cousin.

I was eager to discuss this with Zuki, the interpreter, after the interview, given my challenges in trying to make sense of Sona's experience with Gugu. Zuki was able to offer further context, in terms of how she interpreted Gugu's story:

> *mmh, I think it's because uhm Gugu she is the older sister, and her disability, she has many needs, Gugu is 22 years and Sona is 16 years, and the paternal gogo (grandmother) and the aunt and other older sister is always there, even the mother, uhm, I was surprised she is going there, this does not happen in our culture when there is divorce, but she is still going there, so she (Sona) is not needed.* (Zuki, p3:67-72).

Zuki's interpretation supported my sense that Gugu's disability possibly makes it difficult for Sona to spend time together the way Sona wishes to. Zuki also reflected that their age difference might contribute to them having little in common, and because Gugu receives a lot of support and care from other family members, she requires little from Sona in the form of care. These factors seem to act as barriers to an experience of we-ness for Sona.

In the next extract, the relationship Sona experiences with her cousin is further elaborated on when she discussed the house that she had previously lived in with her family:

(Extract 13)

S: It was where I lived and my cousin, we would do everything together. We do a lot of stuff together, we like play together, hang out at school, even at break time we chill and chat and do things and maybe play, and like we gossip a lot (laughs) ja and share things

T: what do you share?

S: Everything, money, maybe someone talk something to her and she didn't like it, she will come to me and say, 'yoh, you know someone did this', and tell me everything

T: okay, okay (laughs) Do you ever share these things with Gugu

S: nope (Sona, p10:252-285)

Sona describes "*everything*" she and her cousin do together, seemingly in direct contrast to her description of her relationship with Gugu. She relays the fun, sense of togetherness and support she and her cousin share, relational elements that she values, but does not experience with Gugu. In describing the many things she and her cousin do together, including "*playing together*" "*chilling*" and "*sharing things*", Sona provides evidence of an experience of reciprocity and we-ness she has with her cousin, as opposed to her disabled sister. There is a sense that she is highlighting the difficulty she experiences in her relationship with Gugu where these aspects of togetherness are absent, by juxtaposing their relationship with the one she has with her cousin.

Experiences of difficult togetherness were also noted where NDSs perceived their sibling's embodied disability as challenging their expectations of how siblingship should be enacted. In her experience, Sona senses that togetherness is difficult because she and Gugu (her older, intellectually and physically disabled sister) cannot enact their sisterly relationship how she believes they ought to. She describes what she seems to feel being a sister entails as "*play[ing] together, hang[ing] out at* *school ... chill[ing] and chat[ting]... gossip(ing) and shar[ing] things, like money*"*;* which is essentially her description of her relationship with her (same age) "cousin-sister". There is a strong sense of mutuality, shared interaction and common interests in Sona's description.

Sona's familial context, consistent Xhosa family values and principles relating to *ubuntu* worldviews, extended family including aunts and grandmothers have been significantly involved in caring for Gugu, and as her younger sister, Sona has not been required to do so, possibly limiting the amount of time they have had to develop common bonds and establish a sense of togetherness. There is as such a sense that Sona experiences togetherness with Gugu as difficult because of several intersecting factors, including age, cultural values, family context and disability. Given these factors she has in turn established a sisterly bond with her cousin.

The participants discussed aspects of their relationship they found challenging with their disabled sibling and sense of togetherness being difficult was experienced. This was described in light of their sibling's difficult behaviour, the way their relationship was set up, for example, the role they were expected to play in their sibling's life by others, and sometimes their sibling not being what they wanted them to be , or contributing to their siblingship how they wished they could. There was a sense that the participants experienced a lack of we-ness in their togetherness with their disabled sibling. None of the participants were explicit that their sibling's disability contributed to their experienced relational challenges, however, I interpreted the specific examples they gave to describe what they felt to be difficult, such as inexplicable and volatile behaviours, being difficult to understand at times, being non-verbal, or a general sense that they "*just cannot*", that they were trying to imply disability was a contributing factor. Therefore, there is a sense that when disability is more central in their relationship, participants experienced a lack of we-ness, and togetherness was experienced as difficult.

6.6 Summary

In this chapter I described and interpreted the data pertaining to participants' experiences of togetherness with their disabled siblings. Participants in this study reported on the various ways they experience togetherness in their relationships with their disabled siblings. This included reciprocal love, playful interactions, ordinary togetherness and being together as difficult. It was noted that where participants experienced reciprocity as prominent in their relationship, and described feelings of mutuality, they had a sense of we-ness and disability was experienced as marginal. Sometimes where their sibling's disability did not contribute to difference and participants felt the same as their sibling, they felt a strong sense of we-ness. In other instances, disability contributed to feeling different to their sibling, which contributed to experienced togetherness in a different way. Some participants, however, experienced disability as more central in their relationships with their sibling, and less reciprocity and we-ness was experienced, and togetherness was experienced as difficult.

CHAPTER SEVEN

FINDINGS: NON-DISABLED SIBLINGS' EXPERIENCES OF CARE

7.1 Introduction

Experiences of care in their relationships with their disabled siblings was a noted theme for all the participants. Care was, however, set up in two ways: for some, care was experienced as being voluntary, demonstrative of love. For others, caring for their disabled sibling was determined by their familial context, and was experienced as being more obligatory, and sometimes, not something they wanted to do. For many participants in this study, family values pertaining to care contributed to their experiences. For example, where their families valued care as an act of love, participants experienced wanting to care for their disabled sibling. This master experiential theme about caring experiences is divided into four sub-themes: "care as voluntary and an act of love"; "care as a family value"; "care as obligatory and lonely"; and "caring as difficult and sometimes requiring sacrifice".

7.2 Care as Voluntary and an Act of Love

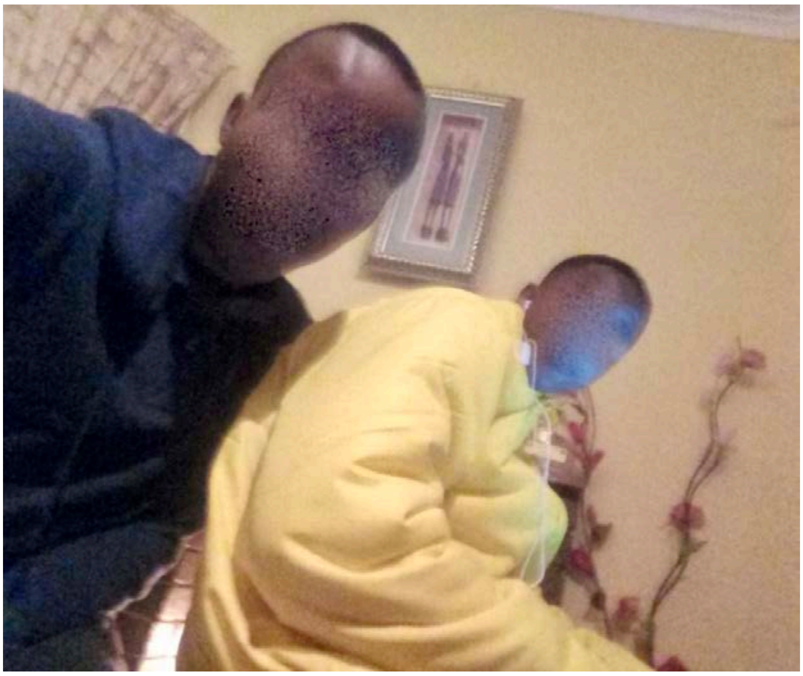
Some participants described wanting to care for their disabled sibling. Their desire to demonstrate love for their sibling was enacted though care.

Bhuti, who has a close bond with his older, disabled brother, Sipho, searches for a memory of caring in response to my question about instances of care in their relationship:

> (Extract 14)
>
> *B: uhm, uhm, I don't know, there were times when we were small when I had to ja, ja, like he would lose is crutches, so I had to carry him around all the time, I don't know if that applies to helping him.* (Bhuti, p25:607-609)

When reflecting on how disability featured in their relationship, Bhuti describes having to physically carry Sipho around. He, however, begins by seemingly having to think about an example, his utterances of "*uhm*" and "*I don't know*", suggest that this is not a memory rapidly conjured up and perhaps not entirely representative of how Bhuti experiences his relational dynamic with Sipho. Although carrying Sipho was something he did at times, it is seemingly accepted by Bhuti as a part of their relationship, as he is seemingly unsure whether carrying his brother would constitute as care or not.

Bhuti goes on to elaborate on his experiences of care within his relationship with Sipho, while reflecting on a selfie taken by Sipho, on a visit home from university:



Photograph 6

(Extract 15)

B: I hadn't been at home for a long time and then, I think me being around he just felt like he needed to take a picture

T: What do you feel when you look at it?

> *B: (sighs), uhm I don't know why, but when I look at this picture, it reminds me of the many, many things he has done for me, I don't know why*
>
> *T: hmmm, could you tell me about that?*
>
> *B: well, uhm /pause/ I didn't know this until matric, but when he was working at Rhodes (university), uh my school fees would come out of his salary, I don't know why, but like ja, I didn't know that*
>
> *T: okay, and how do you feel about that now?*
>
> *B: I feel like it motivates me to do more for him* (Bhuti, p42: 1312-1320)

In considering the photograph of Sipho, Bhuti notes that this picture of them was motivated by Sipho's need to capture them together because he had been away, and there is a sense of experienced care from Sipho. This is then reinforced when he reflects that seeing his brother is a reminder of how Sipho has cared for him. He provides an example of Sipho paying his school fees, without him being aware of it. Bhuti emphasises that there were "*many, many things*" Sipho had done for him, and this experience of being cared "*motivates*" him to reciprocate. Care is seemingly experienced as a mutual act of love for the brothers. Not only does Bhuti indicate that he values the care he has received from Sipho, but in his own desire to care for Sipho, there is evidence that care is experienced by Bhuti as being reciprocal. This experience of care may offer an explanation for why Bhuti did not reflect on his earlier experiences of carrying Sipho as burdensome, or even as a prominent feature of their relationship, because it was something he wanted to do, furthermore, he experienced care as something both given **and** received.

For Bhuti, caring for his older brother was an act of reciprocity; he felt "*motivated*" to care for his brother because of the care he had received from him. Another participant stated that "*he loved looking after*" his older sister, simply "*because [he] loved her*"; caring for her was experienced as an act of love.

Similarly, Luthando indicates his desire to care for his older sister, Amahle, as an act of love:

(Extract 16)

T: and is there someone in your family you think you're closest to?

L: Amahle

T: Amahle, why?

L: because I love to look after her

(...)

L: (I feed her and watch her)

T: ok and how do you feel about that?

L: yes, I like doing that because I love her (Luthando, p24: 557-564)

Luthando describes caring for and "*looking after*" Amahle, because he "*love[s] to look after her*", and in addition he notes that he "*likes doing that because he loves(s) her*". Caring and loving are described as being interchangeable by Luthando. Like Bhuti, caring for his sibling is something Luthando wants to do and is experienced in his relationship with Amahle as reflective of their closeness. Experiences of care are seemingly valuable for Luthando, and like Bhuti, not experienced as burdensome or expected by others.

Aya reflects on past experiences of care with her little brother, Ande, when he was younger, prior to moving to a special needs facility. She describes how caring for him included being his teacher:

(Extract 17)

A: And I remember the time when like, I was teaching him to walk; cause I didn't know he was autistic then, I thought why is he taking so long to walk. So, I was like, ha a (no), I will teach my little brother and I used to hold him and then we used to go around the table until he learnt by himself. Huh- my gosh I miss that kid. ... and sometimes we would take a bath together and

I would be like, 'Khulula (undress) Ande,' and he would try take off his clothes, I taught him that, so I'm like yay, I'm his teacher. (Aya, p.20:568-569)

In Aya's story, the affection she feels for Ande is apparent in her acknowledging Ande as "*[her] little brother*", and declaration of "*missing that kid*". Her descriptions of how she taught Ande to walk and undress, seemingly motivated by her love for him, also suggest a sense of accomplishment she experiences; "*I taught him that, so yay, I'm like his teacher*". She appears to experience pride and purpose in her caring role. There is a sense that caring for Ande is both a way to demonstrate love and contributes to her own self-worth. Pumla expresses the value she places on care and sees it as an act of love within her relationship with Asa in a different way.

Pumla discusses how her sister Asa, increasingly doesn't want her help:

(Extract 18)

P: (she doesn't want me to help anymore)

Z: (what do you think is happening?)

P: (I don't know but she no longer even tells me that she has homework when she gets home, she just puts her bag down and changes her clothes)

Z: Asa is not asking her anymore about homework and she never bothers to ask her as well because she used to ask her to help her with homework but she is not doing that. She will come home from school and she will change her school clothes

T: ok, what is that like for you?

P: (I don't know what to say)

Z:? (What do you think the problem is?)

P: [probably shakes her head]

(Pumla, p43:736-756)

Pumla reports that Asa no longer requests assistance with her homework, "*she no longer even tells [her] that she has homework*". There is a sense that in Asa no longer requesting help, Pumla feels a shift in her caring role; she is no longer needed as much and possibly feels somewhat excluded from Asa's life. She finds it difficult to make sense of the situation, indicating that she possibly feels unsure about Asa's willingness to accept care from her, about her own role in Asa's life. In this instance Pumla interprets Asa's willingness to accept her help as indicative of her willingness to include her in her world. It is possible that she experiences the giving and receiving of care as a way to demonstrate love, however, in Asa's reluctance to receive care from her she interprets her paving a barrier to reciprocal love. Pumla, like Aya, gains additional value from caring for Asa in the form of purpose.

Where participants described care as something they wanted to or chose to do, it was experienced as an act of love, a way to reciprocate experienced care, as well as contributing to their own sense of self-worth and providing them with a sense of purpose.

7.3 Care as a Family Value

Some of the participants also experienced a desire to care for their sibling when care had been experienced as a value within their familial context.

Bhuti's desire to care for his brother, Sipho (as noted in extract 15 above) was experienced as an act of reciprocal love, and is also an attribute he values in his mother, "*I'm really proud of her ..., ja she is affectionate, she cares a lot.*" (p23, 574). Being a caring person is experienced by Bhuti as something to be proud of and it is possible that this further contributes to his willingness to care for Sipho.

Luthando also describes the value he places on care when discussing a photograph (see Photograph 7 below) he took of his father who has become his primary caregiver since his mother had recently become deceased:

Photograph 7

(Extract 19)

L: It is special, there is that [probably points]

T: yeah I wonder what that is, that ring of light around his head?

L: (it's like he's got magic)

T: do you think he's a magic man?

L: yes

T: why do you think he is a magic man?

L: because (he helps the animals)

T: I think you captured that magic hey, and how was it when you took that picture?

L: (I feel like someone is watching over me)

Z: he feels like he is protected

T: okay, so you feel protected by your dad?

L: yes (Luthando, p20:450-484)

Luthando took, and chose to discuss, a photograph of his father, possibly because of how important he is in his life, not only as his father and protector, but because in his daily work caring for animals he engages in a caring role, something Luthando values. Coincidentally, after processing the photograph, an arc of light could be observed around his father's head. Luthando interprets this arc of light as appropriately depicting his father's "*magic*" ability to be caring. In his elaboration that the arc of light elicits a feeling of being watched over by his father, there is a sense that he is likening him to an angel, or a divine entity. Care appears to be a personal attribute that is revered and modelled within their family, and which Luthando has internalised. I interpreted Luthando's desire to care for Amahle as being set up by his internalisation of care as family value.

In our post-interview session, Zuki, the interpreter, noted:

> *Even that dad is a very caring man, I know this, because he is even bathing Amahle, in our culture, this, uhm, this is not usually happening, for the father to look after a daughter this way, usually this is for the mother. And even with the mother, they were not together anymore, but he was looking after the mother when she was sick until she passed, this is not normally happening for us.* (Zuki, p4:93-87).

Zuki seems to be emphasising that Luthando's father's willingness is to care for his family is so notable in that it even transcends certain Xhosa cultural norms. I found this important as it illustrated to me the degree to which he valued care as an attribute and why and how care may be so important to Luthando too.

Similarly, Aya also indicates that she experiences care as a family value when she provides memories where she derived a sense of enjoyment in sharing the care of her baby brother with her mother:

(Extract 20)

T: Okay, and what are some of the memories you have of growing up with Ande?

A: Oh my gosh, I remember when he was still a baby; my mom would wash him and then she would, uhm, kind of like wrap him up in a towel and I would hug him and cuddle and give him, what do you call it, a bottle… English just sometimes runs away when you need it. And then I would take the bottle and feed him and then I would sing to him and he would fall asleep in my arms and I would go very slowly to the bed and put him down. And then he would wake up crying (laughs), but it was cute, he was very cute. (Aya: p13:366-378)

Aya fondly describes caring for Ande in a nurturing, loving manner, by hugging, cuddling and singing to him. In her recollection, this act of caring was shared with her mother. There is a sense that, like Luthando, given that caring is shared by family, it is not considered as burdensome, but valued. Aya reiterates that she experienced Ande as being "*very, very cute*", indicating a sense of affection, and that her experience of caring for him was also an act of love.

Sethu relays her experience of care as a family value when she reports enjoying experiences of care for her brother, Buhle, carrying him around, when they are shared with her sister Sizwe:

(Extract 21)

Sethu: I love it, because he is my brother, but he can be a bit heavy, when we have to carry him and I don't know how to carry a baby on my back, so sometimes Sizwe carries him. (Sethu, p29:818-822)

Sethu indicates that caring for and carrying Buhle is something she "*loves*" doing. It seems that sharing the activity with Sizwe offers an opportunity to literally share the load. In Sizwe's support and willingness to help with carrying Buhle, where both sisters are engaged in the act of caring together, there is a sense that it is a familial value.

7.4 Care as Obligatory and Lonely

Participants in this study did not always experience caring for their sibling as a choice. They reported "having to care for their sibling" because their family circumstances dictated that they needed to. Participants often experienced a lack of support from their family in their care for their brothers and sister. When care was experienced as obligatory and lonely, they tended to experience it as hard. Pumla provides a sense of how her caring role was set up within her family circumstances, where her other siblings refused to assist her:

> (Extract 22)
>
> *P: it is hard (0.5) because (sometimes it does happen that I am all alone with my other sister and Asa, but she just leaves her like that even if she needs a bath so I have to bath her*
>
> *T: What would happen if you couldn't do it?*
>
> *P: who? Who would do it then? (0.5) if I wasn't doing it, I don't know*
>
> *T: what about your other sisters?*
>
> *P: but they'll come from school and they are sitting there not doing anything*
>
> *T: they don't come and help you?*
>
> *P: mhh …*
>
> *T: oh (0.5) and then how does that make you feel towards Asa*
>
> *P: (chuckles softly)* (Pumla, p32:739-757)

In this extract, Pumla acknowledges how she experiences caring for Asa as "*hard*" sometimes. This is largely, because she feels "*all alone*" in her caring responsibilities, because her other siblings do not help with caring for Asa. She indicates that she then experiences bathing Asa as something she has to do, as opposed to wanting to. She experiences the care she has to give as obligatory because it is something she has to do on her own, and because she believes no one else would do it if she didn't do it. The lack of support Pumla receives from her other sisters in caring for Asa also seems to inform how she feels toward Asa at times. She chuckles somewhat benignly as she seems to recognise that there are instances where she doesn't feel positively toward Asa, possibly even resentment or frustration in response to feeling obligatory care, but finds it difficult to state this explicitly.

Similarly, Thando describes experiencing her caring responsibilities without any support:

(Extract 23)

Th: (Because I am the one who must pick up after Portia.) Because it is always me, I am always the one who is always with her, looking after her…

Zuki: Cleaning after Portia and uhm she's not happy at all about that… nobody helps with looking after her (Thando: p47:1349-1387)

Thando emphasises that it is "*always [her]*" that must look after her sister, suggesting she experiences care as ongoing, repetitive and solitary. Although she does not explicitly state that this is an experience, she finds difficult, there is a sense of frustration in her description and tone, and the interpreter recognises this in her interpretation, reinforcing that "*she's not happy at all about that*". Like, Pumla, because she feels as though she is the "*one*", possibly, the only "one", there is no indication that she experiences any support, and in her use of the word "*must*", she does not seem to experience any choice. The absence of choice and support flavour her experience of care as something tedious.

Nkosi also experiences having to care for his little sister as difficult, when he is not supported:

(Extract 24)

N: Sometimes my mom does, she goes to her friends and Kwezi must stay with me at the house and at the night, she doesn't want to sleep she wants to get to my mother.

T: Yes

N: she want to…[probably demonstrates]

T: She wants to breastfeed?

N: Yes

T: And then what do you do?

N: And she cried and cried, but there is nothing, and I feel sad, and I go to her mother and I give Kwezi and she breastfeed and she sleep and I take her and I get her to sleep on the bed after many hours (Nkosi, p27:676-684)

In Extract 24, Nkosi notes that at times, when his mother is not home, he is required to care for Kwezi. However, as a young boy he is physically unable to care for her when she is hungry or distressed as he is unable to breastfeed her. He acknowledges that this makes him feel "*sad*", and there is a sense of helplessness when he describes "*there is nothing*" that he can do or offer. Nkosi's word change from "my mother" to "her mother", subtly indicates that he doesn't feel union or support from his mother, and in this moment feels alone in caring for Kwezi. Nkosi's description of this experience of caring for Kwezi does not indicate that he wants to, or enjoys the experience, however, the sadness he feels at her distress and his inability to meet her needs suggests that he nevertheless cares about her.

Sizwe also experiences caring for her baby, disabled brother as something she *must* do:

(Extract 25)

S: (I must play with Buhle and then my mom will say, 'Sizwe, take the baby,' and I will respond and say, 'no no mom, I am I tired now mom.' And she will tell me to put him on my back and I will tell her that my back is only for my backpack not for me to put Buhle on my back, I can put him on my back only when I am not tired.) (Sizwe, p5:135-149)

Sizwe describes how, when told by her mother to help look after Buhle, she feels resistant. She does not indicate that playing with Buhle is something she wants to do, rather, she has to, and is instructed to do so, and then finds a way to avoid doing so. She may not necessarily feel the lack of support in caring for her sibling that Pumla and Thando do, but she is clear that it is not something she wants to do, and therefore does so under duress, given the expectation from her mother that she *must* help. Sizwe seems to experience caring for Buhle as difficult. In emphasising that it is only something she can do when she "*is not tired*", like Thando, she finds doing so tedious or exhausting and is not intrinsically motivated to do so.

Some of the participants described situations where they were required or expected to care for their disabled sibling out of necessity. Often this was because other family members were not stepping in to do so and participants felt they had no choice. Where participants felt reluctance from others to assist them in caring for their disabled sibling, they felt unsupported and lonely and a sense of resentment or frustration in their relationships with their sibling.

Some participants felt caring for their sibling was difficult, even when it was not experienced as obligatory or without support. Caring as a difficult experience is discussed in the next section.

7.5 Caring as Difficult and Sometimes Requiring Sacrifice

While participants sometimes described caring for their siblings as something "*they loved to do*", and obtained personal value from, and caring as something they had to do, they also acknowledged experiencing care as difficult for other reasons, such as their sibling's behaviour. Aya explains some of the difficulties she experienced when caring for her little brother Ande:

(Extract 26)

A: He's very loving, very loving.… And very aggressive!

T: okay?

A: and if he wants something you had better give it to him now

T: what if you don't?

A: he pulls my hair

T: always, at home or around others too?

A: around others, like my close friends

T: and how do they react?

> *A: They get scared, they'll be like, 'hayi (no), hold him, hold him! and I say 'no its going to be alright, just give him what he wants', its challenging.* (Aya, p18:506-517)

In Extract 26 Aya reflects on how, while being "*very loving*", she also experiences Ande as being "*very aggressive*", to the extent that her friends feel "*scared*" of him and she is required to reassure them. His volatile behaviour makes interactions with him "*challenging*" at times, yet she asserts that "*he is very loving*". Aya's description captures the nuance of her experience, in that she doesn't experience him as either good or bad, but recognises him as being "*loving*" and "*aggressive*". Where their disabled sibling's behaviour (as a result of their disability), made caring for them difficult, some participants also acknowledged that they experienced other familial relationships as being strained. Aya reflects on what it is like at home now that her little brother has gone to a special needs facility:

> (Extract 27)
>
> *T: So have things changed since he (Ande) has moved out?*
>
> *A: ja, yes, cause what I have heard from family members, they would say that Mama is stressing out, because he is destroying everything, he is not listening, he is like, destructive and all that. So now he is gone, she is more calm, relaxed, so it's kinda, a little easier for me to talk to her.*
>
> *T: okay, so do you think, she was stressed and was struggling to cope?*
>
> *A: yes, like she couldn't control him, but she would always try to control me.* (Aya, p12-13:352-363)

Aya acknowledges that because of Ande's "*destructive*" behaviour, her mother was "*stressing out*". She reports that in her inability to control Ande, her mother would "*always try to control [her]*", making it difficult for them to talk to one another and thereby creating strain in their relationship. However, now that "*he is gone*", things are "*easier*". Both Aya and her mother appeared to experience

Ande's challenging behaviour as difficult to manage, possibly making caring for him a challenge at times. Despite this, however, Aya acknowledges earlier that she "*misses that kid*". For Aya, where caring has been voluntary and an act of love, and has been internalised as a family value, even when caring is difficult because of Ande's behaviour, she still cares about him.

Luthndo echoes this experience with his sister who displays challenging and aggressive behaviour too:

(Extract 28)

T: ok… is it always easy to look after Anathi?

L: no

T: when is it hard?

L: (sometimes she gets angry and she beats us)

Z: ... what do you usually do when she does that and dad is not there?)

L: (we run away)

Z: (and then what happens, you leave her behind?)

L (yes she ends up calming down)

T: do you feel sometimes scared when she is like that?

L: yes

T: ja, what do you think she is going to do?

L: (sometimes she scratches our eyes, she scratched my cousin)

Z: sometimes she will attack them and scratch them and recently his cousin also was attacked by Amahle (Luthando, p6:598-616)

Luthando acknowledges that caring for Amahle is not always easy. There are times when she becomes violent, she "*gets angry and she beats [them]*" and he and his cousins are victims of her violence. Like Aya, he experiences this as difficult and scary. Yet, despite these challenging experiences, he has still acknowledged that he “*loves caring for her*”. The participants as such provide a complex depiction of caring for their siblings, in that while they do so out of love, it is also challenging. However, when they experience a desire to care for their sibling, because it is demonstrative of their feelings of love, they are able to navigate challenging moments; difficult moments don’t make them not want to care for their sibling.

Zuki, the interpreter, added further context to Luthando’s experience in our post-interview reflection session. Having worked with Amahle through the organisation where she in an auxiliary social worker, she had a sense of her violent outbursts:

> *When Amahle started to have those moods, I remember I was there once, I tried to, I was helping her, and then she pulled my hair and was hitting at me and the others were unable to get her off. I was uhm shocked, you know what, that she can be aggressive ... uhm, dangerous, now I was imagining Luthando in these situations, I mean when she is reacting like this with her siblings, people trying to help her and this boy is talking about his love for her.* (Zuki, p4: 95-99)

In her reflection Zuki describes her own experiences with Amahle’s aggressive behaviour and provided a sense of how difficult it is to manage. She, like myself, was also struck by the fact that, despite these extremely difficult experiences Luthando has when caring for his sister, this does not influence how much he cares about her, “*his love for her*”. My sense that when caring is a choice, participants were more likely to be able to navigate caring for their sibling even when it is difficult. When caring for their sibling was experienced as something they had to do, difficult moments within care were seemingly more difficult navigate.

Thando elaborates on further challenges experienced when caring for Portia and how she feels about this when discussing a photograph she had taken of Portia just waking up:

Photograph 8

(Extract 29)

T: <u>(Because when she was still asleep, it felt great, no one was disturbing me.) (laughs)</u>

Z: The freedom that she had when Portia was asleep and just be able to do anything that she like to do.

T: So, now when you are looking at this picture, how do you feel, what do you think?

Th: (Laughs) Yoh! How do I feel? <u>(I don't feel great at all</u>) (chuckling) when I <u>(I know that now, I now have work to do).</u>

T: what do you do to look after her, how do you look after her?

Th:. <u>(Uhm so I have to feed her sometimes, bath her multiple times during the day because she likes playing on the soil outside and removing her clothes. So, I have to bring her back into the house, feed her and pick up after her.)</u>

T: Mhh

Z: Just to look after her and I mean look after her, make sure that she baths not once because she'll go out and come back she's dirty and then she had to clean her, feed her and go after *her because if she mess around then she'll have to fix that that's how she, yes that's what she was doing.* (Thando, p35:827-867)

Thando acknowledges that she finds moments when Portia is sleeping as peaceful, a respite from what she describes as "*the work*" of having to care for Portia, which does not "*feel great at all*". She lists the many caring activities required of her, including feeding, repeatedly bathing and clearing up after her. There is a sense that these caring responsibilities are experienced by Thando as chores and burdensome, and not necessarily acts of love, but done out of necessity. As such, she experiences Portia as "*disturbing her*". Zuki's interpretation that Portia being awake impedes on Thando's freedom, reinforces Thando's experience of not feeling that caring for Portia is a choice but rather a penalty she is paying, possibly for being the older sister, and it is difficult for her. Where some participants indicated that caring for their sibling was not always what they wanted to do, yet they still cared about them, others seemed to suggest that having to provide care contributed to feelings of resentment toward their disabled brother/sister and reinforced feelings of care being difficult.

Where care was experienced as difficult, participants frequently described having to make sacrifices:

(Extract 30)

P: so [I wake up and prepare water for bathing and bath (0.5) then I wake Asa up () she wakes up to bath (0.5) sometimes if my mom is there she wakes her up or I wake up and bathe her (0.5) sometimes I don't go to school because if my grandmother is going somewhere that day then there won't be anyone to look after Asa after the transport has dropped her off ... so that's why I sometimes don't go to school (0.5) or maybe there is nothing serious happening at school so I decide not to go then I go and fetch her when the transport drops her off]

Z: at the gate?

P: [yes in front of the gate because sometimes I have found her by herself before when there is no one in the house] (Pumla, p30: 824-827)

In Pumla's description of her day-to-day caring responsibilities, she details her experience of the unreliability or inconsistency of other family members, "*if her mom is there*", "*sometimes [her] grandmother is going somewhere*". It is evident that she feels that if she was not caring for Asa, there is no guarantee that other family members would. As a result of this she feels at times that she has no option but to be truant from school to ensure Asa's safety, and this makes her caring role difficult. It is also evident, that at times, "*[she] decides*" to stay and care for Asa, prioritising caring for her sister over going to school. She demonstrates that while caring for Asa may be a requirement and requires sacrifice, she does, to some degree, choose to do so, because of her love for her sister. There is, however, further nuance expressed in Pumla's experience of caring as a sacrifice:

(Extract 31)

P <u>[it's the fact that she can't walk (0.5) it's a big problem (0.5) sometimes even if I wanted to go somewhere I end up cancelling (0.5) my grandmother also drinks so she won't have someone to look after her. I have to be the one who remains to look after her (0.5) but I understand that]</u>

Z: ok so she says granny is also drinking so sometimes she would go if there is a ritual in the community then she would go there and uhm then there wouldn't be anyone to look after Asa (0.5) then she had to postpone her (0.5) maybe she's supposed to go out then she has to postpone that because there is no one to look after her and thinking that if Asa could walk (0.5) or if she was able to walk then that would be better for her because then she can go and be out there with others as well (0.5) and if she wants to go somewhere and Asa can't go then she has to be there to look after her. (Pumla, p26:705-713)

Pumla emphasises that Asa's disability is "*a big problem*" that at times requires that "*even if she wanted to go somewhere*" she is unable to do so. While she is illustrating that she has to make sacrifices, her use of the word "*even*" suggests that she doesn't always want to go do things and is at times content to stay and care for Asa. She feels, however, that should she want to, this is not available, due the lack of support from other family, where they have not prioritised looking after Asa as she has, opting instead to go drinking. Noting her granny's drinking may also be a way of expressing her sense that she experiences her as unreliable. While there may be some degree of wanting to, her experience of having to care for Asa is prominent, she "*[has] to be the one who remains to look after her*" and she has come to "understand" that because of Asa's disability, this is how things are for her. Despite feeling that she both wants to, and has to care for Asa, she experiences caring for Asa as requiring sacrifices, such as not going to school. Similarly, Thando describes how Portia's disability requires sacrifices pertaining to her schoolwork:

(Extract 32)

T: Okay, so what's it like looking after a sister with a disability?

Th: Yoh! It's not easy

T: It's not?

Th: Yes, <u>(Yes, when I have to study, sometimes I have to wait until everyone is asleep so I can study.)</u> (Thando, p47:1349-1355)

Thando reports that caring for Portia is "*not easy*". Like Pumla, she has to make sacrifices, like waiting for everyone in the house to go to sleep before she can begin doing things for herself, like studying. Where participants feel a lack of support from other family members in caring for their sibling, and they experience care as obligatory, they report having to make sacrifices which contributes to their experienced challenge. Nkosi similarly acknowledges the sadness he feels at times because of the sacrifices he has to make when caring for Kwezi:

(Extract 33)

T: And how does that make you feel?

N: I feel sad.

T: You feel sad?

N: Yes, because when other time when I'm playing and I say my friends must take Kwezi, Kwezi will cry and I will not get time to play.

T: Okay, so sometimes it also feels frustrating for you, because other people can't look after her, only you otherwise she cries. And that means you don't get to play?

N: Yes (Nkosi, p31:777-785)

Nkosi describes Kwezi's reluctance to be cared for by his friends, possibly because of her dependence on him. However, as a result thereof, he does "*not get time to play*". Nkosi has to care for his sibling as opposed to engaging in activities he longs to do, and his experienced sacrifice results in feeling of sadness. Again, his friends' inability to support him in caring for Kwezi possibly contributes to him feeling unsupported, demonstrating a possible relationship between lack of support and experienced sacrifice by participants.

Aya describes how she has given up her social life to look after her little brother, so that her mother is able to go to work:

(Extract 34)

A: like, my mom is a business woman, ... So, now she can't because who is gonna watch Ande if she's not there you know. And for me, I've given up my social life just to watch him so that my mom can go and do her own important stuff so that she can feed us at the same time. (Aya, p19:538-542)

Aya describes how caring for Ande sometimes acts as a barrier to her mother being able to work and "*feed [them]*". In these instances, she has "*given up [her] social life*" to care for Ande and her sense of sacrifice is explicit. I also wondered about her reference to her mother being able to do "*her own important stuff*", and if she was trying to communicate that she feels as though her stuff is not considered important enough by others and her sacrifices not recognised.

Participants described having to make sacrifices, not being able to go to school, do their homework unless the family (including their sibling) were sleeping to avoid disruption, or play with their friends because of their caring responsibilities. Sometimes this was also because of the lack of support they experienced from other family members and caring was obligatory. Even when they opted to make sacrifices to care for their sibling, caring was experienced as "hard" and evoked feeling of frustration and "sadness".

7.6 Summary

In this chapter I presented care as a prominent experiential theme for participants. Where care was experienced as an act of love, there was a desire to care for their sibling. Sometimes this was because they similarly felt cared for by their sibling and wanted to reciprocate. Sometimes they wanted to care for their sibling as they experienced care as a way of demonstrating their felt love. In these instances, caring added to their sense of self-worth. Participants described how care occurred within their family where it was role-modelled and formed a part of their day-to-day family interactions and was as such seen as a family value. Sometimes care was described as obligatory and often when participants felt they had to care for their sibling, it was because nobody else would, or there was expectation from family that they should do so. In these instances, participants felt unsupported and lonely, and this seemed to inform feelings of frustration and resentment toward their sibling. Care was also experienced as difficult for other reasons, such as the challenges that occurred because of their sibling's behaviour. Where siblings experienced care as difficult, but did so voluntarily, it did not inform negative feelings toward their sibling or their ongoing desire to keep caring. However, when care was experienced as obligatory and challenging, this at times contributed to experiencing their siblings as burdensome, or a disturbance.

CHAPTER EIGHT

FINDINGS: BEING AN OUTSIDER

8.1 Introduction

The third and final master experiential theme in this study focuses on participants' experiences of being an outsider in their life worlds. Not all of the siblings' experiences of being an outsider were about their brother or sister's disability. Participants described feeling excluded from their peer groups, due to feeling that they were not good enough or rich enough. As such, they seemed to experience a sense of inadequacy. Feeling inadequate and excluded contributed to experiencing themselves as outsiders in relations to peers and family. They also described stigmatising experiences because of their sibling's disability and how these experiences made them feel different, compounding their sense of being outsiders. To mitigate feelings of inadequacy and being an outsider, participants described various compensatory behaviours, which included focussing on achievement and goals of becoming successful and rich. There was a sense that they equated being successful, rich and famous with happiness, gaining approval from and more connection to others, thereby possibly challenging feelings of being an outsider.

8.2 Exclusion and Inadequacy

Participants in this study described their experiences of feeling excluded by others. Not having enough money or the most up-to-date clothing or devices, having different values and not feeling good enough at various activities, meant they felt inadequate, which contributed to feelings of exclusion. Often participants described isolating themselves further, possibly to obtain a sense of agency and protect themselves from feeling left out by others. Bhuti describes how, as a university student, he feels excluded due to having different priorities:

(Extract 35)

B: (…) like sometimes when/ sigh/ my friends go out, uhm I feel excluded from that because, uhm, like most of them drink, so when they go out, I feel excluded because I don't participate that much so I feel excluded, ja.

T: do you choose not to participate or is there another reason?

B: I feel like now there's another reason, it's work, its work, cause uhm some majors require more, then I have to work, so ja, I think its work

T: so, you feel quite excluded because you can't…

B: and I think because most others, it just feels, the feeling of being left out, it just feels a whole lot more. (Bhuti, p45: 1112-1119)

Bhuti describes his feelings of exclusion, of "being left out". He describes how he is unable to partake in various recreational activities with his peers and acknowledges that this is due to his commitment to his studies. However, when asked whether he experienced this as a choice, he responds to my question by stating that it is because he has to work. Where his peers enjoy a lot more social interaction, Bhuti does not feel this is available to him as he feels he has to focus on his studies, emphasising his sense that his priorities are different to theirs, how his priorities set him apart and contribute to his experience of exclusion. My sense was that Bhuti felt that because of his sense of inadequacy he felt it necessary to focus more on his studies than his friends had to, that it was his situation that contributed to him being excluded more than his peers deliberately leaving him out.

Aya talks about her experiences as an adolescent, moving to a more affluent high school and how not having the most up-to-date gadgets and clothes leave her feeling "left out":

(Extract 36)

A: I was like, oh my gosh, iPhones. I didn't even know an iPhone existed and I felt so left out because everybody had an iPhone and Samsungs but I didn't have these things.… we're not all

> *gonna be rich you know, we all come from different backgrounds, so you can't compare yourself to other kids.… I just promised myself one thing; when I'm rich, I'm gonna buy all the things that I've ever wanted in life. Because as a teenager, you'll be like, oh my gosh, okay, Sammy has, let's say an iPhone and I don't have one and you're gonna feel left out. And then you're gonna ask your parents for an iPhone and then they're gonna shout, 'I don't have money nah nah.' So, you're gonna feel left out and not uhm not cool enough and so, I just choose to distance myself and not stress myself over something so stupid.* (Aya, p8-9:223-249)

Aya describes how not having certain material possessions, as a "*teenager*", makes her feel "*left out*". She describes the emphasis on image and identity that occurs within adolescence and the challenge she experiences because not having the socially acceptable items, seen as status symbols, means she does not feel she measures up. There is a sense that she experiences a sense of inadequacy because she doesn't have these things. Furthermore, her experience of lack is understood in the context of being "*from [a] different background*", where her experience of socio-economic disadvantage contributes to her feelings of inadequacy and exclusion. Where she plays out a seemingly regular and predictable scene of asking her parents for things and them emphasising that they "*don't have money*" serves to heighten her sense of being isolated as she seems to be showing how her parents don't really understand her either. Aya describes her efforts to rationalise her experience, stating that these concerns are "*stupid*" and there is no value in her "*comparing herself to others*". This seems to be an attempt to protect herself from the hurt she experiences from not being "*cool enough*" and being "*left out*". However, she simultaneously stresses that her goal remains being "*rich*" and to "*buy [herself] all the things [she has] ever wanted in life*", indicating while possibly "stupid", overcoming her experience of exclusion and inadequacy due to her lack of wealth are important to her.

Bhuti discusses how his feelings of exclusion date back to his early school life, and like Aya, notes how at times he felt inadequate in relation to his peers:

(Extract 37)

B: ja/pause/ but I think uhm /pause/ I'm kinda used to it, because back in high school, and even primary it was the same thing uhm,/ pause/ People, the majority of people used to be like, do one thing, but I felt I had to, I felt strongly about another thing, so I would be excluded from it. It kinda happened a lot of times, so I'm kinda used to it.

T: ... what made you approach school differently to others then?

B: I feel like because I wasn't pause/ I feel like because I wasn't good at sports or I didn't have a rich family like everyone else, cause that's the kinda people I was always surrounded by people who were good at one thing or weren't good but had a rich family. I think that's why I have to focus on academics, because if I don't do well, I won't have anything, so just let me focus on my schoolwork. (Bhuti, p45-46:1109-1139)

Bhuti acknowledges feeling "*excluded*" has been a pervasive experience throughout his life; "*he is used to it*". Experiencing differing priorities to his peers has been an ongoing theme in his life, as has feeling excluded from others for having different priorities, something he has experienced for most of his life. In his description he relays how his differing priorities stem from not feeling "*good at sports*" and not having "*a rich family*", and as such, he seems, like Aya, to feel inadequate to his peers. There is also a sense that he is suggesting having money can act as compensation for not being good at something. Bhuti describes choosing to focus on his academics to create a niche where he can achieve and do well and possibly, thereby, compensate for his feelings of inadequacy. His statement that if he doesn't do well, he wouldn't have anything, seems to reinforce the overall sense of lack he experiences in his life, possibly on a personal, social and material level.

Aya similarly discusses how she experiences herself as different in relation to her peers because of her SES:

(Extract 38)

A: I wanna have a nice life man, where everything is just chilled. And I wanna have a house far, far away from people, ja (yes), not close, people are very hating these days ja, ja (yes, yes).

T: Why are you experiencing people as hating?

A: ..., most people expect you to dress in a certain way, to talk in a certain way, to do things in a certain way that they feel is right. So, people expect too much from a person, I just wanna be, sometimes I wanna be away from those type of people. Even at school, I don't have friends that I hang out with during break cause, there's just too much. They'll just be like, 'oh my gosh, you don't have Nike sneakers, why would you even wear those shoes.' So, mna I'm not that type of person, if I have my Tommies, then I will wear my Tommies. People are too judgmental these days.

T: Do you feel like you've been discriminated against because you don't have the right brands and the right ...

A: Ja (yes), especially at a school, like, an all-girls school, so I just distance myself from everything. (Aya, p8:222-242)

Aya expresses a desire to have "*a nice life*", "*far from people*" she experiences as "*hating*", inadvertently suggesting she currently experiences her life as difficult because of others whom she experiences as putting pressure on her to be what she can't be. She describes how not having the right, more expensive, branded shoes and clothes has resulted in experiences of others as "*judgemental*" for not having or being enough, reinforcing her experiences of inadequacy in the previous extract. She seems to experience not being the same as her peers, "[*dressing] in a certain way, [talking] in a certain way, [doing] things in a certain way*" as being unacceptable to them. Like Bhuti, she manages this experience of inadequacy by stating that her priorities or values are different, she "*is not that type of person*" and, subsequently, aims to protect herself by getting "*away from those type of people*", "[distancing] herself". Both participants experience a sense of difference that is set up by experiences of not having or being enough. Similarly, they both describe feeling excluded, yet at the same time discuss creating further distance between themselves and their peers, possibly as a means of protecting themselves from ongoing exclusion.

Sona also discusses how her SES contributes to her feeling different and excluded from her peers, however in contrast, this is because she feels others judge her for having too much. She has recently relocated to her grandmother's house because there was not enough space or money for her to stay in the family home where she grew up:

(Extract 39)

S: It's like, I'm fearing for myself. I think many people here see me as I'm better than them. Because when I get home from school like, I'm always staying in the big house so I'm not playing outside, I'm not doing anything. So, maybe they think I'm better than them so I wouldn't know if someone hates me or what he or she plans for me.

T: What are you worried about?

S: I'm worried about the way that, them not like, what can I say, they are not like me, like uhm like familiar with me or friendly with me. So, in that area there are few people that I am talking to. So, many of them, I don't know how they feel about me.

T: So, do you feel like a bit of an outsider in this area?

S: Ja ja (yes, yes) because I am not talking to so many people.

T: Okay, so do you feel like you don't belong here?

S: Ja (yes) maybe.

T: Okay, what is that like?

S: So lonely! (Sona, p20:546-589)

Sona indicates that in her new community, she feels different to others. She seems to suggest that others have positioned her as being superior, possibly because she lives alone "*in the big house*". As such, she suggests that because they "*are not like [her]*" they "*are not friendly*" with her, because they dislike or are jealous of her. To this extent participants seems to share a sensitivity to being excluded. She describes how being different makes her feel less likable and acceptable and contributes to her experience of exclusion. She appears to assume that because they do not know or like her, they may wish ill on her and this makes her feel scared, like Aya, who experiences others as "hating" her for being different, reinforcing her need to isolate. Like Bhuti and Aya, although she feels excluded, she opts to isolate herself further, possibly to protect herself from feelings of rejection or exclusion from others, further contributing to her feeling "*so lonely*".

When asked if there was anything about his life he would change, Bhuti similarly acknowledges wanting more connection to others:

(Extract 40)

B: *... if I could change anything about my life right now? Uhm, I wish I had more leisure time and to feel more /long pause/ to be able to connect, uhm, ja, I don't have a lot of that* (Bhuti, p6:135-136)

Bhuti's statement that he wishes for more "*leisure time*" suggests that most of his current time is not leisurely, but used for work, where he is unable to connect to others, something he misses. By indicating that this would be the primary thing he would change about his life, there is a sense that his experience of isolation is very prominent. Bhuti appears to experience a paradoxical tension between what he "*wishes*" he could do, which is to spend more leisure time, connecting with others, and what he feels he has to do, maintain his focus on work, to overcome his sense of inadequacy that has previously informed feelings of exclusion.

Discussing a photograph of the home she used to live in, Sona also describes feeling excluded within her familial context. She relays how she is no longer able to live in her family home, because, due to financial constraints, there are too many people living there, and there is no space for her.

Photograph 9

(Extract 41)

T: So, when you were taking the picture, what were you feeling when you took the picture?

S: Both happiness and sad.

T: Okay?

S: I'm happy that we have a roof over our heads uhm and I was sad that it is so small and that there are too many people living in there, I cannot live there.

T: And if there was something you could put in this picture, if you could add anything to this picture, what would you add?

S: Yoh! Myself! And I would like, paint the house and make it bigger. (Sona, p9:224-238)

Sona emphasises the logistical and socio-economic constraints that have informed her having to relocate, the fact that the house is "*so small and that there are too many people living in (it)*". Her expressed gratitude that they "*have a roof over (their) heads*" highlight the nature of her reality, which is that for many people around her, this may not be the case. She expresses her sadness at this being the reality that causes her to have to relocate. Sona's sense of isolation or exclusion from her family home occurs because of socio-economic disadvantage. It is interesting, however, that even though she is in a bigger house she is lonelier. In this instance it seems that it is the people that she values over the status of the house.

Some of the participants described feeling "left out" and "excluded", sometimes from peers and sometimes family. Often, they felt that they had been excluded for not having enough material wealth or being good enough; there was a sense of experienced inadequacy. The participants seemed to mitigate their feelings of inadequacy by focussing on achieving or wanting to become rich. In their dedication to achieve, some participants inadvertently further separated themselves from their peers, deepening their experienced lack of connection to others. Other participants seemed to exclude themselves in an attempt to protect themselves from experience "hate" or "judgement" from others.

8.3 Experiences of Disability as Stigmatising and Creating Difference

In addition to feeling different and excluded because of SES, participants also discussed feeling different because of their sibling's disability. Participants described how they experienced stigmatisation, which seemed to contribute to their feelings of being an outsider and reinforced feelings of isolation and loneliness.

Aya describes her experiences of stigmatisation due to her sibling's disability when she would take her little brother, Ande, for walks when she was younger:

(Extract 42)

A: Ahhhh, that stare, it made me want to cry sometimes, because some of them would laugh and I would just take him and we would go home. And my mom told me, no, they are laughing *because he is different, what if my little boy is going to be famous one day, they will eat their words!*

T: and why did it make you want to cry?

A: They stare in such a bad way, I wish, ahh that stare. (Aya, p11:306-316)

Aya reports experiencing extreme sadness and "*wanting to cry*" as a result of the bad stares and laughter from others. She experienced their stares and laughter as judgemental and stigmatising, feeling the need to "*take him*" away and "*go home*", possibly as a means of escape and to seek out protection. In seeking safety and solace at home, her mother emphasises that it is precisely because "*he is different*" that others stare and laugh. While she is not explicit about it in this instance, Aya seems to suggest that Ande's disability is what makes him different and elicits stigmatising behaviours from others, and she seems to take on some of the feeling of otherness, causing her to feel like an outsider too.

Bhuti is more explicit about his experiences of stigma in his youth, due to his brother's disability, even from his friends:

(Extract 43)

B: uhm my friends and like they were like looking, looking and I was really bugged about that, that why do people like looking so much

T: ok

B: when I was younger but I don't think it does anymore

T: ok ok, how does it feel when people look, what does it make you feel?

B: uhm /long pause/ I think I just like /pause/ I dislike the looks because uhm /pause/ I think when they're looking at him he won't be comfortable with it so he won't like, so I think I feel the same way he does, about people looking at him

T: ok, so is some of it feeling protective towards him or is some of it feeling like you are also being judged?

B: uhm, cause /pause/ ja, people, most people when I was really small they used to judge me, judge me and my brother, they used to judge me through my brother, I don't know if I'm making any sense. (Bhuti, p13:308-310)

Bhuti, like Aya, recalls being stared at when he was younger, which caused him feelings of discomfort. He emphasises that this experience was particular to his youth, suggesting that he no longer experiences being stared at, or perhaps that he no longer feels "*bugged*" by it and that he has overcome it. He describes the discomfort from this experience as having come from his sense that it also made his brother uncomfortable, and his sense that neither of them liked being stared at. Specifically, he describes feeling judged by others, "*judged through [his] brother*", suggesting he experienced stigmatisation due to his brother's disability. Bhuti's statement about making sense was interesting to me in that it seemed as though he was showing us his meaning-making process as he was describing it. He had not yet figured out a way to articulate this experience and wasn't sure what it meant or if we would understand it.

My reflection is supported by Nkosi's discussion of feeling different and lonely, because his friends have sisters who can walk.

(Extract 44)

T: And what are some of those feelings?

N: I'm feeling, sometimes when I'm lonely I'm feeling sad, ... and some friends have sisters, children are who are walking.

T: Ah, so you sometimes feel a bit sad that your friend's brothers and sisters can walk but yours can't? This makes you feel lonely?

N: Yes, I am jealous

T: Ahh I understand! Do you wish she could walk?

N: Yes (Nkosi, p76:1966-1972)

There is complexity in Nkosi's experience, in that while he doesn't want another sister, he does wish his sister was different, specifically, not disabled, so that he wouldn't feel different to his peers and would therefore feel a greater sense of belonging. He acknowledges feeling "*jealous*" of them for having something he does not have. Like other participants, there is a sense that his experience of lack causes him to feel inadequate.

Nkosi further demonstrates the sadness he experiences through a picture he included in the photographs he had taken of an "emoji" with a sad face, and the statement "*I am not okay*" printed above it. He was asked to talk to his motive for including this picture in his photographs:

Photograph 10

(Extract 45)

N: (This picture shows me someone who is sad, someone who is not alright and his body is this way, he doesn't have an ear and doesn't have anything, he's just like this, sad.)

Z: This is a picture of just a face of someone who is not happy, this person doesn't have ears and you just see a face of a person who is not happy at all.

T: Why do you think they're not happy?

N: (I think maybe something painful happened to him or he is just not alright or he is going through something painful because of someone.)

Z: Mhh because of something, uhm someone did something wrong to this person and this person this is how he feels or she feels now that he's not happy of what happened to him or to her.

T: And what do you think this person did wrong to him?

N: (I think maybe his friends gossiped about him and then someone told him about it.)

Z: Mhh

N:. (And so now he feels sad.)

Z: Mhh people were gossiping about this person and now this, some other people come and tell this person of what they said about this person is not happy because of what these people were talking about, were gossiping about.

T: Okay, do you ever worry that people might gossip about you?

N: Yes, sometimes I think that when people are, when we are three and the two friends are talking, when I'm not there I think that they are gossiping about me.… And then I ask them and they say they are not talking about me.

T: And what are you worried that they are going to say about you?

N: Because they are going to say something sad about me or something that is, is bad about me, about, they will say about my family or my, or my, or my sister.

T: They're gonna say something bad about your sister?

N: Yes (Nkosi, p72:1849-1891)

Nkosi uses a stylised picture of an emoji face, that is anatomically incorrect, possibly to demonstrate how he experiences disability. The face doesn't have ears, it is missing physical attributes and therefore different to how he perceives a person should look, and Nkosi seems to experience this person as "*not happy*". While at first it seems as if he is representing a disabled person, possibly his sister through the use of the emoji, it becomes evident that the emoji's emotional state is possibly representative of his own. He seems to be communicating that he is "*not alright*". It then becomes evident through his description that he feels "*sad*", because he has experienced others judging him, because of his sister. An important aspect of Nkosi's experience of stigma is his friends gossiping about him when he is "not there", highlighting his experience of feeling like an outsider. I also wondered if he was trying to relay through his depiction of himself through the emoji, who is both sad but also anatomically incorrect, that he experiences the stigma perceived from others as disabling.

Some of the participants described experiences of stigma because of their sibling's disability. Feeling stigmatised contributed to them feeling different to others, including their peers, leaving them feeling as though they were an outsider.

8.4 Seeking Approval and Connection

Participants described their dreams and ambitions for the future. This largely included becoming successful or wealthy. There was a sense that they were perhaps trying to mitigate their experiences of difference, exclusion and inadequacy through these goals, by gaining approval from others in order to feel more connected to others and challenge feelings of being an outsider.

Nkosi has acknowledged experiences isolation and difference in relation to his peers (Extract 40). In the next extract he describes a photograph he took of some toy cars he had made. He describes how he navigates feelings of loneliness by making the cars in the hope that other children will want to play with them, and him:

Photograph 11

(Extract 46)

N: This picture is about, when I'm, when I'm lonely, I like to make these cars and play with them when I don't have some friends to play with.

T: And you said when you're lonely then you like to do this?

N: Yes, when I don't have friends and when I' m lonely, I like to do this.

Z: (<u>when you made these cars, did you make them so that other kids can be happy or</u>…)

M: (they also want them, so they will play with me) (Nkosi, p48:1210-1239)

Nkosi acknowledges that there often times when he feels "*lonely*", when his experience is that he "*doesn't have friends to play with*". In order to mitigate his feelings of loneliness, Nkosi relies on his creativity and resourcefulness to make toy cars in the hope that other children will want to play with them and then play with him. He is seemingly also using resourcefulness in the sense that he is trying to offer something he feels will be appealing to them, "*they also want them*", however, he inadvertently acknowledges feeling as though simply playing with him would be insufficient. This demonstrates his overall sense of inadequacy, possibly informed by experiences of being different and feeling isolated in the past.

His yearning for and attempts at gaining approval are evident elsewhere: When thinking about his plans for the future, Nkosi states that he would "*like to go at these schools, like St Andrews and go play sport with them, … because when people see that you are there, they will know that you can play*" (p7:171-175). By attending an affluent, private school, he seems to feel that he would be recognised and validated for his sporting skills and having more money. It seems that Nkosi thinks that being rich would make him more appealing to others, and obtain greater connection, mitigating his feelings of isolation. Nkosi additionally notes that when he is older, he plans to "*fly overseas, to find a house that is big … with a swimming pool on the inside and a soccer field for (him), (his) sister and (his) friends*" (p11:271-275). In these statements Nkosi again demonstrates his belief that having more wealth is important and having a big house, with a swimming pool and soccer field, would position him better socially. Interestingly, he imagines his future plans of wealth and social connection taking place overseas, possibly suggesting that any such occurrence would not be possible where he is currently situated, in Joza Location, South Africa. Notably, despite feeling a sense of being different and isolated because of his sister's disability (see Extract 40) this does not appear to influence his desire to include her in his future dreams. There is a sense that there is an aspect of his dream that speaks to his yearning for friends that will not be judgemental of his sister.

Thando, who had only recently started living with her biological mother and stepfather, similarly spoke about how she experienced her mother's disappointment with her and how she felt misunderstood but wanted to make her parents proud:

(Extract 47)

Th: (There is a big gap between my grade 10 results and grade 11. ... and then my mom went on and on about it as if it was such a big deal. I hadn't even done that badly, and she just said so much, and I felt, she didn't understand that grade 11 is hard even though she was the one telling me about how hard grade 11 is but she just wouldn't understand when I didn't do so well, you see.)

T: So, you are worried about disappointing mom and dad?

Th: Too much.

T:. (She hasn't said anything but I do see her actions.)... (But I want to make her proud.)

(Thando, p11:316-317)

Thando highlights how "*[I] hadn't even done that badly*", she felt that she had disappointed her mother. Previously she has stated, "*it doesn't sit well with me because I don't know whether my mom, do you know how sometimes a parent can know that their child is not okay or something is going on, just by looking at them, I don't know when it comes to my mom because we don't usually talk like…*" (p22, 55-70). There is a sense that Thando experiences a lack of connection to her mother and in Extract 47, she acknowledges that she feels misunderstood by her. There is a sense that in wanting "*to make her proud*" she hopes to remedy what she experiences as a fragile bond. For Thando, not doing well in school, and disappointing her mother and possibly jeopardising their already fragile connection, would be "*too much*" for her. She as such, experiences the need to obtain and sustain her mother's approval for the sake of connection.

Bhuti also describes how needing to be successful is not only intrinsically driven (possibly as a means to challenge feelings of inadequacy as noted above), but is also due to feeling pressured by his parents to do so:

(Extract 48)

T: and the need to be successful, does that come from inside you?

B: uhm, its an imposed thing, like there are external forces putting pressure

… it is, to be pressured and I mean it really don't feel /pause/ that nice to be pressured because me performing academically although, I like it, but to be pressured to perform its just like a whole other feeling /pause/ because like, with right now, finances aren't good, so like my mother and my father were telling me, you have to do good and uhm, I feel like I am performing at my best but they are persistent at telling me to perform better. It's like my best isn't good enough. (Bhuti, p47:1148-1153)

Bhuti states that his drive to succeed, to "*perform academically*" is "*imposed*". Bhuti's need to achieve academically is informed by feeling that he has to meet his parents' expectations, which are largely informed by their financial status and an overall value on success. However, despite his efforts, his experience is that his best "*isn't good enough*". Bhuti's experience of self-worth, like other participants, is largely informed by the perception that others need him to be and have more. His feelings of inadequacy are experienced both with peers and family. Bhuti feeling that his parents don't understand that he is trying his best echo Thando's experience; both participants seem to feel misunderstood by their parents.

While Bhuti acknowledges the sense of validation he experiences from doing well, he similarly highlights the difficulty he experiences in feeling obligated or "*pressured to perform*" as a means to solve the familial difficulties associated with being socio-economically disadvantaged and obtain approval from his parents. Bhuti has also stated, "*ja uhm that's how I feel because like when we were having a conversation with my mom about the future, she would always like say that me and my sister we have to buy our own houses and move out of the house and that house is going to stay with my brother, so /pause/ that's kind of the expectation as well*" (p10:247-250). As such, in addition, he has an awareness that he has to do well because his parents' financial resources will be allocated to his disabled brother. This may compound the pressure he experiences to succeed. Bhuti's desire to succeed is therefore seemingly multifaceted in that he hopes to be a success to overcome his feelings of inadequacy (which have possibly informed his feelings of being an outsider), but also experiences an imposed pressure to succeed from his parents, possibly because his brother's disability will dictate how their financial resources will be allocated.

When asked whether she thinks about the future, Aya discusses her plans to be rich and famous and how these thoughts help her in managing difficult times in the present. She has previously acknowledged how her current difficulties are related to feeling inadequate and excluded by peers because she does not have the right, expensive clothes and gadgets (see Extract 38).

(Extract 49)

> *A: Yes, (I think about the future) a lot. Sometimes when I'm going through a tough time, sometimes I wanna kill myself and then I think 'haybo (no man) Sugar, one day you're gonna be rich and famous, why would you do that, my gosh why would you do that, you've got a bright future ahead of you, so girl don't?' so ja.* (Aya, p6:147-149)

Aya emphasises the extent to which she experiences her day-to-day challenges, by acknowledging that at times she considers suicide. She, however, then asserts that it is her belief that she will one day be "*rich and famous*" and that offers her solace. There is a sense that she believes wealth and fame will make her happy. Furthermore, given that her current difficulties stem from feelings of exclusion, there is a sense that she feels wealth and fame will gain the approval she yearns for from others, and as such she will feel a greater sense of connection to others. Her focus on achieving future success acts as a coping strategy for Aya. I also wondered if Aya referring to herself as "Sugar" indicated that she had created an idea of the person she wants to be, however, there is a gap between how she experiences herself now and her future self. Her imagined future life may fit better with a self called “*Sugar*”, an alter ego who is rich, famous and popular. By referring to herself as Sugar now, she is able to close the gap between her current reality and her future fantasies. She then reinforces this by saying:

(Extract 50)

A: My fear? Dying before I reach my goal

T: What’s your goal?

A: To be rich (laughs) (Aya, p17:459-461)

Aya is explicit about her primary goal in life which is “*to be rich*”, and although she previously stated that she sometimes wishes to die when things are challenging, she contradictorily, also experiences her greatest fear as dying before becoming rich. I argue that she uses the idea of becoming wealthy as a means to hold onto a sense of future orientation. She later emphasises, “*Yoh! My life would be amazing, everything would be so easy cause I’ll be rich, I’ll be so rich. So, I’ll be able to do whatever I wanna do, whenever I wanna do it, because I’ll be so rich* (p7, 202-203). In this statement Aya describes how “*being rich*” would make life easier, and create happiness, suggesting, as she previously has, that her SES is a primary challenge for her. Not having wealth makes life difficult and seems to impede her freedom, making it hard for her to “*do whatever [she wants] to do, whenever [she wants] to do it*”. Aya, like Bhuti, reports that her primary life objective is to obtain what she feels she does not have in her life at present, a sense of freedom to do whatever she wants, when she wants.

In discussing their fears, participants also acknowledged how these related to not becoming successful. Thando and Bhuti spoke about having fears of failing in life:

T: Do you have any fears?

Th: Uhm, yes, yes I do. Fear of failure

T: Do you think ... this is something that comes from inside you or do you think some of your fear of failing comes from other people’s expectations of you?

Th: (both). (Thando, p56:1150-1155)

Thando readily relates that her primary fear is of failing and this is both intrinsically and extrinsically driven. She seems aware that she both wants to succeed in life for her own benefit, and possibly this is related to wanting to make others proud, as noted above, for example, gaining her mother's approval in order to deepen their connection. She also feels her fear of failure comes from others' expectations of her – she experiences pressure from others, and doesn't want to disappoint them, possibly because she feels doing so would lessen her connection to them.

Bhuti's fears echo Thando's:

(Extract 51)

T: Do you have any fears?

B: ja I really relate to the fear of failure, I really do

T: What does failure look like to you?

B: dropping out of university, uhm, kind of means that my dreams won't come true, so I won't be successful, there is that fear ... (Bhuti, p9:204-208)

Bhuti emphasises his of fear of failing which includes not obtaining a university qualification, and how this would impact on his dreams coming true. He then offers insight into his dreams, which are to be successful. He has at another point in the interview emphasised that he wants "*to be successful, I really wanna be successful. Ja, to be successful*" (p7, 162-168). It seems that for Bhuti, failing means not being successful. Earlier in the interview, Bhuti has acknowledged that the pressure to succeed is both intrinsically driven and extrinsically driven. There is a sense that he shares Thando's experiences pertaining to success and failure which include aiming to mitigate feelings of inadequacy, and gain approval from others, not wanting to disappoint them, to gain a sense of connection to others, to challenge feelings of being an outsider.

8.5 Summary

This chapter related participants' experiences of being an outsider. The participants in this study described the shared experience of being excluded, sometimes from family and sometimes from peers. When feeling excluded from their peer groups, this was not always related to their siblings' disability, rather they seemed to understand this as being due to them not being good enough at certain activities or not being rich enough. There was a sense that they experienced a sense of inadequacy in relation to others, contributing to feelings of being an outsider. Some of the participants also described experiences of stigmatisation because of their sibling's disability. In these instances, there was a sense that they themselves felt stigmatised, as one participant noted, he felt judged through the judgement of his disabled brother. Experiences of stigmatisation seemed to contribute to feeling different to others, adding to their sense of being outsiders.

The participants described the ways in which they aimed to mitigate feelings of inadequacy and exclusion – of feeling like outsiders. They described dedicating themselves to achieving, becoming successful and rich. For some, becoming wealthy seemed to be equated with becoming happy. In their ambitions to become wealthy there was a sense that they would be more appealing and gain approval from others, and possibly challenge the feeling of exclusion and being an outsider. Some participants described the pressure they felt to succeed, and how this was both intrinsically driven and extrinsically driven. When becoming successful was self-informed, there was sense that it was connected to their self-worth and overcoming feelings of inadequacy. Where they felt pressure from others to succeed, it seemed they were trying to mitigate disappointing others and risk losing their approval and possibly connection. In response to their deep desires for success, some participants also described fearing failure. This seemed to be related to their need for approval and connection, and possibly to challenge their experiences of being an outsider.

Participants described experiencing negative "*stares*" from others, informed by their disabled sibling's "*difference*". This elicited feelings of sadness and a need to take their siblings away from situations where stigma was experienced. Bhuti acknowledged that he personally felt judged by others because of his brother's disability, stating, "*they used to judge me, judge me and my brother, they used to judge me through my brother*". Bhuti additionally acknowledged, "*I think when they're looking at him he won't be comfortable with it so he won't like, so I think I feel the same way he does, about people looking at him*". In this instance, Bhuti enacts his experience of judgement by assuming that his brother must feel the same way. Nkosi enacted his experience of stigmatisation, his perception that others were gossiping about him and his disabled sister, through his inclusion of a meme among his photographs, stating "*I am not okay*". Experiences of stigmatisation contributed to participants feeling different to others, which resulted in experiences of being an outsider. This finding supports research that has indicated NDSs' stigmatising experiences in relation to their disabled brother/sister. It, however, contributes further in that it provides subjective accounts of adolescent isiXhosa speaking adolescents.

For example, Nkosi describes his ambitions of going to an expensive private school, buying a big house overseas with an inside swimming pool and soccer field, as he sensed that this would be impressive to others and earn him connection. He also made little toy cars (out of recycled milk cartons and bottle caps) when he felt "lonely" because he hoped other children would like them and want to play with him. This to me, was demonstrative of the dissonance between his ambition, a common adolescent experience, and his reality. The function of this enactment (making toy cars), however, remains the same (as having a big house), in that he hopes that having something of appeal to others will achieve connection.

Aya acknowledged that feeling like an outsider was so difficult at times that she thought of suicide, however, her ambitions to be "*rich*" and "*famous*" offered solace and created a sense of future orientation. From the NDSs' descriptions of their lived experiences, I inferred that by focussing on their dreams and ambitions (for wealth and success) they aimed to gain approval from others in order to feel more connected, and challenge feelings of being an outsider.

Approval was, however, sought out in different ways by the NDSs, for example, wanting to make their parents "*proud*". For Thando, there was a sense that doing well academically would aid her in establishing a connection with her mother. Bhuti similarly experienced a drive to achieve academically to compensate for his feeling of inadequacy linked to being excluded from peer interactions.

While their desires to succeed were often intrinsically driven, they also acknowledged experiencing "*imposed pressure*" from parents. Thando stated (in relation to a lower grade that she had received at school) that her "*mom went on and on about it as if it was such a big deal*" despite the fact that "*[she] hadn't even done that badly*". Bhuti stated, "*finances aren't good, so like my mother and my father were telling me, you have to do good*", however, he felt his "*best [wasn't] good enough*" because they were "*persistent at telling [him] to perform better*". Bhuti experiences pressure from his parents to succeed because of their SES. He has also been told by his parents that he will have to be financially independent because their financial resources will be allocated to his brother. This again speaks to an intersecting enactment of his brother's embodiment of disability and his own embodiment of socio-economic disadvantage (informed by the legacy of racism).

CHAPTER NINE

DISCUSSION

9.1 Introduction

In this chapter I discuss my findings and situate these within the current body of knowledge pertaining to NDSs. I begin by restating my research aims and objective. I then provide a concise summary of the key claims suggested by the findings in this study. This will be followed by a detailed discussion of these findings in relation to what is currently known about the experiences of adolescent NDSs, and how this research supports or challenges related literature. I have, as suggested by Smith et al. (2009), where unexpected themes emerged, added literature (not previously included in this thesis) to frame any "new angle that has developed" (p. 113). Finally, I will consider the strengths and limitations of this thesis.

9.1.1 Research aims

This IPA study's primary objective was to address the question:

What are the experiences of Xhosa adolescent NDSs living in socio-economic disadvantaged contexts, in relation to their disabled brother/sister?

The aims of this research are to:

1) Contribute to the minimal body of knowledge from the Global South regarding first-hand accounts of how young people with disabled siblings, living in disadvantaged socio-economic contexts, experience their life world in relation to their disabled sibling; and
2) Respond to the call for further studies on NDSs from hard-to-reach populations, in this case, the Xhosa culture from a semi-rural context in the Eastern Cape of South Africa.

9.1.2 Overview of key findings

The analysis makes the following claims in relation to the experiences of adolescent Xhosa NDSs living in a disadvantaged socio-economic context, in relation to their disabled brother/sister:

9.1.2.1 Claim 1: Moments of togetherness

Most participants experienced moments of togetherness with their disabled sibling which created a sense of we-ness, where their sibling's disability was very much in the background. Sometimes these moments were experienced as playful and special, and sometimes they were very ordinary, but they were all marked by a feeling of mutual reciprocity experienced between them and their siblings. At other times, togetherness was experienced as difficult, and these moments were marked by a lack of reciprocal feelings experienced in the sibling relationship where often their sibling's disability was in the foreground.

9.1.2.2 Claim 2: Caring for their sibling

For many participants, caring for their sibling was experienced as something they wanted to do. For some this was a way in which they could demonstrate their love for their sibling, and it also provided them with a sense of purpose and contributed to their sense of self-worth. Often feeling that they wanted to care was linked to their family context where caring was valued. At other times participants experienced caring for their sibling as obligatory, which contributed to them feeling lonely and trapped. These feelings of obligation often emerged alongside feeling challenged by their sibling's behaviour when caring for them due to the nature of their sibling's impairment.

9.1.2.3 Claim 3: Being an outsider

Participants experienced themselves as outsiders – they felt that they existed outside of their peer group and sometimes they felt that they existed outside of their family group too. Being an outsider was experienced by the participants as indicative of their sense of inadequacy. Most of the participants desired success, wealth or fame as a means to escape their feelings of exclusion and inadequacy, where they believed being successful or rich was synonymous with happiness and connection to others.

Each of these claims offers additional insight into the lived experiences of Xhosa, adolescent NDSs from a disadvantaged socio-economic context in South Africa. Having outlined each claim, I will now discuss each against the existing body of knowledge on adolescent NDSs.

9.2 Lived Experience of Togetherness

9.2.1 Introduction

A central finding in this thesis was the sense of togetherness experienced by NDSs in their relationships with their disabled brothers/sisters. Togetherness was experienced in nuanced ways. Through their descriptions of enacted togetherness, where reciprocity was prominent, they conveyed a sense of felt we-ness. Where we-ness was less prominent, disability was experienced as more central in their enacted togetherness.

9.2.2 Experiencing we-ness in togetherness

There is a dense body of psychological and sociological literature that has considered siblingship from various angles, but considerably less knowledge that includes detailed descriptions of the everyday manner in which adolescents enact their siblingship, or the way in which they “do” brothering/sistering and what these experiences mean to them, particularly when one sibling is disabled. Furthermore, there is to my knowledge no research on how isiXhosa speaking adolescent NDSs living in disadvantage socio-economic contexts enact their relationships with their disabled brothers/sisters. To this extent, the current study contributes new findings about the enactment of togetherness between siblings to both sibling studies and disability studies, particularly in the Global South.

The concept of togetherness, that is, how siblings experience being with one another, speaks to an important aspect of the relationship that occurs between siblings, irrespective of the presence of disability. It does more than describe what siblings do within their relationships, it provides a sense of what the connection feels like and means to them. The phenomenological nature of this study has allowed for thick, first-hand descriptions of how participants experience togetherness and the meaning they attach to these experiences of togetherness.

Participants in this study described playful moments of togetherness that included banter and teasing one another, laughing and jumping on their bed together and conspiring as a team to make fun of strangers passing by. Qualitative researchers in the Global North (Gorjy et al., 2017; Meltzer, 2015; Pavlopoulou & Dimitriou, 2019, 2020) have previously aimed to understand how NDSs experience their relationships with their disabled brothers/sisters and have also detailed the playful, fun interactions between adolescent siblings where disability is present (Meltzer, 2015; Pavlopoulou & Dimitriou, 2020). Pavlopoulou and Dimitriou (2020) emphasised how in these playful moments, siblings felt as though they could be themselves together, and how these fun-filled moments were equated with feelings of love for their disabled brother/sister. I noted in my participants' descriptions of playful interactions, their emphasis on experienced reciprocity. Participants referred to an appreciation of their sibling's willingness and readiness to partake in enactments of togetherness. Underlying their experience of mutual willingness to be playful together was a sense of reciprocal love. This finding reinforces previous findings pertaining to NDSs' acknowledgments of love and affection (Iannuzzi et al., 2022; Pavlopoulou & Dimitriou, 2020; Correia & Seabra-Santo, 2022), and felt closeness (Riosa, 2023), but additionally noted the experience of love received from their sibling. Participants' emphasis on mutual willingness to connect playfully and the reciprocal love they felt, highlighted their experience of we-ness in their moments of togetherness.

We-ness, a concept more often employed by psychoanalytic researchers in reference to relational mentalizing, is used to explain a sense of shared thinking and being, or underlying mutually accepted intention (Fonagy, et al., 2022). To my knowledge, the experience of we-ness within siblingship has only been cited once, in the context of sibling's experiences of bereavement (Woodrow, 2007). Woodrow (2007) argues that sibling interactions have the capacity to facilitate a sense of we-ness before being developed in other social relationships, thereby bringing meaning each other's life worlds, while adding value to social development.

Reciprocity has been a noted experience in relationships between siblings where disability is present (Kramer et al., 2013). In their qualitative, cross-cultural study, which took place with adult NDSs in America, Kramer et al. (2013) established that siblings build reciprocity through their enactment of family roles and reciprocal support. In this case, Kramer et al. (2013) considered how reciprocity was created through participating together in activities and leisure. The current study extends research on reciprocity to include adolescent NDSs in the Global South, suggesting that reciprocity may be experienced in sibling relationships where disability is present irrespective of the age, culture or socio-economic context.

I argue that where reciprocal love is felt, it may lead to other experiences of reciprocity, such as a mutual willingness to engage playfully, which contributes to an experience of we-ness. Where the participants in this study emphasised a sense of we-ness in their experienced togetherness with their disabled sibling, disability was not mentioned, and as such, did not seem to be experienced as central to their experience of togetherness. This finding supports previous claims that disability does not prevent experiences of reciprocity (Dew, 2011; Kramer et al., 2013). To my knowledge, adolescent NDSs' sense of we-ness with their disabled brothers/sisters, and how this contributes to feelings of experienced togetherness, has not previously been explored, and further research on experienced we-ness within young siblingship, where disability is both present and absent, is needed. Understanding experiences of we-ness, where the role of disability slides into the background, provides insight into a new layer of meaning NDSs' attach to their relationships and experienced togetherness with their disabled siblings.

Togetherness was also enacted through ordinary day-to-day interactions by participants in this study. This finding supports previous qualitative findings which state that young NDSs are able to experience a sense of togetherness in everyday moments (Pavlopoulou & Dimitriou, 2020).

Furthermore, through the use of a phenomenological approach with a focus on everyday experiences, in conjunction with photo-production, which allowed participants to capture what their everyday enactments of togetherness looked like, these subtle experiences were brought to light. Participants described and showed moments where they cleaned their room together, helped one another with homework or were simply bored together. I wondered whether these more mundane moments of togetherness would have been included by the participants in their descriptions of what it is like to be a NDS, if they had not been asked to photograph their life worlds. This study supports claims pertaining to the value added by methods incorporating photo-production in conjunction with semi-structured interviews, when aiming to understand the lived experiences of young people (Latta et al., 2014; Pavlopoulou & Dimitriou, 2020). Furthermore, the use of photographs allowed opportunities for participants to show and talk about the shared spaces in which ordinary moments of togetherness were enacted, such as *their* bedroom or the verandah where *they* like to sit and be bored. In their emphasis on shared space, the sense of we-ness was further emphasised. This finding contributes to the methodological implications of this study – I argue that employing photo-production in conjunction with IPA provides researchers with a means to see the participant's everyday experiences as they occur for the participants, while simultaneously adding a rich layer of detail that could be missed if relying solely on interviews. It has also been suggested that the use of phenomenological approaches for cross-language studies is not recommended, given that participants utilise language to detail their experiences (Squires, 2008; Temple, 2002). I argue, however, that this finding demonstrates that isiXhosa speaking participants, through the careful use of an interpreter, the use of photo-production and semi-structured interviews, were able to capture subtle details and nuances about their lived experience of we-ness.

In moments of ordinary togetherness, where we-ness was highlighted, disability was also experienced as periphery. This is not to say that disability vanishes in NDSs' experience of togetherness, but as was noted in the literature review, it is possible that disability creates space for normative sibling togetherness to occur, challenging non-normative assumptions pertaining to sibling relationships where disability is present (Gorjy et al., 2017; Jacob & McMahon, 2016; Meltzer, 2015, 2017). In light of the experience of we-ness, this finding additionally supports those that have stated that reciprocity may take different forms between siblings (as in ordinary moments), where the presence of disability does not set experiences of reciprocity up as non-normative (Dew, 2011; Kramer et al., 2013; Meltzer, 2018).

In alignment with previous findings, togetherness was not always experienced as playful or ordinary. At times, NDSs described experienced togetherness as difficult (Riosa, 2023). Moments of difficult togetherness were frequently explained by participants as occurring because of their disabled sibling's behaviour (although participants were not explicit that their siblings' disability contributed to challenging behaviour), or when they did not feel agency in how or when they were together with their sibling. It was noted that when NDSs experienced togetherness as difficult, particularly when their siblings displayed challenging behaviour, they did not seem to experience reciprocity. This suggests that when their sibling's disability played a more central role, mutual togetherness was less obtainable. In one instance, where a participant did not experience mutual reciprocity from her older, disabled sister, she sought out togetherness from her cousin of a similar age. McKenzie and Chataika (2018) emphasise that cousins and sibling relationships are considered important for social inclusion in Africa. This is true for adolescent AmaXhosa who have noted their siblings and cousins in particular, when considering how they conceptualised family ties (Smith, 2006). Similar findings were noted in the Global North by Pavloupoulou and Dimitriou (2020), where some sisters with disabled siblings described their cousins as their best friends and social supporters. Based on the findings in the current study, I contend that where we-ness is not experienced, disability may be experienced as more challenging, reinforcing previous claims on the interconnectedness between disability and relationship and how each may mutually inform experiences of the other (Meltzer, 2015). That is, the presence of disability may contribute to how togetherness is experienced, and experiences of togetherness (and we-ness) may contribute to how disability is experienced.

The complex role disability plays within the siblingship has previously been discussed (Meltzer, 2015). Metzer (2015) conceptualises disability as assuming three inter-relating roles. Firstly, disability may **contribute** to the relationship, in that it may be one of several factors influencing how the relationship is experienced. Secondly, disability may **create** relational interactions, where the relationship occurs because of the disability, however, it is not expressed through disability. Thirdly, disability **constitutes** relations, where the relational interaction is expressed though disability and disability essentially determine the relationship.

Meltzer (2015) stresses that the role disability assumes within the siblingship is contextual. Where disability contributes, creates or constitutes relational togetherness, this occurs alongside a scope of influential factors. These include "family context, cultural background and disadvantage, services and service systems, other resources, young adult changes and transitions, contemporary context and generations" (Meltzer, 2015, p. 175). To this extent, it important to note that while this study set out to understand the experiences of Xhosa adolescent NDSs, and specific accommodations were made to allow for the consideration of cultural factors contributing to experiences (such as the use of a Xhosa interpreter), culture was not mentioned by the participants.

The participants' omission of cultural reference was an important aspect of this research. It is hard to establish whether my presence as a white, English speaking researcher impeded participants' willingness to discuss their cultural experiences, or if it was because none of my questions specifically enquired about cultural factors, inadvertently suggesting to participants that this was not information that might be needed or relevant. It is also possible that I have, to some degree, been misguided in assuming that because this study took place in the Global South and included participants from the Xhosa culture, this would be a topic of focus for them. The very nature of IPA is its attempt to forefront what experiences are pertinent to the participants, without imposing a particular agenda. As such, their experiences may be so embedded in their culture that culture is not forefronted. In addition, this finding may serve as an important warning to those researchers aiming to respond to the lack of knowledge about experiences from the Global South where cultures may vary, in terms of anticipating difference where sameness may prevail. Many of the participants in this research shared experiences with young NDSs from the Global North despite their cultural and SES dissonance.

9.2.3 Summary

This finding on the lived experience of togetherness has empirical, methodological and theoretical implications. Firstly, I argue that this finding contributes new knowledge on the experiences of togetherness of Xhosa adolescent NDSs living in disadvantaged socio-economic contexts, with their disabled sibling. Specifically, this finding supports previous qualitative findings that togetherness is experienced in nuanced ways – togetherness may be experienced as playful, ordinary or difficult. Participants emphasised that reciprocal love contributed to their experience of togetherness. Where reciprocal love was prominent, a sense of we-ness was experienced. How we-ness was experienced similarly contributed to how disability was experienced, for example, where we-ness was more prominent, disability was peripheral, however, where less we-ness was experienced, disability was more central. To my knowledge, this is a new contribution to the existing knowledge on young NDSs' experiences of togetherness.

The methodological implications of this finding include the value of employing photo-production in conjunction with IPA to obtain deeper insight into adolescent NDSs' more subtle experiences of togetherness that may otherwise not be brought to light, as well as accommodating for possible language barriers that may have been prevalent.

Finally, this finding contributes useful information on how studies on disability in the Global South are approached. I argue that while the inclusion of research on young people from various cultures and socio-economic contexts is imperative, caution should be taken around expectations or assumptions of difference, where it may be that experiences of certain phenomena may be universally shared.

9.3 Lived Experiences of Care

9.3.1 Introduction

The second prominent theme in this research related to participants' experiences of care for their disabled sibling. It was noted that participants had differing experiences of care, where some experienced care as something they wanted to do because it was an act of love or contributed to self-worth, while others felt that they had to care for their sibling.

9.3.2 NDSs' experiences of wanting to, and having to care for their brother/sister

Chataika and McKenzie (2013) have emphasised the lack of social support families in the Global South receive to assist in raising disabled children. Most families with a disabled child are required to navigate significant social, economic, educational and political barriers which impact negatively on their physical, social, emotional and intellectual development and well-being (WHO & World Bank, 2011, as cited in Grech, 2016). As a result of the minimal support they receive, caring for a disabled child becomes the responsibility of the family (Chataika & McKenzie, 2013; Grech, 2013). The presence of disability may then influence how the family is configured, the roles various members, including siblings, may assume, and familial relationships (Chataika & McKenzie, 2013). Although many families display resilience and ingenuity in their attempts to manage care, they are largely overburdened with caring responsibilities (Chataika & McKenzie, 2013; McKenzie & McConkey, 2016). It is important to consider that while this context speaks to significant imbalances in wealth distribution, it is a situation that is both pervasive and enduring for many South Africans, and forms a part of their normative day-to-day experience. Based on this information, I acknowledge that my initial expectations pertaining to NDSs' experiences of care were that **all** participants in this study would report having to care for their disabled sibling.

Participants in this study emphasised divergent experiences of care, for some care being voluntary, whereas for others care being obligatory. Where NDSs in the current research described voluntary care for their disabled sibling, they indicated that it was an act of love. This supports previous research from the Global North, where non-disabled sisters reported experiencing care as a way to show love and obtained a sense of connection to their sibling (Pavlopoulou & Dimitriou, 2019). Pavlopoulou and Dimitriou (2019) reported that non-disabled sisters additionally reported experiencing pride at being able to help with caring, which was again reinforced by the current study, where participants indicated a gained sense of purpose and achievement in their caring role, which contributed to their sense of self-worth. Furthermore, it was noted in the current study that when caring was voluntary and an act of love, it was linked to their family context and seen as a family value.

In contrast, participants in this study indicated that when they felt they **had** to care for their disabled sibling, because nobody else in their family would or could, they experienced a sense of isolation and felt unsupported, contributing to feelings of resentment and frustration toward their disabled sibling. It is important to note, however, that where care was experienced as obligatory it was also accepted as a normative, everyday experience. Participants from the current study, like participants in studies from the Global North, also acknowledged experiencing care as difficult at times, this often being due to their sibling's behaviour, supporting previous arguments that some types of care are more difficult, particularly when disabled siblings display challenging behaviour (Meltzer, 2017). Some of the participants in this study indicated, however, that even when care was difficult, this did not necessarily impact on the love they felt for their disabled brother/sister, or the willingness to continue to provide care. This finding adds to findings by Iannuzzi et al. (2022) indicating that NDSs' experience of care is nuanced, in that they can feel both compassion and empathy for their disabled brother or sister, and at the same time, experience care as stressful.

Some NDSs also experienced having to make sacrifices because of their caring responsibilities. Sacrifices included not always being able to go to school, having to wait until the family (and their disabled sibling) were sleeping before being able to study, not being able to play with their friends and giving up their social life. This finding supports findings on Latino NDSs living in disadvantaged socio-economic contexts in America (Lobato et al., 2005) and adds to previous research pertaining to the daily struggles encountered by NDSs in relation to care (Pavlopoulou & Dimitriou, 2019). It was specifically highlighted in my literature review that there remains a significant gap in the knowledge pertaining to adolescent NDSs' experiences of care in the Global South. The above-mentioned findings from the current study respond to this particular gap, by indicating that adolescent NDSs from the Global South may at times share similar, nuanced experiences of care as NDSs in the Global North.

Previous research from the Global North has suggested that when NDSs experienced parental expectations to care for their disabled siblings, they were more likely to consider their role as carer to be atypical (Pavlopoulou & Dimitriou, 2019; Petalas et al., 2013). Similarly, when NDSs experienced care as an act of love or morality, or had agency in when or how they chose to demonstrated care, it was experienced as a normal part of their relationship (Meltzer, 2017; Pavlopoulou & Dimitriou, 2019). In these previous studies, NDSs' care for their sibling was supplementary to parental care, and as such, they did not experience themselves alone in their caring responsibilities (Meltzer, 2015, 2017). Meltzer (2017) argues that NDSs are more likely to refer to themselves as carers when their roles and responsibilities are extensive and intersect with contextual factors they are unable to change. This raises an important consideration for the findings in the current research, where participants live in a socio-economically disadvantaged, semi-rural context in South Africa. For my participants, care was not always a choice or supplementary to parental care, yet, while difficult, it was not necessarily experienced as atypical, nor did they specifically refer to themselves as carers.

Meltzer (2017) emphasised that young Australian NDSs, who were in a position of providing supplementary care, were able to put up boundaries, choosing what caring responsibilities they would engage in and rejecting roles and responsibilities that challenged their experience of being a sibling. In these instances, they were able to rely on their parents to fulfil those responsibilities they did not want to assume. NDSs' rejection of certain caring roles acted as a means of protecting their siblingship (Meltzer, 2017). Again, this was an important contrast to the current finding, where some participants, because of their experience of obligatory care due to their SES, were not able to choose how or when they would care for their sibling. While this may be reflective of the hierarchical Xhosa culture where it is not culturally normative to challenge elders, it was indicated that this at times contributed to their relationships with their siblings being experienced as difficult.

Meltzer (2017) highlights that there is often a tendency to ignore the fact that care is characteristic of siblingship in general, irrespective of the presence of disability, and is considered a normative sibling practice, contributing to how the relationship is experienced. Although the kind of care that occurs when disability is present may be different (like navigating difficult behaviour, or assisting with personal care), the fact that care is a regular occurrence in all siblingship is ignored when studying NDSs. As such, it is difficult to determine where care is normative or where it is because of disability (Meltzer, 2017). In this regard, Meltzer (2017) argues that establishing whether the type of care NDSs engage in reflects their normative relational interactions is important to protect the sibling relationship, and how they experience their role as brothers/sisters. Based on the findings of the current study, I posit that when applying Meltzer's (2017) argument to NDSs in the Global South, it is imperative for service providers and policy makers to recognise that differing socio-economic contexts may necessitate NDSs engaging in caregiving responsibilities that may be difficult, yet still socially accepted. In addition, there may be different cultural perceptions of care that include more child contributions to the family's daily functioning, including caring for siblings, irrespective of the presence of disability, and are therefore considered normative experiences of care that vary considerably from those in the Global North. To this extent, it is important that service providers understand the specific challenges encountered by NDSs in their context, and how these might deviate from what is considered normative for them. In this study, two of the participants who experienced care as obligatory and difficult at times, also acknowledged differences between their experience.

Where one participant inferred that having more personal time would be valuable, the other described a more ambivalent experience, at times feeling resentful for having to care for her sister, but at other times feeling hurt when her sister didn't want her help, because she interpreted her caring role as contributing to their closeness.

Another important finding pertaining to NDSs' experiences of care contrasts with research from the Global North, where care has been documented as being gendered, with sisters reporting more care responsibilities (Cridland et al., 2016) and providing higher levels of support than brothers (Orsmond & Seltzer, 2009). I acknowledge that I had anticipated similar findings in the current study given the patriarchal themes in Xhosa cultural values, where men are dissuaded from playing the nurturer or carer role (Mbatyoti, 2018). Findings from this study, however, indicated that this was not always the case, where fathers and non-disabled brothers were actively involved in caring. In these instances, experiences of care were divergent, for example, a participant and his widowed father who both had to and wanted to care for his disabled sister, a young brother who wanted to care for his older brother as a means of demonstrating his love for him, and a young brother who had to care for his baby disabled sister but found this very difficult. This finding therefore challenges previous assumptions about gendered care, however, given the limited data, further investigation pertaining to NDSs care as being gendered in disadvantaged socio-economic contexts in the Global South is warranted.

9.3.3 Summary

The roles, responsibilities and experienced burden of mothers who care for disabled children in disadvantaged socio-economic contexts have been explored (Chataika & McKenzie, 2013; Kittay et al., 2005), however, the experiences of NDSs in similar circumstances is under-researched. This finding contributes to this particular gap in the literature.

Findings from my research have contributed to the knowledge gap pertaining to how Xhosa adolescent NDSs living in disadvantaged socio-economic contexts experience caring for their disabled brother/sister. Findings supported research from the Global North, indicating that NDSs' experiences of care may be globally shared, for example, care for some NDSs is considered an act of love, (particularly when it is experienced as a family value), and can contribute to feelings of self-worth. Care is also a difficult experience for some NDSs, particularly when having to navigate a disabled sibling's challenging behaviours.

Findings from this research additionally reflected that care could be experienced as voluntary or obligatory, highlighting the value of IPA's idiographic underpinnings that allow for unique experiences to come to light. Often NDSs who experienced care as obligatory felt unsupported and lonely, however, they simultaneously accepted their responsibilities without referring to themselves as carers. In contrast to research on NDSs' caring responsibilities in the Global North, some participants in this study did not experience agency in terms of when or the type of care they provided, and was therefore difficult at times. However, care was conveyed by participants as being a normative experience, and this is an important consideration for service providers and policy makers when determining how best to support NDSs in the Global South. Finally, this finding indicated that NDSs' care in the Global South is not always gendered or allocated to sisters, however, this finding warrants further investigation.

9.4 Lived Experiences of Being an Outsider

9.4.1 Adolescent NDSs' experiences and mitigation of being excluded

It has been previously noted that not all young NDSs' experiences will be directly connected to their disabled sibling (Meltzer, 2015). There are many other experiences that NDSs navigate within their life worlds related to their phase of life, sense of self and worldviews that are characteristic of adolescence. For example, a prominent finding in the current study emphasised NDSs' experiences of being an outsider. This was at times in relation to their peers, and at other times their families. NDSs described feeling excluded and experienced a sense of inadequacy because they did not feel good enough or rich enough in relation to their peers.

It has been well documented in the Global North that adolescence is a developmental period during which individuals may aim to examine and understand their sense of self and how they fit in, and form a part of their social context (Steinberg & Morris, 2001). Adolescent self-evaluation may occur across several domains, including their academic and athletic ability, social connection and morality (Steinberg & Morris, 2001). Social identity has been emphasised as a primary element in the development of a sense of self (Arnold, 2017) regarding the impacts of race. Exclusion based on an aspect of one's identity may lead to shame, psycho-social difficulties, an inaccurate sense of belonging, difficult peer relations and social isolation (Arnold, 2017). Nsamenang (2005) postulates that an African worldview, such as *ubuntu*, to which most AmaXhoxa adolescents ascribe, similarly emphasises social maturation as central to development. Young AmaXhosa actualise through their engagement with their community and achieving full personhood entails being "embedded in a community that both confers and *realizes* one's status" (Rice, 2015, p. 56). The participants in this study reported experienced exclusion because they felt different due to their different priorities to those of their peers (such as having to focus more on their studies) as a result of socio-economic disadvantage.

Experiences of exclusion appeared to contribute to feelings of inadequacy and low self-esteem, and in some instances significant distress. This is not necessarily a new finding, as it has previously been recognised that young, black, South Africans experience specific difficulties related to personal and social maturation in a context where racial, socio-economic, gender and class imbalances are still prevalent (Arndt & Naude, 2016). This finding, however, contributes to subjective perspectives of NDSs' experiences, and what experiences of exclusion mean to them within the South African context.

In an attempt to overcome experiences of being an outsider, participants were notably focussed on becoming successful and wealthy. Materialistic inclinations among adolescents in the Global North are progressively studied because of the notable increase in purchasing power among youth consumers and greater exposure to advertising influences (Chan, 2013). While the latter may explain the desire for wealth in economically disadvantaged adolescents, the former is hardly applicable, where adolescents in disadvantaged socio-economic contexts have little purchasing power. Links between adolescent yearnings for wealth and their belief systems in the Global North have previously been made (Chan, 2013). Similar beliefs exist within the Xhosa culture, where an isiXhosa proverb states "*ubuhle bendoda ziinkomo zayo,* the beauty of the man is his cows", indicating a person's attractiveness is determined by what he owns (Simelane-Kalumba, 2014, p. 66). The connection between wealth and social appeal are arguably socially and culturally embedded for NDSs in a global context, yet there is a significant contrast between the belief and the lived socio-economic status, or experienced lack of wealth, for participants in this research. This suggests that a lack of materialistic wealth may contribute to a sense of inadequacy and may be an especially prominent experience for adolescents in disadvantaged socio-economic contexts.

Increasingly, researchers are aiming to understand adolescent experiences within an information-laden, consumerist global culture (Chan, 2013). International research on the impact of capitalism and social networking systems on adolescence is being forefronted, and results indicate a growing tendency toward materialism (Chan, 2013). A need to obtain materialistic wealth has also previously been understood as a coping strategy in adolescents to mitigate experiences of insecurity or rejection by their social groups (Banerjee & Dittmar, 2008; Chan, 2013; Jiang et al., 2015).

As a result of modernisation, urbanisation, the fracture of traditional familial structure, exposure to media and social network systems, many African adolescents have adopted Western, capitalist practices and values, creating peer pressure and elevating the value young people attach to money and material possessions (Duh, 2014). Research (Duh, 2014) has shown that despite prevalent socio-economic disadvantage, South Africa is a very materialistic society, where contemporary youth are more materialistic than previous generations (Duh, 2014). It has been argued that people with lower SES, or who grow up feeling disadvantaged, mitigate feelings of inadequacy by adopting materialistic values and goals (Kim et al., 2017). Chaplin et al. (2014) reported that adolescents from socio-economically disadvantaged contexts had greater tendencies towards materialism than their more affluent peers, due to lower self-esteem.

A desire for wealth has also previously been connected to experiences of rejection or being excluded by peers (Banerjee & Dittmar, 2008; Jiang et al., 2015), and it has been noted that focussing on material wealth may be a compensatory strategy for insecurity (Chan, 2013). Findings from the current study support this claim, in that participants emphasised becoming rich and famous to mitigate feelings of being excluded.

This finding pertaining to participants' experiences of being an outsider has important implications in terms of interventions aimed at assisting NDSs. Firstly, clinicians, service providers and educators should be aware that not all the difficulties NDSs experience will be related to their sibling's disability, but may be due to their particular developmental phase or socio-economic context, or (as in the case of my participants) a combination of both factors. Secondly, this finding reinforces research that has aimed to understand the importance of inclusion during adolescence and emphasises the need for further studies that explore possible interventions aimed at youth who are navigating experiences of exclusion due to socio-economic disadvantage.

Some of the participants in this study acknowledged that their experiences of being an outsider were connected to their disabled sibling. Specifically, participants reported experienced stigma and felt their sibling's disability contributed to them being regarded as different to their peers, which contributed to feelings of being judged, stared at or ridiculed, isolation and being an outsider. Experiences of stigma have recently been reported on in disadvantaged socio-economic contexts in India and Albania, where NDSs acknowledged social exclusion and feelings of isolation (Battashali et al., 2018; Dervishaliaj & Murati, 2014; Viswanathan et al., 2021), which was understood by the researchers as an overall lack of knowledge or understanding from others about their sibling's disability. The current study adds to this previous research on NDSs' experiences of stigma by offering further detail on what it feels like for some NDSs to feel different and isolated because of their sibling's disability.

Previous qualitative research has demonstrated that NDSs in the Global North may feel proud of their disabled brother/sister and simultaneously concerned about other's perceptions, where having a different sibling made them feel uncomfortable (Pavlopoulou & Dimitriou, 2020). NDSs have also been reported as experiencing their peers' reaction to their disabled brother/sister as negative (Petalas et al., 2013). These nuanced experiences of stigma were echoed by participants in the current study who felt protective of and love for their disabled sibling, despite feeling different or judged because of their sibling's disability. Experiences of stigma in relation to disability and mental illness in isiXhosa speaking communities have been considered (Dingana, 2012; Kock et al., 2012; Matshabane et al., 2020; Sipungu, 2021). Some AmaXhosa contend that if one ridicules a disabled person you will be fated to giving birth to a disabled child (Dingana, 2012). Disability is often depicted in proverbs and folklore in negative, stereotypical ways (Sone & Hoza, 2017), and disabled people are pitied (Ntenda, 2012). Greef and Loubser (2008) have, however, reported that AmaXhosa view family as a blessing and emphasised the love that is felt for family members, irrespective of whether disability is present. These varied perceptions of disability within the Xhosa culture highlight the importance of challenging assumptions that all members of a certain culture may have similar beliefs about disability. Furthermore, it is recognised that stigmatising experiences may exist in both the Global North and South, thus are not particular to any culture and may take many forms. This finding, therefore, demonstrates the value of utilising IPA, which has an idiographic focus and allows for the unique experiences of each participant to be highlighted.

Kittay (1999) has emphasised that perceptions of embodied disability can be enacted by individuals who are close to disabled people (like NDSs). Where NDSs perceive their brother/sister's disability as being stigmatised, this may be enacted in various ways. Participants in this research tended to enact their experiences of stigma, through attempts at gaining approval, and through a desire to achieve success – at times this was financial success or fame.

Pressure to succeed was also reported in the context of their families, particularly from parents. This finding overlaps with those from the Global North, where non-disabled sister's experiences were informed by their parent's expectations (Pavlopoulou & Dimitriou, 2020). NDSs' tendency toward approval seeking has previously been documented, where Korean adolescent NDSs reported seeking approval from their parents by striving for achievements or trying to please their parents through exemplary behaviour to differentiate themselves from their disabled siblings (Park et al., 2021). While my participants acknowledged wanting their parent's approval, and aimed at obtaining this through their achievement, their motivations were primarily related to being accepted and a need to achieve financial security because their parents' monetary resources would be allocated to their disabled sibling.

One of the participant's approval seeking tendencies became apparent in his engagement with the data collection process. As noted in the method section (Chapter Five), prior to participants taking their photographs, I provided training on how to take their pictures to describe their experience of being a NDS (Skovdal et al., 2016; Wang, 2006). During the training, which was also interpreted into isiXhosa by the interpreter, I provided some examples of photographs from other photographic research to emphasise that the aim was not to create nice pictures, but rather, the reality of their day-to-day lives. Although this particular participant had created many pictures that met the brief, when discussing them, it was noted that there were several pictures that seemed out of place. The participant acknowledged they were his attempts to recreate the example pictures I and shown him, which he did because he wanted to make sure he was getting it right. Given that his other photographs were appropriate, we surmised that this was demonstrative of his yearning for approval and consistent with other examples in his meaning-making process. There are interesting methodological implications in this finding in terms of working with youth. Although this was an anomaly, it would have been worthwhile for us to be very clear in the training that each person's photographs may look completely different and be unique to their experiences, to avoid this occurrence. Yet, at the same time, through this happening I was afforded a direct example of the participant's yearning for approval, which subsequently became a prominent theme.

9.4.2 Summary

This finding provided several significant insights into the experiences of Xhosa adolescent NDSs living in socio-economically disadvantaged contexts. Firstly, this finding reinforced research from the Global North (Meltzer, 2015) that argues the importance of recognising not all adolescent NDSs' experiences will occur in the context of their sibling's disability. It is therefore imperative that service providers and educators are cognisant of the particular challenges that occur within adolescence, especially the need for social inclusion, irrespective of their cultural orientation. Secondly, adolescents across the globe may be inclined to mitigate experiences of exclusion by aiming for material wealth or success to obtain approval. NDSs living in socio-economic disadvantage, however, experience exclusion which may be because of their sense of inadequacy due to having less material wealth, and the stigmatising experiences that occur because of their sibling's disability and may be especially vulnerable to feeling like an outsider.

Finally, some Xhosa adolescent NDSs share the need for parental approval with NDSs in the Global North, and further research is warranted to better understand how to support NDSs in navigating feelings of inadequacy. Methodological implications include the value of IPA in terms of obtaining idiographic accounts from participants that highlight the instances where participants' experiences are unique. For example, although stigma pertaining to disability may be a globally shared experience, we cannot assume that everyone adhering to a certain culture will have the same perspective of disability. This is also an important theoretical consideration when approaching disability studies, where assuming a phenomenological stance creates space for participants' own, unique perspectives of disability to be foregrounded. Finally, the value of utilising a face-to-face method allowed participants to actually demonstrate their experiences in the interview space, for example, a yearning for approval, thereby enhancing the richness of the data. The use of an interpreter in this instance, in a cross-language study, was also deemed important as it assisted in clarifying our meaning-making process, for example, noting the participants' actions were not as a result of misunderstanding.

9.5 Strengths and Limitations

An important strength of this study was the space it created for the subjective experiences of isiXhosa speaking adolescent NDSs in a disadvantaged socio-economic context to be heard.

Utilising IPA in conjunction with photo-production also proved to be a strength in that participants' photographs were able to capture subtlety in their experiences that might not have easily been conveyed in words, while simultaneously acting as prompts for discussion. Face-to-face interviews, in addition to providing verbatim, first-hand accounts of participants' experiences, also allowed for me at times, to see what participants experienced, for example, a yearning for approval, where they demonstrated these behaviours during the interview process. In addition, my inclusion of an isiXhosa speaking interpreter created a sense of familiarity for the participants while also bridging important cultural gaps for me, offering insights to Xhosa cultural norms and practices during our debriefing sessions, for example, understanding how family hierarchy, often informed by birth order, may inform which siblings assume care roles.

Another strength was that my sample was equally reflective of both non-disabled brothers and sister's experiences, and therefore gave useful insight into the experiences of both genders.

Finally, Smith (2009) emphasises that researchers inevitably bring their own experiences, ideas and assumptions to the phenomenon they aim to investigate. While I do not assert that my own positioning as a NDS means I will know better than a researcher who does not share this experience with the participants, I argue that my own experiences allowed me a unique perspective that afforded me a specific empathic understanding of the participants' experiences, an important and valuable hallmark of qualitative research (Holloway, 2011).

There were also several limitations of this study. While I made concerted efforts to obtain a homogenous sample (all participants were isiXhosa speaking adolescents with a disabled sibling and all were from the same socio-economically disadvantaged community), there were still notable disparities. These included variance between ages (it cannot be ignored that the experiences of a 12-year-old boy will be vastly different from that of an 18-year-old), differences in family constellations (e.g., some participants lived in single-parent homes while others lived in larger families), the fact that their sibling's disabilities varied (e.g., where some experienced challenges with volatile behaviour because of their siblings' disabilities, others did not). As was noted by the literature review, all these factors may contribute to a NDSs' experiences and therefore need to be taken into consideration.

Despite using an interpreter, my inability to speak isiXhosa was a notable limitation. Although for the most part, participants opted to speak English, there were times where this was not the case. In these instances, I was reliant on the interpretations provided in the interviews, and my follow-up questions were informed by the interpretations, not my own direct inferences of what was said by the participants. This may have steered the conversations differently or meant that I may have missed certain meanings made by the participants. Similarly, I would have been unaware at the time if my interpreter missed important meaning-making.

I have also considered where certain power dynamics may have been at play and acted as limitations. Firstly, in addition to being positioned as an expert (which may have resulted in the participants feeling intimidated), being white, and not of the participants' cultural orientation, has significant implications in research conducted in South Africa, where the legacy of racial oppression is still prevalent. This may have caused my participants to censor some of their responses, and as such, I have made efforts to address this in my personal reflections on the participant's culture and in my inclusion of an interpreter. I also tried to accommodate for these limitations by scheduling two interviews in order to establish familiarity and rapport to mitigate feelings of intimidation. However, I argue it would be of significant value for a similar study to be conducted by an isiXhosa researcher to accommodate for any important insights that may have been missed. I also wondered if the fact that there were two professionals and just one participant in each interview might have caused participants to feel outnumbered or intimidated. Despite the fact that the participants appeared confident and comfortable in the interviews, I have subsequently considered the value of including a group session in this process, possibly when doing the training on taking photographs. While there may be logistical and ethical implications (it would challenge their sense of anonymity), in doing so, it could have offered participants a sense of unity and solidarity with others who may share their experiences, challenging possible feelings of being alone.

Furthermore, it could be argued that the setting in which the interviews took place might have impacted on how participants engaged with the interviews. For example, most of the interviews were conducted in the interview room at the APD in Makana, which for some would have been a familiar space given the APD's involvement with their families. However, despite ongoing reassurance that their identities would be protected and interviews were confidential, some participants might have been concerned that anything they said about their families would somehow become known to them, which may have had negative consequences. On a few occasions the interview room at the APD was not available, and in these instances, we used an interview room in the psychology department at the university. While this was a suitable substitute in that interruptions could be avoided and anonymity could be protected, the context itself, a large (unfamiliar for some) academic institution, might have been intimidating.

I have argued my subjectivity as a NDS as a strength in this study. It could, however, also be argued that my insider perspective might have hindered my capacity to be objective, where my viewpoint informed how I construed the participants' meaning-making and thereby shaped their realities. I made efforts to accommodate for this during the interview process through the debriefing sessions with the interpreter, where I was able to establish if/where my interpretations differed from hers. It is noted that our understandings were, however, shared. I also accommodated for possible lack of objectivity during my analytic process through ongoing communication with my supervisor. Following each phase of the analysis I submitted the various theme tables to her. When interpretations were not convincing, or when they could not easily be seen in the data, these were further discussed and reworked. Throughout the writing of this thesis, I have paid heed to the importance of bracketing (Smith, 2006). Smith (2006) emphasises the necessity of reflexivity in IPA studies, whereby the researcher engages in ongoing reflection of oneself, acknowledging and being transparent about their subjective reality. I have, when establishing my positionality in the introduction, and in my reflexive section in my method chapter (Chapter Five), aimed to be as honest and transparent about by own experiences of being a NDS. I have considered how various approaches to disability have been embedded in my experience of being a NDS in an attempt to create space for how this may or may not have been the case for my participants. I have also, throughout the writing of this thesis, tried to track what meaning I attach to being a NDS and noted how meaning-making may change over time, according to one's age, place of residence, family context or specific role in one's sibling's life at any given time. I have done so to remind myself of the idiographic nature of experience, to be open to the unique experience brought by each participant, and in so doing have paid attention to the hermeneutic nature of this research. As noted in the introduction, being the sibling to someone with a disability might, as the primary researcher, create the potential for insider bias, where insufficient distance would limit my ability to conceptualise the participants' experiences objectively (Dwyer & Buckle, 2009). However, as Dwyer and Buckle (2009) illustrate, having membership to a group will not necessarily impact negatively on one's research, provided "disciplined bracketing and detailed reflection on the subjective research process, with a close awareness of one's own personal biases and perspectives" is maintained (p. 59). As such, reflexivity has been a pivotal aspect of this project.

Finally, I acknowledge the absence of the experiences of the disabled siblings, how these are influenced by various intersecting factors and how the role DSs play in the siblingship are not addressed in this thesis. While this is not condoned it is an inevitable consequence of the primary focus of this study which is the experiences of NDS.

9.6 Summary

This chapter discussed the key claims made in the findings chapters. These claims respond to the research question that aimed to understand the lived experiences of nine isiXhosa speaking adolescent NDSs living in a disadvantaged socio-economic context in South Africa. Prominent findings pertaining to participants' experiences of togetherness, care and being an outsider were indicated. I noted that in many instances, findings related to these themes supported previous findings from the Global North. I also argued for several novel insights. These included a sense of we-ness that underlies experiences of togetherness and contributes to disability not being central in the relationship between siblings. I contended that care may be experienced in various ways, sometimes being voluntary and sometimes being obligatory. However, it is important not to assume that where care is obligatory and difficult, it is a non-normative experience. I also established that adolescent isiXhosa NDSs experience feelings of social exclusion and isolation both from their peer group and their families, sometimes because of their SES and sometimes because of experienced stigma due to their sibling's disability. Participants attempted to mitigate feeling like an outsider through striving for material wealth and fame, a coping strategy increasingly prevalent in adolescents, irrespective of their cultural orientation. I then contemplated the various strengths and limitations of this study. Finally, throughout this chapter, I touched on what these findings mean, empirically, methodologically, theoretically and practically. I will, however, provide a concise summary of the implications of these findings in the next and final chapter of this thesis.

CHAPTER TEN

CONCLUSION

10.1 Introduction

It was noted in the literature review that quantitative researchers in the Global North have aimed to measure the impact of disability on NDSs' psychological well-being (noting both positive and negative outcomes) (Meadan et al., 2010). In addition, the impact of caregiving on the sibling relationship where disability is present has also been measured (Bellin & Kovacs, 2006; Floyd et al., 2016; Orm et al., 2022). Qualitative researchers in the Global North have elaborated on quantitative findings, offering further nuance and detail on the experiences of young NDSs. The gap in literature pertaining to the experiences of young NDSs in the Global South, was, however, emphasised. To my knowledge, no researchers have considered how isiXhosa speaking adolescent NDSs living in disadvantage socio-economic contexts experience their relationships with their disabled brother/sisters. This phenomenological study contributes new and unique findings pertaining to the experiences of NDSs to both sibling studies and disability studies, particularly in the Global South. In this final chapter of this thesis, I will highlight the key findings from this research and provide a summary of the implications of these findings. I will then discuss the overall significance of my research before providing recommendations for future research.

10.2 Key Research Findings and their Implications

Findings from this study spoke to participants' experiences of togetherness with their disabled siblings, where some NDSs emphasised reciprocal love contributing to a sense of we-ness. Where we-ness was experienced, participants did not describe their sibling's disability as being central in their relationship, however, where less reciprocity was experienced, a sense of we-ness was less prevalent and disability was more forefronted in their relationship. Participants also described different experiences of care for their disabled sibling. Some experienced care as voluntary, where they felt care was an act of love or contributed to their sense of self-worth. Others described experiencing care as obligatory, occurring because of their familial context. In these instances, they experienced ambivalent feelings toward their disabled sibling, however, they did not indicate that this was a non-normative experience. Participants in this study also described feeling like an outsider, where they experienced a sense of inadequacy, sometimes because of their SES and sometimes because of experiences of stigmatisation because of their sibling's disability. In alignment with research on adolescents in a global context, some participants attempted to mitigate feeling like an outsider by striving for material wealth and fame in order to attain approval from others.

I noted several empirical implications pertaining to each claim. Firstly, it was noted that many of the findings pertaining to togetherness, care and being an outsider supported previous findings from research from the Global North. For example, NDSs' experience of togetherness are both diverse and nuanced, in that togetherness may be playful, ordinary and difficult. NDSs reported caring for their disabled siblings in different ways and their family values and context contributed to the meanings they attached to their caring roles. NDSs as adolescents experienced challenges that were not directly related to their disabled sibling, but rather emanated from their developmental stage and socio-economic context, which also supported research from the Global North. It is important to note that my emphasis on these experiences that support findings from the Global North is not to generalise the findings, but rather to highlight the fact that because the research took place in the Global South, socio-economic disadvantage and cultural disparities did not necessarily distinguish their lived experiences from other NDSs in the world. To this extent these findings support the need to challenge approaches to studies on children from non-Western cultures that position them as othered, simply because of their geographical location, cultural affiliations or socio-economic context.

I also argued for several novel empirical contributions to existing research on NDSs. Specifically, I noted that feelings of reciprocal love contributed to a sense of we-ness and how togetherness was enacted. Where the experience of we-ness was prominent, disability was not experienced as central, and where reciprocity was prominent, disability became peripheral. This finding emphasizes the importance of we-ness in sibling relationships and demonstrates the value of studying diverse sibling relationships in order to contribute to our understanding of siblingship. Studying we-ness across a diversity of sibling relationships may be an important consideration for future research in sibling studies.

Findings from this research additionally reflected that care could be experienced as voluntary and obligatory. In contrast to research on NDSs' caring responsibilities in the Global North, some participants in this study did not experience agency in terms of when or the type of care they provided. Caring for their sibling was as such difficult at times, contributing to ambivalent feelings toward their sibling. Finally, the findings on care indicated that, for NDSs' in this study, care is not always gendered or allocated to sisters, however, this finding warrants further investigation. In the next section, I discuss the implications of these findings.

10.2.1 Practical implications

In developing an understanding of these particular participants' experiences, this research was able to glean where their potential needs may lie. It was noted that many of the participants have a very limited support network in that they did not relay feeling supported by family or peers, and gave no indication that they were accessing support from any organisations. For example, where some participants experienced a lack of we-ness in their moments of togetherness with their sibling, or experienced isolation (because of their SES or stigma), psychological and social supports may assist them in finding ways to work through these experiences. Where some participants felt isolated in their caregiving responsibilities, they may require practical support from service providers.

In their interviews, the participants highlighted the value of being given the opportunity to discuss their experiences with someone, and reported finding the experience valuable. Some noted it was the first time they had been asked what it was like for them to have a disabled brother/sister, some said it was reassuring to hear they were not the only ones, and others stated it made them feel important, indicating they would willingly participate again. This suggests that the participants may benefit from further opportunities to talk about their experiences. Through these discussions, siblings might have the opportunity to be heard (Strohm, 2008). Furthermore, by networking with others, siblings are offered a sense of connecting to a community where interpersonal relations may be developed, which has proven integral during adolescence when familial relationships begin to transform (Strohm, 2008).

There are currently several organizations aimed at NDSs in the Global North, but as yet, to my knowledge, none in South Africa, particularly in disadvantaged socio-economic contexts. There is also, to my knowledge, currently only one non-government organisation in Makhanda that offers services to families with disabled children who could provide such opportunities, The Association for Persons with Physical Disabilities (APD), however this is primarily targeted at caregivers. It may as such, be valuable, for the findings from this research project to be presented to the APD, with the possibility of facilitating a workshop in which the most appropriate ways to support adolescent, NDS in Makhanda may be considered. Conducting a workshop with service providers who are already connected, and a part of the community would be important so that any logistical or socio-economic barriers or cultural considerations that might impact on involved participants is properly considered.

While this workshop may take place with APD, an organisation working specifically with disability, clinicians, service providers and educators should be aware that not all the difficulties NDSs experience will be related to their sibling's disability but may be due to their particular developmental phase or socio-economic context, or (as in the case of my participants) a combination of both factors.

10.2.2 Methodological implications

The methodological implications of these findings include the value of utilising a face-to-face method, which allowed for participants to provide detailed, first-hand accounts of their experiences. Furthermore, through the use of photographs, more subtle experiences of togetherness that may otherwise not have been brought to light were noted. In addition, first person interviews in conjunction with photo-production provided space for participants to actually demonstrate their experiences in the interview space, for example, a yearning for approval, thereby enhancing the richness of the data.

Utilizing an interpreter in phenomenological studies has been warned against (Squires, 2008; Temple, 2002), where the act of translation interrupts the process of studying how participants use language to describe their experiences (Squires, 2009). I argue however, that through the careful use of an interpreter, (and the additional use of a translator, both of whom identified as the same cultural orientation as the participants), not only were language gaps able to be bridged, but valuable cultural insights which contributed to more in-depth interpretations of the participants' experiences were offered. As such, problematizing the study of participants lived experiences across languages may be challenged.

10.2.3 Theoretical implications

Conducting this study from a critical realist perspective created space for developing a detailed understanding of participant's unique, lived experiences of being a NDS in a very specific context. By not assuming a particular theoretical stance, participants' own, subjective perspectives of disability were able to be foregrounded. NDSs are interestingly positioned, when thinking about disability, as they are not disabled, but they live very closely with disability. While their sibling's disability is not always central, in their lives, it is always a part of who they are. However, just because disability is unequivocally a part of their lives, it seemingly does not always define it, just as there are many instances where individuals engage in their life worlds without their siblings, they are always a brother/sister, but being a sibling (irrespective of the presence of disability) is not central to that moment. To this extent, I consider this study as contributing to the body of knowledge that aims to normalize disability.

This research additionally responds to calls from Childhood Disability Scholars (Curran & Runswick-Cole, 2014) that argue for a different approach to the study of disabled children, by including the voices of their young NDS and employing an approach that acknowledges that disabled children and their brothers/sisters lived experiences are not just about disability and inequality. Furthermore, in focussing on diverse sibling relationships (where disability is present and participants are not from western cultural, middle income backgrounds in the global north), it is evident that certain elements that may be common to all siblingships, such as we-ness, become apparent. In so doing, this study challenges the dualistic framing, referred to by Meltzer (2015) that occurs in comparative studies that set out to identify difference in sibling realtionships.

10.3 Significance of the Research

This research has contributed to the existing body of knowledge on the experiences of NDSs. Through the application of IPA, space has been created for the voices of adolescent isiXhosa speaking NDSs in a disadvantaged socio-economic context in South Africa to be heard. By listening to the meaning-making process of a relatively small group of young people about their unique experiences of being the sibling to a disabled person, whilst living in disadvantaged socio-economic circumstances, detailed understandings pertaining to their life world were attained.

A phenomenological perspective of young NDSs' experiences from the Global South has implications for psychology, sibling studies, and disability studies. It is the hope that these understandings might better inform other studies and interventions related to NDSs. Furthermore, it is intended that this study create an awareness amongst those already engaged with families where disabled children are present, regarding the needs of the siblings who are presented with their own, unique challenges.

10.4 Recommendations for Future Research

Given the limitations related to variances in age, gender and the siblings' disabilities in this study, future studies may aim to narrow the focus, either on age range, or considering either a brother's or sister's experiences, or specific disabilities. In addition, since research into the experiences of adolescent isiXhosa speaking NDSs in a disadvantaged socio-economic context is novel, further value may be added to the findings in this study by a Xhosa researcher who has greater awareness of the culture and may better be able to identify nuances in the participant's meaning making when spoken in their first language. Such a study may add further depth to the findings in this study. Finally, findings from this study offer value in deepening the understanding of NDSs' experiences in disadvantaged, socio-economic contexts, and provide some insight into where their needs may lie. To offer appropriate support, however, it would be important to specifically address research into how they would wish to be supported, given needs may be unique to each individual.

10.5 Final Reflections

Completing this research project has felt like an odyssey for me and so as I reflect back, I will extend this metaphor. While I set out as a trepidatious but curious explorer, to reach a particular destination, (to understand what it is like to be an adolescent Xhosa NDS, living in a disadvantaged socio-economic contexts), I recognize, as one sometimes does, the incidental value the journey has offered.

Assuming a retrospective stance, I realise, that until embarking on this journey, I had never properly considered what being a NDS meant to me, nor can I remember if anyone had ever asked me. This may possibly be reflective of trends (as discussed in my literature review) in sibling disability studies that have primarily considered caregivers' experiences. This research, as I have noted has required that I face this unchartered territory. I have done so, alongside my traveling companions, my participants. If we were to compare our social media albums of this journey, I have come to realise that we certainly share hashtags. #shesjustmysister, #whatsthefuss #thisisus, #sibshavingfun, #weloveeachother, #sometimesthissucks. These shared hashtags (experiences) have been profoundly normalizing for me. This was not an intended part of the journey, but surprisingly, my study has shown me that irrespective of culture, SES, (and now age), sometimes being a sibling is… #justbeingasib, #thisisournormal. I recognise that part of me thought that where SES, culture or language differed, so too would the experience of the journey. I cannot refute that these factors may add additional or different aspects to my participants' journey, especially as they continue to live through the legacy of oppression, and in a challenging socio-economic context. While it is not my intention to minimize the uniqueness of NDSs’ experiences or even the difficulties they may encounter, I hope this study contributes to thinking about NDSs and their relationships in a way that does not frame them as abnormal or problematic just because they have a disabled brother/sister, but rather, acknowledges that it is the overall complexity of their humanness that makes them special.

REFERENCES

Adamson, J., & Donovan, J. L. (2002). Research in black and white. *Qualitative Health Research*, *12*(6), 816–825. https://doi.org/10.1177/10432302012006008

Albien, A. J., & Naidoo, A. V. (2016). Social career influences of Xhosa adolescents elicited using the systems theory framework in a peri-urban South African township. *South African Journal of Higher Education*, *30*(3), 111–137. https://doi.org/10.20853/30-3-668

Alderfer, M. A., Long, K. A., Lown, E. A., Marsland, A. L., Ostrowski, N. L., Hock, J. M., & Ewing, L. J. (2010). Psychosocial adjustment of siblings of children with cancer: A systematic review. *Psycho-Oncology*, *19*(8), 789–805. https://doi.org/10.1002/pon.1638

Allan, R., & Eatough, V. (2016). The use of interpretive phenomenological analysis in couple and family therapy research. *The Family Journal*, *24*(4), 406–414. https://doi.org/10.1177/1066480716662652

American Psychological Association (APA). (2023). *APA Dictionary of psychology.* https://www.apa.org/topics/socioeconomic-status#:~:text=Socioeconomic%20status%20is%20the%20position,of%20society%E2%80%94ethnic%20origin%20or

Angell, M. E., Meadan, H., & Stoner, J. B. (2012). Experiences of siblings of individuals with autism spectrum disorders. *Autism Research and Treatment*, *2012*, 949586. 10.1155/2012/949586

Arndt, N., & Naudé, L. (2016). Contrast and contradiction: Being a black adolescent in contemporary South Africa. *Journal of Psychology in Africa*, *26*(3), 267–275.

Arnold, C. K., Heller, T., & Kramer, J. (2012). Support needs of siblings of people with developmental disabilities. *Intellectual and Developmental Disabilities*, *50*(5), 373–382. https://doi.org/10.1352/1934-9556-50.5.373

Arnold, M. E. (2017). Supporting adolescent exploration and commitment: Identity formation, thriving, and positive youth development. *Journal of Youth Development*, *12*(4), 1–15. https://doi.org/10.5195/JYD.2017.522

Aryeh, D. N. A. (2022). The spiritual model of disability and the reorientation of academic employment infrastructure for persons living with disabilities in Ghana. In C. McGunnigle (Ed.), *Disability and the academic job market* (p. 223). Vernon Press.

Ataguba, J. E., Akazili, J., & McIntyre, D. (2011). Socioeconomic-related health inequality in South Africa: Evidence from General Household Surveys. *International Journal for Equity in Health*, *10*(1), 48. https://doi.org/10.1186/1475-9276-10-48

Bachraz, V., & Grace, R. (2009). Creating a different kind of normal: Parent and child perspectives on sibling relationships when one child in the family has autism spectrum disorder. *Contemporary Issues in Early Childhood*, *10*(4), 317–330. https://doi.org/10.2304/ciec.2009.10.4.317

Banerjee, R., & Dittmar, H. (2008). Individual differences in children's materialism: The role of peer relations. *Personality and Social Psychology Bulletin*, *34*(1), 17–31. https://doi.org/10.1177/0146167207309196

Banks, M. (2001). *Visual methods in social research.* Sage.

Barak-Levy, Y., Goldstein, E., & Weinstock, M. (2010). Adjustment characteristics of healthy siblings of children with autism. *Journal of Family Studies*, *16*(2), 155–164. https://doi.org/10.5172/jfs.16.2.155

Barley, R., & Bath, C. (2014). The importance of familiarisation when doing research with young children. *Ethnography and Education*, *9*(2), 182–195. https://doi.org/10.1080/17457823.2013.841552

Barnes, C., & Mercer, G. (Eds.). (2004). *Implementing the social model of disability: Theory and research*. Disability Press.

Barr, J., & McLeod, S. (2010). They never see how hard it is to be me: Siblings' observations of strangers, peers and family. *International Journal of Speech-Language Pathology*, *12*(2), 162–171. https://doi.org/10.3109/17549500903434133

Beauchamp-Pryor, K. (2011). Impairment, cure and identity: 'Where do I fit in?'. *Disability & Society*, *26*(1), 5–17. https://doi.org/10.1080/09687599.2011.529662

Beauchamp-Pryor, K. (Ed.). (2013). A commitment to equality. In *Disabled Students in Welsh Higher Education* (pp. 147-156). Brill.

Beffel, J. H., & Nuttall, A. K. (2020). Influences of parentification and benefit finding on prosocial behavior among typically developing siblings of individuals with autism spectrum disorder. *Research in Developmental Disabilities*, *104*, 103694. https://doi.org/10.1016/j.ridd.2020.103694

Begum, G., & Blacher, J. (2011). The siblings relationship of adolescents with and without intellectual disabilities. *Research in Developmental Disabilities*, *32*(5), 1580–1588. https://doi.org/10.1016/j.ridd.2011.01.056

Bellin, M. H., Bentley, K. J., & Sawin, K. J. (2009). Factors associated with the psychological and behavioral adjustment of siblings of youths with spina bifida. *Families, Systems, & Health*, *27*(1), 1–15. https://doi.org/10.1037/a0014859

Bellin, M. H., & Kovacs, P. J. (2006). Fostering resilience in siblings of youths with a chronic health condition: A review of the literature. *Health & Social Work*, *31*(3), 209–216. https://doi.org/10.1093/hsw/31.3.209

Bellin, M. H., & Rice, K. M. (2009). Individual, family, and peer factors associated with the quality of sibling relationships in families of youths with spina bifida. *Journal of Family Psychology*, *23*(1), 39–47. https://doi.org/10.1037/a0014381

Benderix, Y., & Sivberg, B. (2007). Siblings' experiences of having a brother or sister with autism and mental retardation: A case study of 14 siblings from five families. *Journal of Pediatric Nursing*, *22*(5), 410–418. https://doi.org/10.1016/j.pedn.2007.08.013

Berger, R. J., & Wilbers, L. E. (2021). *Introducing disability studies* (2nd ed.). Lynne Rienner Publishers.

Berghs, M. (2017). Practices and discourses of ubuntu: Implications for an African model of disability?. *African Journal of Disability*, *6*(1), 1–8. https://doi.org/10.4102/ajod.v6.292

Bhaskar, R. (1978). *A realist theory of science.* Harvester.

Bhaskar, R., & Danermark, B. (2006). Metatheory, interdisciplinarity and disability research: A critical realist perspective. *Scandinavian Journal of Disability Research*, *8*(4), 278–297. https://doi.org/10.1080/15017410600914329

Bhattashali, A., Ostrosky, M. M., & Monda-Amaya, L. (2018). Perceptions of typically developing children in India about their siblings with disabilities. *International Journal of Inclusive Education*, *22*(12), 1257–1271. https://doi.org/10.1080/13603116.2017.1420253

Bitsika, V., Sharpley, C. F., & Mailli, R. (2015). The influence of gender, age, psychological resilience and family interaction factors upon anxiety and depression in non-autism spectrum disorder siblings of children with an autism spectrum disorder. *British Journal of Guidance & Counselling*, *43*(2), 216–228. https://doi.org/10.1080/03069885.2014.950944

Brink, H. I. (1993). Validity and reliability in qualitative research. *Curationis*, *16*(2), 35–38. 10.4102/curationis.v16i2.1396

Brody, G. H., & Murry, V. M. (2001). Sibling socialization of competence in rural, single-parent African American families. *Journal of Marriage and Family*, *63*(4), 996-1008.

Bryman, A. (2016). Social research methods (5th ed.). Oxford University Press.

Budlender, D., & Lund, F. (2011). South Africa: A legacy of family disruption. *Development and Change*, *42*(4), 925–946. https://onlinelibrary.wiley.com/doi/pdf/10.1111/j.1467-7660.2011.01715.x

Burke, M. M., Arnold, C. K., & Owen, A. L. (2015). Sibling advocacy: Perspectives about advocacy from siblings of individuals with intellectual and developmental disabilities. *Inclusion*, *3*(3), 162–175. https://doi.org/10.1352/2326-6988-3.3.162

Burke, M. M., Fish, T., & Lawton, K. (2015). A comparative analysis of adult siblings' perceptions toward caregiving. *Intellectual and Developmental Disabilities*, *53*(2), 143–157. https://doi.org/10.1352/1934-9556-53.2.143

Burke, M. M., Taylor, J. L., Urbano, R., & Hodapp, R. M. (2012). Predictors of future caregiving by adult siblings of individuals with intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities*, *117*(1), 33–47. https://doi.org/10.1352/1944-7558-117.1.33

Burton, A., Hughes, M., & Dempsey, R. C. (2017). Quality of life research: A case for combining photo-elicitation with interpretative phenomenological analysis. *Qualitative Research in Psychology*, *14*(4), 375–393. https://doi.org/10.1080/14780887.2017.1322650

Busso, L. D. (2021). Using photographs to explore the embodiment of pleasure in everyday life. In P. Reavey (Ed.), *A handbook of visual methods in psychology: Using and interpreting images in qualitative research* (pp. 43–54). Routledge.

Campbell, F. A. K. (2008). Exploring internalized ableism using critical race theory. *Disability & Society*, *23*(2), 151–162. https://doi.org/10.1080/09687590701841190

Campbell, F. K. (2001). Inciting legal fictions: 'Disability's' date with ontology and the ableist body of law. *Griffith Law Review*, *10*(1), 42–62. http://hdl.handle.net/10072/3714

Caretta, M. A. (2015). Situated knowledge in cross-cultural, cross-language research: A collaborative reflexive analysis of researcher, assistant and participant subjectivities. *Qualitative Research*, *15*(4), 489–505. https://doi.org/10.1177/1468794114543404

Castles, K. (2004). “Nice, average Americans”: Postwar parents’ groups and defense of the normal family. In S. Noll & J. W. Trent (Eds.), *Mental retardation in America: A historical reader* (pp. 351–370). New York University Press.

Chan, K. (2013). Development of materialistic values among children and adolescents. *Young Consumers*, *14*(3), 244–257. https://doi.org/10.1108/YC-01-2013-00339

Chaplin, L. N., Hill, R. P., & John, D. R. (2014). Poverty and materialism: A look at impoverished versus affluent children. *Journal of Public Policy & Marketing*, *33*(1), 78–92. https://doi.org/10.1509/jppm.13.050

Chataika, T., Berghs, M., Mateta, A., & Shava, K. (2015). From whose perspective anyway? The quest for African disability rights activism. In A. de Waal (Ed.), *Reclaiming activism: Western advocacy in contention* (pp. 187-211). Zed Books.

Chataika, T., & McKenzie, J. (2013). Considerations of an African childhood disability studies. In T. Curran & K. Runswick-Cole (Eds.), *Disabled children’s childhood studies* (pp. 152–163). Palgrave Macmillan UK. https://doi.org/10.1057/9781137008220_12

Cheney, K. E. (2011). Children as ethnographers: Reflections on the importance of participatory research in assessing orphans’ needs. *Childhood*, *18*(2), 166–179. https://doi.org/10.1177/0907568210390054

Choi, J., Kushner, K. E., Mill, J., & Lai, D. W. L. (2012). Understanding the language, the culture, and the experience: Translation in cross-cultural research. *International Journal of Qualitative Methods*, *11*(5), 652–665. https://doi.org/10.1177/160940691201100508

Clacherty, G., & Donald, D. (2007). Child participation in research: Reflections on ethical challenges in the southern African context. *African Journal of AIDS Research*, *6*(2), 147–156. https://doi.org/10.2989/16085900709490409

Cluver, L., Operario, D., Lane, T., & Kganakga, M. (2012). “I can’t go to school and leave her in so much pain”: Educational shortfalls among adolescent ‘young carers’ in the South African AIDS epidemic. *Journal of Adolescent Research*, *27*(5), 581–605. https://doi.org/10.1177/0743558411417868

Cocks, A. J. (2006). The Ethical Maze: Finding an inclusive path towards gaining children’s agreement to research participation. *Childhood*, *13*(2), 247–266. https://doi.org/10.1177/0907568206062942

Collier, J. (1957). Photography in anthropology: A report on two experiments. *American Anthropologist*, *59*(5), 843–859.

Collier, R. (2012). Person-first language: What it means to be a “person”. *Canadian Medical Association Journal*, *184*(18), E935–E936. https://doi.org/10.1503/cmaj.109-4322

Collins, P. H. (2006). Some group matters: Intersectionality, situated standpoints, and black feminist thought. In T. L. Lott & J. P. Pittman (Eds.), *A companion to African-American philosophy* (pp. 205-229). Blackwell.

Colver, A. (2005). A shared framework and language for childhood disability. *Developmental Medicine & Child Neurology*, *47*(11), 780. https://doi.org/10.1017/S0012162205001635

Connell, R. (2011). Southern bodies and disability: Re-thinking concepts. *Third World Quarterly*, *32*(8), 1369–1381. https://doi.org/10.1080/01436597.2011.614799

Cook, N. (2020). South Africa: Current issues, economy, and US relations.

Correia, R. A., & Seabra-Santos, M. J. (2022). “I would like to have a normal brother but I’m happy with the brother that I have”: A pilot study about intellectual disabilities and family quality of life from the perspective of siblings. *Journal of Family Issues*, *43*(12), 3148–3167. https://doi.org/10.1177/0192513X211042845

Cortis, N., Katz, I., & Patulny, R. (2009). Engaging hard-to-reach families and children. *FaHCSIA Occasional Paper No. 26*. https://ssrn.com/abstract=1728576

Coyle, C. E., Kramer, J., & Mutchler, J. E. (2014). Aging together: Sibling carers of adults with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *11*(4), 302–312. https://doi.org/10.1111/jppi.12094

Cramm, J. M., Nieboer, A. P., Finkenflügel, H., & Lorenzo, T. (2013). Comparison of barriers to employment among youth with and without disabilities in South Africa. *Work*, *46*(1), 19-24. https://doi.org/10.3233/WOR-121521

Cree, V. E. (2003). Worries and problems of young carers: Issues for mental health. *Child & Family Social Work*, *8*(4), 301–309. https://doi.org/10.1046/j.1365-2206.2003.00292.x

Cridland, E. K., Jones, S. C., Stoyles, G., Caputi, P., & Magee, C. A. (2016). Families living with autism spectrum disorder: Roles and responsibilities of adolescent sisters. *Focus on Autism and Other Developmental Disabilities*, *31*(3), 196–207. https://doi.org/10.1177/1088357615583466

Crosnoe, R., & Johnson, M. K. (2011). Research on adolescence in the twenty-first century. *Annual Review of Sociology*, *37*, 439–460. https://doi.org/10.1146/annurev-soc-081309-150008

Curran, T., & Runswick-Cole, K. (2014). *Disabled children's childhood studies: A distinct approach?. Disability & Society*, *29*(10), 1617–1630. https://doi.org/10.1080/09687599.2014.966187

Cuskelly, M., & Gunn, P. (2006). Adjustment of children who have a sibling with Down syndrome: Perspectives of mothers, fathers and children. *Journal of Intellectual Disability Research*, *50*(12), 917–925. https://doi.org/10.1111/j.1365-2788.2006.00922.x

Dahl, R. E., Allen, N. B., Wilbrecht, L., & Suleiman, A. B. (2018). Importance of investing in adolescence from a developmental science perspective. *Nature*, *554*(7693), 441–450. https://doi.org/10.1038/nature25770

Dalvit, L. (Ed.). (2022). Differently included: A decolonial perspective on disability and digital media in South Africa. In *Vulnerable people and digital inclusion: Theoretical and applied perspectives* (pp. 301–319). Springer International Publishing.

Davis, C. S., & Salkin, K. A. (2005). Sisters and friends: Dialogue and multivocality in a relational model of sibling disability. *Journal of Contemporary Ethnography*, *34*(2), 206–234. https://doi.org/10.1177/0891241604272066

Dervishaliaj, E., & Murati, E. (2014). Families of children with developmental disabilities: Perceptions and experiences of adolescent siblings of children with developmental disabilities. *European Scientific Journal*, *10*(2), 129–142. https://core.ac.uk/download/pdf/236412976.pdf

Dew, A. H. (2011). *Recognising reciprocity over the life course: Adults with cerebral palsy and their non-disabled siblings* [Doctoral dissertation]. University of Sydney, Sydney.

Dingana, C. J. N. (2012). *What are the needs of people with physical disabilities in the district of Butterworth, and how accessible are available resources to them* [Doctoral dissertation]. Stellenbosch University, Stellenbosch.

Doody, M. A., Hastings, R. P., O'Neill, S., & Grey, I. M. (2010). Sibling relationships in adults who have siblings with or without intellectual disabilities. *Research in Developmental Disabilities*, *31*(1), 224–231. https://doi.org/10.1016/j.ridd.2009.09.007

Draper, E. A. (2018). Navigating the labels: Appropriate terminology for students with disabilities. *General Music Today*, *32*(1), 30–32. https://doi.org/10.1177/1048371318792230

Duh, H. I. (2014). Application of the human capital life-course theory to understand generation Y South Africans' money attitudes. *Journal of Economics and Behavioral Studies*, *6*(12), 974–985. https://doi.org/10.22610/jebs.v6i12.554

Dwyer, S. C., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods*, *8*(1), 54–63. https://doi.org/10.1177/160940690900800105

Dyke, P., Mulroy, S., & Leonard, H. (2009). Siblings of children with disabilities: Challenges and opportunities. *Acta Paediatrica*, *98*(1), 23–24. https://doi.org/10.1111/j.1651-2227.2008.01168.x

Earley, L., & Cushway, D. (2002). The parentified child. *Clinical Child Psychology and Psychiatry*, *7*(2), 163–178. https://doi.org/10.1177/1359104502007002005

Eatough, V., & Smith, J. A. (2017). Interpretative phenomenological analysis. In C. Willig & W. Stainton Rogers (Eds.), *The Sage handbook of qualitative research in psychology* (pp. 193–209). Sage Publications.

Edinburgh Young Carers. (2024). *About. What is a young carer?* What is a Young Carer? – Edinburgh Young Carers

Edwards, R., Hadfield, L., Lucey, H., & Mauthner, M. (2006). *Sibling identity and relationships: Sisters and brothers*. Routledge. https://doi.org/10.4324/9780203448809

Eide, A. H., & Ingstad, B. (2013). Disability and poverty – Reflections on research experiences in Africa and beyond. *African Journal of Disability*, *2*(1), 1–7. 10.4102/ajod.v2i1.31

Engward, H., & Goldspink, S. (2020). Lodgers in the house: Living with the data in interpretive phenomenological analysis research. *Reflective Practice*, *21*(2), 1–13. https://doi.org/10.1080/14623943.2019.1708305

Evans, R. (2010). Children's caring roles and responsibilities within the family in Africa. *Geography Compass*, *4*(10), 1477–1496. https://doi.org/10.1111/j.1749-8198.2010.00386.x

Evans, R., & Thomas, F. (2009). Emotional interactions and an ethics of care: Caring relations in families affected by HIV and AIDS. *Emotion, Space and Society*, *2*(2), 111-119.

Fengu, M. & Khumalo, J. 2020. 'Shocking' municipal leadership sees R32bn lost to fraud and corruption. Mboweni. Available at: https://www.news24.com/citypress/news/shocking-municipal-leadership-sees-r32bn-lost-to-fraud-and-corr uption-20200701. Accessed 6 February 2024.

Finkelstein, V., & French, S. (1993). *Towards a psychology of disability.* In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling barriers—Enabling environments* (pp. 26–33). Sage Publications.

Finlay, L. (2002). “Outing” the researcher: The provenance, process, and practice of reflexivity. *Qualitative Health Research*, *12*(4), 531–545. https://doi.org/10.1177/104973202129120052

Finlay, L. (2013). Unfolding the phenomenological research process: Iterative stages of “seeing afresh”. *Journal of Humanistic Psychology*, *53*(2), 172–201.

Finnegan, R. (1970). A note on oral tradition and historical evidence. *History and Theory*, *9*(2), 195–201. https://doi.org/10.2307/2504126

Fonagy, P., Campbell, C., Constantinou, M., Higgitt, A., Allison, E., & Luyten, P. (2022). Culture and psychopathology: An attempt at reconsidering the role of social learning. *Development and Psychopathology*, *34*(4), 1205-1220.

Fleary, S. A., & Heffer, R. W. (2013). Impact of growing up with a chronically ill sibling on well siblings’ late adolescent functioning. *ISRN Family Medicine*, 2013, 1–8. https://doi.org/10.5402/2013/737356

Fleury, J., Keller, C., & Perez, A. (2009). Exploring resources for physical activity in Hispanic women, using photo elicitation. *Qualitative Health Research*, *19*(5), 677–686. https://doi.org/10.1177/1049732309334471

Flink, P. (2019). Assessment of disability services information variability among websites of one university system. *Community College Journal of Research and Practice*, *43*(12), 829–839. https://doi.org/10.1080/10668926.2018.1539676

Firth, N. (2020). Phenomenological participatory research: Opportunities for 'seeing'and producing meaning. In E. J. White (Ed.), *Seeing the world through children's eyes* (pp. 161–176). Brill.

Fiske, S. T, & Taylor, S. E. (1991). *Social cognition* (2nd ed). McGraw-Hill.

Floyd, F. J., Costigan, C. L., & Richardson, S. S. (2016). Sibling relationships in adolescence and early adulthood with people who have intellectual disability. *American Journal on Intellectual and Developmental Disabilities*, *121*(5), 383–397. https://doi.org/10.1352/1944-7558-121.5.383

French, S. (1993). Disability, impairment or something in between?. In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling barriers—Enabling environments* (pp. 17–25). Open University Press; Sage Publications.

Gadamer, H.-G. (1975). Hermeneutics and social science. *Cultural Hermeneutics*, *2*(4), 307–316. https://doi.org/10.1177/019145377500200402

Gadamer, H.-G., Weinsheimer, J. C., & Marshall, D. G. (2013). *Truth and method* (Revised 2nd ed). Bloomsbury Academic.

Gan, L. L., Lum, A., Wakefield, C. E., Nandakumar, B., & Fardell, J. E. (2017). School experiences of siblings of children with chronic illness: A systematic literature review. *Journal of Pediatric Nursing*, *33*, 23–32. https://doi.org/10.1016/j.pedn.2016.11.007

Garland-Thomson, R. (2011). Misfits: A feminist disability concept. *Hypatia*, *26*(3), 591–609. https://doi.org/10.1111/j.1527-2001.2011.01206.x

Ghai, A. (2012). Engaging with disability with postcolonial theory. In D. Goodley, B. Hughes, & L. Davis (Eds.), *Disability and social theory: New developments and directions* (pp. 270-286). Palgrave Macmillan UK.

Giddens, A. (1976). Classical social theory and the origins of modern sociology. *American Journal of Sociology*, *81*(4), 703–729. https://doi.org/10.1086/226140

Giles, H., & Ogay, T. (2007). Communication accommodation theory. In B. B. Whaley & W. Samter (Eds.), *Explaining communication: Contemporary theories and exemplars* (pp. 293–310). Lawrence Erlbaum Associates Publishers.

Giorgi, A. (2009). *The descriptive phenomenological method in psychology: A modified Husserlian approach*. Duquesne University Press.

Glasberg, B. A. (2000). The development of siblings' understanding of autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *30*(2), 143–156. https://doi.org/10.1023/A:1005411722958

Goodley, D. (2011). Social psychoanalytic disability studies. *Disability & Society*, *26*(6), 715–728. https://doi.org/10.1080/09687599.2011.602863

Goodley, D., Hughes, B., & Davis, L. J. (Eds.). (2012). *Disability and social theory: New developments and directions*. Palgrave Macmillan.

Goodley, D., Lawthom, R., Liddiard, K., & Cole, K. R. (2017). Critical disability studies. In B. Gough (Ed.), *The Palgrave handbook of critical social psychology* (pp. 491–505). Palgrave Macmillan.

Goodley, D. (2018). The dis/ability complex. *DiGeSt. Journal of Diversity and Gender Studies*, *5*(1), 5-22.

Goodley, D., Lawthom, R., Liddiard, K., & Runswick-Cole, K. (2019). Provocations for critical disability studies. *Disability & Society*, *34*(6), 972–997. https://doi.org/10.1080/09687599.2019.1566889

Goodley, D., & Runswick-Cole, K. (2011). The violence of disablism. *Sociology of Health and Illness*, *33*, 602–617. https://doi.org/10.1111/j.1467-9566.2010.01302.x

Goodley, D., & Runswick-Cole, K. (2013). The body as disability and possability: Theorizing the 'leaking, lacking and excessive' bodies of disabled children. *Scandinavian Journal of Disability Research*, *15*(1), 1–19. https://doi.org/10.1080/15017419.2011.640410

Goodley, D., & Swartz, L. (2016). The place of disability. In S. Grech & K. Soldatic (Eds.), *Disability in the global South: The critical handbook* (pp. 69–83). Springer.

Gorjy, R. S., Fielding, A., & Falkmer, M. (2017). "It's better than it used to be": Perspectives of adolescent siblings of children with an autism spectrum condition. *Child & Family Social Work*, *22*(4), 1488–1496. https://doi.org/10.1111/cfs.12371

Goudie, A., Havercamp, S., Jamieson, B., & Sahr, T. (2013). Assessing functional impairment in siblings living with children with disability. *Pediatrics*, *132*(2), e476–e483. https://doi.org/10.1542/peds.2013-0644

Graff, C., Mandleco, B., Dyches, T. T., Coverston, C. R., Roper, S. O., & Freeborn, D. (2012). Perspectives of adolescent siblings of children with Down syndrome who have multiple health problems. *Journal of Family Nursing*, *18*(2), 175–199. https://doi.org/10.1177/1074840712439797

Graham, L. (2020). Differences in employment and income poverty between people with and without disabilities in South Africa. *Alter*, *14*(4), 299–317. https://doi.org/10.1016/j.alter.2020.06.011

Grech, S. (2009). Disability, poverty and development: Critical reflections on the majority world debate. *Disability & Society*, *24*(6), 771–784. https://doi.org/10.1080/09687590903160266

Grech, S. (2011). Recolonising debates or perpetuated coloniality? Decentring the spaces of disability, development and community in the global South. *International Journal of Inclusive Education*, *15*(1), 87–100. https://doi.org/10.1080/13603116.2010.496198

Grech, S. (2012). Disability and the majority world: A neocolonial approach. In D. Goodley, B. Hughes, & L. Davis (Eds.), *Disability and social theory: New developments and directions* (pp. 52–69). Palgrave Macmillan UK.

Grech, S. (2013). Disability, childhood and poverty: Critical perspectives on Guatemala. In T. Curran & K. Runswick-Cole (Eds.), *Disabled children's childhood studies: Critical approaches in a global context* (pp. 89–104). Palgrave Macmillan UK.

Grech, S. (2015). Decolonising Eurocentric disability studies: Why colonialism matters in the disability and global South debate. *Social Identities*, *21*(1), 6–21. https://doi.org/10.1080/13504630.2014.995347

Grech, S. (2016). Disability and poverty: Complex interactions and critical reframings. In S. Grech & K. Soldatic (Eds.), *Disability in the global South: The critical handbook* (pp. 217–235). Springer.

Greeff, A. P., & Loubser, K. (2008). Spirituality as a resiliency quality in Xhosa-speaking families in South Africa. *Journal of Religion & Health*, 47(3), 288–301. https://doi.org/10.1007/s10943-007-9157-7

Griffith, G. M., Hastings, R. P., & Petalas, M. A. (2014). Brief report: Fathers' and mothers' ratings of behavioral and emotional problems in siblings of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *44*(5), 1230–1235. https://doi.org/10.1007/s10803-013-1969-6

Groce, N., Kembhavi, G., Wirz, S., Lang, R., Trani, J.-F., & Kett, M. (2011). Poverty and disability – A critical review of the literature in low and middle-income countries. *SSRN Electronic Journal*. https://doi.org/10.2139/ssrn.3398431

Grogan, S., Rothery, L., Cole, J., & Hall, M. (2018). Posting selfies and body image in young adult women: The selfie paradox. *The Journal of Social Media in Society*, *1*(1), 15–36.

Grut, L., Olenja, J., & Ingstad, B. (2011). Disability and barriers in Kenya. In A. H. Eide & B. Ingstad (Eds.), *Disability and poverty: A Global Challenge* (pp. 153–170). Policy Press.

Guan, S. S. A., & Fuligni, A. J. (2016). Changes in parent, sibling, and peer support during the transition to young adulthood. *Journal of Research on Adolescence*, *26*(2), 286–299. https://doi.org/10.1111/jora.12191

Hajat, A., Lucas, J. B., & Kington, R. (2000). *Health outcomes among Hispanic subgroups: Data from the National Health Interview Survey, 1992-95* (No. 310). US Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics.

Hallett, V., Ronald, A., Colvert, E., Ames, C., Woodhouse, E., Lietz, S., Garnett, T., Gillan, N., Rijsdijk, F., Scahill, L., Bolton, P., & Happé, F. (2013). Exploring anxiety symptoms in a large-scale twin study of children with autism spectrum disorders, their co-twins and controls. *Journal of Child Psychology and Psychiatry*, *54*(11), 1176–1185. https://doi.org/10.1111/jcpp.12068

Hamilton, M. G., & Adamson, E. (2013). Bounded agency in young carers' lifecourse-stage domains and transitions. *Journal of Youth Studies*, *16*(1), 101–117. https://doi.org/10.1080/13676261.2012.710743

Hansen, M., Harty, M., & Bornman, J. (2016). Exploring sibling attitudes towards participation when the younger sibling has a severe speech and language disability. *South African Journal of Child Health*, *10*(1), 47–51. https://doi.org/10.7196/SAJCH.2016.v10i1.1046

Harland, P., & Cuskelly, M. (2000). The responsibilities of adult siblings of adults with dual sensory impairments. *International Journal of Disability, Development and Education*, *47*(3), 293–307. https://doi.org/10.1080/713671116

Harper, D. (2002). Talking about pictures: A case for photo elicitation. *Visual Studies*, *17*(1), 13–26. https://doi.org/10.1080/14725860220137345

Harrington, C. F., & Lindy, I. E. (1999). The use of reflexive photography in the study of the freshman year experience. *Journal of College Student Retention: Research, Theory & Practice*, *1*(1), 13–22. https://doi.org/10.2190/882H-WYWR-BKDG-GF25

Hastings, R. P. (2003). Behavioral adjustment of siblings of children with autism engaged in applied behavior analysis early intervention programs: The moderating role of social support. *Journal of Autism and Developmental Disorders*, *33*(2), 141–150. https://doi.org/10.1023/a:1022983209004

Hastings, R. P. (2007). Longitudinal relationships between sibling behavioral adjustment and behavior problems of children with developmental disabilities. *Journal of Autism and Developmental Disorders*, *37*(8), 1485–1492. https://doi.org/10.1007/s10803-006-0230-y

Hastings, R. P., & Petalas, M. A. (2014). Self-reported behaviour problems and sibling relationship quality by siblings of children with autism spectrum disorder. *Child: care, health and development*, *40*(6), 833–839. 10.1111/cch.12131

Hayden, N. K., Hastings, R. P., Totsika, V., & Langley, E. (2019). A population-based study of the behavioral and emotional adjustment of older siblings of children with and without intellectual disability. *Journal of Abnormal Child Psychology*, *47*(8), 1409–1419. https://doi.org/10.1007/s10802-018-00510-5

Heidegger, M. (1962). *Being and time* (J. Macquarrie & E. Robinson, Trans). Harper & Row.

Heisley, D. D., & Levy, S. J. (1991). Autodriving: A photoelicitation technique. *Journal of Consumer Research*, *18*(3), 257–272. https://doi.org/10.1086/209258

Henderson, G., & Bryan, W. V. (2004). *Psychosocial aspects of disability*. Charles C Thomas Publisher.

Hodapp, R. M., Sanderson, K. A., Meskis, S. A., & Casale, E. G. (2017). Adult siblings of persons with intellectual disabilities: Past, present, and future. *International Review of Research in Developmental Disabilities*, *53*, 163–202. https://doi.org/10.1016/bs.irrdd.2017.08.001

Hodapp, R. M., & Urbano, R. C. (2007). Adult siblings of individuals with Down syndrome versus with autism: Findings from a large-scale US survey. *Journal of Intellectual Disability Research*, *51*(12), 1018–1029. https://doi.org/10.1111/j.1365-2788.2007.00994.x

Hodge, N., & Runswick-Cole, K. (2013). 'They never pass me the ball': Exposing ableism through the leisure experiences of disabled children, young people and their families. *Children's Geographies*, *11*(3), 311–325. https://doi.org/10.1080/14733285.2013.812275

Hodgetts, D., Radley, A., Chamberlain, K., & Hodgetts, A. (2007). Health inequalities and homelessness: Considering material, spatial and relational dimensions. *Journal of Health Psychology*, *12*(5), 709–725. https://doi.org/10.1177/1359105307080593

Hole, R. (2007). Working between languages and cultures: Issues of representation, voice, and authority intensified. *Qualitative Inquiry*, *13*(5), 696–710. https://doi.org/10.1177/1077800407301186

Hollinsworth, D. (2013). Decolonizing indigenous disability in Australia. *Disability & Society*, *28*(5), 601–615. https://doi.org/10.1080/09687599.2012.717879

Holloway, I., & Biley, F. C. (2011). Being a qualitative researcher. *Qualitative Health Research*, *21*(7), 968–975. https://doi.org/10.1177/1049732310395607

Howe, N., Rosciszewska, J., & Persram, R. J. (2018). "I'm an ogre so I'm very hungry!" "I'm assistant ogre": The social function of sibling imitation in early childhood. *Infant and Child Development*, *27*(1), e2040. https://doi.org/10.1002/icd.2040

Howlin, P., Moss, P., Savage, S., Bolton, P., & Rutter, M. (2015). Outcomes in adult life among siblings of individuals with autism. *Journal of Autism and Developmental Disorders*, *45*(3), 707–718. https://doi.org/10.1007/s10803-014-2224-5

Hughes, B. (2007). Being disabled: Towards a critical social ontology for disability studies. *Disability & Society*, *22*(7), 673–684. https://doi.org/10.1080/09687590701659527

Hughes, B., & Paterson, K. (2006). The social model of disability and the disappearing body: Towards a sociology of impairment. In L. Barton (Ed.), *Overcoming disabling barriers* (pp. 101–117). Routledge.

Hughes, C., McHarg, G., & White, N. (2018). Sibling influences on prosocial behavior. *Current Opinion in Psychology*, *20*, 96–101. https://doi.org/10.1016/j.copsyc.2017.08.015

Hunt, X., & Watermeyer, B. (2017). A web of gaps: A discussion of research strands concerning Global South families with a disabled child. *Global Health Action*, *10*(1), 1337355. https://doi.org/10.1080/16549716.2017.1337355

Husserl, E., & Moran, D. (2012). *Ideas: General introduction to pure phenomenology*. Routledge.

Iannuzzi, D., Fell, L., Luberto, C., Goshe, B. M., Perez, G., Park, E., Crute, S., Kuhlthau, K., & Traeger, L. (2022). Challenges and growth: Lived experience of adolescents and young adults (AYA) with a sibling with ASD. *Journal of Autism and Developmental Disorders*, *52*(6), 2430–2437. https://doi.org/10.1007/s10803-021-05135-0

Jegatheesan, B., Fowler, S., & Miller, P. J. (2010). From symptom recognition to services: How South Asian Muslim immigrant families navigate autism. *Disability & Society*, *25*(7), 797–811. https://doi.org/10.1080/09687599.2010.520894

Jensen, R. T. & Moran, D. (Eds). (2013). *The phenomenology of embodied subjectivity* (Vol. 71). Springer.

Jiang, J., Zhang, Y., Ke, Y., Hawk, S. T., & Qiu, H. (2015). Can’t buy me friendship? Peer rejection and adolescent materialism: Implicit self-esteem as a mediator. *Journal of Experimental Social Psychology*, *58*, 48–55. https://doi.org/10.1016/j.jesp.2015.01.001

Johnson, K., & Reavey, P. (2022). Designing qualitative research for working with visual data: Insights from psychology. In U. Flick (Ed.), *The SAGE handbook of qualitative research design* (No. 44, pp. 731-747). Sage Publications.

Jones, K. B., Welsh, R. K., Glassmire, D. M., & Tavegia, B. D. (2006). Psychological functioning in siblings of children with attention deficit hyperactivity disorder. *Journal of Child and Family Studies*, *15*(6), 753–759. https://doi.org/10.1007/s10826-006-9048-7

Jones, K. W. (2004). Education for children with mental retardation: Parent activism, public policy, and family ideology in the 1950s. In S. Noll & J. W. Trent (Eds.), *Mental retardation in America: A historical reader* (pp. 322–350). New York University Press.

Joseph, S., Sempik, J., Leu, A., & Becker, S. (2020). Young carers research, practice and policy: An overview and critical perspective on possible future directions. *Adolescent Research Review*, *5*(1), 77–89. https://doi.org/10.1007/s40894-019-00119-9

Jurkovic, G. J., Kuperminc, G. P., Sarac, T., & Weisshaar, D. (2005). Role of filial responsibility in the post-war adjustment of Bosnian young adolescents. *Journal of Emotional Abuse*, *5*(4), 219–235. https://doi.org/10.1300/J135v05n04_03

Kaminsky, L., & Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry*, *43*(2), 225–232. https://doi.org/10.1111/1469-7610.00015

Kao, B., Romero-Bosch, L., Plante, W., & Lobato, D. (2012). The experiences of Latino siblings of children with developmental disabilities: Experiences of Latino siblings. *Child: care, health and development*, *38*(4), 545–552. https://doi.org/10.1111/j.1365-2214.2011.01266.x

Kaplan, I., Lewis, I., & Mumba, P. (2007). Picturing global educational inclusion? Looking and thinking across students' photographs from the UK, Zambia and Indonesia. *Journal of Research in Special Educational Needs*, *7*(1), 23–35. https://doi.org/10.1111/j.1471-3802.2007.00078.x

Kassah, A. K. (2008). Begging as work: A study of people with mobility difficulties in Accra, Ghana. *Disability & Society*, *23*(2), 163–170. https://doi.org/10.1080/09687590701841208

Kim, D., & Jang, S. (2017). Symbolic consumption in upscale cafés: Examining Korean gen Y consumers' materialism, conformity, conspicuous tendencies, and functional qualities. *Journal of Hospitality & Tourism Research*, *41*(2), 154–179. https://doi.org/10.1177/1096348014525633

Kim, J. Y., McHale, S. M., Crouter, A. C., & Osgood, D. W. (2007). Longitudinal linkages between sibling relationships and adjustment from middle childhood through adolescence. *Developmental Psychology*, *43*(4), 960–973. https://doi.org/10.1037/0012-1649.43.4.960

Kittay, E. F. (1999). *Love's labor: Essays on women, equality and dependency.* Routledge.

Kittay, E. F. (2005). At the margins of moral personhood. *Ethics*, *116*(1), 100–131. https://doi.org/10.1086/454366

Knecht, C., Hellmers, C., & Metzing, S. (2015). The perspective of siblings of children with chronic illness. *Journal of Pediatric Nursing*, *30*(1), 102–116. https://doi.org/10.1016/j.pedn.2014.10.010

Kock, E., Molteno, C., Mfiki, N., Kidd, M., Ali, A., King, M., & Strydom, A. (2012). Cross-cultural validation of a measure of felt stigma in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *25*(1), 11–19. https://doi.org/10.1111/j.1468-3148.2011.00644.x

Komulainen, S. (2007). The ambiguity of the child's 'voice' in social research. *Childhood*, *14*(1), 11–28. https://doi.org/10.1177/0907568207068561

Koukouriki, E., Soulis, S.-G., & Andreoulakis, E. (2021). Depressive symptoms of autism spectrum disorder children's siblings in Greece: Associations with parental anxiety and social support. *Autism*, *25*(2), 529–544. https://doi.org/10.1177/1362361320966847

Kovshoff, H., Cebula, K., Tsai, H.-W. J., & Hastings, R. P. (2017). Siblings of children with autism: The Siblings Embedded Systems Framework. *Current Developmental Disorders Reports*, *4*(2), 37–45. https://doi.org/10.1007/s40474-017-0110-5

Kramer, J., Hall, A., & Heller, T. (2013). Reciprocity and social capital in sibling relationships of people with disabilities. *Intellectual and Developmental Disabilities*, *51*(6), 482–495. https://doi.org/10.1352/1934-9556-51.6.482

Krieger, N. (2005). Embodiment: A conceptual glossary for epidemiology. *Journal of Epidemiology and Community Health*, *59*(5), 350–355. https://doi.org/10.1136/jech.2004.024562

Kruger, L.-M. (2014). The whales beneath the surface: The muddled story of doing research with poor mothers in a developing country. *Health Care for Women International*, *35*(7–9), 1010–1021. https://doi.org/10.1080/07399332.2014.906441

Kvale, S., & Brinkmann, S. (2009). *InterViews: Learning the craft of qualitative research interviewing* (2nd ed). Sage Publications.

Laghi, F., Trimarco, B., Di Norcia, A., Lonigro, A., Longobardi, E., Bechini, A., & Gradilone, A. (2023). Internalizing and externalizing behaviors and close relationships in siblings of adolescents with autism spectrum disorder. *Vulnerable Children and Youth Studies*, *18*(2), 169–181. https://doi.org/10.1080/17450128.2022.2106000

Lane, T., Cluver, L., & Operario, D. (2015). Young carers in South Africa: Tasks undertaken by children in households affected by HIV infection and other illness. *Vulnerable Children and Youth Studies*, *10*(1), 55–66. https://doi.org/10.1080/17450128.2014.986252

Langridge, D. (2007). *Phenomenological psychology: Theory, research and method.* Pearson Education.

Langridge, M. E., & Ahern, K. (2003). A case report on using mixed methods in qualitative research. *Collegian*, *10*(4), 32–36. https://doi.org/10.1016/S1322-7696(08)60074-8

Lanthier, R. P., & Campbell, A. J. (2011). Sibling relationships as opportunities for development and learning in adulthood. In C. Hoare (Ed.), *The Oxford handbook of reciprocal adult development and learning* (pp. 381–395). Oxford University Press.

Larkin, M., Eatough, V., & Osborn, M. (2011). Interpretative phenomenological analysis and embodied, active, situated cognition. *Theory & Psychology*, *21*(3), 318–337. https://doi.org/10.1177/0959354310377544

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, *3*(2), 102–120. https://doi.org/10.1191/1478088706qp062oa

Larson, M. L. (1998). *Meaning-based translation: A guide to cross-language equivalence* (2nd ed.). University Press of America.

Latta, A., Rampton, T., Rosemann, J., Peterson, M., Mandleco, B., Dyches, T., & Roper, S. (2014). Snapshots reflecting the lives of siblings of children with autism spectrum disorders: Snapshots. *Child: Care, Health and Development*, *40*(4), 515–524. https://doi.org/10.1111/cch.12100

Laws, S., & Mann, G. (2004). *So you want to involve children in research? A toolkit supporting children's meaningful and ethical participation in research relating to violence against children*. Save the Children. So You Want to Involve Children in Research? A toolkit supporting children's meaningful and ethical participation in research relating to violence against children | Save the Children's Resource Centre

Lawson, D. W., & Mace, R. (2010). Siblings and childhood mental health: Evidence for a later-born advantage. *Social Science & Medicine*, *70*(12), 2061–2069. https://doi.org/10.1016/j.socscimed.2010.03.009

Lee, C. E., Hagiwara, M., & Black, H. (2021). A scoping review of cross-cultural experiences of siblings of individuals with intellectual and developmental disabilities in the United

States. *Research in Developmental Disabilities*, *112*(3), 103916. https://doi.org/10.1016/j.ridd.2021.103916

Leedham, A. T., Thompson, A. R., & Freeth, M. (2020). A thematic synthesis of siblings' lived experiences of autism: Distress, responsibilities, compassion and connection. *Research in Developmental Disabilities*, *97*, 103547. https://doi.org/10.1016/j.ridd.2019.103547

Leibbrandt, M., Woolard, I., Finn, A., & Argent, J. (2010). *Trends in South African income distribution and poverty since the fall of apartheid.* https://www.researchgate.net/publication/46457107_Trends_in_South_African_Income_Distribution_and_Poverty_Since_the_Fall_of_Apartheid

Leibbrandt, M., Woolard, I., & Woolard, C. (2009). *Poverty and inequality dynamics in South Africa: Post-apartheid developments in the light of the long-run legacy.* South Africa Labour & Development Research Unit, University of Cape Town, South Africa. https://ipcig.org/conference/ems/papers/ENG/Leibbrandt_Woolard_Woolard_ENG.pdf

Levitt, H. M., Bamberg, M., Creswell, J. W., Frost, D. M., Josselson, R., & Suárez-Orozco, C. (2018). Journal article reporting standards for qualitative primary, qualitative meta-analytic, and mixed methods research in psychology: The APA Publications and Communications Board task force report. *American Psychologist*, *73*(1), 26–46. https://psycnet.apa.org/fulltext/2018-00750-003.html

Lewis, A. (2010). Silence in the context of 'child voice'. *Children & Society*, *24*(1), 14–23. https://doi.org/10.1111/j.1099-0860.2008.00200.x

Lewis, M., & Staehler, T. (2010). *Phenomenology: An introduction*. A&C Black.

Lincoln Y. S., Guba E. G. (2000). Paradigmatic controversies, contradictions, and emerging confluences. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 163–188). Sage.

Litvak, H. (2002). *Policy lines for the revival of the bedouin settlements.* The Center for Social Policy Research in Israel. (In Hebrew).

Livingston, J. (2006). Insights from an African history of disability. *Radical History Review*, *2006*(94), 111–126. https://doi.org/10.1215/01636545-2006-94-111

Livingston, J. (2008). Disgust, bodily aesthetics and the ethic of being human in Botswana. *Africa*, *78*(2), 288–307. https://doi.org/10.3366/E000197200800017X

Lobato, D. J., Kao, B. T., & Plante, W. (2005). Latino sibling knowledge and adjustment to chronic disability. *Journal of Family Psychology*, *19*(4), 625–632. https://doi.org/10.1037/0893-3200.19.4.625

Loja, E., Costa, M. E., Hughes, B., & Menezes, I. (2013). Disability, embodiment and ableism: Stories of resistance. *Disability & Society*, *28*(2), 190–203. https://doi.org/10.1080/09687599.2012.705057

Long, C. (2002). Psychoanalytic community psychology: Crossing worlds or worlds apart?. In L. Swartz, K. Gibson, & T. Gelman (Eds.), *Reflective practice: psychodynamic ideas in the community* (pp. 113–124). HSRC.

Longmore, P. (2003). *Why I burned my book* (Vol. 12). Temple University Press.

Lourens, H. (2015). *The lived experiences of higher education for students with a visual impairment: A phenomenological study at two universities in the Western Cape, South Africa* [Doctoral dissertation]. Stellenbosch University, Stellenbosch.

Love, V., Richters, L., Didden, R., Korzilius, H., & Machalicek, W. (2012). Sibling relationships in individuals with Angelman syndrome: A comparative study. *Developmental Neurorehabilitation*, *15*(2), 84–90. https://doi.org/10.3109/17518423.2011.637972

Lovell, B., & Wetherell, M. A. (2016). The psychophysiological impact of childhood autism spectrum disorder on siblings. *Research in Developmental Disabilities*, *49–50*, 226–234. https://doi.org/10.1016/j.ridd.2015.11.023

Macks, R. J., & Reeve, R. E. (2007). The adjustment of non-disabled siblings of children with autism. *Journal of Autism and Developmental Disorders*, *37*(6), 1060–1067. https://doi.org/10.1007/s10803-006-0249-0

Majumdar, A. (2022). Thematic analysis in qualitative research: In I. R. Management Association (Ed.), *Research anthology on innovative research methodologies and utilization across multiple disciplines* (pp. 604–622). IGI Global. https://doi.org/10.4018/978-1-6684-3881-7.ch031

Mandleco, B., & Webb, A. E. M. (2015). Sibling perceptions of living with a young person with Down syndrome or autism spectrum disorder: An integrated review. *Journal for Specialists in Pediatric Nursing*, *20*(3), 138–156. https://doi.org/10.1111/jspn.12117

Manor-Binyamini, I., & Abu-Ajaj, O. (2012). Coping of siblings of children with developmental disabilities in the Bedouin community. *Research in Developmental Disabilities*, *33*(3), 825–831. https://doi.org/10.1016/j.ridd.2011.11.016

Martins, A. (2020). Reimagining equity: Redressing power imbalances between the global North and the global South. *Gender & Development*, *28*(1), 135–153. https://doi.org/10.1080/13552074.2020.1717172

Mascha, K., & Boucher, J. (2006). Preliminary investigation of a qualitative method of examining siblings' experiences of living with a child with ASD. *The British Journal of Development Disabilities*, *52*(102), 19–28. https://doi.org/10.1179/096979506799103659

Matshabane, O. P., Campbell, M. M., Faure, M. C., Marshall, P. A., Mayosi, B. M., Stein, D. J., Appelbaum, P. S., & de Vries, J. (2020). Exploring how a genetic attribution to disease relates to stigma experiences of Xhosa patients with schizophrenia in South Africa. *Social Psychiatry and Psychiatric Epidemiology*, *55*, 1679–1686. https://doi.org/10.1007/s00127-020-01875-z

Mazaleni, N. R. (2022). *The influence of linguistic and descriptive meaning of personal names in the individual's identity among Xhosa society* [Master's thesis]. University of the Witwatersrand, Johannesburg. https://wiredspace.wits.ac.za/server/api/core/bitstreams/8baceaf2-0e76-4a79-8edd-72d8993876b9/content

Mbatyoti, P. (2018). *Customary marriage and family practices that discriminate against AmaXhosa women: A critical study of selected isixhosa literary texts* [Doctoral dissertation]. Fort Hare University, Alice.

Mbiti, J. S. (1990). *African religions & philosophy* (2nd ed.). Heinemann.

McHale, S. M., Updegraff, K. A., & Feinberg, M. E. (2016). Siblings of youth with autism spectrum disorders: Theoretical perspectives on sibling relationships and individual adjustment. *Journal of Autism and Developmental Disorders*, *46*(2), 589–602. https://doi.org/10.1007/s10803-015-2611-6

McHale, S. M., Updegraff, K. A., & Whiteman, S. D. (2012). Sibling relationships and influences in childhood and adolescence. *Journal of Marriage and Family*, *74*(5), 913–930. https://doi.org/10.1111/j.1741-3737.2012.01011.x

McKenzie, J., & Chataika, T. (2018). Supporting families in raising disabled children to enhance African child development. In K. Runswick-Cole, T. Curran, & K. Liddiard (Eds.), *The Palgrave handbook of disabled children's childhood studies* (pp. 315–332). Springer.

McKenzie, J., & McConkey, R. (2016). Caring for adults with intellectual disability: The perspectives of family carers in South Africa. *Journal of Applied Research in Intellectual Disabilities*, *29*(6), 531–541. https://doi.org/10.1111/jar.12209

Meadan, H., Stoner, J. B., & Angell, M. E. (2010). Review of literature related to the social, emotional, and behavioral adjustment of siblings of individuals with autism spectrum disorder. *Journal of Developmental and Physical Disabilities*, *22*(1), 83–100. https://doi.org/10.1007/s10882-009-9171-7

Meekosha, H. (2008, September 2–4). *Contextualizing disability: Developing southern/global theory* [Conference presentation]. 4th Biennial Disability Studies Conference (pp. 1-20), Lancaster

University, Lancaster, United Kingdom. https://www.academia.edu/1079773/Contextualizing_disability_Developing_southern_global_theory

Meekosha, H. (2011). Decolonising disability: Thinking and acting globally. *Disability & Society*, *26*(6), 667–682. https://doi.org/10.1080/09687599.2011.602860

Meekosha, H., & Shuttleworth, R. (2009). What's so 'critical' about critical disability studies? *Australian Journal of Human Rights*, *15*(1), 47–75. https://doi.org/10.1080/1323238X.2009.11910861

Meekosha, H., & Soldatic, K. (2011). Human Rights and the Global South: The case of disability. *Third World Quarterly*, *32*(8), 1383–1397. https://doi.org/10.1080/01436597.2011.614800

Meltzer, A. (2015). *Siblings' relational experiences of disability during young adulthood* [Doctoral dissertation]. UNSW, Sydney.

Meltzer, A. (2017). 'I couldn't just entirely be her sister': The relational and social policy implications of care between young adult siblings with and without disabilities. *Journal of Youth Studies*, *20*(8), 1013–1027. https://doi.org/10.1080/13676261.2017.1287889

Meltzer, A. (2018). Embodying and enacting disability as siblings: Experiencing disability in relationships between young adult siblings with and without disabilities. *Disability & Society*, *33*(8), 1212–1233. https://doi.org/10.1080/09687599.2018.1481016

Meltzer, A., & Kramer, J. (2016). Siblinghood through disability studies perspectives: Diversifying discourse and knowledge about siblings with and without disabilities. *Disability & Society*, *31*(1), 17–32. https://doi.org/10.1080/09687599.2015.1127212

Merleau-Ponty, M. (2013). *Phenomenology of perception.* Routledge.

Mfecane, S. (2016). "Ndiyindoda" [I am a man]: Theorising Xhosa masculinity. *Anthropology Southern Africa*, *39*(3), 204–214. https://doi.org/10.1080/23323256.2016.1208535

Mgwili, V. N., & Watermeyer, B. (2006). Physically disabled women and discrimination in reproductive health care: Psychoanalytic reflections. In B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider, & M. Priestley (Eds.), *Disability and social change: A South African agenda* (pp. 261-272). HSRC.

Mills, C. (2021). *Implementing the socio-economic duty: A review of evidence on socio-economic disadvantage and inequalities of outcome*. Welsh Government, GSR report number 68/2021. https://www.gov.wales/sites/default/files/statistics-and-research/2021-11/review-of-evidence-on-socio-economic-disadvantage-and-inequalities-of-outcome-revised.pdf

Mitra, S., Posarac, A., & Vick, B. (2013). Disability and poverty in developing countries: A multidimensional study. *World Development*, *41*, 1–18. https://doi.org/10.1016/j.worlddev.2012.05.024

Miklavcic, A., & LeBlanc, M. N. (2013). Culture brokers, clinically applied ethnography, and cultural mediation. In *Cultural consultation: Encountering the other in mental health care* (pp. 115-137). New York, NY: Springer New York.

Mji, G., Gcaza, S., Swartz, L., MacLachlan, M., & Hutton, B. (2011). An African way of networking around disability. *Disability & Society*, *26*(3), 365–368. https://doi.org/10.1080/09687599.2011.560419

Montgomery, H. (2009). Children within anthropology: Lessons from the past. *Childhood in the Past*, *2*(1), 3–14. http://open.library.ingentaconnect.com/content/oxb...

Mophosho, M., Widdows, J., & Gomez, T. (2009). Relationships between adolescent children and their siblings with cerebral palsy: A pilot study. *Journal on Developmental Disabilities*, *15*(3), 81.

Moran, D. (2000). Heidegger's critique of Husserl's and Brentano's accounts of intentionality. *Inquiry*, *43*(1), 39–65. https://doi.org/10.1080/002017400321361

Moran, D. (2002). *Introduction to phenomenology*. Routledge.

Mtuze, P. T. (2004). *Introduction to Xhosa culture*. Lovedale Press.

Mulumba, M., Nantaba, J., Brolan, C. E., Ruano, A. L., Brooker, K., & Hammonds, R. (2014). Perceptions and experiences of access to public healthcare by people with disabilities and older people in Uganda. *International Journal for Equity in Health*, *13*(1), 1–9. https://doi.org/10.1186/s12939-014-0076-4

Munsaka, E., & Charnley, H. (2013). 'We do not have chiefs who are disabled': Disability, development and culture in a continuing complex emergency. *Disability & Society*, *28*(6), 756–769. https://doi.org/10.1080/09687599.2013.802221

Müller, M. (2020). In search of the global east: Thinking between north and south. *Geopolitics*, *25*(3), 734–755. https://doi.org/10.1080/14650045.2018.1477757

Mutumbi, U., Thondhlana, G., & Ruwanza, S. (2021). Reported behavioural patterns of electricity use among low-income households in Makhanda, South Africa. *Sustainability*, *13*(13), 7271. https://doi.org/10.3390/su13137271

Nairn, K., Munro, J., & Smith, A. B. (2005). A counter-narrative of a failed interview. *Qualitative Research*, *5*(2), 221–244. https://doi.org/10.1177/1468794105050836

Neely-Barnes, S. L., & Graff, J. C. (2011). Are there adverse consequences to being a sibling of a person with a disability? A propensity score analysis. *Family Relations*, *60*(3), 331–341. https://doi.org/10.1111/j.1741-3729.2011.00652.x

Nizza, I. E., Farr, J., & Smith, J. A. (2021). Achieving excellence in interpretative phenomenological analysis (IPA): Four markers of high quality. *Qualitative Research in Psychology*, *18*(3), 369–386. https://doi.org/10.1080/14780887.2020.1854404

Noland, C. (2006). Auto-photography as research practice: Identity and self-esteem research. *Journal of Research Practice*, *2*(1), 1–19. https://files.eric.ed.gov/fulltext/EJ805685.pdf

Noller, P. (2005). Sibling relationships in adolescence: Learning and growing together. *Personal Relationships*, *12*(1), 1–22. https://doi.org/10.1111/j.1350-4126.2005.00099.x

Nomsenge, S. O. (2019). Unpacking the complexities of NGO participation among the youth of Makhanda, South Africa. *Commonwealth Youth & Development*, *17*(1), 1–15. https://doi.org/10.25159/2663-6549/6720

Nsamenang, A. B. (2005). Educational development and knowledge flow: Local and global forces in human development in Africa. *Higher Education Policy*, *18*(3), 275–288. https://doi.org/10.1057/palgrave.hep.8300090

Nsamenang, A. B. (2006). Human ontogenesis: An indigenous African view on development and intelligence. *International Journal of Psychology*, *41*(4), 293–297. https://www.unige.ch/fapse/SSE/teachers/dasen/Nsamenang2006.pdf

Ntenda, J. (2012). *The attitudes of Sakhisizwe local service area community towards people with disabilities* [Doctoral dissertation]. Stellenbosch University, Stellenbosch.

Nuttall, A. K., Coberly, B., & Diesel, S. J. (2018). Childhood caregiving roles, perceptions of benefits, and future caregiving intentions among typically developing adult siblings of individuals with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *48*(4), 1199–1209. https://doi.org/10.1007/s10803-018-3464-6

Nyangweso, M. (2018). *Disability in Africa: A cultural/religious perspective.* East Carolina University. https://www.researchgate.net/publication/325642373_Disability_in_Africa_A_CulturalReligious_Perspective

O'Neill, L. P., & Murray, L. E. (2016). Anxiety and depression symptomatology in adult siblings of individuals with different developmental disability diagnoses. *Research in Developmental Disabilities*, *51–52*, 116–125. https://doi.org/10.1016/j.ridd.2015.12.017

Ohannessian, C. M., & De Los Reyes, A. (2014). Discrepancies in adolescents' and their mothers' perceptions of the family and adolescent anxiety symptomatology. *Parenting*, *14*(1), 1–18. https://doi.org/10.1080/15295192.2014.870009

Ojok, P., & Musenze, J. B. (2019). A defence of identity for persons with disability: Reflections from religion and philosophy versus ancient African culture. *African Journal of Disability*, *8*(1), 1–6. https://doi.org/10.4102/ajod.v8i0.490

Oliver, M. (1981). A new model of the social work role in relation to disability. In J. Campling (Ed.), *The handicapped person: A new perspective for social workers* (pp. 19–32). Radar.

Oliver, M. (Ed.). (1990). The social construction of the disability problem. In *The Politics of Disablement* (pp. 78-94). Macmillan Education UK. https://doi.org/10.1007/978-1-349-20895-1_1

Oliver, M. (2009). *Understanding disability: From theory to practice.* Palgrave Macmillan .

Oliver, M. (2013). Disability issues in the postmodern world. In L. Barton (Ed.), *Disability, politics and the struggle for change* (pp. 149–159). Routledge.

Oliver, M. (2018). *Understanding disability: From theory to practice*. Bloomsbury Publishing.

Oliver, M., & Barnes, C. (2012). Back to the future: The world report on disability. *Disability & Society*, *27*(4), 575–579. 10.1080/09687599.2012.686781

Omi, M., & Winant, H. (Eds.). (2020). Racial formation. In *The new social theory reader* (pp. 405-415). Routledge.

Opperman, S., & Alant, E. (2003). The coping responses of the adolescent siblings of children with severe disabilities. *Disability and Rehabilitation*, *25*(9), 441–454. https://doi.org/10.1080/0963828031000069735

Opoku, M. P. (2022). Special educators' intentions towards supporting practice of inclusive education for students with disabilities in secondary schools in Ghana. *African Journal of Disability*, *11*(0), 875. https://doi.org/10.4102/ajod.v11i0.875

Opoku, M. P., Alupo, B. A., Gyamfi, N., Odame, L., Mprah, W. K., Torgbenu, E. L., & Badu, E. (2017). The family and disability in Ghana: Highlighting gaps in achieving social inclusion. *Disability, CBR & Inclusive Development*, *28*(4), 41–59.

Orm, S., Haukeland, Y., Vatne, T., Silverman, W. K., & Fjermestad, K. (2022). Prosocial behavior is a relative strength in siblings of children with physical disabilities or autism spectrum disorder. *Journal of Developmental and Physical Disabilities*, *34*(4), 591–608. https://doi.org/10.1007/s10882-021-09816-7

Orsmond, G. I., & Mailick Seltzer, M. (2000). Brothers and sisters of adults with mental retardation: Gendered nature of the sibling relationship. *American Journal on Mental Retardation*, *105*(6), 486–507.

Orsmond, G. I., & Seltzer, M. M. (2009). Adolescent siblings of individuals with an autism spectrum disorder: Testing a diathesis-stress model of sibling well-being. *Journal of Autism and Developmental Disorders*, *39*(7), 1053–1065. https://doi.org/10.1007/s10803-009-0722-7

Park, J., Turnbull, A. P., & Turnbull, H. R. (2002). Impacts of poverty on quality of life in families of children with disabilities. *Exceptional Children*, *68*(2), 151–170. https://doi.org/10.1177/001440290206800201

Park, S., Ryu, W., & Yang, H. (2021). A study on the life experiences of adolescents who grew up with younger siblings with developmental disabilities: Focusing on phenomenological analysis methods. *Brain Sciences*, *11*(6), 798. https://doi.org/10.3390/brainsci11060798

Paterson, K. (2001). Disability studies and phenomenology: Finding a space for both the carnal and the political. In S. Cunningham-Burley & K. Backett-Milburn (Eds.), *Exploring the body* (pp. 81–97). Palgrave Macmillan UK.

Paterson, K. (2012). It's about time! Understanding the experience of speech impairment. In N. Watson, A. Roulstone, & C. Thomas (Eds.), *Routledge handbook of disability studies* (pp. 177-189). Routledge.

Paterson, K., & Hughes, B. (1999). Disability studies and phenomenology: The carnal politics of everyday life. *Disability & Society*, *14*(5), 597–610. https://doi.org/10.1080/09687599925966

Paul, A. M., Hussey, M. M., Woodman, A. C., Smith, A. L., & Shriver, T. P. (2022). Experiences of siblings of people with intellectual disabilities: Multiregional perspectives. *Family Relations*, *71*(2), 671–685. https://doi.org/10.1111/fare.12608

Pavlopoulou, G., Burns, C., Cleghorn, R., Skyrla, T., & Avnon, J. (2022). "I often have to explain to school staff what she needs". School experiences of non-autistic siblings growing up with an autistic brother or sister. *Research in Developmental Disabilities*, *129*, 104323. https://doi.org/10.1016/j.ridd.2022.104323

Pavlopoulou, G., & Dimitriou, D. (2019). 'I don't live with autism; I live with my sister'. Sisters' accounts on growing up with their preverbal autistic siblings. *Research in Developmental Disabilities*, *88*, 1–15. https://doi.org/10.1016/j.ridd.2019.01.013

Pavlopoulou, G., & Dimitriou, D. (2020). In their own words, in their own photos: Adolescent females' siblinghood experiences, needs and perspectives growing up with a preverbal autistic brother or sister. *Research in Developmental Disabilities*, *97*, 103556. https://doi.org/10.1016/j.ridd.2019.103556

Pentz, S. (2021). Managing vulnerability and change through Amakhosi spirit possession. In E. Prah & S. Levine (Eds.), *Bodies of knowledge: Children and childhoods in health and affliction* (pp. 203–226). African Sun Media.

Perenc, L., Radochoński, M., & Radochońska, A. (2015). Prosocial competencies among adolescent siblings of the physically disabled. *Current Issues in Personality Psychology*, *3*(4), 195–202. https://doi.org/10.5114/cipp.2015.53897

Petalas, M. A., Hastings, R. P., Nash, S., Lloyd, T., & Dowey, A. (2009). Emotional and behavioural adjustment in siblings of children with intellectual disability with and without autism. *Autism*, *13*(5), 471–483. https://doi.org/10.1177/1362361309335721

Petalas, M. A., Hastings, R. P., Nash, S., Reilly, D., & Dowey, A. (2012). The perceptions and experiences of adolescent siblings who have a brother with autism spectrum disorder. *Journal* *of Intellectual & Developmental Disability*, *37*(4), 303–314. https://doi.org/10.3109/13668250.2012.734603

Petalas, M. A., Hastings, R. P., Nash, S. & Duff, S. (2013). Typicality and subtle difference in sibling relationships: Experiences of adolescents with autism. *Journal of Child and Family Studies*, *24*(1), 38–49. https://doi.org/10.1007/s10826-013-9811-5

Peters, S., & Chimedza, R. (2000). Conscientization and the cultural politics of education: A radical minority perspective. *Comparative Education Review*, *44*(3), 245–271. https://doi.org/10.1086/447614

Pietkiewicz, I., & Smith, J. A. (2012). Praktyczny przewodnik interpretacyjnej analizy fenomenologicznej w badaniach jakościowych w psychologii. *Czasopismo Psychologiczne*, *18*(2), 361–369.

Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Psychological Journal*, *20*(1), 7–14. https://doi.org/10.14691/CPPJ.20.1.7

Pollard, C. A., Barry, C. M., Freedman, B. H., & Kotchick, B. A. (2013). Relationship quality as a moderator of anxiety in siblings of children diagnosed with autism spectrum disorders or Down syndrome. *Journal of Child and Family Studies*, *22*(5), 647–657. https://doi.org/10.1007/s10826-012-9618-9

Potter, J., & Hepburn, A. (2005). Qualitative interviews in psychology: Problems and possibilities. *Qualitative Research in Psychology*, *2*(4), 281–307. https://doi.org/10.1191/1478088705qp045oa

Quintero, N., & McIntyre, L. L. (2010). Sibling adjustment and maternal well-being: An examination of families with and without a child with an autism spectrum disorder. *Focus on Autism and Other Developmental Disabilities*, *25*(1), 37–46. https://doi.org/10.1177/1088357609350367

Ramphele, M. (2002). *Steering by the stars: Being young in South Africa*. Tafelberg.

Reavey, P. (Ed.). (2012). *Visual methods in psychology.* Routledge. https://doi.org/10.4324/9780203829042

Reeve, D. (2012). Psycho-emotional disablism: The missing link?. In N. Watson, A. Roulstone, & C. Thomas (Eds.), *Routledge handbook of disability studies* (pp. 78–92). Routledge.

Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, *18*(1), 20–23.

Republic of South Africa. (2004). *National Health Act 61 of 2003.* https://www.gov.za/sites/default/files/gcis_document/201409/a61-03.pdf

Republic of South Africa. (2007). *Children's Act 38 of 2005.* https://www.justice.gov.za/legislation/acts/2005-038%20childrensact.pdf

Rieser, R. (Ed.). (2006). Disability equality: Confronting the oppression of the past. In *Education, equality and human rights* (2nd ed., pp. 152-174). Routledge.

Rice, K. (2015). *"Most of them, they just want someone to under them": Gender, generation, and personhood among the Xhosa* [Doctoral dissertation]. University of Toronto, Canada. https://tspace.library.utoronto.ca/bitstream/1807/69452/3/Rice_Kathleen_F_201506_PhD_thesis.pdf

Riosa, B. P., Ensor, R., Jichici, B., & Davy, B. (2023). How my life is unique: Sibling perspectives of autism. *Autism*, *27*(6), 1575–1587. 10.1177/13623613221142385

Rivers, J. W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support coping. *Journal of Autism and Developmental Disorders*, *33*(4), 383–394. https://doi.org/10.1023/A:1025006727395

Roger, K. S., & Blomgren, C. (2019). Elicitation as a mind-set: Why visual data matter?. *International Journal of Qualitative Methods*, *18*, 1609406919835378. https://doi.org/10.1177/1609406919835378

Rose, P. (1985). *Writing of women: Essays in a renaissance.* Wesleyan University Press.

Rossiter, L., & Sharpe, D. (2001). The siblings of individuals with mental retardation: A quantitative integration of the literature. *Journal of Child and Family Studies*, *10*(1), 65–84. https://doi.org/10.1023/A:1016629500708

Roulstone, A., Thomas, C., & Watson, N. (Eds.). (2012). The changing terrain of disability studies. In N. Watson, A. Roulstone, & C. Thomas (Eds.), *Routledge handbook of disability studies* (pp. 3–11). Routledge.

Rukwong, P. (2008). Lived experience of middle-aged women living with a disability in Isaan, Thailand. *Nursing & Health Sciences*, *10*(1), 59–64. https://doi.org/10.1111/j.1442-2018.2007.00369.x

Sadler, G. R., Lee, H.-C., Lim, R. S.-H., & Fullerton, J. (2010). Recruitment of hard-to-reach population subgroups via adaptations of the snowball sampling strategy. *Nursing & Health Sciences*, *12*(3), 369–374. https://doi.org/10.1111/j.1442-2018.2010.00541.x

Sage, K. D., & Jegatheesan, B. (2010). Perceptions of siblings with autism and relationships with them: European American and Asian American siblings draw and tell. *Journal of Intellectual & Developmental Disability*, *35*(2), 92–103. https://doi.org/10.3109/13668251003712788

Satumba, T., Bayat, A., & Mohamed, S. (2017). The impact of social grants on poverty reduction in South Africa. *Journal of Economics*, *8*(1), 33–49. https://doi.org/10.1080/09765239.2017.1336304

Saville Young, L. (2016). Key concepts for quality as foundational in qualitative research: Milkshakes, mirrors and maps in 3D. *South African Journal of Psychology*, *46*(3), 328–337. https://doi.org/10.1177/0081246316630146

Sawyer, S. M., Azzopardi, P. S., Wickremarathne, D., & Patton, G. C. (2018). The age of adolescence. *The Lancet Child & Adolescent Health*, *2*(3), 223–228. https://doi.org/10.1016/S2352-4642(18)30022-1

Saxena, M., & Adamsons, K. (2013). Siblings of individuals with disabilities: Reframing the literature through a bioecological lens: Bioecological framework and siblings. *Journal of Family Theory & Review*, *5*(4), 300–316. https://doi.org/10.1111/jftr.12021

Scavarda, A. (2023). Disability by association for siblings of adolescents and adults with cognitive disabilities. *Disability & Society.* Advance online publication. https://doi.org/10.1080/09687599.2023.2215393

Sefotho, M. M. (2021). Basotho ontology of disability: An afrocentric onto-epistemology. *Heliyon*, *7*(3), e06540. 10.1016/j.heliyon.2021.e06540

Seltzer, M. M., Greenberg, J. S., Orsmond, G. I., & Lounds, J. (2005). Life course studies of siblings of individuals with developmental disabilities. *Mental Retardation*, *43*(5), 354–359.

Shakespeare, T. (1992). Making disability: Exploring the social transformation of human variation. *Disability, Handicap & Society*, *7*(4), 384–385. https://doi.org/10.1080/02674649266780471

Shakespeare, T. (Ed.). (1998). *Disability reader: Social science perspectives*. A&C Black.

Shakespeare, T. (2006). The social model of disability. In L. J. Davis (Eds.), *The disability studies reader* (pp. 197–204). Psychology Press.

Shakespeare, T. (2008). Debating disability. *Journal of Medical Ethics*, *34*(1), 11–14. https://doi.org/10.1136/jme.2006.019992

Shakespeare, T. (2013). *Disability rights and wrongs revisited.* Routledge. https://doi.org/10.4324/9781315887456

Shakespeare, T. (Ed.). (2015). *Disability research today: International perspectives*. Routledge.

Shakespeare, T., & Watson, N. (2001). The social model of disability: An outdated ideology?. In S. N. Barnartt & B. M. Altman (Eds.), *Exploring theories and expanding methodologies: Where we are and where we need to go* (pp. 9–28). Emerald Group Publishing.

Shakespeare, T., & Watson, N. (2010). Beyond models: Understanding the complexity of disabled people's lives. In G. Scambler & S. Scambler (Eds.), *New directions in the sociology of chronic* *and disabling conditions* (pp. 57–76). Palgrave Macmillan UK. https://doi.org/10.1057/9780230297432_4

Shapiro, L. A. S., & Margolin, G. (2014). Growing up wired: Social networking sites and adolescent psychosocial development. *Clinical Child and Family Psychology Review*, *17*(1), 1–18. https://doi.org/10.1007/s10567-013-0135-1

Shildrick, M. (2009). *Dangerous discourses of disability, subjectivity and sexuality*. Palgrave Macmillan.

Shinebourne, P. (2011a). Interpretative phenomenological analysis. In N. Frost (Ed.), *Qualitative research methods in psychology: Combining core approaches* (pp. 44–65). Open University.

Shinebourne, P., & Smith, J. A. (2010). The communicative power of metaphors: An analysis and interpretation of metaphors in accounts of the experience of addiction. *Psychology and Psychotherapy: Theory, Research and Practice*, *83*(1), 59–73. https://doi.org/10.1348/147608309X468077

Shivers, C. M. (2013). *Risk and protective factors predicting sibling emotional intelligence among adolescent siblings of individuals with and without intellectual and developmental disabilities* [Doctoral dissertation]. Vanderbilt University, Nashville. https://ir.vanderbilt.edu/bitstream/handle/1803/12225/ShiversDissertation.pdf?sequence=1&isAllowed=y

Shivers, C. M., Deisenroth, L. K., & Taylor, J. L. (2013). Patterns and predictors of anxiety among siblings of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *43*(6), 1336–1346. 10.1007/s10803-012-1685-7

Shivers, C. M., & Dykens, E. M. (2017). Adolescent siblings of individuals with and without intellectual and developmental disabilities: Self-reported empathy and feelings about their brothers and sisters. *American Journal on Intellectual and Developmental Disabilities*, *122*(1), 62–77. https://doi.org/10.1352/1944-7558-122.1.62

Shivers, C. M., Jackson, J. B., & McGregor, C. M. (2019). Functioning among typically developing siblings of individuals with autism spectrum disorder: A meta-analysis. *Clinical Child and Family Psychology Review*, *22*(2), 172–196. https://doi.org/10.1007/s10567-018-0269-2

Shome, R. (2019). Thinking culture and cultural studies – from/of the Global South. *Communication and Critical/Cultural Studies*, *16*(3), 196–218. https://doi.org/10.1080/14791420.2019.1648841

Simelane-Kalumba, P. I. (2014). *The use of proverbial names among the Xhosa society: Socio-cultural approach* [Doctoral dissertation]. University of Western Cape, South Africa.

Sipungu, T. (2021). *Embodied difference in manhood: A sociological analysis of the intersection of visible physical impairments and manhood among Xhosa men in the Eastern Cape* [Unpublished Doctoral dissertation]. Rhodes University, Makhanda.

Skotko, B. G., & Levine, S. P. (2006). What the other children are thinking: Brothers and sisters of persons with Down syndrome. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, *142C*(3), 180–186. https://doi.org/10.1002/ajmg.c.30101

Skotko, B. G., Levine, S. P., & Goldstein, R. (2011). Having a brother or sister with Down syndrome: Perspectives from siblings. *American Journal of Medical Genetics Part A*, *155*(10), 2348–2359. https://doi.org/10.1002/ajmg.a.34228

Skovdal, M. (2016). “It’s because they care”: Understanding pathways to classroom concentration problems among HIV-affected children and youth in Western Kenya. *AIDS Care*, *28*(sup2), 42–48. https://doi.org/10.1080/09540121.2016.1159651

Smith, J., & Dunworth, F. (2003). Qualitative methodology. In J. Valsiner (Ed.), *Handbook of developmental psychology* (pp. 603–621). Sage.

Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology & Health*, *11*(2), 261–271. https://doi.org/10.1080/08870449608400256

Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, *1*(1), 39–54. https://doi.org/10.1191/1478088704qp004oa

Smith, J. A. (2019). Participants and researchers searching for meaning: Conceptual developments for interpretative phenomenological analysis. *Qualitative Research in Psychology*, *16*(2), 166–181. https://doi.org/10.1080/14780887.2018.1540648

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretive phenomenological analysis: Theory, method, and research*. Sage.

Smith, J. A., & Nizza, I. E. (2022). *Essentials of interpretative phenomenological analysis*. American Psychological Association.

Smith, J. A., & Osborn, M. (2015). History and theoretical background. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (p. 25). Sage Publications.

Smith, J. A., & Shinebourne, P. (2012). Interpretative phenomenological analysis. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds.), *APA handbook of research methods in psychology, Vol 2: Research designs: Quantitative, qualitative, neuropsychological, and biological.* (pp. 73–82). American Psychological Association. https://doi.org/10.1037/13620-005

Smith, P. N. (2006). *Resilience in Xhosa families* [Doctoral dissertation]. University of Stellenbosch, Stellenbosch.

Sone, E. M., & Hoza, M. (2017). Re-engaging cultural perspectives on disability discourse: An analysis of the Bakossi and isiXhosa oral traditions. *Southern African Journal for Folklore Studies*, *27*(1), 10–29. https://doi.org/10.25159/1016-8427/2258

Spaull, N. (2013). Poverty & privilege: Primary school inequality in South Africa. *International Journal of Educational Development*, *33*(5), 436–447. https://doi.org/10.1016/j.ijedudev.2012.09.009

Spivak, G. C. (2000). Translation as culture. *Parallax*, *6*(1), 13–24. https://doi.org/10.1080/135346400249252

Squires, A. (2008). Language barriers and qualitative nursing research: Methodological considerations. *International Nursing Review*, *55*(3), 265–273. https://doi.org/10.1111/j.1466-7657.2008.00652.x

Squires, A. (2009). Methodological challenges in cross-language qualitative research: A research review. *International Journal of Nursing Studies*, *46*(2), 277–287. https://doi.org/10.1016/j.ijnurstu.2008.08.006

Stalker, K., & Connors, C. (2004). Children's perceptions of their disabled siblings: 'She's different but it's normal for us'. *Children & Society*, *18*(3), 218–230. https://doi.org/10.1002/chi.794

Statistics South Africa. (2011). *Formal census*. https://www.westerncape.gov.za/Text/2003/vote_13_statssa_02.pdf

Statistics South Africa. (2015). *Living conditions of households in South Africa: An analysis of household expenditure and income data using the LCS 2014/2015*. Isibalo House.

Stead, G. B. (2004). Culture and career psychology: A social constructionist perspective. *Journal of Vocational Behavior*, *64*(3), 389–406. https://doi.org/10.1016/j.jvb.2003.12.006

Steinberg, L., & Morris, A. S. (2001). Adolescent development. *Annual Review of Psychology*, *52*(1), 83–110. https://doi.org/10.1891/194589501787383444

Stolorow, R. D., & Atwood, G. E. (1984). Psychoanalytic phenomenology: Toward a science of human experience. *Psychoanalytic Inquiry*, *4*(1), 87–105. https://doi.org/10.1080/07351698409533532

Stoneman, Z. (2005). Siblings of children with disabilities: Research themes. *Mental Retardation*, *43*(5), 339–350. https://doi.org/10.1352/0047-6765(2005)43[339:SOCWDR]2.0.CO;2

Streng, J. M., Rhodes, S., Ayala, G., Eng, E., Arceo, R., & Phipps, S. (2004). *Realidad Latina*: Latino adolescents, their school, and a university use photovoice to examine and address the influence of immigration. *Journal of Interprofessional Care*, *18*(4), 403–415. https://doi.org/10.1080/13561820400011701

Strohm, K. (2008). Guest editorial: Too important to ignore: Siblings of children with special needs. *Australian e-Journal for the Advancement of Mental Health*, *7*(2), 78–83. https://doi.org/10.5172/jamh.7.2.78

Sullivan, H. S. (1954). *The interpersonal theory of psychiatry.* Norton.

Swartz, L. (2014). Five challenges for disability-related research in sub-Saharan Africa: Original research. *African Journal of Disability*, *3*(2), 1–6.

Swartz, L., & Marchetti-Mercer, M. (2018). Disabling Africa: The power of depiction and the benefits of discomfort. *Disability & Society*, *33*(3), 482–486. https://doi.org/10.1080/02684527.2017.1400240

Sydor, A. (2013). Conducting research into hidden or hard-to-reach populations. *Nurse Researcher*, *20*(3), 33–37. https://doi.org/10.7748/nr2013.01.20.3.33.c9495

Symeonidou, S., & Beauchamp-Pryor, K. (2013). Introduction. In S. Symeonidou & K. Beauchamp-Pryor (Eds.), *Purpose, process and future directions of disability research* (pp. 1–6). Springer Science & Business Media.

Tajfel, H., & Turner, J. C. (2004). The social identity theory of intergroup behavior. In J. T. Jost & J. Sidanius (Eds.), *Political psychology* (pp. 276–293). Psychology Press. https://doi.org/10.4324/9780203505984-16

Taylor, J. L., Burke, M. M., Smith, L. E., & Hartley, S. L. (2016). Families of adolescents and adults with intellectual and developmental disabilities. *International Review of Research in Developmental Disabilities*, *50*, 195–231. https://doi.org/10.1016/bs.irrdd.2016.04.001

Taylor, J. L., & Hodapp, R. M. (2012). Doing nothing: Adults with disabilities with no daily activities and their siblings. *American Journal on Intellectual and Developmental Disabilities*, *117*(1), 67–79. https://doi.org/10.1352/1944-7558-117.1.67

Tebes, J.K. (2005). Community science, philosophy of science, and the practice of research. American Journal of Community Psychology, 35(3), 213 – 230. doi: 10.1007/s10464005-3399-x

Temple, B. (2002). Crossed wires: Interpreters, translators, and bilingual workers in cross-language research. *Qualitative Health Research*, *12*(6), 844–854. https://doi.org/10.1177/104973230201200610

Temple, B., & Edwards, R. (2002). Interpreters/translators and cross-language research: Reflexivity and border crossings. *International Journal of Qualitative Methods*, *1*(2), 1–12. https://doi.org/10.1177/160940690200100201

Temple, B., & Young, A. (2004). Qualitative research and translation dilemmas. *Qualitative Research*, *4*(2), 161–178. https://doi.org/10.1177/1468794104044430

Theron, L., Cameron, A. C., Didkowsky, N., Lau, C., Liebenberg, L., & Ungar, M. (2011). A “day in the lives” of four resilient youths: Cultural roots of resilience. *Youth & Society*, *43*(3), 799–818. https://doi.org/10.1177/0044118X11402853

Theron, L. C. (2016). Researching resilience: Lessons learned from working with rural, Sesotho-speaking South African young people. *Qualitative Research*, *16*(6), 720–737. https://doi.org/10.1177/1468794116652451

Theron, L. C., & Theron, A. (2013). Positive adjustment to poverty: How family communities encourage resilience in traditional African contexts. *Culture & Psychology*, *19*(3), 391–413. https://doi.org/10.1177/1354067X13489318

Thomas, C. (1999). *Female forms: Experiencing and understanding disability*. McGraw-Hill Education.

Thomas, C. (2002). The 'disabled' body. In M. Evans & E. Lee (Eds.), *Real bodies: A sociological introduction* (pp. 64–78). Palgrave.

Thomas, C. (2004). How is disability understood? An examination of sociological approaches. *Disability & Society, 19*(6), 569–583. https://doi.org/10.1080/0968759042000252506

Thomas, C. (2007) *Sociologies of illness and disability: Contested ideas in disability studies and medical sociology.* Palgrave MacMillan.

Thomas, C. (2010). Medical sociology and disability theory. In G. Scambler & S. Scambler (Eds.), *New directions in the sociology of chronic and disabling conditions* (pp. 37–56). Palgrave Macmillan. https://doi.org/10.1057/9780230297432_3

Tisdall, E. K. M. (2009). Equal opportunities for children? Anti-discrimination law in Great Britain. In A. Cleland & E. Sutherland (Eds.). *Children's rights in Scotland* (3rd ed., pp. 167–178). W. Greens.

Titchkosky, T. (2000). Disability studies: The old and the new. *The Canadian Journal of Sociology/Cahiers canadien de sociologie*, *25*(2), 197–224. https://doi.org/10.2307/3341823

Titchkosky, T., & Michalko, R. (2017). The body as a problem of individuality: A phenomenological disability studies approach. In J. Boys (Ed.), *Disability, space, architecture: A reader* (pp. 67-294). Routledge.

Tomeny, T. S., Baker, L. K., Barry, T. D., Eldred, S. W., & Rankin, J. A. (2016). Emotional and behavioral functioning of typically-developing sisters of children with autism spectrum disorder: The roles of ASD severity, parental stress, and marital status. *Research in Autism Spectrum Disorders*, *32*, 130–142. https://doi.org/10.1016/j.rasd.2016.09.008

Tomeny, T. S., Barry, T. D., & Bader, S. H. (2014). Birth order rank as a moderator of the relation between behavior problems among children with an autism spectrum disorder and their siblings. *Autism*, *18*(2), 199–202. https://doi.org/10.1177/1362361312458185

Tomeny, T. S., Barry, T. D., Fair, E. C., & Riley, R. (2017). Parentification of adult siblings of individuals with autism spectrum disorder. *Journal of Child and Family Studies*, *26*, 1056–1067. https://doi.org/10.1007/s10826-016-0627-y

Tozer, R., Atkin, K., & Wenham, A. (2013). Continuity, commitment and context: Adult siblings of people with autism plus learning disability. *Health & Social Care in the Community*, *21*(5), 480–488. https://doi.org/10.1111/hsc.12034

Tsai, H. W. J., Cebula, K., & Fletcher-Watson, S. (2016). Influences on the psychosocial adjustment of siblings of children with autism spectrum disorder in Taiwan and the United Kingdom. *Research in Autism Spectrum Disorders*, *32*, 115–129. https://doi.org/10.1016/j.rasd.2016.09.007

Tsai, H. W. J., Cebula, K., Liang, S. H., & Fletcher-Watson, S. (2018). Siblings' experiences of growing up with children with autism in Taiwan and the United Kingdom. *Research in Developmental Disabilities*, *83*, 206-216. https://doi.org/10.1016/j.ridd.2018.09.001

Tudor, M. E., & Lerner, M. D. (2015). Intervention and support for siblings of youth with developmental disabilities: A systematic review. *Clinical Child and Family Psychology Review*, *18*(1), 1–23. https://doi.org/10.1007/s10567-014-0175-1

Turner, B. S. (2001). Disability and the sociology of the body. In G. L. Albrecht, K. Seelman, & M. Bury (Eds.), *Handbook of disability studies* (pp. 252–266). Sage Publications.

UNICEF. (2023) *Children with Disabilities.* Retrieved 6 February, 2024, from https://data.unicef.org/topic/child-disability/overview/

United Nations (UN). (2008) *Convention on the Rights of Persons with Disabilities.* United Nations. https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

van der Merwe, C., Borman, J., Donohue, D., & Harty, M. (2017). The attitudes of typically developing adolescents towards their sibling with austism spectrum disorder. *South African Journal of Communication Disorders*, *64*(1), e1–e7. https://doi.org/10.4102/sajcd.v64i1.184

Vazquez-Garcia, H. A., Garcia Coll, C., Erkut, S., Alarcon, O., & Tropp, L. (1995). *An instrument for the assessment of family values and functioning of Latino parents.* Poster presented at the biennial meeting of the Society for Research in Child Development, Indianapolis, IN.

Vehmas, S., & Watson, N. (2014). Moral wrongs, disadvantages, and disability: A critique of critical disability studies. *Disability & Society*, *29*(4), 638–650. https://doi.org/10.1080/09687599.2013.831751

Verté, S., Roeyers, H., & Buysse, A. (2003). Behavioural problems, social competence and self-concept in siblings of children with autism: *Autism and Siblings*. *Child: care, health and development*, *29*(3), 193–205. https://doi.org/10.1046/j.1365-2214.2003.00331.x

Visagie, S. (2015). *Disability and health care access in an isolated quarter of the Karoo* [Doctoral dissertation]. Stellenbosch University, Stellenbosch.

Viswanathan, P., Kishore, M. T., & Seshadri, S. P. (2022). Lived experiences of siblings of individuals with autism spectrum disorder in India: An interpretative phenomenological analysis. *Indian Journal of Psychological Medicine*, *44*(1), 45–52. https://doi.org/10.1177/02537176211029111

Vladeck, B. C. (2007). How useful is ‘vulnerable’ as a concept? *Health Affairs*, *26*(5), 1231–1234. https://doi.org/10.1377/hlthaff.26.5.1231

Vorster, G. (2016). *These are the 20 most expensive schools in South Africa*. Businesstech. https://businesstech.co.za/news/trending/108409/top-20-most-expensive-schools-in-south-africa/

Wahoush, E. O. (2009). Reaching a hard-to-reach population such as asylum seekers and resettled refugees in Canada. *Bulletin of the World Health Organization*, *87*(8), 568–568. https://doi.org/10.2471/BLT.08.061085

Wallin, A.-M., & Ahlstrom, G. (2006). Cross-cultural interview studies using interpreters: Systematic literature review. *Journal of Advanced Nursing*, *55*(6), 723–735. https://doi.org/10.1111/j.1365-2648.2006.03963.x

Walton, K. M., & Ingersoll, B. R. (2015). Psychosocial adjustment and sibling relationships in siblings of children with autism spectrum disorder: Risk and protective factors. *Journal of Autism and Developmental Disorders*, *45*(9), 2764–2778. https://doi.org/10.1007/s10803-015-2440-7

Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior*, *24*(3), 369–387. https://doi.org/10.1177/109019819702400309

Wang, C. C. (2006). Youth participation in photovoice as a strategy for community change. *Journal of Community Practice*, *14*(1–2), 147–161. https://doi.org/10.1300/J125v14n01_09

Watermeyer, B. (2006). Disability and psychoanalysis. In B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider, & M. Priestley (Eds.), *Disability and social change: A South African agenda.* HSRC.

Watermeyer, B. (2012). Is it possible to create a politically engaged, contextual psychology of disability? *Disability & Society*, *27*(2), 161–174. https://doi.org/10.1080/09687599.2011.644928

Watermeyer, B., & Swartz, L. (2008). Conceptualising the psycho-emotional aspects of disability and impairment: The distortion of personal and psychic boundaries. *Disability & Society*, *23*(6), 599–610. https://doi.org/10.1080/09687590802328477

Watermeyer, B. P. (2009). *Conceptualising psycho-emotional aspects of disablist discrimination and impairment: Towards a psychoanalytically informed disability studies* [Doctoral dissertation]. University of Stellenbosch, Stellenbosch.

Watson, L., Hanna, P., & Jones, C. J. (2021). A systematic review of the experience of being a sibling of a child with an autism spectrum disorder. *Clinical Child Psychology and Psychiatry*, *26*(3), 734–749. 10.1177/13591045211007921

Watson, N. (2012). Theorising the lives of disabled children: How can disability theory help? *Children & Society*, *26*(3), 192–202. https://doi.org/10.1111/j.1099-0860.2012.00432.x

Watson, N. (2019). Agency, structure and emancipatory research: Researching disablement and impairment. In N. Watson, A. Roulstone, & C. Thomas (Eds.), *Routledge handbook of disability studies* (2nd ed., pp. 127–141). Routledge.

Webb, L. (2012). Multilingual teachers' voices: Perceptions about the impact of language. *Education as Change*, *16*(2), 231–240. https://doi.org/10.1080/16823206.2012.745752

Williamson, D. L., Choi, J., Charchuk, M., Rempel, G. R., Pitre, N., Breitkreuz, R., & Kushner, K. E. (2011). Interpreter-facilitated cross-language interviews: A research note. *Qualitative Research*, *11*(4), 381–394. https://doi.org/10.1177/1468794111404319

Williamson, I. (2019). *'I am everything but myself'*: Exploring visual voice accounts of single mothers caring for a daughter with Rett syndrome. *Qualitative Research in Psychology*, *16*(4), 566–590. https://doi.org/10.1080/14780887.2018.1431751

Willig, C. (2001). *Qualitative research in psychology: A practical guide to theory and method.* Oxford University Press.

Willig, C. (2013). *Introducing qualitative research in psychology* (3rd ed.). Open University Press.

Woodrow, E. (2007). *The experience of the loss of a sibling: A phenomenological study* [Doctoral dissertation, University of Pretoria].

https://repository.up.ac.za/bitstream/handle/2263/24135/Complete.pdf?sequence=11&isAllowed=y

Yamauchi, F. (2011). School quality, clustering and government subsidy in post-apartheid South Africa. *Economics of Education Review*, *30*(1), 146–156. https://doi.org/10.1016/j.econedurev.2010.08.002

Yeo, R., & Moore, K. (2003). Including disabled people in poverty reduction work: "Nothing about us, without us." *World Development*, *31*(3), 571–590. https://doi.org/10.1016/S0305-750X(02)00218-8

Zaks, Z. (2023). Changing the medical model of disability to the normalization model of disability: Clarifying the past to create a new future direction. *Disability & Society.* Advance online publication.

Zola, I. K. (1991). Bringing our bodies and ourselves back in: Reflections on a past, present, and future "medical sociology". *Journal of Health and Social Behavior*, *32*(1), 1–16. https://doi.org/10.2307/2136796

Zukow, P. G. (1989). Siblings as effective socializing agents: Evidence from Central Mexico. In P. G. Zukow (Ed.), *Sibling interaction across cultures* (pp. 79–105). Springer.

APPENDICES

Appendix A: Demographic Questionnaire

Demographic Questionnaire (English)

RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

PSYCHOLOGY DEPARTMENT • Tel: (046) 603 8500 / 85001 • Fax: (046) 622 4032 • e-mail: psychology@ru.ac.za

Person interviewed in order to complete this questionnaire	1= mother 2=caregiver
If caregiver (other than mother), what is relationship to child?	1=Father 2=Grandmother 3=Grandfather 4=Sibling 5=Relative 6=Neighbour 7=Friend 8=Other ___________________
Responsible for how much of child's care?	1=All the time (day and night) 2=Day only 3=Night only 4= After school care 5=other___________________
Home language	1=English 2=Xhosa 3= Zulu 4=Afrikaans 5=Other___________________
Current marital status	1= Married 2= Living together 3=Divorced 4= Separated 5=Widowed 6= Never married
Do you work?	1=yes, full time

	2= yes, part time 3= no, seeking work 4=no, not seeking work
Where does your main source of income come from?	1=Regular income from working 2= Occasional income from working 3=Pension 4=Child support grant 5=Disability grant (for self) 6= Disability grant (for child) 7= Foster care grant 8= Maintenance grant 9=Income from husband 10= Income from other family members 11= Other _______________ 12. No income
Approximate monthly income?	
Number of occupants in the house?	Children:_____ Adults: _____
Total income of household per average month?	1=R500- R1000 2= R1000-R3000 3=R3000-R5000 4=Unknown
From where does the household earn income? (more than one option may be circled)	1= Regular income from working 2= Seasonal income from working 3= Occasional income from working 4= Pension 5= Child support grant 6= Disability grant (adult) 7= Care dependency grant (child) 8= Foster care grant 9= Maintenance grant 10= Other _______________ 11= No income at all 12=Unknown
Construction material of main house walls?	1= brick, cement blocks 2= wood 3= informal/shack 4= mud 5= other________________
Construction materials of main houses roof?	1= Tiles, cement, bricks 2= Corrugated iron, wood, asbestos 3=Thatch 4=Informal/shack
Main water supply?	1= Tap in house 2= Tap in yard 3= Tap in street 4= Water truck 5= cement well 6= Traditional well 7= Open, unprotected (pond, river, dam) 8= Rainwater tank

Demographic Questionnaire (Xhosa)

RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

PSYCHOLOGY DEPARTMENT Tel: (046) 603 8500 / 85001 Fax: (046) 622 4032 e-mail: psychology@ru.ac.za

Lomntu ozophendula lemibuzo ilandelayo.	1= unguMama 2=Ungumntu okhathelela umntwana
Ukuba umntu okhathalela umntwana ayingomama womntwana, bobuphi ubudlelwana bakho nalomntwana?	1=unguTata 2=unguMakhulu 3=unguTamkhulu 4=unguMnakwe/dadewabo 5=uSizizalwana sakhe 6=unguMelwana 7=uSisihlobo 8=Ukuba ikhona enye into oyiyo engabhalwanga apha ngentla, bhala kulomgca_________________
Umkhathalela ixesha elingakanani umntwana?	1=Amaxa onke (emini nasebusuku) 2=Emini qha 3=Ebusuku qha 4= Xa ephuma eskolweni 5=Ukuba likhona elinye ixesha omkhathalela ngalo elingabhalwanga apha ngentla, bhala kulomgca _________________
Uwimi lwasekhaya	1=IsiNgesi 2=isXhosa 3= isiZulu 4=iAfrikaans 5= Ukuba lukhona olunye ulwimi olithethayo elingabhalwanga apha ngentla, bhala kulomgca __________________
Ingaba	1= Utshatile 2= Uyahlalisana

	3=Wohlukana ngokomthetho (divorce) 4= Wohlukene 5=Ungumhlokazi 6= Zange watshata
Uyaphangela?	1=ewe, full time 2= ewe, part time 3= hayi, ndisakhangela umsebenzi 4=hayi, andikhangeli msebenzi
Ingaba imali uyifumana njani?	1=Yilendiyifumana emsebenzini 2= Yilendimana ndiyifumana xandithe ndabhaqa umsebenzi 3=Kwindodla (grant) 4=Kwindodla (grant) yabantwana 5=Indodla yam yabantu abakhubazekileyo 6= Indodla yabantwana abkhubazekileyo yomntwana wam 7= Indodla yabantwana abangenabazali 8= Indodla yabantwana ebhatalwa ngotata babo (support grant) 9=Imali efunyanwa ngumyeni emsebenzini 10= Imali esuka kwabanye abantu balapha ekhaya 11= Ukuba ikhona enye indlela oyifumana ngayo imali engabhalwanga apha ngentla, bhala kulomgca _______________ 12=Akukhomali ingenayo
Xa uqikelela yimalini imali enganayo ngenyanga?	
Bangaphi abantu abahlala apha endlini?	Abantwana: _____ Abantu abadala: _____
Yimalini imali enganayo ngenyanga?	1=R500- R1000 2= R1000-R3000 3=R3000-R5000 4=Andiyazi
Ingaba imali engenayo apho endlini iza ngoluphi uhlobo? (wamkelekile ukuba ungazikhetha zonke indlela imali enganazo)	1= Yilendiyifumana emsebenzini 2= Yilendimana ndiyifumana xandithe ndabhaqa umsebenzi 3= Occasional income from working 4= Kwindodla (grant)

	5= Kwindodla (grant) yabantwana 6= Indodla yam yabantu abakhubazekileyo 7= Indodla yokukhathalela umntwana 8= Indodla yabantwana abangenabazali (ifoster care) 9= Indodla yabantwana ebhatalwa ngotata babo (isupport grant) 10= Ukuba ikhona enye indlela oyifumana ngayo imali engabhalwanga apha ngentla, bhala kulomgca ________________ 11= Akukhomali ingenayo 12=Andiyazi

Appendix B: Letter to Association for Persons with Physical Disabilities

RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

PSYCHOLOGY DEPARTMENT • Tel: (046) 603 8500 / 85001 • Fax: (046) 622 4032 • e-mail: psychology@ru.ac.za

Chairperson
APD

To the Chairperson,

I am currently doing a doctoral degree in psychology at Rhodes University under the supervision of Prof. Lisa Saville Young (046 603 8047, l.young@ru.ac.za). The focus of my research is on developing an understanding of how young people who have siblings with a disability experience their lives. This research has received ethics approval from the Department of Psychology at Rhodes and the Rhodes University Ethical Standards Committee. (Letters with ethics approval are attached). As I have a sister with a disability, who has worked for the APD in Port Elizabeth for 10 years, this matter is very close to my heart. One of my goals would be to inform the public, including APD and the families they are affiliated with, about what it is like for siblings of children with disabilities so that appropriate support could be offered where possible.

I am therefore writing to request your assistance with my research project.
Briefly, it would entail:

Firstly, someone from the APD making contact with families affiliated with the APD, (who have a disabled child and a non-disabled child between the age of 12 and 18 years of age and who can be considered to come from a disadvantaged socio-economic context) and providing them with the attached information letter telling them about the research and giving them an opportunity to indicate their willingness to participate. The tear-off slip would need to be returned to me.

Once they have agreed to me making contact with them, I will disseminate a more detailed information letter and consent forms (for parents) and assent forms (for young participants). These forms will request permission for me to interview one (or more) of their children who have a brother/sister with a disability. The participants will also be provided with disposable cameras and be requested to photograph their lives. The identities of all the participants and those in the photographs will be kept

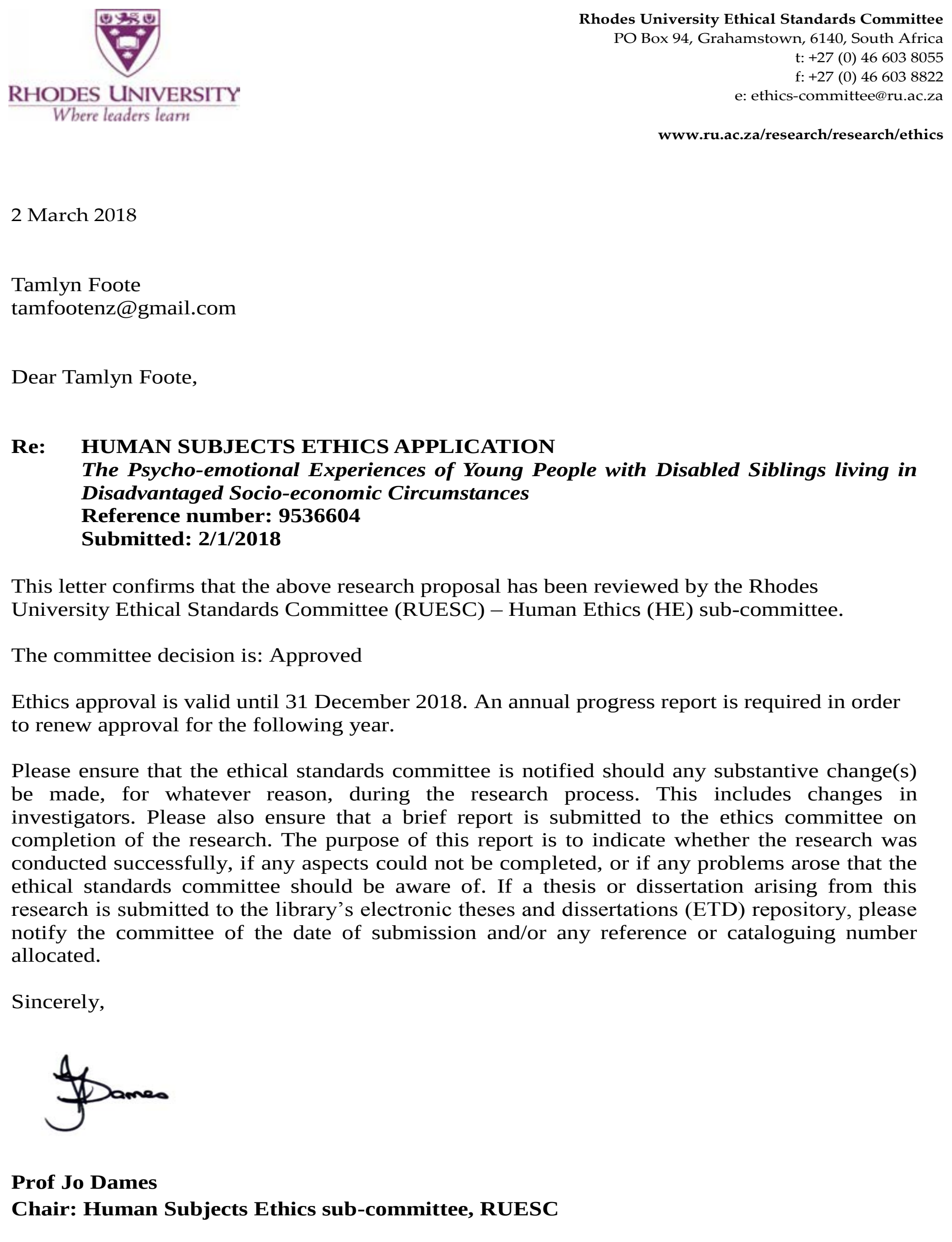
confidential (should it be desired) and both the parents and the participants will sign a consent form. (Please see both letters attached.)
It will also be made clear to the participants and their parent/guardian that their participation in this project will not impact on the services they receive from the APD.

Secondly, I would like to request the use of a room at the APD in which to conduct the interviews, as it is an environment the parents will be familiar with and will pose few interruptions during the interviews.

I am hoping that the information I get from the interviews will help me in contributing to the very small body of knowledge pertaining to young people who have a sibling with a disability in the future as these children are often somewhat excluded or carry a great deal of responsibility in the caretaking of their siblings with a disability. I would greatly appreciate your assistance.

Thank you kindly for your time and consideration. I look forward to hearing from you regarding my requests.
Tammy Foote
(Primary researcher)
072 460 3480
tamfootenz@gmail.com

Appendix C: Ethics Approval



RHODES UNIVERSITY
Where leaders learn

Rhodes University Ethical Standards Committee
PO Box 94, Grahamstown, 6140, South Africa
t: +27 (0) 46 603 8055
f: +27 (0) 46 603 8822
e: ethics-committee@ru.ac.za

www.ru.ac.za/research/research/ethics

2 March 2018

Tamlyn Foote
tamfootenz@gmail.com

Dear Tamlyn Foote,

Re: HUMAN SUBJECTS ETHICS APPLICATION
The Psycho-emotional Experiences of Young People with Disabled Siblings living in Disadvantaged Socio-economic Circumstances
Reference number: 9536604
Submitted: 2/1/2018

This letter confirms that the above research proposal has been reviewed by the Rhodes University Ethical Standards Committee (RUESC) – Human Ethics (HE) sub-committee.

The committee decision is: Approved

Ethics approval is valid until 31 December 2018. An annual progress report is required in order to renew approval for the following year.

Please ensure that the ethical standards committee is notified should any substantive change(s) be made, for whatever reason, during the research process. This includes changes in investigators. Please also ensure that a brief report is submitted to the ethics committee on completion of the research. The purpose of this report is to indicate whether the research was conducted successfully, if any aspects could not be completed, or if any problems arose that the ethical standards committee should be aware of. If a thesis or dissertation arising from this research is submitted to the library's electronic theses and dissertations (ETD) repository, please notify the committee of the date of submission and/or any reference or cataloguing number allocated.

Sincerely,

Prof Jo Dames
Chair: Human Subjects Ethics sub-committee, RUESC

Appendix D: Parent Consent Form

Parent Consent Form (English)

RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

PSYCHOLOGY DEPARTMENT • Tel: (046) 603 8500 / 85001 • Fax: (046) 622 4032 • e-mail: psychology@ru.ac.za

Dear (Insert Parent Name)

I am doing research at Rhodes University. I am going to be studying 'what it is like for young people who have a brother or a sister with a disability'. My hope is to try and help the APD (and other organizations like them) and the families they work with to offer emotional support to these youth. This research has received ethics approval from the Rhodes Psychology Ethics Review Committee and the Rhodes University Ethical Standards Committee.

You have been given this letter because you have a child between the ages of 12 and 18 years old, and you also have a child with a disability. I would like you to consider allowing your child, should they so wish, to participate in my research which will involve being interviewed about their experiences of being a sibling of a disabled person.

The process will mean that I will meet with you and your child to tell you more about the research. Once you have consented and signed some forms and your child has agreed to participate, I will do 2 separate interviews with your child. I will be asking your child about their experiences of having a disabled brother or sister. I will also give them a disposable camera to take pictures of their lives. We will talk about your child's photographs in the second interview. The interviews will take place at the APD offices and your child's transport costs will be paid for and they will receive refreshments at the interview. They will also receive a copy of their photographs.

Whether or not you and your child agree to participate in this research the services you receive from APD will not be affected. If you and your child are interested in participating in this research, please fill in the slip below and give it to the APD so that I can make contact directly with you.

Many Thanks
Tammy Foote
(Intern Psychologist, Fort England Hospital)
072 4603480
tamfootenz@gmail.com

Dear Tammy

My child is interested in participating in your research and I am interested in finding out more about the study before giving my consent. Please contact me so that we can arrange to meet so that I can receive more information about the research.

My name is: ______________________________________

My telephone number is: ______________________________

My address is: ____

My non-disabled child's name is: ________________________

He/she is ___________________ years old

Parent Consent Form (Xhosa)

RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

PSYCHOLOGY DEPARTMENT Tel: (046) 603 8500 / 85001 Fax: (046) 622 4032 e-mail: psychology@ru.ac.za

Mzali othandekayo

Igama lam nguTammy Foote ndenza uphando lwezifundo eRhodes University. Ndizobendiphanda 'ukuba kunjani ukubano dade okanye umnakwe womntu okhubazekileyo ophila kwisimo sokuhlupheka'. Ithemba lam kukuzazama ukunceda iAPD (namanye amaziko afana neAPD) kunye namanye amasapho (iifamily) iAPD (namanye amaziko) esebenzisana nazo ukunika olulutsha inkxaso. Oluphando luyifumene imvume yokuqhubekeka eRhodes University kwiSebe lakwa-Psychology Ethics Review Committee kwakunye neSebe laseRhodes University Ethical Standards Committee.

Leleta uyinikwe kuba ungumzali womntwana oneminyaka ephakathi kweshumi elinambhini (12) kunye neshumi elinesbhozo (18) kwaye unomntwana okhubazekileyo. Ndingathanda ukuba ungavuma ukuba umntwana wakho abeyinxaxheba yoluphando, ukuba yena umntwana uyafuna ukuthatha inxaxheba. Kuzobakhona i-interview malunga nendlela umntwana aziva ngayo ngokubano dade okanye umnakwe okhubazekileyo. Lonto iyakuthetha ukuba ndizodibana nawe mzali kunye nomntwana wakho apho ndizokuthi ndinixelele kalubanzi ngoluphando ndilwenzayo. Ndizokuthi ndikucele ukuba uphendule imibuzo embalwa esephepheni aphondizobona khona ukuba umntwana wakho angalilo na ilungu loluphando. Kuyakuthi ke, xa sele usityikitye phantsi isivumo sakho kwaye nomntwana wakho evumile ukuthatha inxaxheba koluphando, ndizokwenza i-interview kunye nawe mzali wedwa kunye nomntwana eyedwa. Kule-interview ndizobe ndimbuza umntwana ngendlela aziva ngayo ngoba nodade okanye umnakwe okhubazekileyo. Abantwana bazofumana ne-camera apho bazothi bafote izinto ezenzekayo ebomi babo. Kwi-interview yesibini ndizothetha nomntwana ngeefoto ebezithatha. Ezi-interview zizoqhutyelwa ezi-ofisini zaseAPD, imali yokukhwela iitaxi nizokuyinikwa (eyokuza neyokubuya) kwaye nawuthi nifumame nezimuncumuncu ngelixesha nawukube nize kwi-interview. Abantwana bazothi bafumane neekopi zefoto zabo.

Igama lomntwana wakho lizokhuselwa ngokuthi kusetyenziswe elinye igama endaweni kokuba kusetyenziswe igama lakhe. Kwaye nasezifotweni kuzoqinisekiswa ukuba ubuso bomntwana wakho abucaci. Elokugqibela, xa oluphando lugqityiwe ndizodibana nawe nomntwana wakho kunye neziko iAPD apho ndizothi ndinixelele ngeziphumo zoluphando.

Ukuba wena nomntwana wakho nivumile okanye anivumanga ukuthatha inxaxheba koluphando lonto ayuzukwenza ukuba ningalufumani uncedo enilifumana kwiziko iAPD. Ukuba wena mzali nomntwana wakho niyafuna ukuthatha inxaxheba koluphando ncedani niphendule lemibuzo ikweliphepha lilandelayo. Nawukuthi xanigqibile nilithathe eliphepha nilifake kwiziko iAPD ukwenzela ndizonxumelelana nawe.

Ngomkhulu umbulelo,
Tammy Foote
072 4603480
tamfootenz@gmail.com

Tammy othandekayo

Umntwana wam angathanda ukuthatha inxaxheba koluphando, nam ndingathanda ufumanisa ngoluphando phambi kokuba ndikunike isivumo zam. Ndicela uze unxebelelane nam kwenzela sizovumelana ngexesha esiyakuthi sidibane ngalo, apho ndawukuthi ndifumanise ngolubanzi ngoluphando.

Igama lam ngu: ______________________________________

iphone number yam: ______________________________

Ndihlala: ____

Igama lomntwana wam ongakhubazekanga ngu: ________________________

Uneminyaka eyi_____________

Appendix E: Parent Information Letter

RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

PSYCHOLOGY DEPARTMENT Tel: (046) 603 8500 / 85001 Fax: (046) 622 4032 e-mail: psychology@ru.ac.za

Dear (Insert parent name)

Thank you for saying I can contact you on the tear-off slip.

I am currently doing research for my PhD in Psychology and am being supervised by Lisa Saville Young (046 603 8047, l.young@ru.ac.za). My research has received ethical clearance from the Rhodes Psychology Ethical Review Committee and the Rhodes University Ethical Standards Committee. I am going to be studying 'what it is like for youth who have a brother or a sister with a disability' who live disadvantaged socio-economic circumstances. My hope is to try and help the APD (and other organizations like them) and the families they work with to offer emotional support to these youth.

I would very much like INSERT NAME to be a part of this study. If you agree to let your child participate, I will need you to fill out a quick questionnaire (in your language) to make sure that your child meets the criteria to be included in the study. I will then interview him/her twice. He/she will also be given a disposable camera, and will be asked to take pictures of objects/people relevant to his/her lives.
Once he/she has taken the photographs, I will collect the cameras and they will be printed. We will then discuss his/her pictures. A field worker from the APD, who is isiXhosa speaking will be helping me during the interviews if your child is more comfortable speaking in isiXhosa. If your child would prefer to have the interview in English or Afrikaans then this will be accommodated, as I am fluent in both languages.
Our discussions during the interviews will be recorded, translated into English and typed up. Once I have finished my research the recordings will be deleted. The discussions and photographs will be included in my research, so your child's real name will not be used and the identity of the people in the pictures will be blurred.
I would like to do 2 interviews with your child (at a time that suits him/her), at the APD facility in Grahamstown or PE. I will reimburse your child for transport to and from the interviews.

I will give your child lunch and a juice and try to make them feel comfortable. At the end of the project, your child will get a copy of his/her photographs.
It might be that your child talks about difficult things during the interview, but we will try to make sure they do not feel unhappy and everything they say will be the children afterwards, I can facilitate referral for counseling services at Rhodes Psychology Clinic, Fort England Hospital or NMMU Psychology Clinic. Once the research has been completed and thesis has been written, a feedback session on the findings will be provided to the APD, to which you and your child will be invited, should you wish to attend.

It is also important to note that the services you and your family receive from the APD will not be affected by your child's participation or non-participation in this study.
I have attached a consent form for you to tick and sign if you are happy to let your child partake in this study.

Many Thanks
Tammy Foote
Intern Psychologist
072 4603480
tamfootenz@gmail.com

Appendix F: Parent Questionnaire

RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

PSYCHOLOGY DEPARTMENT • Tel: (046) 603 8500 / 85001 • Fax: (046) 622 4032 • e-mail: psychology@ru.ac.za

I have a child with a disability.	YES	NO
Please say (if possible) what kind of disability.		
I have other children between the ages 0f 13 years and 18 years of age who may wish to participate in this research.	YES	NO
I understand that my child's participation is voluntary and that they can withdraw at any time.	YES	NO
I understand my child's identity will be kept confidential in the write up of the research (if he/she wishes).	YES	NO
I agree to let my child participate in this study if he/she wants to.	YES	NO
All details about the study described in the information letter have been explained to me and I understand what it says.	YES	NO
I have been given an opportunity to ask any questions that I have about the study.	YES	NO
My child's name is................................		
My child's age is....		

Signature:
Full Name:

Date:
Relationship to child participating in the research:

Appendix G: Participant Information and Assent Form

Participant Information and Assent Form (English)

RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

PSYCHOLOGY DEPARTMENT Tel: (046) 603 8500 / 85001 Fax: (046) 622 4032 e-mail: psychology@ru.ac.za

Dear………….

Your mom/dad/granny has said that I can introduce myself to you. I am Tammy and I am busy studying a PhD at Rhodes University. Part of my studies involves trying to understand what it is like for a young person like you to have a brother or sister with a disability. I am interested in this because I too, have a disabled sister!

As I don't speak isiXhosa, someone from the APD has agreed to help me with my work should you prefer to speak isiXhosa. If you would prefer to speak in English or Afrikaans, that is fine as I am able to speak both languages. I am hoping that you will join me for two interviews. In the first interview, I will ask you some questions about yourself and what it is like to have a disabled brother or sister. You will also be given a disposable camera. I'll then ask you take pictures of your life and things that are meaningful to you, as a sibling of a disabled child/person. I'll then collect the cameras and print the photographs. We will then meet again and talk about the photographs.

Our talk will be recorded and the information will be included in my research. To protect your identity, I won't use your real name. Also yours and all the people in your photographs faces will be blurred in the project. I will give you cards to give the people you take pictures of where they say they are happy to be in the pictures or not. Some of the pictures you take may be included in my final research but you can tell me at any time if you don't want me to include them.

If you decide that you are happy to join in, then we can choose a time that suits you. We will meet at the APD twice only. You will also be given lunch and a drink at each meeting, and I will reimburse your transport money. I will also give you copies of your photos at the end of our meetings. If you decide at any time to change your mind about talking to me that will be okay. You don't have to do anything you don't want to.

I understand that some of the things you talk about might be difficult. If it does happen that you feel sad or uncomfortable about anything spoken about during the interview, you are welcome to contact me and I will assist you in contacting either Rhodes Psychology Clinic, Fort England Hospital or the NMMU Psychology Clinic for counselling.

Once the research has been completed and thesis has been written, a feedback session on the findings will be provided to the APD, to which you and your parents will also be invited, should you wish to attend.

Please tick the boxes below that apply to you:

YES, all details of this study have been explained to me and I understand them ☐

YES, I have had the chance to ask any questions that I have about the study ☐

YES, I would like to take part in this research, take pictures of my life, and talk about them with you. ☐

YES, I am happy for our discussion and pictures to be included in the research. ☐

In the interview, I would rather talk in: English ☐ isiXhosa ☐ Afrikaans ☐

YES, If I am in the pictures I take, I would like my face blurred in the photographs I am in. ☐

NO, If I am in the pictures I take, I would NOT like my face blurred in the photographs I am in. ☐

NO, I would not like to be a part of this study ☐

Signature:

___________________________________ ________________________
(Print Name) Age

____
Tamlyn Foote
(Primary Researcher)
072 4603480

Participant Information and Assent Form (Xhosa)

RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

PSYCHOLOGY DEPARTMENT Tel: (046) 603 8500 / 85001 Fax: (046) 622 4032 e-mail: psychology@ru.ac.za

………………………. othandekayo

Umama/utata/umakhulu wakho undinikile imvume yokuba ndikwazise ukuba ndingubani. Igama lam nguTammy, ndingumfundi waseRhodes University, ndenza izifundo zobugqirha kwisebe lwakaPsychology. Enye yezinto ekufuneka ndiyenzile kwezizifundo zam kukufumanisa ukuba umntwana ofana nawe ozalwa nodade okanye umnakwe okhubazekileyo uziva njani. Unobangela wokuba ndibenomdla ngokufumanisa uba uziva njani yinto yokuba nam ndinodade okhubazekileyo!

Mna andikwazi ukuthetha isiXhosa, ngoko ke kuzokubakhona umntu ophangela eAPD okwaziyo ukuthetha isiXhosa ozakuthi anditolikele. Ukuba ufuna ukuthetha isiNgesi okanye iAfrikaans akuzubakho ngxaki kuba ndiyakwazi ukuzithetha zombini. Ndiyathemba ukuba uzokuza kwi-iinterview ezimbini. Kweyokuqala ndizokubuza imibuzo ngokuba uzivanjani ngokuba nodade okanye umnakwe okhubazekileyo. Ndizothi ndikunike icamera ozokuyisebenzisa xa uthatha iifoto zezinto ezenzeka ebomini bakho okanye abantu ababalulekileyo ebomini bakho. Ndizophinda ndiyithathe icamera leyo ndikhuphe iifoto zakho. Emvenkokuba ndizikhuphile iifoto sokuphinda sidibane kwi-interview yesibini apho sizoncokola ngezifoto uzithathileyo. Incoko yethu izogcinwa kwi-tape recorder kwenzela ndizokwazi ukuyisebenzisa koluphando ndilwenzayo. Ukukukhusela ukwenzele ukuba abantu abafunda izibhalo zoluphando ndilwenzayo bangakwazi, andizukusebenzisa igama lakho lamanyani, kwaye iifoto zona azizukubonakalisa ubuso babantu abasezifotweni ngokucacileyo. Ndizokunika amakhadi abhalwe isivumelwano sokusetyenziswa kweefoto zakho, lamakhadi uzowanika bonke abantu obafotileyo kwenzele batsho ukuba bayafuna okanye abafuni ukuba ndizisebenzise iifoto zabo. Ezinye zeefoto ozithathileyo ndizokuzisebenzisa kwizibhalo zoluphando ndilwenzayo, uzuyiqonde ukuba uvumelekile naninina ukuba undixelele ukuba awufuni ndizisebenzise.

Ukuba ke uyavuma ukuthatha inxaxheba koluphando, ndizodinga ukuba ukhethe ixesha esinokwazi ukudibana ngalo. Sizodibana amatyeli abemabini qha, phaya ezi-ofisini zaseAPD. Uzokufumana isidlo kunye nento yokusela xawuze kwi-interview, kwaye uzoyifumana nemali yokukhwela itaxi (eyokuza kwi-interview neyokugoduka). Ndizokunika nee-copy zefoto zakho xasele ndigqibile ngoluphando. Unelungelo lokuyeka ukuthetha nam xa ufuna, awunyanzelekanga ukuba wenze nantonina ongafuniyo ukuyenza.

Ndiyayiqonda ukuba ezinye izinto esizothetha ngazo zingabuhlungu, ukuba kuyekwenzeka uzive ukhathazekile ngezinto esithethe ngazo kwi-interview uze uncede undixelele kwenzela ndizokufunela uncedo eRhodes Psychology Clinic okanye eFort England Hospital okanye eNMMU Psychology Clinic apho uzothi ufumane uncedo khona.

Xa oluphando lugqityiwe ndizodibana nawe nomzali wakho kunye neziko iAPD apho ndizothi ndinixelele ngeziphumo zoluphando.

Uze uncede kwibhokisi ovumelana nayo ufake umkorekitsho (tick):

EWE, zonke iinkcukaca zoluphando ndizicaciselwe kwaye ndiyaziqonda ☐

EWE, ndilifumene ithuba lokubuza imibuzo ebendinayo ngoluphando ☐

EWE, ndingathanda ukuthatha inxaxheba koluphando, ndithathe iifoto zobomi bam, ndithethe nawe ngazo ☐

EWE, ndingavuya ukuba incoko yam nawe kunye neefoto zam zingasetyenziswa koluphando. ☐

Ndingathanda ukuthetha: **iEnglish** ☐ **isiXhosa** ☐ **iAfrikaans** ☐

EWE, ukuba ndikhona kwezifoto ndizithathileyo ndingathanda ukuba ubuso bam bungabonakaliswa ngokucacileyo. ☐

HAYI, ukuba ndikhona kwezifoto ndizithathileyo ndingathanda ukuba ubuso bam buvezwe ngokucacileyo ☐

HAYI, andifuni ukuthatha inxaxheba koluphando ☐

Tyikitya (Signature):

______________________________ _____________________
(Igama lakho) Iminyaka yakho

____
Tamlyn Foote
(Umphandi ophambili)
072 4603480

Appendix H: Interview Schedule

Interview 1

A. *Rapport building and Self Concept*

1) Could you tell me about your self?

Prompt: what sorts of things do you like to do?/ Are you good at doing some things?/ What are they?/ Are you a happy, sad, quiet, loud, friendly, shy person?

2) How do you think other people would describe you?
3) Would you change anything about yourself, if so, what and why?
4) Do you think about the future much? *(prompts: what are your plans or goals?)*
5) If you could change anything about your life, what would you change?
6) Can you tell me (if you feel comfortable to) about some of the things you dream about?
7) Do you have any fears? What are they?

B. *Sibling*

1) Could you tell me about your siblings? *(prompts about birth order, gender)*
2) Who do you think you are closest to?
3) How do you feel about your disabled brother/sister?
4) How are you different from your brother/sister?
5) *If there were an awareness of the sibling's disability*- How would you describe your brother/sister's disability?
6) What are some of the things you remember about growing up with your disabled brother/sister?
7) How does having a brother/sister with a disability make you feel?
8) Are there times when it is difficult to have a disabled brother/sister? Can you tell me more about this?
9) What do you think other people feel about your brother/sister?
10) Do you have any friends with disabled siblings?
11) What do you think it would be like if your brother/sister was not disabled?

B. *Family and Daily Living (including financial and time constraints)*

1) Can you tell me about your average day?

Prompt: what do you do after you wake up?/ Who takes you to school?/ Who cooks the meals at home?/What do you do when school is finished?

2) Could you describe your home to me?
3) Which family member are you closest too?
4) How would you describe your relationship with your caregivers?
5) Can you think of any difficult parts or your day, week?
6) What are your favourite parts of the day, week?
7) Could you tell me what your (caretakers) do during the day while you are at school?

   Promt: Do they have to go to work?/ Do you know where they work?/ Do you know why they work?
8) What does your (sibling with a disability) do during the day?

   Promt: Does he/she go to school?/ Who looks after him/her?
9) Do you ever have to look after or help your brother/sister? How do you feel about this?
10) What do you think would make life for you easier?

<u>Interview 2</u>

1. Have you thought at all about our interview since we last me?
2. Could you share some of those thoughts with me?
3. What was it like for you being interviewed the last time we met?

Questions pertaining to photographs

1) Can you tell me what is happening in this picture?
2) What made you choose to take this picture?
3) Can you tell be what you feel or think when you look at this picture now?
4) Is there anything else that you think it is important that I know about your experience of being a sibling of a disabled person?

Appendix I: Table of Pumla’s Emergent Themes and Experiential Statements

Pumla’s Emergent Themes and Experiential Statements		
Emergent Themes	Page & Line	Experiential Statements
Experiences: Moments of shared togetherness/ reciprocity	P22:514-527	*P: (chuckles) [for instance she always asks me what I did at school and so I show her and she also shows me what they did at school too and sometimes she asks me to help her (0.5) so I help her (0.5) she likes asking for help with her Xhosa homework (0.5) and then she asks me if I don’t have homework and I tell her no I did get one this is what we did]*
Experiences: Joy in Asa’s happiness	P16:260-278	*T: ja sjoe! And how did Asa feel when you took that picture?* *P: she was smiling* *T: and how do you feel when you look at this picture?* *P: I feel happy* *T: what about this picture makes you feel happy when you look at it?* *P: (because Asa was also excited when I took it and she wanted to see it but I told her that she couldn’t see it then, she would see it some other time)* *T: what do you think she’s going to say?* *P: [chuckles] I think she’s going to be happy*
Experiences: Shared moments of fun with sister	P26:604621	*[she likes to (0.5) we like to laugh and joke around when we are together (...)*
Experiences: Feelings of care and	P39: 924-945	*[it is when Asa is sick (0.5) I get so nervous because there was a child who had the same condition that Asa has (0.5) that child got sick and ended up*

concern for sister due to disability		*dying (0.5) so whenever Asa is not well we think about that and worry that she might die (0.5) so that's how it is]*
Experiences: A sense of admiration for sister	P30:693-702	*P: (yes), Asa is a very friendly girl, she's not quiet, uhhhm shy… [Asa is a very talkative person (0.5) she talks to everyone and asks them their names and where they're from and so on]*
Experiences: Sense of hurt when she no longer feels needed	P43:736-756	*P: akasafuni (she doesn't want me to help anymore)* *(I don't know but she no longer tells me that she has homework when she gets home, she just puts her bag and changes her clothes)* *T: ok does this make you feel sad?* *P: (I think maybe I don't know what to say, (Asa is growing (adolescence) so I don't know, sometimes when she is talking to someone she'll be a bit cheeky and so I don't really want to interact much with her because I'll just beat her up if she decides to be cheeky with me)*
Experiences: Disability as informing closeness in their relationship	P35: 813-836	*T: mhh and do you think your relationship with her would be different if she wasn't disabled* *P: [maybe we wouldn't be friends maybe she would not pay as much attention to me because she would be playing with her friends]*
Experiences: Caring for Asa as a necessity	P35:827-867	*[I wake up and prepare water for bathing and bath (0.5) then I wake Asa up … she wakes up to bath (0.5) sometimes if my mom is there she wakes her up or I wake up and bathe her (0.5) sometimes I don't go to school because if my grandmother is going somewhere that day then there won't be anyone to look after Asa after the transport has dropped her off so] –*

		... because sometimes I have found her by herself at the gate before when there is no one in the house]
Experiences: A lack of support from others in caring for Asa	P2045 8-468	*T: ja (0.5) is it hard? for you sometimes to have to do all of those things*^{0} *P: it is hard (0.5) because (sometimes it does happen that I am all alone with my sister and she just lives her like that even if she needs a bath so I have to bath her (0.5) so it's mostly me and my grandmother who always take care of Asa)*
Experiences: Sacrifice to care for Asa	P30:70 7-714	*P: [it's the fact that she can't walk (0.5) it's a big problem (0.5) sometimes even if I wanted to go somewhere I end up cancelling (0.5) my grandmother also drinks so she won't have someone to look after her I have to be the one who remains to look after her (0.5) but I understand that]*
Experiences: Resentment towards Asa due to disability, and subsequent guilt	P32:73 9-757	*T: does it happen a lot?* *P: [every weekend]* *T: so do you feel like often you can't do the things you would want to do?* *P: [I can't]* *T: oh (0.5) and then how does that make you feel towards Asa* *P: (chuckles softly) [sometimes I do feel that way] [But I don't shout at her I just tell her that if she could walk but she also tells me that she never asked to be on a wheelchair either]* *[it hurts because sometimes I wish I hadn't said that to her because I never expected to have a sister like her] [I then apologise for saying it]*
Experiences: Disability as informing dissonance	P44:10 39-1049	*P: [if I had magic powers I would cause Asa to walk so that we are the same] [and the fact that the people in my family do not want to take care of Asa]*

between her and Asa		

Appendix J: Table of Personal Experiential Themes from Pumla's Analysis

Table of Personal Experiential themes from Pumla's Analysis		
Theme	Page/line	Quotes
Experience of care as an act of love and a requirement	P35:827-867	*(0.5) sometimes I don't go to school because if my grandmother is going somewhere that day then there won't be anyone to look after Asa after the transport has dropped her off so]*
	P30:707-714	*P: [it's the fact that she can't walk (0.5) it's a big problem (0.5) sometimes even if I wanted to go somewhere I end up cancelling (0.5) my grandmother also drinks so she won't have someone to look after her I have to be the one who remains to look after her (0.5) but I understand that]*
	P35: 813-836	*P: [maybe we wouldn't be friends maybe she would not pay as much attention to me because she would be playing with her friends]*
Experiences of socio-economic disadvantage contribute to day-to-day challenges of disability	P23:534-575	P: *[yes because she can't push herself in other places most of the time we have to push her even in the yard when she has to go to the toilet she struggles (0.5) so we have to assist her]*
	P27:622-644	*P: because I know they (other siblings) will be rude sometimes my 12 year old sister says 'I will never look after Asa because my mom doesn't even give me a cent from the money Asa is getting' something like that (0.5) as for my older sister I think she doesn't want to look after Asa because she no longer gets the grant and so my sister knows that she won't get anything in return so that's why]*

Experience of loneliness /isolation in the context of disability	P2, 25-32	*P: cause I was shocked like (1) ingathi ndim ndedwa [it seems like I am the only one]*
	P41:957-972	*P:[I get alone when I'm at home because it's either I'm with Asa or when she is playing with her friends I sometimes go next door to visit that other lady while Asa is playing with her friends (0.5)*

Appendix K: Pocket Photo Consent Card

Photo Consent Card (English)

Front View of card

I am taking part in a research project through Rhodes University.
I have to take photographs of my life in relation to my disabled sibling and I would like you to be in one of my pictures.
This card is to let you know that the photographs I take may be included in the final research which will be available to the public, but if you want your identity protected, it's ok! The main researcher will blur your face. Please can you fill in the back of the card if you consent to your photo being taken.
Thank you for taking the time to read this and enjoy your day!

Back View of card

My Name is: ____

My telephone number is: ____________________________________

I am happy to be in these photographs ☐

I am happy for people to see my face in the photographs ☐

I don't want people to see my face in the photograph ☐

Signed ______________________________________

Date____

Photo Consent Card (Xhosa)

Umphambili wekhadi

Ndithatha inxaxheba koluphando lwaseRhodes University.

Kufuneka ndithathe iifoto zobomi bam malunga nokuba nodade okanye umnakwe okhubazekileyo kwaye ndifuna wena ubekwenye yefoto zam.

Elikhadi lelokuxelela ukuba kungenzeka ukuba ezinye zezifoto ndizithathayo zifakwe kwizibhalo zoluphando ezizokukhutshwa zifundwe nguye nabanina ofuna ukuzifunda. Umphandi ophambili wezizibhalo uzoqinisekisa ukuba ubuso bakho abuveli ngokucacileyo ezifotweni, ukwenzela ukuba abantu bangakuboni. Ukuba uyavuma ukuba ifoto yakho ithathwe, ndicela ubhale isivumo sakho ngemva kwelikhadi.

Ndiyabulela ngokuba uthe wathatha ixesha lokufunda ezinkcukaca, uzulonwabele usuku lwakho!

Umva wekhadi

Igama lam ngu: ____

iPhone number yam: ___________________________________

Ndingathanda ukuthatha iifoto ☐

Tyikitya (Signed) ____________________________________

Umhla______________________________________