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"I WON'T SAY I FEEL HAPPY OR SAD": EXPERIENCES OF SIBLINGS OF YOUNG DISABLED PEOPLE IN DISADVANTAGED SOCIO-ECONOMIC CIRCUMSTANCES

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Abstract

The impact of having a disabled sibling has been well researched in first world countries, revealing complex and varied results. However, in disadvantaged socio-economic contexts, where disability has been found to be more prevalent, and where arguably, the functioning and quality of life of a disabled person is more likely to be affected by an impairment, very little is known about how siblings of young disabled people are affected. In response, this qualitative study explores the experiences of five, isiXhosa speaking adolescents, living in Joza Township, Grahamstown, who have a brother or sister with an intellectual, physical or developmental impairment. Semi-structured interviews were conducted and an interpretative phenomenological analytic approach was utilized to ascertain how the participants make sense of their worlds in relation to their sibling's disability. Specifically, this research aimed at developing an understanding of how the participants experienced their family climate, self-concept, interpersonal relations and daily living in relation to their disabled sibling.

The results of this study reveal a prevailing sense of incongruity experienced by the participants, although there are variances between their experiences. While family climate was largely experienced as warm, the participants were ambivalent about their relationship with their mothers who are experienced more as providers than nurturers. The participants described oscillating between feelings of protectiveness and alliance, and responsibility and sacrifice toward their sibling. A high incidence of incongruity pertaining to their sense of self was noted; this was described as impacting on their interpersonal relations where an underlying sense of negative public perception in relation to the disability is perceived. Although the participants expressed feeling supported within their homes, it was evident that they experienced little support from peers or the community at large.

Four out of the five participants did not report experiencing a sense of deprivation, despite their socio-economic contexts and described a day-to-day existence that allows for their needs to be met. This included adequate time during their day to pursue personal interests as opposed to their time being spent taking care of their disabled sibling or assisting their parents, who may be overburdened due to the added care and responsibilities a disabled child might require.

Furthermore, it is suggested that the incongruity experienced by the participants could be the result of various factors including age, gender, birth order and the nature of their sibling’s impairment.

On the basis of the findings of this research, it can be concluded that the experiences of siblings of young, disabled people living in disadvantaged socio-economic contexts cannot necessarily be described as being positive or negative, but are highly nuanced. In addition, the participants to some extent experience disability by association and are lacking in adequate support and opportunities to discuss their unique challenges. These insights serve to better inform disability studies in disadvantaged socio-economic circumstances.

These findings are in accordance with earlier research.

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Chapter One: Introduction

1.1 Overview

This research explores the experiences of siblings of young disabled people, living in disadvantaged socio-economic circumstances. Through this exploration, the study aims to understand how siblings make sense of their family climate, daily living, self-concept and interpersonal relations in the context of their siblings' disabilities.

1.2 The Motivation for this Research

When a child is affected by an impairment, there are repercussions for the whole family, including the siblings. The impact of having a disabled sibling, on young people, in the global north has been extensively documented (Bitsika, Sharpley & Mailli, 2015; Mandleco &Webb, 2015; Meaden, Stoner & Angell, 2009; Opperman & Alant, 2003; Petalas, et al., 2009). These studies have revealed varied findings noting that siblings of young disabled people have highly nuanced experiences within their daily lives. The variations in the research have been explained in terms of certain contributory factors, including the nature of the disability, the age and gender of the sibling and birth order of the children.

There is significantly less literature pertaining to siblings of young disabled people in poorer contexts, yet the prevalence of disabled persons has been reported to be twice as high in low socio-economic contexts as it is in middle to high-income contexts (Woolard, 2002). Subsequently, it follows that there are a significant number of siblings of young, disabled people in South Africa, living in poverty, whose lives will be affected by their particular circumstances. Although contributions to the body of literature pertaining to childhood disability in developing countries are increasing (Graham et al, 2014; Mgwili & Watermeyer, 2006; Maulik & Darmstadt, 2007; Mji et al, 2011; Schneider 2009; Swartz, 2014; Watermeyer, 2012), very little focuses on the experiences of the young person or those of their siblings.

Existing literature has confirmed that poverty impacts negatively on the health, productivity, physical environment, emotional well-being and family interaction in families of children with disability (Park, Turnbull & Ruthford –Turnbull, 2002). There is however, a question around if/how this might specifically impact on the experiences of siblings of young, disabled people.

As noted above, there is minimal research documenting the experiences of siblings of young, disabled people in poorer contexts, as told by them. By using Interpretive Phenomenological Analysis (IPA), an approach to qualitative research that emphasizes the concerns and perspectives of the participants (Larkin, Watts & Clifton, 2006), this study aims at contributing to the understanding of the life worlds of siblings of young disabled people in poorer contexts. In gleaning an understanding of how the participants in this study make sense of their worlds, it is hoped that their specific needs may be located and that efforts be made to address some of the many shortcomings existing around disability services in South Africa.

1. 3 Locating the Researcher

A fundamental element of Interpretive Phenomenological Analysis is its hermeneutical (interpretive) grounding. As the primary 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 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 confirmed, "There is no neutrality. There is only greater or less awareness of ones biases" (1985, p 77). Reflexivity is thus a critical component of IPA and consistent efforts were made throughout the project to consistently adhere to reflexive practices (Willig, 2001).

Postmodernism has accentuated the value of understanding the researcher's context as an aspect of narrative interpretation (Dwyer & Buckle, 2009). It therefore seems essential, from the outset that as the primary researcher, endeavoring to be both reflexive and transparent, I locate myself within this project.

As I attempt to position myself in 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 emphasizes 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).

Although I conducted this research as part of the academic requirements necessary to complete my training as a Clinical Psychologist, this research question has arisen both from 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. Having these experiences allowed me to approach the meanings the participants in this study offered with empathy. However, I am also aware of how differing contextualization, cultural background and socio-economic status separate me from the participants’ unique experiences. As such my positioning could be considered from both an insider and outsider perspective.

In addition, prior to engaging in a master’s degree in psychology, I was invested in a Non Government Organization located in poverty stricken townships in and around Port Elizabeth. This experience offered me insight into the many barriers to quality of living those residing in disadvantaged socio-economic contexts are faced with and how this impacts on their day-to-day existence. It subsequently followed that I should want to investigate how context might impact on the experiences of siblings of young disabled people. Therefore, this is not a disinterested scholastic effort, but a personal investment into further developing understanding around disability in developing countries.

1.4 Structure of the thesis

Chapter two provides both a traditional review of the relevant literature pertaining to siblings and disability as well as a clarification of the theoretical framework through which this phenomenon was approached. It thus considers childhood disability through the lens of Interpretive Phenomenological Analysis and the Social Relational Model. Finally, it will examine the limited literature related to siblings of disabled children in low-income contexts and deliver a rationale for this particular study.

Chapter Three proposes the research question and presents the research design. This is followed by a detailed account of the methodology in which IPA as a method will be explained. The methodology also offers an explanation of how the process of sampling was undertaken, how participants were recruited and the demographic details of the participants. Subsequently, in the section pertaining to data collection, the semi-structured interview is discussed along with the utilization of a fieldworker. The analytic procedure is then laid out, explaining how the results were systematically extrapolated. Issues pertaining to reflexivity, validity and reliability are then presented. Finally, ethical considerations including informed consent, confidentiality, anonymity and maleficence in relation to this study are discussed.

In chapter four a comprehensive examination of the findings obtained through themed analysis of the transcripts is presented. In addition the findings are discussed in light of the relevant literature accessible.

Conclusively, chapter five consolidates the various issues pertaining to the experiences of siblings of young disabled people in disadvantaged socio-economic circumstances that have manifested throughout this project. The implications and limitations of the current study are considered and suggestions for further research are provided.

Chapter Two: Literature Review

1. Introduction

The purpose of this research study was to develop an understanding of how siblings of disabled children (with developmental, intellectual and/or physical impairments), living in disadvantaged socio-economic circumstances, experience their lives. In the following chapter I will firstly, elaborate on the theoretical stance from which this study was approached. I will then provide a definition of childhood disability and review the findings generated by previous studies on siblings of disabled children. As the majority of these studies were conducted in developed countries, I will subsequently examine the limited research done in disadvantaged contexts on young people with disabled siblings, where environment and circumstance could potentially compound life stressors. Finally, I will provide an argument for the necessity for this particular study.

2.1 Theoretical point of departure

According to Larkin, Watts and Clifton (2006), Interpretive Phenomenological Analysis (IPA) is more than a technique used for analysis, but can be considered a stance from which one can approach qualitative research. The following section aims to offer the reader insight into the theories that informed the manner in which the phenomena central to this study were approached and understood.

IPA has its theoretical underpinnings within three philosophies; phenomenology, hermeneutics and idiography and is grounded in the field of psychology (Eatough & Smith, 2008).

An explanation of each of these contributing theories and their historical underpinnings will be provided below.

2.1.1 Phenomenology: an exploration of lived experience

Phenomenology is a philosophical movement, which emphasizes the value of insight into ‘personal experiences’ in an attempt to understand human phenomena, as opposed to scientific approaches, that focus on causality. It is an approach that requires a shift in attitude pertaining to the study of human sciences which, emphasizes moving away from being “unreflectively immersed in the taken for granted world” (Shinebourne, 2011, p.17).

There are two approaches to phenomenological inquiry, descriptive phenomenology and interpretive phenomenology. IPA incorporates both approaches. Descriptive phenomenology, developed by Edmund Husserl (1927), aims merely to describe lived experiences in their essence. Husserl proposed that the researcher suspend their previous knowledge in order to reflect on the phenomenon itself, evading the inclination to assign meaning (Smith et al., 2009).

Interpretive phenomenological inquiry expanded on by Heidegger (1962), Merleau-Ponty (1962) and Sartre (1956) however, aims to extend the descriptive process noted above, requiring instead a deep engagement with, and reflection on human experience.

Returning to the Greek etymology of the term phenomenon: ‘to bring into light’, Heidegger, (1962) stated the purpose of phenomenology as revealing and interpreting the meaning a subject attaches to their lived experiences (Smith, et al., 2009). 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). Merleau-Ponty (1962) further emphasized that we cannot, as Husserl originally suggested, detach ourselves from our previous knowledge and understanding of the world in this process. Thus, an attempt to reveal meaning in experience is always in relation to the perspective of the researcher. In addition, Sartre (1956) suggests that none of the components in the aforementioned meaning making process are static, but instead are processes unto themselves. That is, the participants and their experiences and the researchers and their perspectives are constantly in the process of unfolding as the story develops, everything is continuously becoming itself. Thus through a phenomenological approach I was able to engage with the siblings of young disabled people living in disadvantaged socio-economic contexts, as they revealed the meaning they attached to their experiences.

2.1.2 Hermeneutics: the theory of interpretation

Heidegger postulates that hermeneutics (the theory of interpretation), although developed as a separate philosophical movement, is a prerequisite to phenomenology (Shinebourne, 2011). This is because, the way in which human experience appears, can by virtue of its existence within a specific context, also mask aspects of itself.

According to Shinebourne, “the task of interpreting is therefore to engage in the dynamic of conceal/reveal, making manifest what may lie hidden” (2011, p 47). 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.

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 their interpretation of their lifeworld.

Interpretation in IPA, is however, 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, 2008). 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.

The interpretive element of IPA can however, can be further expanded on in the consideration of the different levels of interpretation that occur (Shinebourne, 2011). Thus according to Smith (2004), in order for me to holistically understand the lived experiences of siblings of young 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, Flowers & Larkin, 2009. p22).

2.1.3 Idiography: a detailed focus on the particular

Lastly, IPA is considered to be idiographic. Idiography is the analytic process of singularly exploring each unique case, allowing the researcher to make specific statements about the participants. Through a detailed exploration, it is the intention of the researcher to generate various themes, noting similarities and differences between the various narratives. This mode of inquiry is valuable as it returns people's experiences and perspectives to the forefront of psychological study (Larkin et al., 2006).

In summary, by employing IPA it is my intention to understand what it is like for each participant, the sibling of a young disabled person residing in low socio-economic context, to engage in the world in which they reside. These first hand descriptions will then be analyzed and interpreted, and placed into a broader social milieu (Larkin, 2012). Psychological approaches based on phenomenology subsequently acknowledge that a person's perception of reality is determined by variety of factors and experiences. In this particular study, it is my intention to develop insight into the participants' lived experiences, including how they understand their role within their family, their daily living (including the financial implications and potential time constraints that might occur), self-concept and interpersonal relations, in order to glean what meaning they attach to being the sibling of a young disabled person, living in disadvantaged socio-economic circumstances.

2.2 Defining childhood disability

In a mixed methods study examining the impact of childhood disability on siblings from 116 families, Burke (2009) revealed that brothers and sisters experience 'disability by association' as a result of the interactive effect of living with a disabled sibling. Although the study revealed that living with a disabled sibling has both positive and negative implications for the young person, and they will likely accept their sibling's disability as a part of their 'normality' (Connors & Stalker, 2007, 2004), stigmatizing experiences outside of the home context can be constructed as 'disability by association'. It therefore seems imperative to develop an understanding of the definition of childhood disability as its impact, like a butterfly effect, reaches beyond those immediately affected, including siblings.

Past decades have been witness to ongoing debates between researchers, on how disability should be understood. Two models have essentially dominated this discourse; the medical model and the social model. Where the former views disability as the result of a physical condition (Oliver & Barnes, 2012; Shakespeare, 2014; Watermeyer, 2013), the latter postulates that society, in its oppressive attitude to those with impairments, imposes disability (Beauchamp-Pryor & Symeonidou, 2014; Oliver, 2009). More recently however, researchers acknowledge that disability should be considered as a multidimensional phenomenon (Martiny, 2015).

The World Health Organization (WHO, 2011) 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" (WHO, 2011p. 5).

It is evident from the above 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 child's ability to access and interact with their community. However, it is also important to emphasize that unlike the social model of disability, the social relational model acknowledges, "People are disabled both by social barriers and by their bodies" (Shakespeare & Watson, 2001, p. 17). That is, it should be recognized that impairments may cause a certain amount of limitation, however, this does not in itself constitute as 'disability' (Thomas, 2010).

An understanding of the social relational model's definition of disability was imperative to this study as it considers the macro and micro environments in which the young disabled person exists and therefore directly impacts on the siblings' lived experiences. Thomas 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." (Thomas, 1999, p. 60)

In addition, Thomas (1999) elaborates further, that disability is rooted in unequal social relationships, like racism or sexism that in turn manifest as a 'barrier to being' within the life of a disabled child. The author suggests that 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 (2007), 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 personal and psychic boundaries are in fact central to how disabled people are socially positioned and thus inform their lived experiences. These personal and psychic boundaries as conceptualized by the authors are the result of skewed socialization processes and inaccessible resources, which ultimately contribute to internalized disablism.

Contributory factors to psycho-emotional disablism include downplaying ones 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, 2007).

It follows that where the responses, attitudes and involvement of others can affect the disabled child, conversely the child's disability may affect those around them, principally family members, including siblings. Therefore, if disability is considered in terms of the social relational models definition, and Burke's (2009) theory of 'disability by association' is simultaneously applied, there is a question around how siblings themselves experience their relationships with others and their sense of being in the world and whether they experience a sense of imposed limitation or exclusion created by society? Furthermore, there could be questions about the extent to which siblings contribute to disabilism themselves, in an effort to defend against disability.

Haegele and Hodge emphasize "The way in which disability is understood is important because the language people use to describe individuals with disabilities influences their expectations and interactions with them" (2016, p193). In this research, I have chosen to utilize the terminology offered by the social model as it is currently used interchangeably in the social relational model. As such 'impairment' is used to refer to the limitation that is not necessarily a disability if functioning is facilitated and the term 'disabled person' is utilized as people are regarded to be disabled through discriminatory societal practices (Lourens & Swartz, 2016). I shall therefore use the terms 'disabled sibling' and 'person/sibling with impairment'.

In the following section I will provide a review of the research that has been conducted on the siblings of disabled youth.

2.3 Review of the research conducted on siblings of disabled children

Edwards, Hadfield, Lucey and Mauthner (2006), note that sibling relationships contribute holistically to one's self-identity. In a review of the research on 'siblingship' in childhood and adolescence, spanning the last two decades, McHale, Updegraaf and Whiteman (2012) document the impact of siblings on the operation of families as social and socializing systems. According to the authors, it is known that siblings have a direct influence on one another's developments as well as the larger family dynamic into which they are incorporated, subsequently, it can be deduced that these influences would impact on personal experiences.

Although interventions that acknowledge the role of the family in improving the quality of life for disabled children are becoming increasingly central (Dyke, Mulroy & Leonard, 2008), the majority of the research informing these interventions, has focused on the primary caregiver and less so on other family members. The results of these studies have revealed that being a caregiver (irrespective of socio-economic status) to a disabled child yields significantly varied psychological experiences; from an increase in depressive symptoms, to augmented meaning and enrichment (Boström, Broberg & Hwang, 2009; Greeff & Nolting , 2013; Gupta & Singhal, 2004; Kearney & Griffin, 2001; Kelly, 2005; Lawrence ,2008; Mobarak, 2000).

According to Wetherell and Lovall (2015) the fact that there is so little research on the other family members is notable considering the unique challenges that may be faced as a result of being a sibling of a disabled child. The fairly limited research that has been conducted over the last decade on siblings of disabled children has however, revealed similar variances to those of their caregivers. As it is my intention to specifically glean insight into the lived experiences of young people with disabled siblings, I will provide a review of the current literature that has a phenomenological focus where possible, again with the emphasis pertaining to family experiences, their daily living, self-concept and interpersonal relations to glean what meaning they attach to being a sibling of a young disabled person.

2.3.1 Family Experience

With reference to family experience, a qualitative study by Connors and Stalker, (2007), where twenty-four typical siblings and thirty-eight parents were interviewed on their views and experiences of disabled children revealed:

> "The relationships between siblings are presented as robust, with a similar balance of fun and conflict that would be expected in a family without a disabled child. Furthermore, familial relationships are characterized by affection and reciprocity, with an emphasis on sameness rather than difference" (2007, p925).

However, a thematic analysis conducted by Bitsika, Sharpley and Mailli (2015), on the experiences of seventy-five Australian children with a sibling with developmental impairments yielded different results. According to the authors, slight variances in the age of the participants directly affected their relationship with their siblings and their reported access to and relationships with their parents. In this case younger children reported spending considerably more time with their siblings compared to adolescent participants who were more inclined to want to spend time with their peers.

Mandleco and Webb (2015) confirmed the positive familial interactions experienced by the siblings in the study by Bitsika (2015) highlighted above. They however, also noted in an integrated review on the perceptions of siblings of intellectually and developmentally disabled youth, that the nature of the disability also determined the extent of the positive experiences. Both siblings of young people with intellectual impairments and developmental impairments reported enjoying quality time with their brother or sister, considered their relationship with their sibling valuable and expressed pride at their siblings accomplishments. However, the degree to which these positive experiences were expressed occurred more frequently in those with siblings with intellectual impairments then developmental impairments. The siblings of children with developmental impairments in this study also reported higher degrees of stress pertaining to their brother or sister's unpredictable and sometimes-volatile behavior, which impacted on their relationship, as they were more inclined to avoid interactions (Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, & Dowey, 2012; Sage & Jegatheesan, 2010). Aksoy and Yildirim (2008) also confirmed that a non-disabled youth's experience of their relationship with their disabled sibling varied according to their diagnosis and degree of impairment.

In addition to the above findings on the relationships between non-disabled and disabled siblings, Mandleco and Webb (2004) found that the siblings of youth with developmental impairments reported feeling less noticed by their caregivers due to the amount of attention required by their sibling. These results were however, contrary to those found by Opperman and Alant (2002) in a qualitative study on the coping responses of nineteen adolescent siblings of children with severe impairments. The authors noted that adolescents with severely disabled siblings did not feel that their personal needs were being unmet due to their brother or sister. It should however, be highlighted that the majority of the adolescents in the aforementioned study also admitted to not wanting to partake in family activities, preferring to spend time alone or with peers, which could be considered a developmentally appropriate response to family interactions in an attempt to carve out a sense of independence.

It is thus apparent that there are variances in previous studies that consider the familial experience for a young person with a disabled sibling. The variances are influenced by several factors including the nature and degree of the disability in question as well as the age of the siblings.

2.3.2 Daily Living

Some of the challenges that have been documented with reference to the daily living experiences of young people with a disabled sibling include less available financial resources and greater household and caretaking responsibilities, which may in turn limit personal time and reduce social opportunities (Barak-Levy, Goldstein, & Weinstock, 2010, Dyke, Macks & Reeve, 2007, Moyson & Roeyers, 2012 & Mulroy, & Leonard, 2009).

Opperman and Alant (2002) noted, that the majority of the adolescent participants in their study were positive about care-giving responsibilities or acknowledged that they were rarely involved in taking care of their sibling and most did not see their disabled sibling as a financial burden. Other researchers have however found that not all sibling experiences of home life are positive, according to Meyer and Holl (2014), one of the more frequently documented complaints by young people with disabled siblings is the inequality and different standards within the home. Where brothers and sisters with special needs are exempted from household chores or are permitted to engage in behavior deemed unacceptable by their siblings, sentiments of jealousy or resentment are evoked within the non-disabled sibling. In order to further understand this particular phenomenon, the authors created a forum on a social media platform in support of adolescents with disabled siblings. This platform provided a space for young members to voice their sentiments related to this concern, some of the responses added are as follows:

> *"There's a big difference in the way I am treated versus the way my brother is treated. My parents tip toe around him, and when it's time for chores, I end up doing most of them".*
>
> *"Instead of teaching my sister to do something she doesn't know how to do well, my parents just expect me to do it. I'm also expected to do well in school whereas my sister is not."*
>
> *"My brother never seems to have any responsibilities to take care of himself [...] So I'm stuck being the housekeeper and the baby sitter."*
>
> (Meyer & Holl, 2014, p7).

Although there are marked variances in the research pertaining to the experiences of young people with disabled siblings in relation to daily living, there is a lack of evidence on how day-to-day activities are experienced, particularly in socioeconomically disadvantaged contexts. This particular study thus aims to establish if/how the participant's experience of their daily routine might be impacted on by having a disabled sibling.

2.3.3 Self-concept

Late childhood and adolescence are well documented as being a time of change in an individual's life, physically, socially and psychologically. Erikson (1959) detailed this stage of development; 'identity versus role confusion' as a period determined by the prevailing question "Who am I and what can I be?" According to Opperman and Alant (2002), being the sibling to a disabled individual can exacerbate the difficulties pertaining to a young person's psychological adjustment during this period due to feelings of shame and guilt. Feelings of shame and guilt may subsequently impact on how an individual understands who they are and how they experience themselves in the world.

Self reports documented by Meyer and Holl (2014) from youth with disabled siblings include: feeling self-conscious as a result of their sibling's unpredictable and socially unacceptable behavior; feelings of guilt around the resentment they occasionally feel toward their sibling or pertaining to opportunities they might have but their siblings will not; feelings of isolation and being misunderstood by others; feeling different to their peers during a time they wish to be accepted and feeling obligated to compensate for their sibling's disability by trying to be perfect. These feelings of guilt, shame, self-consciousness and isolation might subsequently impact on their psychosocial adjustment.

Research (Lovell & Wetherell, 2015; Macks & Reeve, 2007; Mascha & Boucher, 2006; Ross & Cuskelly, 2006) has revealed difficulties in the psychosocial adjustment of young people with siblings with developmental impairments. It follows that this would subsequently affect the manner in which they experience their life-worlds, particularly their sense of self and interpersonal relationships.

In contrast however, Hastings (2003) and Benson and Karlof (2008) noted no significant difficulties in the psychosocial adjustment of siblings. Moreover, in a qualitative study, utilizing secondary data on the effects of developmental impairments on well-siblings Williams, Piamjariyakul, Graff and Stanton (2009) noted that parents described their non-disabled children as displaying increased sensitivity toward others, being more tolerant, being more mature than their peers, being more self- reliant and displaying increased levels of cooperation and helpfulness.

These findings were confirmed through the self-reports gathered by Meyer and Holl (2014), where adolescents describe themselves as more mature than their peers, patient, tolerant, appreciative, accepting, loyal, understanding and compassionate, indicating positive experiences of self.

Again there are notable variances pertaining to the self-concept of young disabled people. Opperman and Alant (2003) highlight the fact that access to coping resources such as available support systems including a cohesive family system and supportive peer network are influential in determining a young person's ability to adjust effectively.

2.3.4 Interpersonal Relations

According to Schuntermann (2007), positive relationships with peers are considered integral in psychosocial functioning due to their potential to enhance self- worth, assist in the development of coping skills, increase resilience and reduce vulnerability. There is however, limited recent literature available on young people with disabled sibling's interpersonal relationships with their peers. Earlier research by Bagenholm and Gillberg (1991) revealed that young people with siblings with developmental impairments were inclined to high levels of loneliness, social isolation and problems with peers. Hastings (2003) confirmed the above findings in a review of parental reports on siblings of children with autism, particularly with reference to brothers. Meyer and Holl (2014) documented the following responses by adolescents with disabled siblings in reference to their social experiences:

> *"What embarrassed me most was the way other kids at school saw her. They thought she was weird. [...] And the assumptions they made about her they made about me too, just because I was her sister."*
> *"My brother has Down Syndrome. He's fifteen [...] Sometimes he tries to hug, hold hands or even kiss my friends. It is so embarrassing!"*
> *"Until recently I was never embarrassed of my brother. But he is fourteen now and still not toilet trained.[...] So I don't want to bring friends over to my house anymore for fear they will smell poop, or he 'll het upset and grab them."* (Meyer & Holl, 2014, p 9-10)

There is thus a conundrum in that although it is assumed that positive peer relationships contribute to the psychosocial adjustment of youth with disabled siblings, it is apparent from the literature and self-reports that having a sibling with a disability may contribute to the avoidance of social interactions by youth. These attempts at avoiding social situations may lessen the opportunity to develop positive peer relations, thereby impacting on their overall social experiences.

In conclusion, from the above review of previous literature pertaining to youth with disabled siblings, it appears that there are many variances with regards to their experiences. Bitsika, Sharpley and Mailli (2015), note that the differences in experience could occur as a result of the age and gender of the participant as well as the amount of time spent with their sibling and access to parents.

Furthermore, in a review of 12 studies spanning a decade, Meaden, Stoner and Angell (2009) highlighted that the experiences of siblings of disabled children couldn't be predicted as either positive or negative. They emphasized the fact that researchers should be mindful of the many variables including age, gender, size of family, birth order, economic status of the family and severity of the disability that may affect siblings. The authors argue that future research be focused on the experiences and needs of the siblings from their own perspective as a majority of the data reviewed was from a caregiver's perspective.

Research by Moyson and Roeyers (2016), investigating how young siblings of children with intellectual disability define their quality of life, also revealed that responses from parents differed considerably to the responses from the younger participants. Where parents demonstrated more concern with regards to issues pertaining to behaviour, participants reported greater concerns around affection and emotional issues, highlighting the need for further investigation from the perspective of children with disabled siblings.

By further developing a phenomenological body of research, broached from the perspective of people with young, disabled siblings, a more detailed picture of their world and how they understand it can be painted. Subsequently a more informed approach to meeting their needs could be addressed. In considering the needs, it follows that one should, among other aspects, examine their environment, the following chapter specifically looks at existing literature pertaining to siblings of disabled youth in disadvantaged socio-economic contexts.1.4 Siblings of disabled children in economically disadvantaged contexts

In the following section I will provide a brief definition of child poverty, noting its prevalence and its various implications, as this specific qualifier contextualizes the participants in this study. I will then review the limited literature available on youth with disabled siblings living in disadvantaged socio-economic circumstances.

2.4. A Definition of Child Poverty, the Prevalence and the Implications thereof for Families with Disabled Children

The United Nations Children's Emergency Fund (UNICEF), define child poverty as follows:

> Children living in poverty [are those who] experience deprivation of the material, spiritual and emotional resources needed to survive, develop and thrive, leaving them unable to enjoy their rights, achieve their full potential or participate as full and equal members of society (Cited by Minjuin et al, 2006, p. 485)

The participants in this particular study reside in Joza Township in Grahamstown, South Africa. The residents of Joza Township are largely disadvantaged, earning on average 20% of what the middle class population of South Africa earn and thus are considered to be residing in low socio-economic circumstances (http://beta2.statssa.gov.za/publications/P0302/P03022014.pdf).

2.4.1. The Prevalence of disabled children in disadvantaged contexts

According to the Global Burden of Disease Report (2004) there is an estimated 100 million disabled children under the age of fifteen, most of whom live in lower and middle income (LAMI) countries. A study conducted by Woolard (2002), determined that the prevalence of persons with impairments in disadvantaged contexts in South Africa is twice as high as it was in middle to higher income contexts and although no cause and effect between poverty and disability has been proven, obvious links have been noted (Emmet, 2006). Specifically it is understood that poor nutrition, inaccessibility to health care providers and less understanding pertaining to prevention is exacerbated by poverty. In addition, disability itself increases financial burden, discrimination within employment and education thus potentially adding to poverty.

2.4.2 The Implications of poverty on families with disabled children

A review of the literature examining the impact of poverty on the quality of life of families of disabled children yielded a variety of findings pertaining to health, productivity, physical environment, emotional well being and family interaction (Park, Turnbull & Ruthford –Turnbull, 2002). These particular themes were of importance to this study in the attempt to develop an understanding of how young people with disabled siblings experience their worlds.

Barriers to healthcare for disabled people living in poverty have been researched and are found to include limited or inaccessible health services, insufficient funding required to access the services that are available, lack of transport and lack of information regarding available health services (Saloojee, Phohole, Saloojee, & Ijsselmuiden, 2007), Van Rooyen *et al.* 2012). Although such studies have proven valuable in detailing welfare needs, they do not give an indication of the particular experiences of family members, including siblings of disabled people.

Saloojee, *et al* (2007) and Lansdown (2002) further confirm the negative impact living in impoverished circumstances has on families where a disabled child is present, particularly on caregivers who are frequently unemployed mothers. Neither of the aforementioned studies detail how this might impact on the other children in the household.

Grut, Mji, Braathen and Ingstad (2012) confirm that the challenges faced in accessing health care are not isolated to the disabled person, but affect the whole family. As the parents of the participants in this study are employed and are very dependent on their daily earnings, escorting a disabled child to a health service facility may subsequently become the responsibility of an extended family member or sibling. This task is in itself a potential challenge as public transport in Joza township does not frequently cater for disability, furthermore there are psychological and emotional difficulties involved, as some disabled people (particularly with developmental impairments) are prone to unpredictable behavior under stressful circumstances which might be experienced as embarrassing or traumatic by those accompanying them (Grut et al, 2012).

Productivity (participating in and contributing to useful and enjoyable daily activities) is affected by poverty in that it impacts on a young person's schooling and family leisure. There are only two schools that cater specifically for the needs of disabled children near Joza Township; one specifically for young people with learning difficulties that runs on a waiting list, the other, a severely under-resourced, non-government organization for learners considered to be struggling academically or emotionally. The majority of the learners at the latter school are considered to be severely socially marginalized, are victims of extreme poverty, reside in shelters or are considered street children. Aggressive behavior and addiction are common occurrences within the school, it thus follows that attending school in such circumstances might not be experienced as positive and learners (including a participant from this particular study), subsequently choose instead not to attend at all.

The South African Constitution however, stipulates that all children have equal access to educational opportunities, yet there is still blatant evidence of poverty and unequal distribution of funding and resources and institutional capacity within the education system (Engelbrecht, 2006). The implementation of inclusive education in mainstream schools in South Africa, (where potential barriers to participation should be minimized and the involvement of all learners is increased) has not proven successful as under-resourced schools and ill-equipped teachers fail to meet the needs of the learners (Engelbrecht et al, 2003). The lack of adequately equipped public transport for disabled people also contributes toward creating academic disadvantage.

Furthermore, the transport system is unreliable making it potentially challenging for a person with an intellectual impairment to comprehend.

Poverty directly impacts on the family's physical environment. Bartlett (1999) asserts that there is significant evidence demonstrating that children are disproportionately affected by the environmental obstacles to be dealt with in disadvantaged urban settlements. Inaccessibility to clean water, inferior sanitation and poor household conditions that rarely accommodate for those with impairments make day-to-day functions challenging both for young disabled people as well as their families. Along with having to cope with the limited basic resources above, this might entail added household responsibilities, such as collecting water or care taking for the non-disabled sibling.

Overcrowded homes and lack of basic utilities may restrict a young person's ability to gain sufficient rest or complete homework and may result in stress and depression in adults (Park, Turnbull & Ruthford –Turnbull, 2002). This would impact significantly on the participants of this study who are as adolescent at a pivotal point in their school careers. Furthermore, often less advantaged families live in unsafe neighborhoods where crime, violence and drug abuse may be more prevalent and access to good quality schooling and safe play facilities are minimal (Park et al. 2002).

Park et al. (2002) reported that higher income families with a disabled child show greater resilience as a result of more choices and access to resources. It is also noted that higher incomes are related to increased marital satisfaction and greater father participation in families with children with developmental impairments, whereas in disadvantaged families caring for the child with disability was often left to the sibling. Furthermore, it is suggested by the authors that excessive responsibility placed on brothers and sisters of disabled youth, can be detrimental to their well-being. Maulik and Darmstadt (2007) confirmed that insufficient resources and interventions significantly hindered families with disabled children residing in disadvantaged communities.

Another fundamental aspect pertaining to disability in South Africa is stigma and prejudice. Swartz, Schneider and Rohleder (2006), note how disabled people are frequently considered as undesirable or contaminated. According to Lansdown (2002), some South African cultural beliefs associate disability with curses and bad luck. Mothers are frequently deemed responsible for offending the ancestors and bearing a disabled child is seen as punishment, resulting in fathers who abscond. Consequently, disabled children are hidden or families fear being ostracized. Attempts at concealing the disabled child from the community yield further negative consequences, as their basic human rights are not met. One might subsequently deduce that fear of stigmatization or being raised by a single mother, burdened by the communities shunning, would impact negatively on all the children in the household, no research pertaining to this could however be located.

Although there is a growing body of literature pertaining to disability in developing countries where disadvantaged communities are a majority (Graham et al, 2014; Mgwili & Watermeyer, 2006; Maulik &Darmstadt, 2007; Mji et al, 2011; Scheider 2009; Swartz, 2014; Watermeyer, 2012), the lived experiences of the people who are impacted are largely excluded.

2.4.3 Siblings of disabled youth living in disadvantaged socio-economic circumstances.

It is important to note that most of the research pertaining to siblings of disabled children has been conducted in the global north and again, the majority of the research predominantly considers the caregiver. Only minimal research (Lobato et al, 2005; Lorenzo, 2006; Manor-Binyami & Abu-Ajaj, 2011,) addressing the experiences of siblings of disabled children in disadvantaged contexts could be located.

The implications of having a sibling with a disability in poorer contexts reveal several challenges, which would impact on the experiences of a young person. A qualitative study pertaining to economically disadvantaged Latino children [1] with disabled siblings from fifteen families (Kao, Romero-Bosch, Plante & Lobato, 2011) revealed that the participant's interpersonal experiences, self-concept and family experiences were all impacted on. In terms of their interpersonal experiences, participants reported feeling embarrassed by their disabled sibling's behavior. They also expressed sentiments of disappointment at having limited time with peers as they were expected to help with caring for their sibling due to limited resources. The

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

participants expressed ambivalent feelings toward their disabled sibling acknowledging that at times they felt sadness and sympathy toward their sibling because of their impairment. In addition, differential treatment from parents was highlighted.

As a result of the aforementioned challenges, Kao et al. (2011) acknowledge that a greater risk for psychological and adjustment problems, (specifically internalizing symptoms, such as depression) may be present. This could subsequently impact on a young person's experience of self, their academic performance, their interpersonal experiences and day-to-day functioning, where they might feel shame, guilt, withdrawn, irritable, lonely or anxious (Carr, 1999).

A mixed methods study conducted on the coping resources of siblings of children with developmental impairments in comparison with siblings of children without impairments in the Bedouin community[2] in Israel (Manor-Binyami and Abu-Ajaj, 2011), revealed contrasting findings. The aforementioned research concluded that siblings of disabled children did not experience significantly more stress in terms of their relationship with their disabled sibling or their peers. Furthermore, the participants displayed high levels of personal growth. These findings were correlated with religious beliefs. The authors explain this phenomenon in light of literature that refers to growth after crisis.

> "People who experience crises may deal with the ensuing stress and pain by searching for positive meaning/positive reappraisal and/or by coping with the actual problem with the purpose of solving it, and sometimes through recourse to religious faith." (Manor-Binyami & Abu-Ajaj, 2011, p. 830)

Interestingly however, the authors note that the overall self-esteem of the siblings in this study was negatively affected. The authors explain this in terms of the systems approach, where the family is considered as one emotional unit and the functioning of one person may impact on the unit. Although the authors do not state it explicitly, one might deduce that the overall experience of family life is thus impacted on by the presence of a disabled child.

In addition, Carr (1999) emphasizes that although there is a natural drop-off in a young person's self-esteem, it gradually increases during adolescence and failure in

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[2] According to Litvak (2002), Bedouin communities are categorized as falling into the below average income bracket, and are characterized by high unemployment rates with large families (an average of 5-12 children) existing predominantly on child and disability benefits. Unremitting inaccessibility to basic resources including transport, water and electricity is also prevalent.

this occurring may be the result of critical self-appraisal. A sibling of a disabled child may consider themselves different or inferior to their peers. A low self-esteem may subsequently result in them feeling unable to achieve goals or isolating themselves, thereby impacting on their experience of self, interpersonal experiences and day-today experiences.

It is difficult to draw any conclusions based on the limited literature available on siblings of disabled children living in disadvantaged circumstances, it appears there are both positive and negative implications with regard to their experiences. Also, gauging from the above-mentioned literature, variations in cultural and religious affiliations, as well as geographical location, might all impact on the experiences of young person with a disabled sibling, living in disadvantaged socio-economic circumstances. It is however, clear that there is a gap in the research pertaining to this subject and further investigation is necessary.

In the following chapter, I will provide a rationale for the necessity of this particular study.

2.5 Rationale for this research

Although many of the studies mentioned above are qualitative or mixed method studies, their emphasis has primarily been on the cost and effects of having a disabled sibling and are therefore causal in nature as opposed to a detailed exploration of the personal, lived experiences of children with disabled siblings.

Furthermore, as was demonstrated above, very little research pertaining specifically to the experiences of children with disabled siblings in disadvantaged contexts, particularly African contexts, is available. It is evident from the research on child poverty, that this factor has significant effects on the experiences of children and adolescents.

It has been argued that both childhood and 'siblingship' are in themselves social constructs and are explained by the meanings and experiences attached to them and therefore differ according to the socio-cultural contexts in which they are formed (Edwards, Hadfield, Lucey & Mauthner, 2006). It is however evident that despite demographic orientation, these relationships contribute holistically to one's self-identity. Furthermore, children and adolescents should be recognized as having a unique perspective and be seen as actively contributing toward shaping their own lives (James, 1993; James & Prout, 1997; Mayall, 2002). Listening to young people's accounts of their experiences has encouraged recognition that their lives are not homogeneous and need to be studied in all their diversity (Connors & Stalker, 2007). In order to understand general themes in children's lives it is necessary to pay attention to their narratives and personal experiences. By focusing on the aforementioned narratives, it is my intention to develop an understanding of what meaning siblings of children with a disability living in disadvantaged circumstances attach to the concept of 'siblingship' and how they experience themselves within it, how they experience their role within their family, their daily living, self-concept and interpersonal relations in relation to their sibling's impairment.

Chapter Three: Methodology

3.1 Introduction

In the following chapter I will provide a description of the research question. This will subsequently be followed by an explanation of the research design and a brief discussion of the theoretical underpinnings of Interpretive Phenomenological Analysis. I will then offer a description of the inclusion criteria for the participants as well as the sampling technique employed. There will then be an explanation of how the data for this study was collected and how reflexivity was approached. Issues around the utilization of a fieldworker will be explored within the aforementioned discussion. I will explain how data analysis ensued and a brief discussion on interpretation will be provided. Finally, issues concerning validity and reliability are reviewed and the various aspects relating to ethical considerations will be considered.

3.2 Research aim and research question

The aim of this study was to develop an understanding of how youth who live in economically disadvantaged circumstances and have a sibling with a disability make sense of their personal and social world in relation to their sibling's impairment.

Specifically, the research aims to explore how siblings understand their family life, their daily living, self-concept and interpersonal relations. Furthermore, this study aims to understand how young people experience the financial implications, time constraints, social barriers and emotional implications of living in a disadvantaged context with a sibling with special needs. The underpinning question of the research is: 'What are the lived experiences of siblings of young, disabled people living in disadvantaged socioeconomic circumstances?'

3.3 Research Design

For this research, a qualitative research design was utilized. Qualitative research according to Smith (2003) is a paradigm that focuses on the subjective aspects of human experience whereby the main form of data gathered are words used by an individual as a means to interpret or understand personal experiences related to their worldview. As it was my objective in this case to develop insight into how the participants understood their lived experiences through interviews, this paradigm was deemed the most appropriate. By establishing a platform whereby the participants were able to think and talk about themselves in relation to others and their context, I was able to gain insight into how they construct meaning about their worlds. Interpretive Phenomenological Analysis was specifically chosen as it enabled me, through honed analysis, to develop an understanding of the phenomenon in question from the participants' unique frame of reference (Griffiths, M. 2009). In this study I was aiming to access specific, individual and personal accounts of the participant's lived experiences

There is a growing body of research conducted with children and adolescents using IPA (Connors & Stalker, 2007; Griffiths et al, 2011; Jacobs & McMahon, 2016; Majors, 2009; Petalas et al., 2009). Although no specific research pertaining to the limitations or benefits of using IPA with children and adolescents could be located, Smith (2004), notes that the researcher, while interviewing young participants, might need to be more interventionist and include more prompts in order to encourage more elaboration and expansion of ideas.

3.3.1 Theoretical underpinnings of Interpretive Phenomenological Analysis

IPA aims specifically to develop an interpretative analysis, which places the participant's personal descriptions of their experiences into a more holistic social and cultural context (Larkin et al., 2006). As it was the intention of this research to glean what meanings are formed and experienced by siblings of young disabled people in socio-economically disadvantaged circumstances, IPA was deemed the most appropriate framework. As the three primary philosophical contributories to IPA (phenomenology, hermeneutics and idiography) were discussed in detail in the theoretical point of departure (section 1.1) above, in this section I will attempt to translate these theoretical strands into methodological processes. Phenomenologically oriented research aims to understand

> "(s)ubject's perspectives of their worlds; attempts to describe in detail the content and structure of the subjects' consciousness, to grasp the qualitative diversity of their experiences and to explicate their essential meanings."
> (Kvale, 1996, p. 53)

In such, it is the intention of phenomenology, to steer our thinking about human experience, to establish what it is like to be a particular person in particular circumstances (Smith et al, 2009). By creating space for someone to describe their experiences of their world and the meanings they attach to those experiences, we not only provide an opportunity for them to assimilate their own understanding of their experiences, but we too get insight and perspective into their lives. The task of the phenomenologically oriented researcher, is therefore to focus their lens on what is being said by the subject, and how it is being said, as opposed to examining why a certain phenomena manifests as it does. In order to understand the participants' experience of their world, I considered their context, that is, their physical environment, the people that occupy their environment alongside them and the various activities they engage in within their environment. I wondered how they made sense of who they were, as young people with a disabled sibling, in this context and what their day-to-day experiences looked like. My personal musings were guided by phenomenological theory in order to conceptualize the manner in which I sought to answer the above questions.

In attempting to make meaning of the experiences described by the participants, descriptions in themselves would not suffice. IPA requires interpretive engagement with data. The art of interpretation or hermeneutics, according to Schleiermacher (1998), requires grammatical and psychological elucidation, that is both the textual meaning and the uniqueness of the speaker are taken into consideration. Smith and Osborne (2003), note that interpretation takes place on various levels. On the first level, the participant expresses their understandings of specific experiences or phenomena; this is usually through (but not limited to) dialogue. Next, the researcher tries to understand what the participant is attempting to convey, this can be affected both by the participant's ability to express themselves effectively as well as the researcher's ability to interpret what is being said.

The analytic process in IPA involves an intimate interaction between the researcher and the data as she attempts to make sense of the participant's meaning making. It is for this reason that the analytic process is referred to in terms of the 'double hermeneutic'; where firstly the participant aims to make sense of (interpret) their world and in turn the researcher attempts to decipher (interpret) the participant's meaning making (Smith & Osborne, 2008).

The analytic process is however, directly informed by the researcher's previous understanding pertaining to the experience or phenomena in question. According to Heidegger (1962) it is not possible for the analyst to divorce themselves from their preconceptions, subsequently, she will always view new information through a lens constructed by previous personal experience. It is therefore imperative that the researcher employs reflective practices, ensuring personal biases are noted, so that the data's uniqueness may speak for itself (Smith, 2009).

Finally, the third theoretical underpinning of IPA, idiography, is primarily concerned with the distinctiveness of individual cases. Each participant's narrative is carefully unpacked to reveal themes that may be unique to their circumstance, prior to cross-case analysis occurring. Although a pattern may emerge through the analytic process, it is the task of the researcher to allow each participant's experience to speak for itself. Although Smith et al (2009) note that idiography does not necessarily abjure generalizability; it suggests an alternative manner in which to arrive there.

3.4 Participants

3.4.1 Sampling Technique

Due to IPA's idiographic underpinnings (discussed in the chapter above) , purposive sampling methods were deemed most appropriate. Purposive sampling entails selecting participants with direct reference to the research question (Bryman, 2012). In this study the stipulated criteria required that the participants were between the ages of 10 and 18 years old, thus deeming them mature enough to participate in an interview. The participants were also required to have a sibling with whom they resided who presented with an intellectual, motor, auditory, visual or neurological impairment. Finally, they had to fall within the bracket of being 'socio-economically disadvantaged' and were thus recruited from Joza Township, Grahamstown.

Furthermore, as it is the intention of the IPA researcher to create rich, detailed descriptions of the experiences of a specific population, Smith (2007, p.57) suggests smaller sample groups so that allowance is made for "sufficient in-depth engagement with each individual case." For this research five isiXhosa adolescents were interviewed.

3.4.2 Recruitment

This study required the participation of a sample of children between the ages of ten and eighteen years who each respectively, had a sibling with an impairment and resided in Joza Township. The sample was accessed via the Association for Persons with Physical Disabilities (APD) in Grahamstown

The APD was identified as an appropriate gatekeeper firstly, as they already had contact with a significant number of families enrolled for services that met the criteria required for the purpose of the study. Secondly, a relationship between members of the psychology department at Rhodes University, to which I am affiliated as a master's student, and the APD had already been established. A meeting was coordinated between members of the psychology department and the management of the APD to assess if the research was feasible and could be of benefit to the APD. Following this meeting, a formal letter requesting permission to access participants though the APD was sent to their chairperson (appendix i). During this contact period it became apparent that a fieldworker might be necessary due the potential language barrier, it was thought that allowing the participants to speak in their home language would make it easier for them to express themselves. One of the volunteers at APD was suggested as a potential candidate as she successfully met the criteria required. Request was granted to employ and train her to assist in the recruitment and research process.

Once ethical permission had been granted, the APD were approached to assist in identifying siblings considered suitable for the research. Seven families with children meeting the required criteria were initially identified as feasible candidates. Of the aforementioned seven, five children participated. After meeting with each of the families, two declined participation; the first due to logistical limitations and the second due to resistance from the caregiver. The fieldworker understood the resistance to be as a result of the caregiver feeling overburdened by her current circumstances and feeling as though partaking in the study might potentially add to her existing commitments.

3.4.3 Details of Participants

Table 1: Demographic table of participant data

Participant	Age	Gender	Sibling (Pseudonym)	Age	Diagnosis
Anathi	15 years	Female	Siphe	5years	Developmental Impairment
Busi	15 years	Female	Lithando	8 years	Developmental Impairment
Siya	16 years	Male	Ayanda	8 years	Physical impairment
Dina	18 years	Female	Sipho	22 years	Physical impairment
Eric	16 years	Male	Sipho	22 years	Physical impairment

* Note:

1. Anathi is the half sister of Siphe although they have resided together since Siphe's birth.
2. Dina and Eric are the younger sister and brother (respectively) of Sipho.
3. Siya, although only 16 no longer attends school as claims he too afraid to as he experiences it as a hostile environment. His family do not have the financial resources to send him to school elsewhere.

3.5 Data Collection

3.5.1 The semi-structured interview

Smith and Osborne (2008) suggest the semi-structured interview as the most exemplary method for IPA as it permits the researcher and the participant to converse in a manner in which initial focus questions can be adapted in the light of the response in order to probe areas of interest that may arise.

As the respondents in this particular research were young, a more flexible interview approach was deemed most appropriate. Edwards, Hadfield, Lucey and Mauthner (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.

An interview schedule (Appendix H) was drawn up taking various aspects of the participant's psychosocial sphere into consideration, namely; family, daily living and self-concept. Key questions were structured in an open ended way to create a space for individual interpretation. Follow up questions were oriented around more specific aspects of the participants understandings to facilitate further disclosure. Furthermore, simple prompts were provided should the participant be unable or refuse to answer the question posed. These were to be used as seldom as possible as it was imperative that participants were able to relay 'their stories' in their own way.

In the planning phase of this research it was thought that in order to further enable the participants' discourse, a drawing method (adapted from Edwards, et al. (2006) could be implemented. The drawing method consists of a circle map on which children locate significant people in their lives, allowing for freer elaborations on how they perceive their roles in their family and their interpersonal relations. This method was however discarded during the training for the pilot study as it was experienced both by the participant in the pilot study (discussed in further detail in the following section) and the fieldworker as being superfluous.

In research conducted by Harden et al (2000) it was found that not all forms of play (role paying, drawing, use of props) enhance the conversation or levels of comfort and can often create barriers in rapport building.

According to Darbyshire, Macdougall and Schiller (2005), although adults are inclined to believe that standard interviewing techniques are inappropriate for research with young people due to their assumed lack in ability to think abstractly, research by Scott (2000), Burmerman (1994), Walkerdine (1993) and Dockett and Perry (2003) provide evidence that this is likely to only be true in the case of children under eight years of age. In reflecting about this with the fieldworker it was decided that as the participants in this study were over the age of fifteen and capable of thinking and talking about their family dynamics, the activity felt redundant.

Finally, following the interview, the fieldworker requested that each participant wrote briefly on his or her experience of being interviewed. The motive behind allowing them to write their thoughts down as opposed to questioning them directly was to allow an element of privacy, where each could reflect and record honestly about the process, their rapport with the fieldworker and providing space for reflection.

3.5.2 Utilization of a fieldworker

Each of the five participants was interviewed individually, by a fieldworker, who was able to converse both in English and isiXhosa. The decision to make use of a fieldworker was made in order to create a space for the participants to converse freely in their home language (isiXhosa) should they choose to do so. Interestingly, of the 5 participants, only 2 spoke in isiXhosa.

The remaining 3 participants opted to converse in English, their second language.

This raised the question as to whether the utilization of a fieldworker in these interviews was necessary. According to Irwin and Johnson (2005), researchers should be mindful of the linguistic limitations of children and adolescents and be able to provide required prompting when necessary. In all of the cases mentioned above, although most of the interview was conducted in English, there were moments where clarification or elaboration was required in isiXhosa.

Furthermore most of the participants, noted after the interviews in the aforementioned narratives, the rapport and ease of the process, which might in part be attributed to various shared commonalities with the interviewer.

Irwin and Johnson (2005) note that although adults are inclined to grasp the value of rapport building in interviews, this is not always the case with young people. Consequently developing a rapport with parents is necessary. In this case, the participants had a sense of familiarity and trust with the fieldworker as she had been encountered previously when doing ‘home visits’ with the APD and thus had established relationships with the parents.

It has also been noted by Barley and Bath (2013) that familiarization is important in research with children in order to establish a dynamic where there is a sense of trust and the participants are comfortable to discuss sensitive topics. Familiarization, according to Barely and Bath (2013) includes being well versed in the norms, beliefs, rules, rituals and language associated with the culture of the child in order to minimize offense and have an awareness of social cues that could encourage more natural discourse. The fact that the fieldworker employed for this research was of the same cultural background ensured that she was aware of more discrete social nuances and the participants were able to relate to her freely.

Greene and Baxon (2003) detail two major themes relating to the selection and recruitment of field workers These include firstly, ‘The Criteria for Selection’, namely: academic knowledge, research related experience and skills, understanding of the target context, linguistic competence, personal characteristics and practical criteria and secondly, ‘Recruitment Practices’, namely: personal contact and networking, development of fieldworker pool, and advertisement

The fieldworker employed for this study was specifically selected, as she is a volunteer for the primary gatekeeper, The Association for Persons with Disabilities. The recruitment process was therefore through personal contact. Furthermore she met the requirements for the task at hand in that she is the mother of a disabled child and has significant experience with families with disabled children, giving her an in-depth understanding of the target context. Furthermore, she met linguistic requirements and the practical requirements, in that she had access to and was familiar with each participant.

It was crucial that the field worker had a holistic understanding of the aims of the study and how it was going to be implemented, therefore a significant amount of time was spent training her. It was imperative that sufficient time was allocated to explaining the purpose of IPA and demonstrating and practicing the process of a semi-structured interview. Time was dedicated to discussing the necessity of rapport building, administering and using the interview schedule so that she would be able to respond accordingly without leading the participants unnecessarily, allowing them sufficient time and space to respond, and how to offer natural prompts.

A pilot study was subsequently conducted which offered an opportunity to provide any further feedback and training where necessary. During this time it became evident that the circle map method (discussed above) would not be useful. Being the mother of a disabled child, it also offered her an opportunity to reflect on her own thoughts, potential bias and responses to the questions.

An example of this being that her own personal therapy, following the event that rendered her child disabled was experienced as valuable and positive. This coupled with her more ‘outgoing’ and talkative personality gave her the sense that talking about difficult things is “good” and should come with ease. However, we had to consider how to approach instances where a participant might not be talkative or be more reserved in nature. She was able to acknowledge here that in the Xhosa culture (to which both she and the participants belong), discussing personal subject matter is traditionally considered taboo. On a more practical level, it allowed us to resolve technical difficulties with the voice recorder.

The interviews were conducted in a private office on the APD premises. A cool drink and snack was provided and an incentive to participate and to assist in creating a relaxed atmosphere in which the interviews were conducted. All the interviews were recorded using a digital voice recorder, transcribed verbatim, and translated where necessary. The transcriptions and translations were conducted by Zanto Translations, a professional translating service.

3.6 Analytic Procedure

Eatough and Smith (2008) emphasize the methodological practice of IPA, where "analysis is an iterative, inductive process, beginning with several close, detailed readings to provide a holistic perspective, noting points of interest and significance" (p187). Furthermore it is highlighted by Larkin and Thompson (2012) that the foremost intention of the researcher is to identify what matters to the participant, and then to explore the meaning behind these aspects. Only once the researcher has developed an overarching understanding of these core themes can an interpretive synthesis commence.

The analytic procedure was guided by Smith et al. (2009) in which an idiographic tactic was applied; where the researcher aims to explicate individual meanings. The steps outlined by Smith entail firstly, an in-depth reading of each transcript; this is followed by a detailed 'noting' process. The aforementioned notes are then developed into themes, which are then 'mapped' together in order to discover connections between them. The researcher then repeats this process with each transcript before looking for patterns between the cases.

Initially, several in depth readings of the transcripts were undertaken, during which a journal was kept to note significant ideas, potential themes or metaphors. This process, referred to as 'free coding' (Larkin & Thompson, 2012) additionally creates space for reflexivity, which is imperative throughout IPA. Once an in-depth understanding of each transcript had been achieved, a more detailed, line-by-line analysis (coding) proceeded. At this point Larkin and Thompson (2012) suggest mapping out a 'phenomenological core' which includes identifying 'objects of concern' or 'experiential claims' as these are often clues to imbedded meanings. Here emergent themes were identified and organized in a tentative manner to allow for flexibility. While Larkin and Thompson (2012) suggest at this stage, to begin noting patterns between and within transcripts and 'cautiously opening dialogue with theory', Smith (2004) reiterates that a key feature of IPA is that it is inductive. Thus it utilizes techniques that create space for 'unanticipated or unpredicted' themes to emerge during analysis. It was therefore imperative that, while applying a methodological approach, I remained open to novel themes that emerged.

I then formed "clusters of concepts that share meanings or references" (Willig, 2009, p58) or grouped themes into hierarchical relationships. These clusters were then edited (according to how relevant they were in relation to the experience being investigated) and tabulated, along with quotations that aptly depicted each theme. The table was then integrated in order to develop a compilation of 'master themes'. (Appendix J)

In the final stage, I was able identify central themes that had transpired which could then be composed into a detailed interpretive analysis. Smith (1999) emphasizes that this juncture in analytic procedure requires close interaction between the researcher and the text as the researcher attempts to reveal the meanings presented whilst simultaneously, using their own interpretative resources.

According to Smith and Osborne (2008) the IPA process is dynamic in nature, where the researcher assumes an active role, participating in a dual interpretation. It is the aim of the researcher to try and understand how the participants understand their lived experiences. A double hermeneutic is therefore at play within IPA , where participants attempt to make sense of their experiences and the researcher, in turn, attempts to make sense of, or interpret, the participants' making sense of their experiences (Smith, 2004).

It is recognized that the manner in which a researcher interprets their participants' experiences is directly influenced by their own experiences and understandings (Willig, 2009). It was therefore imperative that particular heed be paid to reflexivity throughout this study. The application of reflexivity in IPA will be explored in more depth below.

3.7 Reflexivity

According to Gilgun (2008), it is agreed that reflexivity in qualitative research implies the reciprocal nature of the relationship between the research and the researcher (cited in Probst, 2015). In being reflexive, the researcher is able to note how they (their ideas, previous experiences or bias) affect the research and vice versa. Where in quantitative studies, the researcher's presence (experimenter effect) is considered methodologically problematic, in qualitative research, particularly in the constructivist paradigm, the researcher is recognized as a co-creator of knowledge (Probst, 2015). In providing evidence of reflexivity, the researcher is contributing to the overall transparency of the study, which according to Lincoln and Guba (1985, cited in Saville Young, 2016) is imperative in establishing credibility and trustworthiness.

According to Saville-Young (2016), not only is reflexivity a crucial element in qualitative research, but so is the manner in which one demonstrates their approach to reflexivity. Ones approach to reflexive practices should be coherent with the paradigmatic perspective underlying the research and should be clearly demonstrated.

At this point it should be noted, that my decision to conduct a study of this nature stemmed from my own experience as a sibling of a person with an intellectual disability, along with my occupational experiences working with children in economically disadvantaged contexts. From the outset I was aware that I could not consider myself a 'neutral' or 'objective' researcher. Furthermore, the interpretive nature of the method employed and the double hermeneutic (detailed in section 2.3.1. The Theoretical Underpinnings of IPA, above), meant I could not necessarily make claims pertaining to 'truth' or 'validity' as understood in positivist research. According to Sermijn et al. (2008) however;

> "The qualitative process of research does not aim to establish or reveal supposedly authentic elements of a specific truth about the subject. What is achievable through qualitative research is a construction, a point of entry, or multiple points of entry, which have meaning in specific circumstances for both researcher and study participant" (cited in Medico and Santiago-Delefosse, 2015, p350).

I therefore instead, needed to ensure the process of analysis was visible and transparent (Ortlipp, 2008). In order to create transparency I made use of a reflexive journal throughout the course of the study. The use of reflective journals in qualitative research is a "strategy that can facilitate reflexivity, whereby researchers use their journal to examine "personal assumptions and goals" and clarify "individual belief systems and subjectivities" (Ortlipp as cited in Russell & Kelly, 2002, p. 2).

My reflexive journal was divided into three sections; pre-analysis, analysis and post- analysis. In the pre-analysis section I recorded my motivations for conducting this particular study, anxieties pertaining to the research as well as a thorough exploration of the interview schedule whereby I personally addressed each question relating to my own experiences and recorded anticipated responses from the participants. According to Shaw, "To be reflexive, we need to reveal our presuppositions in order to not be surprised by them or what they do" (2010, p244).

During the process of analysis I recorded "details of the nature and origin of any emergent interpretations" (Biggerstaff & Thompson, 2012, p 10). I also made note of my thoughts and feelings and how they converged or diverged from that of the participants.

In the final section I documented both my and the fieldworker's overall sentiments on the research process as a whole, ideas about going forward with the research and ways in which limitations noted might be avoided in future.

3.8 Validity and Reliability

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 qualitative research.

According to Guba and Lincoln, applying criteria traditionally purported by quantitative research such as generalizability, objectivity, and reliability to qualitative research is illegitimate; akin to "Catholic questions directed to a Methodist audience" (2005, p. 202). The concepts of reliability, validity and generalizability 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 ones claims, acknowledging the possibility of various interpretations of data and framing ones analysis tentatively (Bryman, 2012). Validity in qualitative research is substituted with recognisability. According to Hollway and Jefferson (2000), recognisability is ensured by providing interpretations that are coherent or methodologically, rhetorically and clinically convincing. Generalizability 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 ones method and subjects (Bryman, 2012).

In an article addressing the pursuit of quality in qualitative research, Saville Young (2016), notes the usefulness of various guidelines that have been conceptualized, (Tracey, 2010), in order to effectively evaluate the methodological soundness of qualitative research. Saville Young (2016) describes various concepts that can be utilized 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 utilization 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 the it is executed (Saville Young, 2016).

My research question centered on understanding the lived experiences of the participants. I would then be interpreting, analyzing and reflecting on these stories, bringing in my own values and context. The research was therefore interpretive in nature and therefore could be viewed through the Interpretivist paradigm. Utilizing the methods purported by Interpretive Phenomenological Analysis was deemed most appropriate in order to ensure coherence.

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 in section 2.7.

Saville Young (2016) describes rigour in qualitative research as being akin to being provided with an infinitely detailed map of how one arrived at ones 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 emphasizes 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, Saville Young defines good quality research as being “rich in its description and interpretation of data” (2016, p 8). By providing clear examples of themes I 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).

3.9 Ethical Considerations

Prior to the commencement of this study, ethical clearance was granted by the Rhodes University Research Projects and Ethics Review Committee (RPERC) and the Rhodes University Department of Psychology Ethical Standards (RUESC). Receiving clearance by both ethical boards was deemed necessary as the research participants involved were young and thus considered a potentially high-risk population.

3.9.1 Informed Consent

According to Ponterotto (2013), informed consent in constructivist paradigms, including phenomenology can pose challenges as neither researcher nor participants can be certain of where the interviews will lead or what will be uncovered. The researcher can therefor not be certain of what they should be preparing the participant for, this is exacerbated when working in multicultural contexts where language nuances and cultural attitudes may not be understood.

In order to minimize the above-mentioned risks, I involved the fieldworker, who is of the same cultural background and speaks isiXhosa in the recruitment process. The fieldworker was trained on how to explain the entire process to both the participants and their guardians allowing time for questions and concerns to be addressed should there be any. This included emphasizing that the questions posed in the interview would be personal and could potentially evoke some discomfort.

On meeting the participants and their guardians it was emphasized in isixhosa, that involvement was voluntary and that withdrawing at any stage was permitted.

As the participants were considered minors, both consent forms and assent forms were required. These were provided in English and Xhosa and were written in language that was age appropriate and sans jargon. According Phelan and Kinsella (2013) it is important when conducting research with children and adolescents to allow them to sign assent forms as not only does this reinforce the child's right to refuse to participate, but the physical act of signing gives the child agency in the process. It also creates a window for the child to ask questions.

Along with an agreement to participate, participants (and their guardians) also consented to the interviews being recorded, transcribed and the data stored securely for a ten-year period.

Once the consent and assent forms had been signed and collected a meeting was set up with the fieldworker to reflect on whether there was certainty that both the guardians and the participants fully understood the process ahead and whether further clarification was necessary.

3.9.2 Confidentiality

Although a document of confidentiality was signed by the fieldworker, it later occurred to me that it might have been worthwhile to include similar documents with APD, the gatekeeper, as not only were the interviews conducted on the APD premises, but there is frequent contact between the families of the participants and the gatekeepers due to the role the APD plays.

3.9.3 Anonymity

Anonymity is a form of confidentiality that involves keeping the identity of the participants secret. According to Kritzinger, Kritzinger and Saunders (2015) however, anonymity should be viewed on a continuum as it idealistic to assume one can achieve complete anonymity. 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, Kritzinger & Saunders, 2015). In this research the primary researcher, the supervisor and the fieldworker were privy to the identities of the participants, however pseudonyms have been used throughout the research.

3.9.4 Maleficence

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.

3.9.5 Conclusion

The above chapter offered a detailed description of the methodological process undertaken in this study. It offered an explanation of the research design along with a brief account of the theoretical underpinnings of IPA in relation to methodological practices. A description of the participants and the sampling process were included. Data collection, reflexivity and the various issues related to the inclusion of a fieldworker were discussed. A thorough depiction of the analytic process was provided and validity and reliability were discussed in detail. Finally, the ethical considerations were presented. In the following chapter the findings of the study are presented.

Chapter Four: Findings and Discussion

4.1 Introduction

The aim of this study was to develop insight into the lived experiences of non-adult siblings of disabled people, who live in disadvantaged socio-economic circumstances. In this chapter the findings of this research will be presented and linked with relevant literature where possible.

Five participants were recruited to partake in the study. All of the participants were adolescents ranging in age from fifteen to eighteen years. Their siblings range in age from five years to twenty-two years and present with various impairments, including Autism, Spina Bifida and Spastic Diplegia.

Although each participant falls into the same developmental stage (adolescence), is the sibling to someone with an impairment and resides in similar socio-economic circumstances, a striking factor evident from the outset of the analysis was the variance in opinions and experiences. This was especially highlighted in the narratives of two participants, Dina and Eric, who reside in the same household and are the younger brother and sister to Sipho, yet have very different sentiments and experiences regarding their lives.

Furthermore there are obvious 'incongruities' within each participant's discourse. An example of this being when asked how they feel about having a disabled sibling, all participants acknowledged elements of distress and hardship, yet simultaneously expressed sentiments of love and alliance toward their sibling.

The profound incongruity within the narrative is in accordance with a study conducted by Jacobs and McMahon (2016), who highlight the complexity with which young people with disabled siblings experience and describe their worlds as opposed to simply defining it in positive or negative terms. Earlier research by Opperman and Alant (2003), on the coping responses of adolescent siblings of children with severe impairments yielded similar results with the authors thus noting that 'ambivalence' could in itself be a coping strategy used to deal with uncertainty and stress of having a disabled sibling.

As mentioned in the introduction and methodology sections, the inclusion of my own voice was fundamental to this study. I have subsequently chosen to include summarized sections of the reflexive process I engaged in during the project, in italics throughout this chapter, firstly to "illustrate the role of reflexivity both in data generation and in interpretative analysis" (Shaw, 2010), but also as evidence of transparency.

4.2 Themes

After multiple readings of each interview, the prevailing sense of 'Incongruity' was recognized within each transcript as the overarching theme. Four superordinate themes emerged and were clustered and categorized (as detailed in the method chapter), according to IPA requirements. A further eight subordinate themes emerged and followed from each superordinate theme in turn, with 'Incongruity' succinctly binding the thematic narrative.

The superordinate themes, largely influenced by the research questions include: *(1) Sibling Relationship, (2) Family Climate, (3) Sense of Self and (4) Daily living.*

While categorizing and clustering the subordinate themes, the overarching theme of 'Incongruity' was strikingly apparent and the subordinate themes themselves became easier to understand in terms of their binary aspects. That is, for every subordinate theme that emerged an equally prominent contrary theme emerged. The seven subordinate themes listed with their binary composites include: *(1) Alliance and Protectiveness / Sacrifice and Responsibility, (2) Awareness and Acceptance/Not Knowing, (3) Family warmth / dissonance, (4) Mother: nurturer, provider and someone who understands / feared, authority who lacks understanding (5) Incongruence of self / authenticity, (6) Indistinctive/typical / atypical, 7) Sense of deprivation / sense of adequacy.*

It was further noted that a sub-theme of 'Religious Attribution' emerged with regard to the subordinate theme of 'Awareness and Acceptance/Not Knowing'. Also 'Negative Public Perception' was a recurrent sub-theme pertaining to the subordinate theme 'Incongruence of self / authenticity'. The following table maps out the various emergent themes.

Table 2: Thematic Overview

Over-arching Theme	Superordinate Theme	Subordinate Theme	
Incongruity/ Ambivalence	1. Sibling Relationship	1.1. Alliance and Protectiveness/Sacrifice and responsibility	
		1.2. Awareness and Acceptance/Not Knowing	1.2.1 Religious attribution
	2. Family Climate	2.1 Warmth and Belonging/dissonance	
		2.2 Mother: nurturer, provider and someone who understands/feared, authority who lacks understanding	
	3. Sense of Self	3.1 Incongruence of self/sense of authenticity	3.1.2 Negative public perception
	4. Daily Living	4.1 Indistinctive/typical/atypical	
		4.2 Sense of deprivation/sense of adequacy	

4.2.1. Sibling Relationship

The manner in which each of the participants made sense of and discussed their relationship with their sibling demonstrated that, although, having a disabled sibling is a significant aspect of their daily lives, it is complex and cannot be viewed as being simply arduous as earlier literature suggested (Barak-Levy, Goldstein, & Weinstock, 2010; Dyke, Mulroy, & Leonard, 2009; Macks & Reeve, 2007, Moyson & Roeyers, 2012). It became evident through the process of data analysis that the participants felt a strong alliance toward their sibling as well as feeling protective of them. These feelings however, frequently oscillated to becoming a sense of responsibility and sacrifice. Furthermore, most of the participants did not have a clear understanding of their sibling's impairment, yet the lack of awareness did not obviously affect their acceptance of their sibling, even though, as Opperman and Alant claim, “this would seem necessary in order to employ effective coping strategies” (2002, p. 449).

4.2.1.1. Alliance and Protectiveness / Responsibility and Sacrifice

It was evident that not unlike typical sibling relationships, strong alliances existed between the participants and their siblings. The alliance they displayed was occasionally expressed in the form of ‘protectiveness’. Likewise, feelings of alliance and warmth were often combined with a sense of sacrifice and responsibility. It is thus apparent how nuanced their feelings toward their sibling are, often teetering between being positive or negative within the same instance, fluctuating rapidly between ‘protectiveness’ and ‘responsibility’ or ‘burden’.

When Eric (a 16 year old boy with an older brother with Spina Bifida), was asked if there was anyone in his family he felt closest to, his response was his brother. When asked how he feels about his brother’s impairment again the alliance is demonstrated.

> **Extract 1:**
>
> …“Closest to? My brother… My brother. He understands me, I understand him. I just open up to him more.” (Eric, p.1: 12)
>
> … “He’s just somebody I can talk to about anything. He’s somebody I am comfortable with, I can go with him anywhere.” (Eric, p1: 28)

Further into the interview he offers an example of how he confides in his brother and seeks affirmation and advice from him. He relays the story in the context of how his thoughts of the future are often in terms of consequences related to events. In this particular instance some peers invited him to take steroids with them. He felt conflicted by his desire to be included and the consequences of the action. Ultimately he declined but sought solace in his brother’s acknowledgement.

> **Extract 2:**
>
> “…I told my brother, I told my brother about it and he was like congratulating me for not doing it.” (Eric, 7: 212)

Eric's older sister, Dina, also demonstrates her sense of alliance to her older brother, however in her discourse the incongruity is more apparent. One gets a clear sense of her feelings of resentment toward his impairment.

> **Extract 3:**
>
> "…Sometimes I feel like I want a big brother who would be able to walk by himself, do his own things by himself but eventually… Even when I'm sad he's always there, a shoulder to cry on so yah he's a nice person." (Dina, p1: 15-19)

In discussing the challenging aspects of her daily routine she is direct about the sense of responsibility she feels to 'cover' for her brother when he is not adhering to household rules and how she resents having to do so. While demonstrating the challenge in this, it is also indicative of the alliance she feels toward him.
It is also worth noting that the sense of obligation and responsibility she describes in the following extract is not unlike those seen in typical sibling relationships.

> **Extract 4:**
>
> "It's when I have to lie for my brother. Usually Sipho doesn't like to come home earlier so he'd ask me to come up with a lie or something that okay, so when I see that oh it's past his time like my parents are stuck to me like ["Dina, where is Sipho?"] so I'd be like yoooh Sipho you know I'll call him so that's one part I have to feel like that's the saddest day cause they're on to me and he's not answering his phone or something like that so." (Dina, p2: 62-67)

Dina's sense of obligation and responsibility was of particular interest to me as this particular phenomenon is not at any point apparent in her younger brother's discourse. Furthermore, both interviews suggest that neither of the siblings have been assigned more responsibility than the other by their parents, yet the experience of their relationship with Sipho appears quite distinct. Although both Eric and Dina describe their relationship with Sipho as close, Eric does not specifically acknowledge his brother's impairment as a predominant factor in their relationship whereas Dina describes feeling concerned about her brother's impairment at times. Eric also emphasizes the fact that him and Sipho engage in typical brotherly activities such as playing sport together, something that Dina does not share. This might be explained by the fact that of the two non-disabled siblings, Dina is the oldest and is therefore more inclined to instinctively assume added accountability for her brothers.

McHale et al (2012) confirm that in cross-cultural research on non-disabled sibling dynamics, care-giving responsibilities of older siblings and hierarchies in sibling roles are prevalent universally. Interestingly, Petalas et al. (2009) describe a similar finding in their study on the experiences of siblings with a brother with a developmental disorder. The authors noted a divergent attitude towards their disabled brother, by a brother and sister, where the sister "recounted more negative experiences and was less accepting of her older brother" (2009. p393). The authors, along with Bitsika, Sharpley and Mailli (2015), suggest that the variance in sibling's experiences may be age determined but that further investigation is required to corroborate these findings.

The discrepancy in the experiences above might also be understood in terms of gender. Mandleco and Webb (2015) noted in their study on the perceptions of siblings with mental and developmental impairments, that siblings displayed more empathy and were prouder of their disabled sibling if of the same gender. Bitsika et al. (2015) also found that female participants of brothers with developmental impairments were more influenced by their brothers than male participants. The authors however, caution against assuming that female siblings might undertake more responsibility for their disabled siblings as further investigation into the perceptions of siblings according to age, gender and birth- order is required.

When Busi (a fifteen year old girl with an eight year old brother with Autism and ADHD) is asked to describe her relationship with her brother, she initially does so with affection. Later when describing her average day, her little brother is clearly an integral aspect. She often refers to their relationship as a unit or a team in opposition to their mother emphasizing their alliance, frequently using the word "we" and describing common activities to demonstrate the unity.

Extract 5:

…"My brother, when I think about him like, he makes me smile, I love him so much. He is cute, he is loveable, he is smart, he is just great"… (Busi, p1: 9)

…"On weekends, I wake up, he is already awake, (…) We eat, and then he takes a bath and then I also take a bath and we just chill the whole day, maybe we play, we love eating, we both love eating and then we eat the whole day

> and we jump on the couches like do naughty things, mom gets angry, yah it is pretty nice". (Busi, p1: 35-39)

Yet, when asked to describe the most challenging aspects of her day Busi acknowledges the added sense of burden her brother's impairment contributes to her life. The fact that she is occasionally responsible for his caretaking inevitably means that she is expected to sacrifice time with her friends, or when he breaks household items while in her care, she feels she is required to use her pocket money to fix the item.

> **Extract 6:**
>
> "…The hardest part is having to watch Lithando when my mother is out doing like important stuff not like going out with friends, and I have to watch Lithando all the time. (…) Sometimes I get really angry but I just calm myself down, like yesterday I was supposed to go out with my friends, just to take a short walk around because I haven't seen my friends in a long time." (Busi, p2: 58- 61)
>
> **Extract 7:**
>
> "…Most of the time he breaks stuff around the house and I usually take blame for whatever he does, he broke the broom and I had to take the blame and use my pocket money to go and buy glue and fix the broom, you see, so I always get in trouble as if I was not watching him, I am it is just that he is strong and I tried taking the broom away from him but he was just strong so yah." (Busi, p3: 63-66)

As mentioned in the introduction above, themes of alliance, protectiveness, responsibility and sacrifice do overlap with typical sibling experiences. Busi's tendency to accept the blame for her brother breaking household items might however be due the fact that she recognizes that some of his behavior is beyond his control, and is a result of her brother's impairment, thus requiring her protection and defense. While it is not uncommon for older siblings to assume care-taking responsibilities in less advantaged circumstances, this dynamic might be prolonged in households where there is a younger disabled child, as their impairments frequently delay their independence.

Siya, a sixteen-year-old boy with an eight-year-old sister with Spastic Diplegia, is being single parented by his mother (with whom he has a very tumultuous relationship) and his grandparents. It was evident in his discourse that his sister is very central to his world but he seemed constantly challenged by how to make sense of his feelings toward her as a result of her impairment or how to express his relationship with her. Initially when asked about his family, he expresses love for each member but includes his sister as though feeling this way should be something exceptional or difficult to do by using the word ‘even’.

Extract 8:

“I love all the people in my family, even Ayanda.” (Siya, p1: 6)

He however, expressed the alliance he feels toward her by emphasizing her role in mediating the difficulties he experiences with his mother, giving him the sense that he is wanted. It is however noted that her impairment is central in his relationship with her.

Extract 9:

“… I know Ayanda can’t walk right, I can walk. When I have an argument with my mother and she chases me away, it is Ayanda who begs her to let me come back. Then I go back home….” (Siya, p3: 74-75)

When asked directly how he felt about his disabled sister, he expresses his affection in terms of his desire to make sacrifices for her. This phenomenon reoccurred later when he was asked about his thoughts of the future.

Extract 10:

“ I feel okay, with Ayanda even when I was still at school, sometimes I skipped school just so that I can take her to school…Sometimes her transport would leave her and she would cry to go to school whilst I’m also going to school. So I would choose to take her to school instead.” (Siya, p3: 34-39)

”…[When I think about the future] “I think about working [to provide] for my sibling”. (Siya: p7: 201-202)

The subordinate theme *Alliance and Protectiveness / Sacrifice and Responsibility* reveals how the participants experienced certain aspects of their relationship with their siblings. Where some viewed their sibling as their closest confidant and someone they enjoyed leisure activities with, other participants felt predominantly protective of their sibling. This sense of protectiveness occasionally morphed into feelings of responsibility and sacrifice. The tensions noted in their relationships with their siblings echo that of previous studies, indicating that while a close bond is often shared, a non- disabled sibling may experience challenges navigating their role in the relationship (Jacobs & McMahon, 2016, Opperman & Alant, 2003, Petalas et al. 2009).

Petalas et al. (2009) note that non-disabled siblings are on occasion expected to assume atypical roles that require concessions or sacrifices. This may, as in Busi's case include navigating idiosyncratic behavior, emotional outburst and damage to belongings or assuming added caretaking responsibilities.

The findings also suggest that birth order, gender and age could be associated with the roles and responsibilities fulfilled by the participants, however there is insufficient evidence to make a definite claim around how this impacts on the dynamics between the siblings. These findings however, concurred with previous research by Bendrix (2007), who noted "Siblings' experiences of having a sense of responsibility for their brother or sister varied in different ages and in different families" (2007. p414), yet experiences of responsibility seem to increase with age. Jacobs and McMahon (2016), further reiterate the growing sense of responsibility that develops with age and is seemingly prevalent across cultures. The authors however, suggest that siblings often take on care giving responsibilities to the extent that they become parentifide, this did not appear to be the case in the current study. Instead evidence suggests that the participants experience a sense of alliance toward their sibling.

4.2.1.2 Awareness and Acceptance/Not Knowing

Of the five participants interviewed, only one fully understood the diagnosis and two directly acknowledged that they did not know what their sibling's diagnosis was and could only explain the disability in terms of the physical limitations exhibited. It should be emphasized however, that many children residing in disadvantaged socio-economic circumstances do not receive a formal diagnosis. A study conducted by UNICEF for the South African Department of Education (Deaprtment of Education &

UNICEF, 2015), listed the following as barriers to early identification and formal diagnosis in disabled children: variations in the normal developmental milestones, lack of effective measures for nature, severity and onset, stigmatization and underreporting, the adult-centric nature of disability programming and the influence of different cultures on the paradigms of childhood and disability, which subsequently affect responses to census measuring disability (2015).

Furthermore, even when a diagnosis is given, the South African health care system currently approaches disability from the medical model perspective, which categorizes and pathologizes disability and rarely is it explained to parents properly. (Anastasiou, & Kauffman, 2011).

According to Opperman and Alant (2003), an understanding of the nature and consequences of the disability should be considered necessary in developing positive coping strategies amongst siblings, yet with the exception of one, the participants in this study demonstrated very limited knowledge. Furthermore, the participants did not describe their experience of their sibling's impairment in a way that suggested their understanding impacted either positively or negatively on their emotions.

When asked 'if' or 'how' they understood their sibling's impairments, their responses were as follows:

> **Extract 11:**
>
> "Ha.a [No…]. Ey I don't know how I am going to answer this question. There are things that Siphe cannot do because of the way she is that I can do. For example speaking, she can't speak but I don't perceive her like "yho this child" or something like that…the way she does things, she does not do things normal kids do, sometimes she does, but most of the time she does things the way she is and she is always vibrant than other people etc. I can't remember everything." (Anathi, p1: 25- 27)
>
> **Extract 12:**
>
> "Yo I don't know sister (…) It's her feet sister (…) They are not straight." (Siya, p2: 51-62)

It is apparent that Anathi does not have a clear understanding of her sister's diagnosis, however, she recognizes that her sister is unable to perform certain tasks the way others do. Yet in acknowledging that she does things in her own way and emphasizing that she is vibrant, one gets the sense that on some level, Anathi values her uniqueness. In addition, by emphasizing the fact that she does not perceive her sister in a negative light, one gets the sense that she is potentially rejecting the 'othering' of her sister as a result of her impairment. This is in accordance with findings by Jacobs and McMahon (2016), who noted while participants realize the uniqueness of their situation (and their sibling), they similarly inclined to reserve negative judgment.

Later when asked how their sibling's impairments made them feel, the participants expressed varied responses. Anathi displayed obvious feelings of incongruity, implying that this was not something she necessarily felt positive or negative about, but something that just required acceptance even without clear insight. She attributed her acceptance to her religious beliefs. There is however, the sense that acceptance is something expected of her and is not necessarily internally driven.

Extract 13:

"I won't say I feel happy or sad or something, I'll just say I am okay with the way she is (…) it doesn't make me feel bad inside, since I am a believer I can't judge other people because of the way they are, like saying " yhu since Siphe is like this I regret having a sister like this or something" I am okay with it." (Anathi: p1: 19 & 44-46)

Following the interview, each participant was allocated time to write about their experience of the interview and further add any information they felt they might have forgotten to include or felt uncomfortable discussing. In her 'write-up' Anathi reiterated her acceptance of Siphe's impairment as an attribution of her faith.

Extract 14:

"I am also a God fearing person, having a sister like Siphe is not a problem to me and I've also accepted her."

Yet, when asked if there was anything in the world she would change, her first statement was; "If there's anything I could change, it's disabled people" (Anathi, p.6: l.157-158). The incongruity in her sentiments is therefore reiterated, in that although she claims to accept her sister's impairment; she would also change or remove it if she could.

Siya acknowledges the negative emotions evoked by his sister's impairment and furthermore indicates that he thinks it causes her distress too as demonstrated by the following extract:

Extract 15:

Interviewer: How does having a sister with a disability make you feel? How do you feel about *Ayanda's disability?

Siya: I don't feel good

Interviewer: What makes you to not feel good?

Interviewee: I don't stay well

Interviewer: How does *Ayanda stay?

Interviewee: She also does not stay well but if she was able to walk she was going to stay well.

(Siya, p.3, l 70-72 & 79-83)

Yet, when asked if there was anything in the world he could change, he refers only to a school matter.

Extract 16:

Interviewer: If you could change anything what would you change? Whether its at home, where you used to go to school at Masango, around the neighbourhood, about disabled people like *Ayanda, in your family as a whole, in you *Siya?

Interviewee: There isn't sister

Interviewer: There is nothing you could change?

Interviewee: I could change schools

(Siya, p.7, l 216-222)

Thus, there is the sense form the extract above that although not necessarily positive about her impairment, he accepts it sans in-depth understanding of it.

Neither Anathi nor Siya indicated openly that they wished for any deeper understanding pertaining to the impairment, however, in interpreting the resistant manner in which Siya responded to the questions, around his understanding of the impairment (demonstrated in the following extract), it seems that he felt a sense of regret for his lack of understanding.

Extract 17:

Interviewer: How would you describe your sister's disability?

Interviewee: Yo I don't know sister

Interviewer: How is *Ayanda disabled?

Interviewee: *silence*

Interviewer: Do you know that *Ayanda is disabled?

Interviewee: Yes

Interviewer: How is *Ayanda disabled?

Interviewee: It's her feet sister

Interviewer: Do you know what happened to *Ayanda?

Interviewee: Yuu I don't know sister

Interviewer: You don't know...did no one tell you?

Interviewee: Ha.a [nu-uh]

(Siya, p. 2, l 49-59)

Dina and Eric do not indicate that they have precise insight into Sipho's diagnosis, however, they seemed more able to express how they understood it and what it means to them personally. Again the variance in their responses was noteworthy. It is also interesting to note that they seem to measure the degree of Sipho's impairment quite differently. Where Dina experiences it as quite severe and limiting, Eric is adamant that to him, it is hardly apparent.

When asked how they think Sipho is different to them, Dina highlights Sipho's physical limitations and the emotional impact it has had on him.

Extract 18:

"I'm different in a way that I'm able to walk on my own, he walks on crutches and he spent a life where he was threatened, people teased him and all of the stuff not compared to me." (Dina: p1:21-23)

Eric on the other hand downplays his brother's impairment to the point of being seemingly evasive.

> **Extract 19:**
>
> "Well, I'm younger than my brother… Yah it's just the ages that makes us different, otherwise (…) he's a church-going person so that also separates us. I'm not as Christian… that's all that separates us." (Eric, p1: 31-35)

When Eric is asked directly how he understands his brother's impairment, one gets the sense that Sipho is only mildly physically limited which is in contrast to his sister's understanding. Dina explains Sipho's impairment in terms of how it impacts on her life and again one gets the sense of obligation and pity not at all present in Eric's narrative.

> **Extract 20:**
>
> "His disability? Uhm he can't walk properly, he uses crutches to walk. That has limited him to stuff that he can do but (…) he doesn't have a disability, he just can't do some things. I can't say [it is limiting] that much because [we play] soccer, cricket. We do everything together so I wouldn't really call it disability." (Eric: p2: 40-44)
>
> **Extract 21:**
>
> "I'd describe it as a tough one because sometimes when I'm angry and I have to do something for him he'd be like "do something like that" inside I'm angry with him, but eventually I would do it because he doesn't know how to do it himself, so I have to do it for himself you know and It's tough, It's challenging and anything that you can imagine that's hurtful so yah" (Dina, p1: 31- 36)

It appears from the above extracts, that of the five participants, Eric seems to display the greatest sense of acceptance although he has a moderate understanding of his brother's impairment. According to Burke, this occurs when the young person is "able to adapt towards a positive view of the disability, by resisting stigmatizing labels associated with disability" (2009, p1696). When with his brother, Eric does not experience their interaction as limited, nor does he feel different when he is with him, he is therefore not affected by a sense of resentment. In assuming a positive response, Eric is able to transcend demeaning experiences. In such (perhaps unknowingly), Eric demonstrates in this instance, the underlying essence of what social-relational model of disability purports: that discrimination and resentment are a reaction to a negative perception of difference caused by psychological and physical barriers set in place by society.

One however, gets the sense that like Busi (extract 7, p9), Dina as the older sister, feels more responsibility and obligated to make concessions for Sipho, making his impairment challenging to accept at times. Although she describes feeling angry, she seems to concede, possibly out of guilt or frustration. According to Petalas et al. (2009), this type of tension is prevalent in some siblings as they constantly attempt to come to terms with their brother or sister's condition, while still wanting to change things. Subsequently, to some degree, Dina and Busi demonstrate how they have internalized psycho-emotional disabilism, by making concessions for their sibling because of their impairment (Watermeyer & Swartz, 2007).

In the following extract Dina also acknowledges that she would change the fact that her brother is disabled; this however, is relayed empathically, as though to relieve him of the difficulties she assumes he is faced with. One does however sense, that she feels the challenge of Sipho's disability more acutely then Eric does. This again, as noted above, could be explained by the fact that she is the elder of the two non-disabled siblings and assumes more care-taking responsibilities, therefore, perhaps some of her desire to 'remove' the impairment is for her own self-preserving benefit.

Extract 22:

> "I'd like to change the way my brother is, so yah I have to say that, like he struggled a lot you know, he's doing the grade 12 that I'm doing now. If he was normal maybe he'd be in university or working right now. So if I could change it, I would change him." (Dina: p4: 115- 118)

Of all five participants, only Busi was able to provide a detailed understanding of her sibling's diagnosis and the developmental implications of the disability. When she was asked to describe how she felt her brother was different to her, she was able to acknowledge his potential but also his difficulties, such as his behavioral challenges.

Extract 23:

> "Okay well, my brother is autistic, he cannot speak, he is not like other children, other children like start speaking like at the age of two years old but

> then my brother cannot do things at a later age like at the age of seven, so he is going to do stuff later than other children. (…) I think if he was not disabled, he would have been really smart, he would have been really smarter than I am, if you teach him something he is going to get it like really fast and uhm…what else, he is naughty, I don't know like we different maan." (Busi: p1:14-16)

Like Anathi, Busi attributes her acceptance of her brother's impairment to her religious beliefs and not the deeper insight she has of the disability itself.

Extract 24:

> "You know sometimes when I am like sitting at home, I sometimes question God, 'why did He make my brother like that' like, He is God right! He is like the savior of all people, so now I am thinking is it a punishment or something like that but I think it is like a blessing in disguise." (Busi, p1: 26-29)

From the above statement, it seems that even with a detailed understanding of her brother's diagnosis and her faith, Busi at times feels challenged by her brother's impairment and considers it difficult to accept.

Subsequently, based on the findings from the current study, it cannot necessarily be assumed that awareness and insight into their sibling's impairment will necessarily lead to further acceptance. However, awareness in itself does not necessarily equate to more positive experiences. These findings support those of Burke's, who suggests although siblings might not have a vivid understanding of the diagnosis per se',

> "they are aware of how disability imposes on their brothers or sisters, plus the restrictions placed on their own lives. These views show an acceptance of a situation that appears unchangeable, and that is probably the best indictment for not assuming that consequently all must be well. This is because it is evident that the experience of disability impacts on the quality of their lives." (2009, p1692)

In their study, Opperman and Alant (2003), also noted the participants displayed a superficial understanding of their sibling's disability and relate this to the limited professional support received, ultimately contributing to their feelings of ambivalence. The value of support systems for siblings has been noted not only for increasing awareness, but increasing coping mechanisms and offering normalizing experiences (Burke, 2009, Opperman & Alant, 2003, Petalas et al., 2009). In such, although simply having awareness might not increase acceptance, the act of acquiring knowledge, through support could possibly reduce negative experiences and subsequently increase acceptance.

These findings are however, contrary to earlier findings (Glaser & Strauss, 1991 cited in Petalas et al., 2009), that claim that young people who had increased knowledge of their sibling's disability reported feeling less embarrassment in relation to their brother or sister and displayed greater acceptance of their circumstances.

In the above subordinate theme, *Awareness and Acceptance/Not Knowing*, the participants' understanding of their siblings' impairment was uncovered and related to their overall acceptance. It became evident that only one participant fully understood their sibling's diagnosis, yet overall this did not impact on their acceptance of their sibling's impairment.

I was seven years old when my sister was born. Disability, then, as it is to some (although perhaps lesser) degree now, was perceived in a negative light in our white, middle class context. It was very much viewed through a medical lens, as a "tragic, physical illness" (Lourens, 2016, p.2). The hospital staff proposed that my parents institutionalize her as soon as possible to relieve themselves of further trauma. My parents declined the offer. They however, had the means to educate themselves on what her particular impairment entailed, and before she was brought home I was given a detailed explanation of her diagnosis and how it would affect our family. For the first few years of her life the Glen Doman program was executed in our home. This entailed teams of volunteers participating in a twelve hour per day rotation of various physical and sensory activities to stimulate my sister's brain and body.

As earlier research claims I was required to mature faster and I did (like many older siblings), suddenly receive less attention from my parents (Dyke et al., 2009; Macks & Reeve, 2007 & Moyson & Roeyers, 2012). This did not necessarily impact on my experience of my relationship with my sister negatively, it did however, present a different construct of siblingship to that I had seen experienced by my peers. The bond we share is unique in that my interactions with her are more maternal then sisterly. I have however, throughout the years been acutely aware of how having an understanding of her disability assisted in my ability to cope with changes that *occurred in our lives after her birth. Somehow, knowing, also allowed me to manage potential feelings of frustration.*

I had not expected the participants in this study to have a clear understanding of their sibling's impairment, I had however anticipated the lack of awareness to result in difficulty coping with the adjustment, thus impacting on their experiences of being a sibling to a disabled person. This has not been the case. As such, during my readings of the transcripts I had to suspend my expectations in order to notice the experience 'alliance' the participants depicted. Furthermore, in engaging in Dina and Busi's narratives and the literature pertaining to their sense of responsibility, I have been forced to question whether my maternal reaction toward my sister is strictly a response to her impairment or also a result of our birth order, the age gap between us and my gender (Bitsika, Sharpley & Mailli, 2015).

4.2.2 Family Climate

It was evident throughout the interviews that family climate, whether positive or negative, formed an integral function in each of the participant's experiences of living with a disabled sibling. Burke (2009) highlights the fact that young people with disabled siblings may have a different experience of family life as a result of several factors, including limited time together (due to the amount of time required to care for a disabled child) and the fact that siblings are often required to assist with caregiving responsibilities.

It is however, important to note that the family structures of the participants varied considerably and that this in itself is likely to impact on each participant's lived experiences in relation to their disabled sibling. McHale, Updegraaf and Whiteman (2012) emphasize that even within families unaffected by disability, siblings have a large impact on one another's lives and the overall operation of the family, conversely the family dynamic will affect the sibling relationship. It therefore feels imperative to contextualize the participants within their family system (see table 3).

Table 3

Participant (age and gender)	**Sibling (age and gender)**	**Sibling's Diagnosis**	**Family Context**	**Relationship with mother**	**Closest family Ally**
Anathi (15) female	Siphe (5) female	Autism	Lives with grandmother, aunt and uncle and brother and her parents and 2 sisters live in a house nearby	Ambivalent	None
Busi (15) female	Lithando (8) male	Autism and ADHD	Lives with her parents and brother	Positive	A male cousin
Siya (16) male	Ayanda (8) Female	Spastic depligia	Lives with his maternal grandparents, mother, brother and sister	Strained	Grandmother
Dina (18) female	Sipho (22) male	Spina Bifida	Lives with her parents, her aunt and her 2 bothers	Ambivalent	Father
Eric (16) male	Sipho (22) male	Spina Bifida	Lives with parents, aunt, brother and sister	Ambivalent	Brother (Sipho)

Strong emerging themes within the context of 'family climate' included the participants' relationships with their mothers and the sense of warmth and belonging they experienced within their families. Much of the previous literature on childhood and adolescent disability focuses on the caregiver in relation to the disabled child, highlighting that although there are many positive aspects, caregivers are frequently under strain. Living in disadvantaged socio-economic contexts has been found to compound this stress (Kearney & Griffin, 2001; Mobarak, 2000; Lansdown, 2002; Saloojee et al., 2007), I was therefore interested in understanding the dynamic of the relationship between the mother and her non-disabled child.

4.2.2.1 Warmth and Belonging / Dissonance

When some of the participants spoke of their family climate, they referred to it in positive terms using words such as ‘good’, ‘love’ and ‘we’ indicating a sense of warmth and belonging. Thus one is given the sense that the togetherness described is all-inclusive. This was of interest to me as it is not uncommon for non-disabled siblings to feel sidelined due to the amount of extra care a child with impairments requires (Burke, 2004; Strohm, 2008).

> **Extract 25:**
>
> “The people in my family are good people, they understand yeah” (Anathi, p1:9)
>
> **Extract 26:**
>
> “…we live as a family, we are a crazy family I would say. We are energetic, funny yah, we love each other more than anything.” (Dina, p1: 2-4)

When asked to describe their home they further demonstrated the sense of warmth and belonging by highlighting a sense of comfort and shared interests that brought pleasure to their experience of their family. The following extracts provide evidence of these.

> **Extract 27:**
>
> “It’s a good home, it has relaxed people who can talk, they don’t keep things inside, if someone wants to say something they just tell you that it’s like this and that.” (Anathi, p2: 61-61)
>
> **Extract 28:**
>
> “Gosh, my home… like we are all friendly, it is a peaceful home, sometimes I think my family is really weird because we really do weird stuff but it is actually a really cool and loving home.” (Busi, p2:49-52)
>
> **Extract 29:**

> "It's a warm home, loving, caring, kind all the words you can imagine. It's that one place I feel like okay yah I'm one person who knows that people love me unconditionally. They don't fake it and I know it's there so yah" (Dina, p2: 58-60)

> **Extract 30:**
>
> "Well, my home, what I can say about my home is that music has affected me that much and my home because my sister, she likes music very much and at one hand at school I'm involved in a music band and my brother likes gospel songs. So my home is just a musical home" (Eric, p3: 78-81)

In the above extracts the participants relay their experiences of home. One does not get a sense from their discourse that the presence of a young, disabled person inhibits or hinders their day-to-day activities or impacts negatively on the family dynamic. In fact the environments depicted appear to be harmonious places of comfort. Furthermore, there is evidence of shared quirks and character traits that emphasize the sense of 'we-ness' experienced by the participants. These findings are quite distinct, as adolescence is generally understood as a period where individuals begin to establish their individuality, forming views that differ from their parents, potentially resulting in conflict in the home, often exacerbated by the presence of disabled child (Opperman & Alant, 2003).

Dina further illustrates her sense of belonging when she describes her favorite day of the week as being time spent with her family. She specifically includes both her brothers, indicating that her overall experience of the family climate, particularly in relation to her brother, is mostly positive.

> **Extract 31:**
>
> "It's during weekends (…) I usually spend my day with my brothers and family." (Dina, p3: 70-73)

In contrast to the above findings; when Siya is asked about his family, although initially claiming to love all its members, it becomes evident, through his resistance to discuss life at home, that there is a sense of incongruity and dissonance. When asked to describe his home, he replies with a giggle and a long period of silence. After some prompting the interviewer enquires directly if he is able to describe his home to which he simply replies “no”. Finally, after more silence he seems to offers the response he thinks is required of him, although somewhat unconvincingly.

> “*Giggles*It’s a good home sister.” (Siya, p5: 143)

Siya displayed similar resistance when asked if he felt close to anyone at home, eventually acknowledging his grandmother. His sense of connectedness to his grandmother is again illustrated when asked about his favorite day of the week and one gets the sense that although complex, at some level there is a sense of belonging although his dominant feeling is one of disconnect and dissonance.

> **Extract 32:**
>
> “*Silence* (…) It’s Sunday, because on Sunday I can go to church with my grandmother. When we come back from church we stay at home and then she goes out and comes back and does whatever she wants to do at home. And then we stay well.” (Siya, p5: 160-162)

Although it is not the purpose of this research to enquire into the causation of the findings but instead to explore the meanings the participants ascribe to their experiences, by offering a more holistic understanding of the family context in which the participants exist, a more accurate grounding for interpretation is provided.

It is evident that the participant’s family structures vary from the traditional concept of the nuclear family made up of a husband, wife and children. According to Paruk et al. (2005), and Swartz, (1997) it is not uncommon for families in South Africa to present with varying structural arrangements, where extended family partake in or become responsible for raising the children in order to allow the parents the necessary time to earn an income, as do the parents of the participants in this study.

Most of the participants seem to experience their mothers as providers, more so than nurturers (discussed in detail in the following section) revealing fluidity in their understanding of the role ascribed to motherhood. Similarly, the differentiation from typical, nuclear family structures might contribute to a more positive experience of living with a disabled sibling, where caring responsibilities are shared with extended family members. Examples of this include: Anathi living predominantly with her grandparents and extended family, although her parents live nearby and when asked who looks after her sister during the day, she replies, “Its me, grandpa and our middle sister” (Anathi, p23: 108). Busi, refers to her cousin as ‘cousin brother' and describes him as her closest family ally. He is also largely responsible for the caretaking of her disabled sibling. Siya and his siblings are raised by a single mother and their grandparents and no mention is made of a father figure. When asked who he is closest to in his family, Siya claims it is it his grandmother.

Subsequently the presence of extended family seems to allow for alliances to be formed and sufficient nurturance to be obtained. In addition the participants might be less inclined to experience feelings resentment toward their disabled sibling should they require more attention or caring from their parents. Furthermore, the presence of extended family may reduce feelings of loneliness or isolation subsequently contributing the participant's experiences of their family climate as warm and a place of belonging.

4.2.2.2 Mother as nurturer, provider and someone who understands / feared authoritative and lacking understanding.

As can be noted in Table 2, only one out of the five participants reported their relationship with their mother as being distinctively positive, although she did not describe her mother as her strongest ally. When asked to describe her relationship with her mother Busi bases her positive sentiments on shared understanding and warmth.

> **Extract 33:**
>
> "My relationship with my mother is pretty awesome, like, we understand each other, we talk about anything, and it's great, it is filled with lots of laughter and love." (Busi, p1: 6-7)

Along with a sense of nurturance and understanding, Busi has a very clear sense of her mother as a provider. She has, unlike some of the other participants, a detailed understanding of what her mother does for a living, which demonstrates an interest in her mother's world and further emphasizes the shared understanding between them. She is also able to hold her mother in mind when describing why her mother works and why she is tasked with chores:

> **Extract 34:**
>
> "I think what she is doing right now is to try and provide for both me and Lithando because if she was not doing it, my dad like he is an alcoholic so he

> spends most of his money on alcohol and then my mom is just trying her best to make sure that I live a life that other children are living too, like let us say like my friends they go to VG, she is going to try and make sure that I also fit in the group, you get me! Like, she is just trying to make life, no let me put it like this, she does not want my life to be like hers, like she wants me to get everything that I need, that is why she is doing what she is doing." (…) Now me and my mom take turns, like it is holidays so she can't overwork, I mean she has to watch Lithando, I have to do all the cooking and cleaning." (Busi, p3: 78-84)

One does not get the sense that Busi feels resentful of her responsibilities around the house but has an understanding of what is required of her in order to assist her mother with her brother.

A dominant sense of incongruity was however, noted in the other participants' narratives pertaining to their relationships with their mothers. Anathi (who does not reside with her mother during the week) noted the recurrent disputes that occur between herself and her mother as a result of lack of understanding. Furthermore she made no attempt to highlight any positive attributes in their relationship. She also did not acknowledge any particular alliances to any other family member, yet still experienced the environment as benevolent.

> **Extract 35:**
>
> "My relationship with my mother is okay, sometimes we fight, sometimes we don't see eye to eye on a lot of things." (Anathi, p1: 16-17)

Although unable to detail what her mother did for a living, when asked if she knew why her parents worked, she acknowledged that it was to support the family. One could possibly infer that her experience of her relationship with her mother is currently more as a provider than a nurturer.

Brother and sister, Eric and Dina also expressed feelings of incongruity when asked about their relationship with their mother, although there were again variances in their expereience of this. Both described their relationship with her in positive terms but provided little evidence to suggest that they experience her as being particulary nurturing or warm. It is also worth noting that their mother is a teacher at the school they attend and this, as depicted in their narratives, does impact on their relationship with her. It appears as if they experience her more in her professional context as an authority figure and provider and thus their dominant sentiment is one of respect.

Extract 36:

> "Relationship with my mother uuhm, my relationship with my mother uuuhm, I don't know but uuhm I think I have a close relationship with her too. We speak basically about a lot of things that happen at school. So it's also a mutual relationship." (Eric, p1: 18-21)

Eric emphasizes that he is not a "mama's boy" (Eric, p1: 22-23) and that his closest family alliance is with his brother. He makes no other references to his mother throughout the interview except to acknowledge that the reason she works is "to provide" (Eric, p4: 122) and to emphasize that even she is aware that his personality changes when at home (discussed in further detail in the following section).

Dina describes her strongest family ally as her father due to their shared interests and hobbies. Although she relays her relationship with her mother in positive terms, again one senses the dominant feeling is one of respect as a provider. The fact that Dina feels that her mother knows what is "right or wrong" (Dina: p1: 11-12) for her implies that she feels that her mother understands her.

Extract 37:

> "I have a strong relationship with my mother but it's not that strong enough compared to my father but we love each other that's one thing that I love about her. She's a strict person but I respect her because she knows what's right and what's wrong for me. (…) My mother is the provider for anything I need during school time." (Dina, p1: 9-12)

Siya was the only participant that expressed his relationship with his mother in negative terms. This was an aspect of his narrative that manifested repeatedly throughout the interview and although he struggled at times to converse freely on the matter, he brought it up in various contexts. Siya's father does not feature at all and he describes his strongest family alliance as being with his grandmother. Initially a sense of incongruity is apparent, but later in the conversation he illustrates how this relationship causes him distress.

Extract 38:

"Yo I don't know, Okay we do get along but eish my mother"

"… sometimes we don't get along. She is the one who turns on me and I just leave her like that. Tomorrow she'll be the one begging me. She calls me her child and then I call her mother." (Siya, p1: 21-26)

From the above extract one gets the sense that Siya experiences his mother as inconsistent, contributing to the sense of incongruity underlying their relationship. He seems to be illustrating how he finds her unpredictable, being uncertain on any given day as to how she will react. It appears as though he does not have a solid experience of her as a mother, but feels bound to her simply by the names of their roles in relation to one another, that is; she is the mother and he is the child. The manner in which Siya describes their relationship using these formally assigned titles that lack typical emotive content, suggests perhaps that Siya experiences his relationship with her as empty and formal, with little personal understanding or nurturance.

Siya is also no longer able to attend school as he was involved in a fight and he claims he is scared to return, something that causes him much distress. He wishes to attend a new school but cannot, a decision that was made by his grandmother. He expresses fear and a sense of hopelessness at confiding in his mother about the matter. It is evident through Siya's dialogue that there is very little shared understanding between him and his mother.

Extract 39:

193 **S:** "Yoo my mother swears"
196 **I:** "How do you feel when she swears at you?
197 **S:**" I don't feel good"
198 **I:** "Do you ever tell her that you don't feel good because she swore at you?"
199 **S:** " No"
202 **I:** "What happens inside of you when your mother swears at you?"
203 **S:** " I become heartbroken"
(Siya, p8: 235-246)

It appears from the extracts above that the participants' dominant experience of their relationship with their mothers was one of incongruity, yet there were distinct variances. Where on the one hand there is evidence of connectedness in the form of mutual understanding (Eric and Busi), there is also evidence of feeling misunderstood (Anathi and Siya). It is important to bear in mind that developmentally each of the participants is at a stage that is synonymous with establishing independence, therefore seeking nurturance might not be prioritized as much as 'being understood', however according to Laible, Carlo and Raffaelli, "adolescence is now conceptualized as a period of both growing autonomy and connectedness to parents and other significant adults" (2000, p3).

It is evident from Table 2 above, that four of the participants have substituted their mothers with alternative significant family members as central attachment figures. If this is considered alongside the data provided above, pertaining to their home life and context, one might deduce that their need for nurturance and connectedness are being met albeit not strictly by their mothers.

According to Opperman and Alant (2003), when families with a disabled child receive support from extended family, they experience their circumstances as less stressful, which in turn impacts on how the siblings perceive their disabled sibling. When Grandparents, aunts and uncles assist with baby-sitting responsibilities, cleaning and meal preparation, some of the onus might be removed from the sibling, thereby potentially reducing experiences of resentment. In addition extended family may offer emotional support, which might not be available when both parents are employed and have to care for a disabled child.

This section revealed how the participants experienced family life in the context of the presence of a disabled sibling It took into consideration that the family the structures in this study do not fit the western concept of a traditional, nuclear family mold. This however, is considered the norm for this particular cultural context and was deemed potentially beneficial as some of the caretaking responsibilities were distributed among extended family and did not become the sole responsibility of the participant.

The subordinate theme; *Warmth and Belonging/ Dissonance* emerged as most of the participants relayed their feelings pertaining to their family in terms of warmth, togetherness, belonging and understanding, where their disabled sibling was included but not necessarily central. The participants did not indicate feeling sidelined as a result of the added attention their disabled sibling might require due to special needs being met. This could be explained in terms of the presence of extended family members who are able to offer support and attention. This finding was in accordance with that of Connors and Stalker (2007), who noted from their study on siblings of disabled children, that the family climate was positive and focus was predominantly on similarities as opposed to difference.

These findings were however, contrary to those of Mandleco and Webb (2004), where adolescent participants reported feeling both ignored by their caregivers and not wanting to spend time with their families, opting to be alone or with friends. This was explained by the authors as potentially being developmentally appropriate behavior. It is possible that the variance between the findings by Mandleco and Webb (2004) and the current study can be explained by the presence of extended family.

One of the participants who is being raised by his single mother and grandmother, expressed a contrary perspective, emphasizing feelings of disconnectedness and dissonance in relation to his experiences of family. Of all the participants in the study, he was the most severely affected by his socio-economic circumstances. Supporting evidence suggests that extreme poverty may negatively impact on familial relationships particularly when there is a disabled child present in the family (Bartlett, 1999; Maulik & Darmstadt, 2007; Park et al., 2002).

It also became apparent that the participants felt a sense of incongruity in relation to their experience of their mothers. This was discussed in the subordinate theme *Mother as nurturer, provider and someone who understands / feared, authority who lacks understanding*. Except for one participant, none of the other participants described their relationship with their mother as positive nor did they experience her as particularly nurturing. There was however, a dominant sense that they understood their mother's role as one of provider and most expressed a level of understanding present in the relationship.

The outlying participant experienced his relationship with his mother as unpredictable and gave the impression that he felt quite fearful of her. He, along with the others listed other family members as their dominant ally, indicating that although their relationship with their mother is not typically nurturing, other family members may meet these personal needs. Although one cannot make causal links, one might infer that this dynamic might be due to the stress experienced by the mothers, firstly, as a result of firstly raising a disabled child and secondly, contending with constant financial strain (Kearney & Griffin, 2001; Mobarak, 2000; Lansdown, 2002; Saloojee et al., 2006). These findings were however, contrary to those of Jacobs & McMahon who noted mothers as "central in facilitating a sense of belonging and involvement of siblings " (2016, p3). Again, however, in the absence of the mother, but presence of other attachments figures, this study demonstrates that siblings do in fact experience belonging and involvement.

In engaging with this theme, I was acutely aware of my 'outsider' status. Firstly, raised in a small, white, nuclear family, my experiences varied significantly to those of the participants in this study. Like many nuclear families, our extended family has always resided in a different province. Secondly, as an adolescent, unlike these participants, I was more inclined to want to be with peers then at home with my family despite the fact that relations with peers were fraught with their own unique tensions. According to Finlay (2003) however, through the process of reflexivity and in being transparent we are able to come to terms with our own understandings and subsequently those who are different to ourselves.

> *"Our understanding of 'other-ness' arises through a process of making ourselves more transparent. Without examining ourselves we run the risk of letting our unelucidated prejudices dominate our research. New understanding emerges from a complex dialectic between knower and known; between the researcher's past pre-understandings and the present research process, between the self- interpreted co-constructions of both participant and researcher. Between and beyond..." (Finlay, 2003, p 108)*

Although cautious not to imply causal links between (most of) the participant's positive experiences of their family climate and the presence of extended family, I was struck by the extent of the value the presence of extended family contributed to the participant's experiences. Furthermore, considering their developmental stage, I had not expected the participants to relay their experiences of their family climate with such high degrees of warmth and belonging. Furthermore, I had formed certain *assumptions about how poverty may impact on the participants' experienced which proved to be inaccurate.*

4.2.3. Sense of Self in Relation to Disabled Sibling

It is well reported that adolescents experience incongruent thoughts about a host of matters (Opperman & Alant, 2003). The following section highlights the prevailing theme of incongruity in the participants' experience of their sense of self in relation to their disabled sibling.

According to Erikson (1950) identity formation is considered to be the primary developmental task of adolescence as it is during this phase of life that individuals are in the midst of discovering and asserting themselves within their social spheres and overall context. Adolescence is considered a stage in development when profound changes occur in one's sense of 'self' as a result of heightened self-consciousness and sensitivity to peer influence (Sebastian, Burnette & Blakemore, 2008). Opperman and Alant emphasize that "this period in itself is a stressful encounter for adolescents and will have an effect on their coping with the stress of having a sibling with a severe disability" (2002, p442). In the following section it is my intention to interpret the meaning the participants in this study ascribe to their experiences of self in relation to their disabled sibling in this particular phase of life.

It must again be emphasized that although there was diversity amongst the experiences the participants portrayed, which is indicative of the idiographic nature of the data, the pervasive theme of incongruity continued to prevail.

4.2.3.1 Incongruence of Self/Sense of Authenticity

It was noted in the narratives that the participants had a sense of being 'authentic' or their 'true selves', in certain contexts and 'incongruent' in others. Examples of this phenomenon are demonstrated in the following excerpts.

> **Extract 40:**
>
> "Yeah, I am a quiet person but not too quiet (...) when I have to act I get out of my shell but when I'm at home I become quiet."(Anathi, p5: 127-128)

> **Extract 41:**
>
> "I'm usually that crazy person at school and stuff but a person who knows me very well would know that I'm a quiet person who likes to chill alone, talk to nobody and just be myself." (Dina, p3: 93-96)
>
> **Extract 42:**
>
> "So at home I'm like this funny person who's talking to everybody and at school I'm a quiet guy I'm not that fun person." (Eric, p5 : 151-152)

The participants seemed acutely aware that how they perceived themselves was at odds with how they thought their peers perceived them. When asked simply to describe herself, Anathi, unprompted, reveals the incongruence between how she might experience herself and how others might perceive her. Later, when asked directly, how she feels others perceive her, the incongruence displayed initially, is confirmed. Although she acknowledged that others' opinion of her might vary, she appears quite concerned with how she is perceived and seems to assume they have a negative perception, indicating a potential lack in self-esteem.

> **Extract 43:**
>
> "... I do not want to say I am a good person and stuff and then maybe other people see me differently." (...) "I don't know because people see me in different ways, they dont think the same way about me. Maybe one person might say" Yhoo no man this kid is timid" since I am quiet most of the time and someone else might say "why is this child always like this" like that". (Anathi, p5: 136-137)

Interestingly, Anathi experiences herself as most authentic when being gregarious, yet finds it easier to be that way with her peers then she does at home. This indicates to me that she feels less authentic at home which contradicts her depiction of her home life above (extract 24), where people are free to be themselves.

> **Extract 44:**
>
> "I like smiling and laughing, I like talking to people, sometimes I am quiet so at home they would say I am timid because of that." (Anathi, p 4: 119)

Busi initially describes her extroverted tendencies as something she seems fond of, yet when asked to think about herself through a public lens she reveals that this is the very thing she would change about herself if she could.

> **Extract 45:**
>
> … I am a very friendly and bubbly person and I love talking to people (…) I am a pretty dramatic person, I love drama, drama is my passion and art (…). I am pretty loud, I am always loud, talkative yeah. (…) One thing [I would change], is being talkative, I talk a lot, I hate it sometimes, I can't close my mouth, I don't know, I think some people get irritated. There are some people out there who will be like, 'oh gosh this child talks a lot, she is kind of irritating, so there are some people who are like that. So I wish I could be just more down to earth, you know but then I can't. (Busi, p4: 109-111)

Both Anathi and Busi give the impression that they feel they are not well received by others at times; Anathi feels she is experienced as too timid and Busi feels she is irritating because she is too verbose. Both seem to feel it necessary to take on a certain role to be accepted and to avoid being ostracized by their peers (Dyke et al., 2008). It should be taken into consideration, as highlighted by Opperman and Alant, that "the period of adolescence is characterized by personal and emotional conflicts resulting from teenagers' search towards self-identity and autonomy" (2002, p441). Furthermore being accepted by peers and supported by peers is vital in the development of self- identity (Opperman & Alant, 2002). According to the authors however, the support of peers for adolescents with a disabled sibling is crucial in coping with the potential stress and complexities their sibling might bring, subsequently, lack thereof may potentially contribute to siblings experiencing difficulties with self-esteem and self- confidence, loneliness and isolation.

This also relates back to Burke's (2009) theory of 'disability by association', in which the daily experiences siblings are confronted with, are impacted on by their disabled sibling. In this case the girls feel it necessary to censor their self-portrayal to accommodate for something they assume is lacking in themselves. Although there is a risk of over interpretation, this might possibly as a result of their sibling's impairment. Sensitivity to negative public perception is explored in further detail in the following section.

Eric considers himself quiet when with peers and attributes this to his lack of confidence. He is so acutely aware of how this alters his sense of self that he makes reference to wanting only “one personality” (Eric, p6: 179) as opposed to the two he seems to experience himself as occupying. It is also evident in his narrative that the incongruence of self he experiences causes him distress and is something he would want to change.

Extract 46:

> “I’m a different person at home compared to when I’m with people. So what I’d like to do is to have one personality so the person I am at home is translated to when I’m with everybody so that’s the person I would like to be. So the funny outgoing person that I am at home, I would like to be around people. (…) If I could change anything about myself I’d change the way I see myself because I am not really confident about myself, with making friends. I’m not that easily outgoing person but when people approach me and talk to me they really wanna know me more… So what I would change about myself is my confidence.” (Eric, p6 :177-181)

Siya responded with questions pertaining to his sense of self with resistance and much silence. After much prompting he responded by referring to himself as a “quiet child who likes his friends” (Siya, p4:196). This lack of willingness to discuss himself and the use of a diminutive pronoun suggests perhaps that he may have a perception of himself as being inferior and not worth talking about. When asked how he thought others would describe him he says “as a good child.” Again, although ‘good’ he expects others would consider him as little, which may suggest incapable or irresponsible.

As indicated above, the participants all related different understandings of how they experienced their sense of self. It seems they conducted themselves in their interpersonal relationships based on assumptions of what others would find most appealing which would then lead to acceptance and inclusion. According to Opperman and Alant;

“issues surrounding self-identity and peer conformation are particularly important (…) yet the impact of having a disabled sibling may exacerbate the challenges in the psychological adjustment of adolescents, as they appear to be prone to experiences of shame, guilt, stigma and extra care giving responsibilities" (2003, p 442).

4.2.3.2 Negative public Perception

It was evident in two of the participants' discourse how the fear of negative public perception, especially pertaining to their sibling's disability impacted on them. When Eric was asked how having a disabled brother made him feel, although predominantly positive about his brother, he acknowledges in this instance how he experiences being considered 'different' as a result of his brother's disability. He elaborates by saying how being separated from the crowd due to this difference causes him some distress. He also notes how discussing the matter with his peers causes him discomfort.

> **Extract 47:**
>
> "Having a brother with a disability also separates me from the crowd. So my friends always like ask me about my brother and I'm different because I have a brother with a disability. (…) I don't like to be separated from the crowd that much so at times I feel like 'Why are you asking and stuff?' I'm not comfortable talking about it actually." (Eric, p2: 47-48 & 56)

When Dina is asked the same question, she also emphasizes the difficulty she experiences talking to others about her brother's disability to the point of wanting to avoid acknowledging his disability when in the company of peers.

> **Extract 48:**
>
> "[It doesn't make me feel] good because sometimes when people ask me about my brother or anything else it's hard to tell them 'ba' no guys I have a brother who's disabled. I just say yah I have a brother, a big brother that's all I don't go further and explain to them because I don't want them to ask me questions and all those stuff so I let it be just like okay fine. It's like that I have a brother that's all. Any questions? Please don't ask." (Dina, p2: 38-42)

It is evident from the above excerpts, that neither Eric nor Dina feel comfortable discussing matters pertaining to their brother's disability with peers, which leaves one wondering whether they feel supported by their peers at all.

According to Opperman and Alant (2003) peer conformation is a crucial element of the development of self- concept during adolescence as they try to establish independence. Seiffge-Krenke and Shulman (1993) highlight the fact that during adolescence it is often peers who assume the role of the significant emotional support structure and provide the context where feelings of self-worth may be fostered. If the reaction of peers is assumed to be negative, according to Sebastian et al (2008), this may also translate into a negative evaluation of self. In addition a perceived negative response from peers toward their disabled sibling may possibly affect their relationship with their sibling (Opperman & Alant, 2002).

It was noted that, unlike the other participants, at no point during the interview does Dina mention her friends. She describes her preferred leisure activities as spending the day with her brothers and family and her favorite aspect of school as acquiring new knowledge, making no social references. She also describes, “chilling alone, talking to no one” (Dina, p3: 95-96) as something she is most inclined to do. One does not get the sense that Dina experiences much support from her peers. Although Eric describes himself as “ a quiet guy” and “not that fun person” (Eric, p5: 152) he reveals he does have friends, although he struggles to confide in them and feels more confident with his siblings.

Extract 49:

> “I do have friends at school, I have a lot of friends at school. Everybody sees me as a friend. I have boundaries . (…)Well when I get used to people, I open up I have confidence in myself, which is with my siblings. My siblings understand me as a very different person to what people at school would.” (Eric, p5: 154-156)

It is more evident in Eric’s narrative that, unlike his sister, he has a social world that is separate from his family, albeit seemingly superficial. He relays his difficultly making friends as being due to his lack of confidence, potentially as a result of fear of stigmatization due to his brother’s disability. The following excerpt provides evidence of this.

Extract 50:

> “Recently we went to a youth camp that was seven days long and there was this guy that was in my group and he introduced himself to me and we spoke.

> And we were so alike, we were really alike, we were like close friends and I was asking myself why didn't I walk up to this guy earlier. So what I would change about myself is my confidence levels." (Eric, p5: 160-165)

Both Eric and Dina express difficulty in being open about their brother's impairment, feeling silenced by what they perceive others will think. Heidi Lourens (2016) offers valuable insight on the politics of silence in relation to disability via the social model. According to Lourens, disability related silences are "created through the confluence of inaccessible physical and social environments and the psychological internalization of these worlds" (2016, p 1). That is, much of societies negative perception on disability is in fact internalized by the disabled and their families (Burke, 2009), often diminishing their confidence to speak out about disability for fear of not being stigmatized or making others uncomfortable. Although Anathi did not indicate that she felt personally stigmatized by her sibling's disability, she did acknowledge that she was very aware that disabled people are often mistreated and when asked if there was anything in the world she would change, she highlights wanting to change the way people view and treat disabled people.

> **Extract: 51**
>
> "If there's anything I could change it's disabled people. With the people who are not disabled I could change the way they treat disabled people, like they dont treat them right and then ya, they dont treat them well and then like if there's a disabled person at their home who is old they dont take care of them but when they get grant money they want to be close to them and then leave them again. "(Anathi, p 6: 157-161)

In attempting to understand how the participants understood their selves as the sibling of a disabled person, a strong sense of incongruity is noted. The subordinate theme *Incongruence of Self/Sense of Authenticity* examined the tensions described by the participants between feeling and being authentic versus trying to be what they assume others want them to be. The sense of incongruity experienced by the participants was considered in light of the developmental stage they are in, that is; adolescents attempting to forge an identity, but also in terms of Burke's (2009) theory; disability by association. Consequently, the participants' experiences of themselves and how they assume the world perceives them is impacted on by their sibling's impairment. This led to a further sub-theme: *Negative Public Perception.* The participants expressed fear of negative public perception due to their sibling's disability, listing feeling different or separate and feeling unable to discuss their sibling's disability with peers as contributory factors. As was highlighted in the literature review, stigma and prejudice are significant features pertaining to disability in South Africa, as cultural beliefs assert links with curses and punishment (Lansdown, 2002). Subsequently it may be inferred that sibling's experiences will be affected by common community beliefs and discourses resulting in fear that others might have negative views of them.

The findings in this study concurred with research by Bendrix and Sivberg (2007) who ascertained that having a disabled sibling may negatively impact on interpersonal relations. Young people, according to the authors, fear being teased and are apprehensive about discussing their brother or sister's disability with their peers. Jacobs and McMahon (2016) noted in their research that siblings frequently experienced being different as challenging and assimilated it with negative prominence, being misunderstood by non-family members and isolation. Petalas et al. (2009), recorded similar findings, highlighting the fact that sibling frequently acknowledged prejudice, misunderstanding, feeling rejected by peers and anxious about interpersonal relations. Participants also described feeling awkward about their peer's curiosity pertaining to their sibling's disability. As in the case of the current study, young people were often inclined to withdraw from social interactions.

These results are however, contrary to those in research by Opperman and Alant (2003), where participants indicated that they experienced positive interpersonal relations and thought their peers admired them for being able to cope with a disabled sibling. Although a South African study, the context from which the sample in the aforementioned research was drawn is not indicated, it is therefore not clear how cultural factors may impact on aspects such as stigmatization, which may impact on sense of self and interpersonal relations. Furthermore the differences in the findings further illustrate the fact that sibling's experiences are nuanced and varied, and the results obtained in this research specifically reflect the views of the participants involved.

Of all the themes that emerged in this study, I found this one to be the most emotionally confronting. This is perhaps because my own (like many) adolescence *was fraught with existential quandary, but also because with hindsight I am able to acknowledge how significantly my sister's impairment has contributed to my own identity and experiences. As such this reiterates Burke's (2009) theory of disability by association. My choice of occupation, my leisure activities, the manner in which I engage with the world and how I have assumed the world perceives me, have all been informed by my experience of being a sibling to a disabled person.*

Furthermore, I have become aware of how I, like Lourens (2016), had psychologically internalized society's negative perceptions and inability to cope with their discomfort pertaining to disability. I have, on countless occasions silenced myself when someone used the term 'retarded' as a derogative or mocking term. I have even, gone as far as to put people at ease, when they have jokingly used the term and precipitously and awkwardly become aware of my presence. As such, I found myself relating to the meanings the participants conveyed on many levels. This is as Armstrong emphasizes, one of the challenges of being a member of the studied group, to the extent that she claims, "I still remain unclear whether this is my interpretation of an actual phenomenon, or if I am projecting my own need . . . onto my participants." (2001,p. 98). Subsequently, I had to be cautious of projecting any personal assumptions (Russell & Kelly, 2002).

My practice of caution involved personal engagement with the interview schedule, prior to resuming the analytic and interpretive process. This allowed the contrasts between the participants and my experiences to remain discernible.

While analyzing the incongruence the participants experienced in terms of sense of self, and their tendency to oscillate between being who they are and who they feel they ought to be, both similarities and disparities were evident. I have, unlike some of the participants never been particularly concerned with being 'different', however, I have always placed significant pressure on myself to be accomplished and please others. On some level I understand this as my need to compensate for the things my sister may not achieve, but I have also started to embrace the idea that this has largely been because I too, want to be considered 'special'. Similarly, unlike a few of the participants, I never wanted to change the fact that my sister was impaired. At the risk of over interpreting, I wondered if their yearning to be different was an unconscious attempt to change themselves into something society would consider 'good', subsequently compensating for their assumed negative public perception.

4. 2. 4 Daily Living

Where Erikson (1968) highlighted the value of the environment and society in the successful attainment of a stable self- concept in adolescents, Yoder (2000) argued that contexts could also limit adolescents' potential to develop a strong sense of self. Factors including low socio-economic status, limited educational opportunities, or political restrictions are illustrations of such barriers, which would subsequently impact on an individual's experiences of their daily life. Trying to ascertain how the participants experienced their particular contexts based on the fact that they reside in low socio-economic circumstances was a fundamental aspect of this study.

It became evident however, as the participants described their day-to-day routines, that the socio-economic status was not a significant aspect of their experience in terms of living their daily lives. Furthermore, although an underlying awareness of their context was present it was not dominant.

The two subordinate themes that emerged within this superordinate theme were daily living experienced as 'indistinctive or typical / atypical and a sense of 'adequacy / deprivation' amongst the participants.

4.2.4.1 Typical Daily Living/Atypical Daily Living

Much previous research has emphasized that the presence of a disabled child can negatively impact on a typical sibling's daily living experiences in that there is often a lack of family recreational time, there is the increased burden of taking care of their sibling or assisting their overburdened parents with household chores, and subsequently a lack of personal leisure time or opportunities (Bendrix & Sivberg, 2007; Dyke, Mulroy and Leonard, 2008). In less advantaged contexts these challenges may be compounded by high unemployment rate, limited basic resources, difficulty accessing health care, lack of readily available transport (making mobility difficult for those in wheelchairs) and poor service delivery.

The participants in this study did not indicate that they felt overburdened by chores, although most included household responsibilities as a part of their day-to-day activities, albeit sans feelings of resentment. Siya was the only participant that did not mention doing any chores at home. The following extracts provide evidence of this.

> **Extract 52:**
>
> "Maybe I have to do chores like cleaning. My mom cooks in the evening when she comes home then I wash dishes after that." (Anathi, p2: 54-55)
>
> **Extract 53:**
>
> After school… "I sit around with my friends, clean around the house yah" (Busi, p2: 47)
>
> **Extract 54:**
>
> "When I'm at home or doing nothing I usually watch TV, sleep, eat, cook that's all." (Dina, p2: 53-54)
>
> **Extract 55:**
>
> "My mother cooks and then sometimes we take turns. I also cook and my brother also cooks. I get home and then I watch TV and then I do my homework and that's my day basically." (Eric, p3: 70-74)

It was also evident in some of the participant's narratives that there was no sense that their roles were in any way experienced as unusual. Their daily activities included time spent relaxing, watching television and spending time with friends. This gives one the sense that they do not feel limited by the expectations placed on them to relieve their parents of household duties or responsibilities. Only one participant expressed a sense of limitation in her daily routine due to her brother's disability. Busi, described having on occasion to forfeit social time with her friends to look after her brother when her mother had chores to do. She also describes her weekends as consisting of considerable time spent with her brother, although from her description one senses that this is not done regretfully. Furthermore, it appears as though there are no added responsibilities on an average day.

> **Extract 56:**
>
> "When I come back from school, even when we have to write, I can't write during the day, I always feel like doing it at night during the day I become lazy, I don't know why(…) I like watching TV." (Anathi, p2: 58-59 & 69)
>
> **Extract 57:**
>
> "Average day? Okay, I wake up and then fall asleep, eat and brush my teeth and then I go take a bath and then after that I go to school, I take a taxi. After

school… I just sit around with my friends. My favorite part of the day is when *Generations* comes on and then I get to eat.” (Busi, p2: 35-39)

Extract 58:

“I wake up and brush my teeth then bath. (…) I don’t do anything.(…)My friends come to my house early and then I go with them.” (Siya, p3: 92- 102)

Extract 59:

“I get home and then I watch TV and then I do my homework and that’s my day basically.” (Eric, p3: 73-74)

All of the participants, except Siya (who can no longer attend school), describe being involved in various extra mural activities indicating that they experience sufficient free time in their lives to pursue personal pleasures.

Extract 60:

“I like doing drama at school and went to the Shakespeare festival.” (Anathi, p5: 127-128)

Extract 61:

“I hate sport but I love being active doing stuff, being out there and I am a pretty dramatic person, I love drama, drama is my passion and art. If you like, did you see my drawing when you were at the house? I love drawing, you should see it. ”
(Busi, p4: 100-102)

Extract 62:

“When I’m at home or doing nothing I usually watch TV, sleep, eat, cook that’s all. Besides school I like boxing that’s my favourite sport, I’m usually a sit at home person who likes to chill especially with my family (…) I like to do some couple of things like run.” (Dina, p2: 53-56)

Extract 63:

“I think I stopped tennis because my days were very busy because I have rugby on Tuesdays and Thursdays and tennis on Mondays and Wednesdays and it often clashes with band practice. So I get really busy.” (Eric, p5: 144-147)

4.2.4.2 Sense of Adequacy/Deprivation

All of the participants are residents of Joza Township, a community that is largely disadvantaged, earning on average 20% of what the middle class population of South Africa earn and therefore are considered to be residing in low socio-economic circumstances (http://beta2.statssa.gov.za/publications/P0302/P03022014.pdf).

In many low socio-economic circumstances having a disabled child in the family dictates that one of the parents and potential breadwinners is required to stay at home to care for the child reducing monthly income even further (Lansdown, 2002). However, the participants in this study all come from homes where both parents (if present) work. While most were able to at least describe where their parents worked there was incongruity from some about the exact role their parents assumed at work or the details of their duties. The participants' parent's job titles include, street vendor, teacher, employed by army base, employed by radio station and employed by bank. Subsequently, there is a great variance in the potential family income.

When asked why they thought their parents worked, they all replied, "to support us". Siya specifically listed what these provisions included, and it is evident by what he describes that these are very basic needs that need to be met.

Extract 64:

"To take care of us, so that we can eat and have clothes." (Siya, p6: 179)

It could be deduced that the participant's might equate work purely with survival, yet when asked what kind of work they personally hoped to do, it seemed some of their choices were based more on personal fulfillment and passion and were not primarily dictated by income or the need to survive. To me this suggests that perhaps their life experiences are not predominantly dictated by a sense of deprivation, but instead there is a sense of adequacy and hope.

Again, the thread of incongruity is apparent as some of the participants included seemingly unrelated options in their ideas for future employment. It appears as if they list a job choice that might satisfy their sense of fulfillment and one they assume will provide a better living.

> **Extract 65:**
>
> "For now I am confused about what I want to be. I wanted to be an actor but I also want to be a lawyer so I dont know which one" (Anathi, p5: 146-147)
>
> **Extract 66:**
>
> "Yes, yooo every day, I dream, even when I look at things I'd be like I'm going to change that, I'm going to do this, I'm going to do that. I've always wanted to be a chartered accountant (…) Boxing I'd like to be a promoter and promote boxing yeah but I'll always be an official." (Dina, p4: 103-108)
>
> **Extract 67:**
>
> I've always wanted to be a scientist so I've narrowed down because scientist is a broad term. I said I want to be a biologist and this year I was like no I want to be something with medicine, to help people maybe come up with a different theory about things that are killing people so I've been with people that are hurt and crying and that does a lot of pain to me. I'd like to keep everyone happy. That's one of the things I'd like to do." (Eric, p7: 223-229)

It is noted in some of the narratives above that there are aspects about their status quo that they wish to change and wanting to provide for others seemed prevalent in some of the following responses. Dina, in responding to a question about the future replies; "Okay yah, I see myself in my Jeep car, you know, providing for my parents" (Dina, p4: 106-107) and when asked the same question, Siya replied simply that he wished to be a soldier so that he could provide for his sibling. When asked if there was anything in the world she could change, Busi makes particular reference to poverty as a whole and highlights the fact that her family does not own a home, yet she is aware that there are other who have less than she does.

> **Extract 68:**
>
> "I feel like the government is not doing enough by helping the people like in South Africa like there are people who do not have houses for example us we don't have a house, we have been looking for a house for years but we still do not have a house. Some kids can't go to school, there is no water, children out there are sleeping on the streets, so what I would change is how the government thinks." (Busi, p4: 118-123)

Although all of the participants were asked to describe their homes, only Busi made reference to material aspects, highlighting its modesty by saying “my home is not one of those big house like, with a huge flat screen TV” (Busi, p2; 49-50) The other participants (excluding Siya, who resisted answering the question) described their homes in terms of their abstract attributes using terms such as ‘peaceful’, ‘relaxed’, ‘musical’, ‘warm’ and ‘loving’.

In contrast to the above however, a sense of deprivation was most evident in Siya’s narrative. When asked which days he experiences as being the most challenging, Siya replies; “On Wednesday we can run out of food and then my grandmother gets into a lot of debt. So when people want their money they don’t ask for it nicely.” (Siya, p5: 147-151). Furthermore when describing his favourite day, (with what seems like embarrassment) acknowledges that it is Sunday, because along with time spent with his grandmother, it is a day when there is food.

Extract 69:

Interviewer: “ Do they cook at home on Sundays?’
Siya: “yes sister.”
I: “Is that why you like Sundays?”
S: *giggles* yes
(Siya: p6: 165- 168)

With insight into Siya’s experience of deprivation and based on consistent research findings confirming that mothers of disabled children experience more stress (Kearney & Griffin, 2001; Mobarak et al., 2000, Woolfson, 2004), which is compounded by socio-economic challenges, one can further understand the strain depicted in his relationship with his mother as described in previous extracts. According to Dyke et al., “financial hardship is one of the social and economic determinants impacting on family functioning” (2008, p 23). Park, Turbull and Turbull (2002) also confirmed in their research on the impacts of poverty in families with disabled children, that economic pressure increases conflict between parents and their children especially when a family member is disabled.

The current theme has demonstrated that although the socio-economic circumstances in which most of the participants exist influence their thoughts and decisions, it does not seem to dominate their overall experience of life and one does not sense that they all feel largely deprived in anyway. Other than in Siya's case, there is generally, a sense of adequacy of resources derived from the discourses.

The first subordinate theme *Typical Daily Living/Atypical Daily Living,* revealed that the participants' general day-to-day activities were not experienced by them as distinctive to those of their peers. That is, they did not relay that they thought their roles were in anyway unusual. Four of the five participants did not describe experiencing any extra caretaking responsibilities or household duties as a result of their disabled siblings' needs. Although most participants partook in daily chores, these were not experienced as burdensome and time for leisure activities and relaxation featured in all of their lives.

In the subordinate theme, *Sense of Adequacy/Deprivation,* the participants' experiences of their socio-economic circumstances were explored. All of the participants have working parents and understood that their parents worked to provide for them. Interestingly, most of the participants did not indicate at all that they felt a sense of deprivation or that a lack of financial resources hindered them or dictated their decisions regarding the future. Some of the participants did however suggest that wanting to provide for their families and having certain possessions associated with wealth was something they aspired toward. The facilitators of this sense of adequacy experienced by the participants might again, be explained by the presence of extended family members allowing the parents to work and share care taking and household responsibilities.

In contrast to the dominant findings in this section, one of the participants relayed negative experiences of his socio-economic circumstances, where lack of food, being unable to attend school and a familiarity with debt collectors were familiar occurrences in his world. It was suggested that this added stress might be contributory to his negative experiences with his mother who is confronted with same stressors.

Initially when thinking about the questions for the interview schedule, I had, as a white, privileged sibling, expected to be acutely aware of my 'outsider' researcher status in relation to this theme.

As an adolescent, I had been acutely aware that my sister's impairment had at times incurred large financial costs that impacted on our daily living. Besides the fact that my family has always employed a caregiver, she required special education, *which meant my mother has always had to contribute to the family income. Even with a caregiver, my mother's absence meant that I have been largely responsible for caregiving responsibilities. I had subsequently anticipated that the socio- economic status of the participants would weigh heavily on their overall experiences in relation to their sibling. The fact that I had intentionally included socio-economic status as a qualifying inclusive factor of this study is demonstrative of how significantly I had assumed it would impact on the findings.*

The findings presented above however, relay a different story. Initially I found the disparity between what I had expected to find and what I actually found challenging to accept. The notes I recorded during this stage of the analytic process reveal frustrated attempts to discover an elusive phantom. Nevertheless, through reflective practice, I came to see that I was no longer trying to make sense of the participants making sense of their experiences (Smith & Osborn, 2008), I was superimposing my expectations and in so doing losing the essence of the emerging theme. As Shaw (2010), highlights, through demonstrating my own challenge-to-competency, I hope to have provided evidence of the value of my own reflexivity during this analysis.

4.3 Summary

In this chapter, I presented various issues pertinent to the participants' experiences of being non-adults with a disabled sibling, living in disadvantaged socio-economic circumstances. I was interested in establishing if/how these experiences of disablement affect a non-disabled sibling in disadvantaged socio-economic circumstances and what meaning they ascribe to these experiences.

As such I attempted to understand the meanings presented in light of the social relational model, which does not *simply* equate disability with restricted activity as a result of impairment, but also takes into consideration the social limitations cast on those with impairments (Thomas, 2004) and Burke's (2009), theory of disability by association.

The areas of primary concern were those pertaining to participant's experiences of their family climate (in relation to their disabled sibling), daily living, self-concept and interpersonal relations. Throughout the process of analysis a strong overarching theme of 'Incongruity/Ambivalence' became apparent, where participants seemed at times, unable to express their understanding of their life worlds as either positive or negative. Instead, their narratives conveyed highly nuanced, often contradictory sentiments with an underlying sense of incongruity weaving the four emergent superordinate and seven subordinate themes together. Although, previous research has indicated that a certain amount of ambivalence is synonymous with this developmental stage (Sebastian, Burnette & Blakemore, 2008), it has also been highlighted (Jacobs & McMahon, 2016, Opperman & Alant, 2003) that the presence of a disabled sibling can further impact on the way a young person experiences themselves and their world. It was also evident that strong variances existed between the participants' perspectives. Subsequently the idiographic nature of the study became apparent. At times, the incongruence was more prevalent between the participants' experiences, then within them. An example of this includes the theme 'family climate' where most participants expressed definite positive experiences and only one participant expressed feelings of dissonance.

The findings and discussion summarized in this chapter have provided insight into the life-worlds of the participants and have answered the questions pertaining to their understanding of the relationship with their disabled sibling, their family climate, their self-concept and daily living highlighted in chapter two (Methodology). Moreover it has demonstrated that the participants at times feel incongruent about their experiences and that their experiences in themselves are unique and not generalizable. Several potential factors contribute to the variances in experience including age, gender, birth order, and the type and severity of the impairment their sibling presents with, however, further investigation into these factors is required.

In feeling ambivalent about their experiences, particularly at this stage of their lives, I feel the participants allow for a certain psychological flexibility, that is, it allows them to adapt to a variety of social and personal demands they may encounter as a sibling of a disabled person (Kashdan & Rottenberg, 2010). Feelings of incongruity do not appear to be atypical, and have been suggested by other authors (Opperman & Alant, 2003) to be a means of coping with potential experiences of insecurity and stress.

In relation to the social relational model, this study attempts to understand the meanings the participants ascribe to their sibling's impairment on a micro and macro in "terms of impairment, difference, other people's behaviour towards them, and material barriers" (Connors & Stalker, 2007, p19). It appears from this study, that in accordance with Burke (2009), siblings in disadvantaged socio-economic contexts do experience disability by association. Although not personally impaired, the barriers constructed by the lack of resources, such as transport (as in Siya's case), impact on their lives, in their attempt to assist their siblings. In addition, siblings experience psycho emotional disablism (Thomas, 1999) that is they perceive or anticipate negative responses from society, which impacts on their experiences of self and how they interact with the world. Consequently, 'impairment effects, barriers to doing and barriers to being' are prevalent in the participants' experiences (Connors & Stalker, 2007).

Chapter Five: Conclusion

5.1 Summary of claims from the findings

This research endeavored to understand the lived experiences of young people with a sibling with an impairment, living in disadvantaged socio-economic circumstances. Specifically, it aimed to establish how they experienced their family life, their daily living, self-concept and interpersonal relations.

By utilizing Interpretive Phenomenological Analysis, an approach that employs semi-structured interviews to gather data and a systematic and in-depth approach to analysis it was possible to glean what meanings the participants attach to their life experiences.

Findings from this research suggest that the participants experience a dominant sense of incongruity pertaining to their life world. That is, they do not report their experiences to be either positive or negative, but instead, expressed highly nuanced and often ambivalent understandings of their experiences. Furthermore, within the sample, there were variances between the participant's responses. This is in alignment with previous research conducted on young people with disabled siblings (Bitsika, Sharpley & Mailli, 2015; Mandleco &Webb, 2015; Meaden, Stoner & Angell, 2009; Opperman & Alant, 2003; Petalas, et al., 2009). It is suggested that these variances might be the result of several factors including the nature and degree of their sibling's impairment, the gender and age of the participant and birth order placement of the participant.

The findings from this study revealed that the participants experience a sense of alliance and protectiveness toward their siblings, however, at times these sentiments blur with feelings of sacrifice and responsibility. Furthermore, only one of the five participants wholly understood her sibling's diagnosis and the implications thereof, yet, limited understanding did not appear to impact on the other participants' acceptance of their sibling. In addition two of the participant's attributed their acceptance to their religious orientation.

Four out of five participants reported experiencing a sense of warmth and belonging within their family climate, while one participant, raised only by his mother and grandparents, reported feelings of dissonance. It should also be noted that although all the participants are considered to be socio-economically disadvantaged, the latter participant's financial circumstances are extreme in comparison. It was suggested that this factor might impact on his experiences of family climate.

None of the participants in the current study reported experiencing their mother as nurturing, however, they all had a sense of their mother as a provider. It was noted that all of the participants' mothers are employed; this is considered an anomaly in disadvantaged contexts where usually the mother stays at home to care for the disabled child. In the case of this sample, caretaking responsibilities were divided amongst family members, including extended family and only one participant noted that caring for her sibling impacted negatively on her life. Only one participant described their relationship with their mother as being entirely positive.

A high incidence of incongruity pertaining to self-concept in relation to the disabled sibling was noted among the participants. Although this was considered in light of their developmental stage, it was apparent that concerns with negative public perception, particularly pertaining to peers, concerning their sibling's disability, impacted on the participant's sense of self. In such the participants felt ambivalent pertaining to their interpersonal experiences.

Overall, most of the participants described their day-to-day activities as being not unlike those of a typical adolescent. Only one participant indicated a sense of deprivation in relation to his socio-economic circumstances.

5.2 Implications of this study

As was highlighted in the review section above, there is to date, limited research on the experience of siblings of disabled youth in disadvantaged socio-economic circumstances. Yet, it is known that having a disabled sibling presents with unique challenges and impacts on the experiences of the non-disabled sibling (Bitsika, et al., 2015; Mandleco &Webb, 2015; Opperman & Alant, 2003; Petalas, et al., 2009; Wetherell & Lovall, 2015). Similarly, the barriers that present themselves to families with a disabled child, living in disadvantaged socio-economic circumstances have been documented (Grut et al., 2012; Maulik & Darmstadt, 2007; Park, Turnbull & Ruthford –Turnbull, 2002; Saloojee et al. 2007).

In developing an understanding of these particular participants' experiences, this research aimed to glean where their potential needs may lie. It was noted that at present the participants experience challenges relating to their self-esteem, which may have ramifications for their social and psychological well-being currently and in the future. It was also noted incidentally, that the participants have a very limited support network, besides family. They did not relay feeling supported by peers and gave no indication that they were accessing support from any organizations.

In their write-ups following their interviews, the participants highlighted the value of being given the opportunity to discuss their experiences with someone, describing the experience as pleasant, thought provoking and empowering. One participant noted that it was the first time anyone had enquired about her thoughts and experiences. As a trainee psychologist and the sibling of a disabled person it is suggested that further opportunities to talk about their experiences, be given to young people with disabled siblings in disadvantaged circumstances. Through these discussions, siblings might have the opportunity to be heard and be assisted with in developing coping strategies (Strohm, 2008).

There are currently two non-government organizations in Grahamstown that offer services to families with disabled children who could provide such opportunities; The Association for Persons with Physical Disabilities (APD) and Masibambane. A further suggestion is that a support-group be established. It has been noted (Meyer & Holl, 2009), that connecting with others in similar circumstances is normalizing and can reduce feelings of isolation. Furthermore, by networking with others in similar circumstances, 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 transmogrify (Strohm, 2008). The value of a support-group in this particular context would however, require further investigation as logistical barriers and stigmatization might impact on the adherence of the participants.

In sum, the intention of this study was to gather the voices of the participants so that their experiences might inform future efforts that aim to assist them and others like them in having potential needs met. It could be deduced that the sibling relationships examined in this study reflect a microcosm of the interactions between disabled and non-disabled people in a way that might contribute to how we think about psychoemotional disablism.

5.3 Strengths of this Study

A prominent strength of this study is that it provides a platform for seldom-heard voices. To date there is very little evidence of the experiences of young siblings of disabled people living in poorer contexts, as told by them. In addition, it highlights some of the challenges faced by siblings in relation to their experiences of self and interpersonal relations, drawing attention to aspects, which should be addressed in intervention programs.

A second strength includes the fact that the participants' experiences are viewed in light of the more contemporary, social relational model of disability. Therefore, attention is paid to physical, social and psychological implications of having a disabled sibling. Subsequently this study goes some way to filling in prevailing gaps in the existing literature. Finally, most of the research pertaining to young siblings of disabled people has taken place in the global north, in focusing specifically on a sample from a disadvantaged socio- economic context, this research explores a largely excluded population.

5.4 Limitations of this study

As was stated in the methodology section, a fieldworker was employed to conduct the interviews for this research as none of the participants speak English as a first language. It however, transpired that most of the participants opted to speak in English. Although the utilization of a fieldworker in this study proved useful to some degree, during the process of analysis, certain queries around the overall necessity of a fieldworker arose. This was especially the case where certain themes felt as though they could have been explored more thoroughly had the conversations around them been further developed. Although the fieldworker was trained, was well versed in the interview schedule and had participated in a pilot study, certain topics, although seemingly trivial at face value, might have contributed to the thematic content of the research. As a trainee-psychologist, the primary researcher might have been better equipped to elucidate these intricate details in the narratives during the interviews.

Furthermore, this limitation might have been addressed if a second round of interviews had been set up, but due to time constraints and logistical issues this was not possible.

The fact that some of the participants chose to convey their understanding of their experiences in a second language and the remaining transcripts were translated could in itself constitute as a limitation. It has been acknowledged by Smith et al.

(2009) that, as in the case of this study, the primary means of expressing meaning in IPA is through the use of language. It has therefore been contended that IPA is reliant on representational soundness and authority of language (Willig, 2001). In such it might be argued that some of the essence of what the participants were aiming to convey may have been lost through the means in which they attempted to deliver it. This has however, been contended by Eatough and Smith (2008), who claim that language is in itself culturally bound and subsequently encompasses the participants' life world.

A further possible limitation of this study was that all the interpretations were done by someone from a different cultural and socio-economic background to the participants. This might potentially have created a barrier for total immersion and coloured the manner in which the participants' understandings of their life world was implied. Through the use of thorough reflexive practice I attempted to mitigate this.

Finally, as noted in the introduction, being the sibling to someone with a disability, might as the primary researcher, create the potential for insider bias to transpire. Where it might be determined that insufficient distance would limit my ability to conceptualize the participant's experiences objectively (Dwyer & Buckle, 2009). However, as Dwyer and Buckle, 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 (2009, p59). As such reflexivity has been a pivotal aspect of this project.

5.5 Suggestions for further research

A distinctive aspect of the findings of this study was the variance in the participants' responses pertaining to their experiences in relation to their sibling's disability and how it impacts on their day-to-day life. This finding, as stated above (in section 5.1) is in alignment with research findings by other authors (Bitsika, Sharpley & Mailli, 2015; Mandleco &Webb, 2015; Meaden, Stoner & Angell, 2009; Opperman & Alant, 2003; Petalas, et al., 2009). The aforementioned authors have suggested that the variances may be the result of several factors including the nature and degree of the disability, the age and gender of the sibling and the birth order of the children in the family. One suggestion for further research would be to compare the experiences of young female siblings to those of young male siblings of disabled children, living in socio-disadvantaged circumstances. It would be of value to establish how/if gender differences impact on the sibling's overall experiences in contexts that are largely dominated by patriarchal and gender specific practices.

A second suggestion for further research would be a deeper exploration into siblings' of disabled children experiences of their relationship with their mother. Although this was encompassed in the current study, it would have been of value to have a clearer understanding of the lack of nurturance depicted in the narratives and if the participants thought their disabled sibling experienced more nurturing from their mothers. Furthermore, it would be of interest to establish if the experience of limited nurturance from their mother correlates with the fact that they are employed.

Finally, it would be valuable to invite the participants to engage in a support group for a specific period and then to repeat the study, following their engagement, in order to ascertain the value and feasibility of such groups in disadvantaged socio-economic circumstances. It would also be of interest to gauge whether participation in a support group impacts on the participants' experience of incongruity with regards to their sense of self and interpersonal relations.

Concluding remarks

By listening to the stories told by a relatively small group of young people about their 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. It is the hope that these understandings might better inform other studies and interventions related to the field of disability. Furthermore, it is intended that this study create an awareness amongst those already engaged with families where disabled children are present, around the needs of the siblings who are presented with their own, unique challenges.

References

Bagenholm, A., & Gillberg, C. (1991). Psychosocial effects on siblings of children with autism and mental retardation: A population-based study. Journal of Intellectual and Developmental Disability, 35, 291–307.

Bantjes, J., Swartz, L., Conchar, L., & Derman, W. (2015). When they call me cripple: a group of South African adolescents with cerebral palsy attending a special needs school talk about being disabled. *Disability & Society*, *30*(March), 241–254. doi:10.1080/09687599.2014.997352

Barak-Levy, Y., Goldstein, E., & Weinstock, M. (2010). Adjustment characteristics of healthy siblings of children with autism. Journal of Family Studies, 16, 155–164.

Barley, R., & Bath, C. (2013). The importance of familiarisation when doing research with young children. *Ethnography and Education*, *7823*(March), 1–14. doi:10.1080/17457823.2013.841552

Bartlett, S. (1999). Children's experience of the physical environment in poor urban settlements and the implications for policy, planning and practice. *Environment and Urbanization*. doi:10.1177/095624789901100207

Bartlett, S. (1999). Children's experience of the physical environment in poor urban settlements and the implications for policy, planning and practice. *Environment and Urbanization*, *11*(2), 63–74. doi:10.1177/095624789901100207

Beauchamp-Pryor K and Symeonidou S (2014) Introduction. In: Symeonidou S and Beauchamp-Pryor K (eds) *Purpose, Process and Future Directions of Disability Research*. Rotterdam, The Netherlands: Sense Publishers, pp. 1–6.

Biggerstaff, D. L. & Thompson, a. R. (2008). Interpretative Phenomenological Analysis (IPA): a Qualitative Methodology of Choice in Healthcare Research. *Qualitative Research in Psychology*, *5*(March 2016), 173–183. doi:10.1080/14780880802314304

Bitsika, V., Sharpley, C. F., & Mailli, R. (2015). Experiences of Australian siblings of an individual with an Autism Spectrum Disorder. *Child & Family Behavior Therapy*, *37*(2), 93–104. doi:10.1080/07317107.2015.1035972

Bostrom, P. K., Broberg, M., & Hwang, P. (2009). Parents' descriptions and experiences of young children recently diagnosed with intellectual disability. *Child: care, health and development, 36* (1), 96-100. doi: 10.1111/j.1365-

2214.2009.01036.x

Bringewatt, E. H., & Gershoff, E. T. (2010). Falling through the cracks: Gaps and barriers in the mental health system for America's disadvantaged children. *Children and Youth Services Review*, *32*(10), 1291–1299. doi:10.1016/j.childyouth.2010.04.021

Brink, H. I. (1993). Validity and reliability in qualitative research. *Curationis*, *16*(2), 35–38.

Bryman, A. (2012). *Social Research Methods*. (4th ed.). Oxford: Oxford University Press. Children with Autism. 2003;33:99–104.

Chokoe, T., Albino, N., Mthethwa, Z., Viviers, A., Philpott, S., Bailie, S., … Mycroft, Z. (n.d.). Study on Children with Disabilities From Birth to Four years old.

Connors, C & Stalker, K. (2007) Children's experiences of disability: pointers to a social model of childhood disability, Disability & Society, 22:1, 19-33, DOI: 10.1080/09687590601056162

Day, S. (2012). A reflexive lens: Exploring dilemmas of qualitative methodology through the concept of reflexivity. *Qualitative Sociology Review*, *8*, 60–85. doi:10.1017/CBO9781107415324.004

Department of Basic Education & UNICEF. (2015). *Study on Children with Disabilities from Birth to Four Years Old.* Pretoria: UNICEF South Africa

Dunst, C.J. (2007). *Early intervention for infants and toddlers with developmental disabilities*. In S.L. Odom, R.H. Horner, M.E. Snell & J. Blacher (Eds.), Handbook of developmental disabilities (P161-180). New York: The Guilford Press

Dwyer, S. C., & Buckle, J. L. (2009). The Space Between: On Being an Insider-Outsider in Qualitative Research. *International Journal of Qualitative Methods - ARCHIVE*, *8*(1), 54–63. doi:10.1177/1468794112446107

Dyke, P., Mulroy, S., & Leonard, H. (2009). Siblings of children with disabilities: Challenges and opportunities. Acta Pædiatrica, 98, 23–24.

Eatough, V. and Smith, J. A. (2008). Interpretive phenomenological analysis. In Willig, C., Stainton-Rogers, W. *The SAGE Handbook of Qualitative Research in Psychology* (p179-194). London: Sage Publications.

Eatough, V. and Smith, J. A. (2008). Interpretive phenomenological analysis. In Willig, C., Stainton-Rogers, W. *The SAGE Handbook of Qualitative Research*

in Psychology (p179-194). London: Sage Publications.

Edwards, R., Hadfield, L., Lucey, H. and Mauthner, M. (2006). *Sibling identity and relationships, sisters and brothers*. London: South Bank University.

Emmet, T. (2006). Disability, Poverty, Gender and Race. *Disability and Social Change*, 207-231. Cape Town, HSRC Press.

Erikson, E. (1968). Identity, Youth and Crisis. New York: Norton.

Finlay, L. 2003: Through the looking glass: intersubjectivity and hermeneutic reflection. In Finlay, L. and Gough, B. (editors) *Reflexivity: a practical guide for researchers in health and social sciences*. Oxford: Blackwell Publishing.

Graham, L., Ismail, Z., Moodley, J., Munsake, E. & Ross, E., 2014, 'National study on poverty and disability: Summary of key findings: Release 2', Centre for Social Development in Africa, University of Johannesburg, Johannesburg.

Greeff, A. P., & Nolting, C. (2013). Resilience in Families of Children with Developmental Disabilities. *Families, Systems, & Health, 31* (4), 396-405. doi: 10.1037/a0035059

Griffin, Krista M; Lahman, Maria KE; Opitz, M. F. (2014). Shoulder-to-shoulder research WITH children: Methodological and ethical considerations. *Journal of Early Childhood Research*, 1–10. doi:10.1177/1476718X14523747

Griffiths, M. (2009). Parent and child experiences of childhood cancer: An Interpretative Phenomenological Analysis Approach. *Faculty of Health, School of Psychology and Counselling, Queensland University of Technology*, 1–218.

Grut, L., Mji, G., Braathen, S. H., & Ingstad, B. (2012). Accessing community health services: challenges faced by poor people with disabilities in a rural community in South Africa. *African Journal of Disability*, *1*(1), 1–7. doi:10.4102/ajod.v1i1.19

Gupta, A., & Singhal, N. (2004). Positive Perceptions in Parents of Children with Disabilities. *Asia Pacific Disability Rehabilitation Journal, 15* (1), 22-35.

Hastings, R. P. (2003). Brief report: Behavioral adjustment of siblings of children with autism. Journal of Autism and Developmental Disorders, 33, 99–104.

Haegele, J. A., & Hodge, S. (2016). Disability Discourse: Overview and Critiques of the Medical and Social Models. *Quest*, *6297*(March), 1–14. doi:10.1080/00336297.2016.1143849

Irwin, L. G. (2005). Interviewing Young Children: Explicating Our Practices and Dilemmas. *Qualitative Health Research, 15*(6), 821–831. doi:10.1177/1049732304273862

Jacobs, P., & McMahon, K. (2016). "It's different, but it's the same': perspectives of young adults with siblings with intellectual disabilities in residential care. *British Journal of Learning Disabilities*. doi:10.1111/bld.12169

Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: being a parent of a child with developmental disability. *Journal of Advanced Nursing, 34* (5), 582-592.

Kelly, S. E. (2005). "A Different Light": Examining Impairment through Parent Narratives of Childhood Disability. *Journal of Contemporary Ethnography, 34* (2), 180-205. doi: 10.1177/0891241604272065

Lansdown, G. (2002). Disabled Children in South Africa: Progress in Implementing the Convention on the Rights of the Child. Retrieved March 20, 2014 from http://www.predoc.org/docs/index-145988.html

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. Qualitative Research in Psychology, 3, 102-120.

Lawrence, L. P. (2008). Hardly a Walk in the Park: Examining Disability through a Mother's Eyes. *Journal of Loss and Trauma, 13*, 528-540. doi: 10.1080/15325020802173488

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.

Lipenga, K.J., 2014, 'Disability and masculinity in South African autosomatography: original research', *African Journal of Disability* 3(1), 1–9. h p://dx.doi. org/10.4102/ajod.v3i1.85

Lobato, D. J., Kao, B. T., & Plante, W. (2005). Latino sibling knowledge and adjustment to chronic disability. *Journal of Family Psychology : JFP : Journal of the Division of Family Psychology of the American Psychological Association (Division 43)*. doi:10.1037/0893-3200.19.4.625

Lourens, H. (2016). Driving in unheard silence: Disability and the politics of shutting up. *Journal of Health Psychology*. doi:10.1177/1359105316643856

Lourens, H., & Swartz, L. (2016). "It"s better if someone can see me for who I am': stories of (in)visibility for students with a visual impairment within South

African Universities. *Disability & Society*, *7599*(March), 1–13. doi:10.1080/09687599.2016.1152950

Lovell, B., & Wetherell, M. A. (2016). The psychophysiological impact of childhood autism spectrum disorder on siblings. *Research in Developmental Disabilities*, *49-50*, 226–234. doi:10.1016/j.ridd.2015.11.023

Lungile, S., Thwala, K., Ntinda, K., & Hlanze, B. (2015). Lived Experiences of Parents' of Children with Disabilities in Swaziland. *Journal of Education and Training Studies*, *3*(4), 206–215. doi:10.11114/jets.v3i4.902

Macks, R. J., & Reeve, R. E. (2007). The adjustment of non-disabled siblings of children with autism. Autism and Developmental Disorders, 37, 1060–1067.

Martiny, K. M. (2015). How to develop a phenomenological model of disability. *Medicine, Health Care and Philosophy*, *18*(4), 553–565. doi:10.1007/s11019-015-9625-x

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*, 138–156. doi: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. doi:10.1016/j.ridd.2011.11.016

Maulik, P.K. & Darmstadt, G.L. (2007). Childhood disability in low and middle-income countries: Overview of screening, prevention, services, legislation and epidemiology. Pediatrics, 120, S1-S55.

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. doi:10.1111/j.1741-3737.2012.01011.x

Meadan, H., Stoner, J. B., & Angell, M. E. (2009). Review of Literature Related to the Social, Volume 22, Issue 1, pp 83–100.

Medico, D., & Santiago-Delefosse, M. (2014). From Reflexivity to Resonances: Accounting for Interpretation Phenomena in Qualitative Research. *Qualitative Research in Psychology*, *11*(March), 350–364. doi:10.1080/14780887.2014.915367

Meyer, D. & Holl, E. (2014), *The Sibling Survival Guide: Indispensible information for brothers and sisters of adults with disabilities*. Bethesda, The United States: Woodbine House Inc.

Mgwili, V.N. & Watermeyer, B., (2006), 'Physically disabled women and discrimination in reproductive health care: Psychoanalytic reflections', *Disability and social change: A South African agenda*, 261–272.

Miech, R., Essex, M. J., & Goldsmith, H. H. (2001). Socioeconomic status and the adjustment to school: The role of Self-regulation during early childhood. *Sociology of Education*, *74*, 102–120.

Minujin, A., Delamonica, E., Davidziuk, a., & Gonzalez, E. D. (2006). The definition of child poverty: a discussion of concepts and measurements. *Environment and Urbanization*, *18*(2), 481–500. doi:10.1177/0956247806069627

Mji, G., Gcaza, S., Swartz, L., MacLachlan, M. & Hutton, B., 2011, 'An African way of networking around disability', *Disability and Society* 26, 365–368. http://dx.doi.org/10.1080/09687599.2011.560419

Mji, G., Maclachlan, M., Melling-Williams, N. & Gcaza S., 2009, 'Realising the rights of disabled people in Africa: An introduction to the special issue', *Disability and Rehabilition* 31, 1–6. http://dx.doi.org/10.1080/09638280802280288

Mobarak, R., Khan, N.A., Munir, S., Zaman, S.S. & McConachie, H. (2000) Predictors of stress in mothers of children with cerebral palsy in Bangladesh. *Journal of Pediatric Psychology*, *25(6), 427-433.*

Moolman, K. (ed.), 2010, *Tilling the hard soil: Poetry, prose and art by South African writers with disabilities*, University of KwaZulu-Natal Press, Pietermaritzburg.

Moyson, T., & Roeyers, H. (2012). 'The overall quality of my life as a sibling is all right, but of course, it could always be better'. Quality of life of siblings of

Moyson, T., & Roeyers, H. (2012). "The overall quality of my life as a sibling is all right, but of course, it could always be better". Quality of life of siblings of children with intellectual disability: The siblings' perspectives. *Journal of Intellectual Disability Research*, *56*(1), 87–101. doi:10.1111/j.1365-2788.2011.01393.x

Oliver M (2009) *Understanding Disability: From Theory to Practice* (2nd edn). Basingstoke: Palgrave MacMillan.

Oliver M and Barnes C (2012) *The New Politics of Disablement*. Basingstoke: Palgrave Macmillan.

Opperman, S., & Alant, E. (2003). The coping responses of the adolescent siblings of children with severe disabilities. *Disability and Rehabilitation*, *25*(9), 441–454. doi:10.1080/0963828031000069735

Ortlipp, M. (2008). Keeping and Using Reflective Journals in the Qualitative Research Process. *The Qualitative Report*, *13*(4), 695–705. Retrieved from http://www.nova.edu/ssss/QR/QR13-4/ortlipp.pdf

Parish, S., Rose, R., & Grinstein-Weiss, M. (2008). Material hardship in US families raising children with disabilities. *Exceptional Children*, *75*(1), 71–92. doi:Article

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), pp 151–170. doi:10.1016/S0168-9525(99)01751-5

Payne, S., Ward, G., Turner, A., Clare Taylor, M., & Bark, C. (2013). The social impact of living with developmental coordination disorder as a 13-year-old. *British Journal of Occupational Therapy*, *76*(August), 362–369. doi:10.4276/030802213X13757040168315

Petalas, M. a., Hastings, R. P., Nash, S., Dowey, A., & Reilly, D. (2009). “I Like That He Always Shows Who He Is”: The perceptions and experiences of siblings with a brother with autism spectrum disorder. *International Journal of Disability, Development and Education*, *56*(4), 381–399. doi:10.1080/10349120903306715

Phelan, S. K., & Kinsella, E. a. (2012). Picture This . . . Safety, Dignity, and Voice--Ethical Research With Children: Practical Considerations for the Reflexive Researcher. *Qualitative Inquiry*, *19*, 81–90. doi:10.1177/1077800412462987

Probst, B. (2015). The eye regards itself: Benefits and challenges of reflexivity in qualitative social work research. *Social Work Research*, *39*, 37–48. doi:10.1093/swr/svu028

Reindal, SM. Journal, E.,. (2016). A social relational model of disability : a theoretical framework for special needs education ?, (May 2008). doi:10.1080/08856250801947812

Rose, P. (1985). *Writing on women: Essays in a renaissance*. Middletown, CT: Wesleyan University Press.

Saloojee, G., Phohole, M., Saloojee, H. & Ijsselmuiden, C., (2007), ’Unmet health, welfare and education needs of disabled children in an impoverished South African peri- urban township', *Child; care, health and development* 33(3), 230–235. http://dx.doi. org/10.1111/j.1365-2214.2006.00645.x, PMid:17439434

Saunders, B., Kitzinger, J., & Kitzinger, C. (2014). Anonymising interview data: challenges and compromise in practice. *Qualitative Research*, 1468794114550439–. doi:10.1177/1468794114550439

Saville Young, L. (2016). Key concepts for quality as foundational in qualitative research: milkshakes, mirrors and maps in 3D. *South African Journal of Psychology*, 1–10. doi:10.1177/0081246316630146

Schneider, M., 2009, 'The difference a word makes: Responding to questions on "disability" and "difficulty" in South Africa', *Disability and Rehabilitation* 31(1), 42–50. http://dx.doi.org/10.1080/09638280802280338

Schneider, M., Dasappa, P., Khan, N. & Khan, A., 2009, 'Measuring disability in censuses: The case of South Africa', *ALTER - European Journal of Disability Research / Revue Européenne de Recherche Sur Le Handicap* 3(3), 245–265. http://dx.doi.org/10.1016/j.alter.2009.04.002

Sebastian, C, Burnette,S and Blakemore, SJ. (2008) Development of the self-concept during adolescence Trends in Cognitive Sciences, Volume 12, Issue 11, 441 – 446.

Seiffge-Krenke I, Shulman S. Stress, coping and relationships in adolescence. In: Jackson S, Rodriguez-Tome H (eds.) Adolescence and its social worlds. Hove: Lawrence Erlbaum Associates Publish- ers, 1993.

Shakespeare, T. & Watson, N. (2001) The social model of disability: an outdated ideology? in: *Research in social science and disability, volume 2, exploring theories and expanding methodologies* (Elsevier Science Ltd), 9–28.

Shakespeare T (2014) *Disability Rights and Wrongs Revisited.* London: Routledge.

Shaw, R. L. (2010). Embedding reflexivity within experiential qualitative psychology. *Qualitative Research in Psychology*, *44*(0), 233–243. doi:10.1080/14780880802699092

Simkiss, D. E., Blackburn, C. M., Mukoro, F. O., Read, J. M., & Spencer, N. J. (2011). Childhood disability and socio-economic circumstances in low and middle income countries: systematic review. *BMC Pediatrics*, *11*, 119. doi:http://dx.doi.org/10.1186/1471-2431-11-119

Smith, J. a. (2010). Interpretative phenomenological analysis, 1–27. doi:10.1037/13620-005

South African Statistics. *Monthly earnings of South Africans 2014.* Pretoria. Retrieved from http://beta2.statssa.gov.za/publications/P0302/P03022014.pdf [accessed on 5 March 2015]

Stalker, K., & Connors, C. (2004). Children's perceptions of their disabled siblings: "She"s different but it's normal for Us'. *Children and Society*, *18*(3), 218–230. doi:10.1002/chi.794

Stanescu, D. F., & Romer, G. (2013). What are the Main Coping Strategies Used by Adolescents with Traumatic Brain Injured Parent? An Interpretative Phenomenological Analysis. *Procedia - Social and Behavioral Sciences*, *78*, 345–349. doi:10.1016/j.sbspro.2013.04.308

Strohm, K. (2008). Guest Editorial Too important to ignore : Siblings of children with special needs, *7*(2).

Swartz, L., Scheider, M. & Rohleder, P. (2006) HIV/AIDS and Disability: New Challenges. *Disability and Social Change,* 108-115. Cape Town, HSRC Press.

Swartz, L. (2014). Five challenges for disability-related research in sub-Saharan Africa. *African Journal of Disability*, *3*(2), 6 pages. doi:10.4102/ajod.v3i2.149

Swartz, L., van der Merwe, A., Buckland, A. & McDougall, K.L. , 2012, 'Producing boundary-breaking texts on disability issues: The personal politics of collaboration', *Disability and Rehabilitation* 34, 951–958. http://dx.doi.org/10.3109/09638288.2011.624248

Swartz, S. (1997). Preface: Families in the social context. In C. de la Ray, N. Duncan, T. Shefer & A. van Niekerk (Eds.), Contemporary Issues in Human Development: A South African Focus. Johannesburg: Thompson.

Thomas, C. (1999). *Female forms: experiencing and understanding disability* (Buckingham, UK, Open University Press).

Tracey, S. J. (2010). Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. *Qualitative Inquiry*, *16*(OCTOBER 2010), 837–851. doi:10.1177/1077800410383121

Van Allen, K., & Sterling, Y. M. (2011). Pediatric Nurses Address Children and the Economy. *Journal of Pediatric Nursing*, *26*(4), 369–372. doi:10.1016/j.pedn.2011.04.026

Van Rooy, G., Amadhila, E.M., Mufune, P., Swartz, L., Mannan, H. & MacLachlan, M., 2012, Perceived barriers to accessing health serivces among people with disabilites in rural northern Namibia. *Disability and Society* 1–15, iFirst ar cle. DOI: 10.1080/09687599.2012.686877.

Watermeyer, B. (2008). Conceptualising the psycho-emotional aspects of disability and impairment: the distortion of personal and psychic boundaries. *Disability & Society*, *23*(6), 599–610. doi:10.1080/09687590802328477

Watermeyer, B., (2012). *Towards a contextual psychology of disablism,* Routledge, London.

WHO (World Health Organisation). (2011). The international classification of functioning, disability and health (IFC). Geneva: WHO

Williams, P.D., Piamjariyakul, U., Graff, J.C. & Stanton, A. (2009). Developmental Disabilties: Effects on Well Siblings. *Issues in Comprehensive Pediatric Nursing,* 3:39–55, 2010. DOI: 10.3109/01460860903486515

Wojnar, D. M., & Swanson, K. M. (2007). Phenomenology: An Exploration. *Journal of Holistic Nursing*, *25*, 172–180. doi:10.1177/0898010106295172

Yoder, A. E. (2000). Barriers to ego identity status formation: A contextual qualification of Marcia's identity status paradigm. Journal of Adolescence, 23, 95–106.

Yoshikawa, H., Aber, J. L., & Beardslee, W. R. (2012). The effects of poverty on the mental, emotional, and behavioral health of children and youth: implications for prevention. *Am Psychol*, *67*(4), 272–284. doi:10.1037/a0028015

Appendices

Appendix A: RPERC Approval Letter

RHODES UNIVERSITY
Grahamstown • 6140 • South Africa
PSYCHOLOGY DEPARTMENT Tel: (046) 603 8500/8501 Fax: (046) 603 7614 e-mail: psychology@ru.ac.za

RESEARCH PROJECTS AND ETHICS REVIEW COMMITTEE

Tamlyn Foote Department of Psychology RHODES UNIVERSITY 6140

Dear Tamlyn

ETHICAL CLEARANCE OF PROJECT PSY2015/22

3 June 2015

experiences of siblings of children with disabilities in disadvantaged socio- served at the Research Projects and Ethics Review Committee (RPERC) of the Psychology Department of Rhodes University on 3 June 2015. The project has been given ethics clearance.

Please ensure that the RPERC is notified should any substantive change(s) be made, for whatever reason, during the research process. This includes changes in investigators.

Yours sincerely

Dr Jacqueline Marx CHAIRPERSON OF THE RPERC

Appendix B: RUESC Approval

RHODES UNIVERSITY
Where leaders learn

Rhodes University Ethical Standards Committee, Rhodes University, P O Box 94, Grahamstown, 6140
Tel: +27 46 603 7366 Fax: +27 46 603 8934 Email: ethics-committee@ru.ac.za

13-Oct-2015 Dear Tamlyn Foote

Ethics Clearance: 'The lived experiences of siblings of children with disabilities in disadvantaged socio economic circumstances'

Principal Investigator: Tamlyn Foote

This letter confirms that a research proposal with tracking number: RU-HSD-15-06-0009 and title: **'The lived experiences of siblings of children with disabilities in disadvantaged socio economic circumstances'** was given ethics clearance by the Rhodes University Ethical Standards Committee.

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 or not 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.

Yours Sincerely,

Professor M. Goebel: Chairperson RUESC.

Matthias

Appendix C: APD letters of consent

Dear Tammy

With regards to our meeting on 7th October 2015 and your requests as stated below:

- Assistance with your research project. Which would include making contact with families affiliated with the APD and obtaining their consent to interview one (or more) of their children who have a brother/sister with a disability.
- Obtaining the assistance of Zuki, (who will be reimbursed for her time) to conduct the interviews and assist with obtaining consent from all participants to voluntarily be involved..
- Potentially utilizing our counseling room at the APD, if it is available at the requested time
- Making use of the APD vehicle provided an APD staff member drives it and you cover all the costs of the petrol

We hereby acknowledge your requests and grant approval for the process to go forward.

From the APD (Association for Persons with Disabilities)

Signed

Appendix D: Parent Consent Form (English)

RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

PSYCHOLOGY CLINIC l Tel: (046) 603 8502 l Fax: (046) 603 7203 l e-mail: y.scheepers@ru.ac.za

Dear ………….

I am doing degree in clinical psychology at Rhodes University. I am going to be studying 'what it is like for children who have a brother or a sister with a disability'. My hope is to try and help the APD and the families they work with to offer emotional support to these children. I hope to use the information with further studies.

Francine at the APD has said I can contact you, as you are a parent to a child with a disability who has brothers and sisters without a disability.

I would very much like to spend an hour with your child at the APD. If this is fine with you we can arrange safe transport to the APD from your home.
A field worker from the APD, Zuki will be helping me. She will ask your child a few questions in isi Xhosa about what it is like to have a brother or sister with a disability. We will give your child a snack and a juice and try to make them feel comfortable. Some of the questions Zuki will ask may be difficult for your child to answer, but we will try to make sure they do not feel unhappy and everything they say will be private.

If you would like to help me with this study, please tick the box below and return this form, signed to the Francine at the APD.

I have a child with a disability	YES	NO
Please say (if possible) what kind of disability		
I have other children between the ages Of 10 years and 18 years of age	YES	NO
I agree to let my child to participate in this study if he/she wants to	YES	NO
My child's name is…………………………….		
My child's age is….		

Signed
Thank you for your time and help,

Tamlyn Foote
(Primary Researcher)
079 4757758
tamlynburger@hotmail.com

Lisa Saville-Young
(Supervisor)
046 603 8047
l.young@ru.ac.za

Appendix E: Parent Consent form (isiXhosa)

RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

PSYCHOLOGY CLINIC l Tel: (046) 603 8502 l Fax: (046) 603 7203 l e-mail: y.scheepers@ru.ac.za

………….obekekileyo

Igama lam nguTammy, ndifundela ukuba ngunolwazi ngqondo eYunivesiti yase Rhodes. Ndenza uphando olujonga ukuba kunjani ukuba ngumntwana onobhuti okanye usisi okhubazekileyo. Umnqweno wam kukunceda iAPD kwinkxaso abayenzayo kwiintsapho zababantwana.

UFrancine ophangela eAPD undinike imvume yokuqhagamshelana nawe kuba wena ungumzali womntwana okhubazekileyo onobhuti okanye usisi ungakhubazekanga.

Ndingathanda ukuthetha nomntwana wakho eAPD malunga nokuphila nobhuti okanye usisi okhubazekileyo. Sizakuchitha ixesha elingangeyure kunye nomntwana wakho. Ukuba uyavuma sizakuwenza amalungiselelo malunga nokumthatha umntwana asiwe eAPD aphinde abuyiselwe ekhaya.

Umphandi wase APD uZuki uzakundinceda kulomsebenzi. Izakuba nguye uzakubuza umntwana wakho imibuzo (ngesiXhosa) malunga nokuba nobhuti okanye usisi okhubazekileyo. Umntwana wakho uzakufumana isiselo kunye nento esiwa phantsi kwempumlo.

Eminye imibuzo ingaba nobunzima kumntwana kodwa sizakwenza kangangoko sinakho ukuba umntwana angabi nakungonwabi, kwaye yonke into esizakuyithetha naye izakuhlala ilihlebo phakathi kwam, naye noZuki. Ukuba umntwana wakho uye wakhathazwa yinto ethethiweyo okanye ebuziweyo ungaqhagamshelana no Prof. Lisa Saville-Young osebenza eRhodes Psychology Clinic, yena uzakudibanisa umntwana wakho kunye nomntu ozakumnceda.

Ukuba uyavuma ukundinceda kulophando, nceda beka uphawlo kwezi bokisi zingezantsi, ifom uyinike uFrancine eAPD.

Ndinomntwana okhubazekileyo	EWE	HAYI
Umntwana ukhubazeke phi okanye njani?		
Ndinabanye abantwana abaneminyaka 10-18	EWE	HAYI
Ndiyavuma ukuba umntwana wam athathe inxaxheba koluphando	EWE	HAYI
Igama lomntwana…		
Umntwana wam uneminyaka eyi….		

Enkosi ngoncedo kunye nexesha lakho,

Tamlyn Foote
(Umphandi)
079 4757758
tamlynburger@hotmail.com

Lisa Saville-Young
(Umphathi)
046 603 8047
l.young@ru.ac.za

Appendix F: Participant Assent Form (English)

RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

PSYCHOLOGY CLINIC l Tel: (046) 603 8502 l Fax: (046) 603 7203 l e-mail: y.scheepers@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 at Rhodes University. Part of my studies involves trying to understand what it is like for children like you to have a brother or sister with a disability.

As I don't speak isiXhosa, Zuki has agreed to help me with my work, and she is hoping to speak to you about your life in your family and about what it is like to be a brother/sister to __________.

If you decide that you are happy to talk to Zuki, then Zuki will arrange a time and place with your parents to meet with you. Talking to Zuki about your life as ________'s brother/sister will take about 1 hour and afterwards, you will get something to eat and drink. If you decide at any time to change your mind about talking to us, that will be okay. You don't have to do anything you don't want to.

Zuki and I understand that some of the things you talk about might be very private, and we will make sure that nobody except Zuki and I will be able to know what you said. If it does happen that you feel sad or uncomfortable about anything spoken about during the interview, you are welcome to tell your mom/dad/grandmother to contact Dr Lisa Saville-Young at the Rhodes Psychology Clinic and she will make sure someone is able to talk to you and help you with your feelings.

If you would like to talk with Zuki and be a part of this work then tick this box:

YES, I would like to talk to Zuki about being 's brother/sister ☐

If you would not like to talk with Zuki and you would rather not be a part of this work tick this box:

NO, I would not like to talk to Zuki about being______________'s brother/sister
☐

Signed
(Print Name) age

Tamlyn Foote	Lisa Saville-Young
(Primary Researcher)	(Supervisor)
079 4757758	046 603 8047
tamlynburger@hotmail.com	l.young@ru.ac.za

Appendix G: Participant Consent form (IsiXhosa)

RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

PSYCHOLOGY CLINIC l Tel: (046) 603 8502 l Fax: (046) 603 7203 l e-mail:
y.scheepers@ru.ac.za

…………obekekileyo

Umamawakho/utatawakho/umakhulu wakho undinike imvume yokuzazisa kuwe. Igama lam ngu Tammy ndifunda kwi Yunivesity yase Rhodes. Umsebenzi wam kuku zama ukuqonda kunjani ukuba ngumntwana ofana nawe ono bhuti okanye usisi okhubazekileyo.

Kuba ndingasithethi isiXhosa ndicele uZuki andincede kulo msebenzi. UZuki uzakuthetha nawe malungana nendlela eniphila ngayo kokwenu, ufuna nokuqonda ukuba kunjani ukuphila no………….

Ukuba uyavuma ukuthetha noZuki sizakuthetha nabazali bakho malunga ne ndawo kwakunye nexesha esinokudibana nawe ngalo. Lencoko yakho noZuki izakuthatha iyure enye emva koko uzakufumana isiselo kunye nento yokutya. Khumbula, akunyanzelekanga ukuthetha noZuki. Unelungelo lokutshintsha ingqondo nanini na.

Yonke into oyixelela uZuki izakuhlala phakathi kwam, nawe noZuki. Akekho omnye umntu ozakuyazi, izakuhlala iyi mfihlelo yethu sobathathu. Ukuba uye waziva ukhathazekile emva kwale ncoko malunga nezinto ezithethiweyo kule ncoko uzuncede uxelele umama wakho/utatawakho/umakhulu wakho aqhagamshelane no Prof. Lisa Saville-Young osebenza kwi Yunivesity yase Rhodes, yena uProf. Lisa Saville-Young uzakudibanisa nomntu ozakunceda.

Ukuba uyafuna ukuthetha noZuki nokuthatha inxaxheba kulomsebenzi, nceda beka uphawlo kule bokisi ilandelayo:

EWE, ndiyavuma ukuthetha noZuki malunga nokuba ngubhuti/sisi ka……… ☐

Ukuba akuvumi ukuthetha noZuki kwaye akufuni ukuthatha inxaxheba kulomsebenzi, nceda beka uphawlo kule bokisi ilandelayo:

HAYI, andivumi ukuthetha noZuki malunga nokuba ngubhuti/sis ka……☐
Nceda, tyikitya
(Igama lakho) (Iminyaka yakho)

Tamlyn Foote
(Umphandi)
079 4757758
tamlynburger@hotmail.com

Lisa Saville-Young
(Umphathi)
046 603 8047
l.young@ru.ac.za

Appendix H: Interview Schedule

The Semi-structured Interview Schedule

A. *Family*

(Note: The map drawing method can be used to enable the conversation, see appendix 2)

1) Could you tell me about the people in your family?
2) Who do you think you are closest to?
3) Could you tell me about your relationship with your mother/caretaker/
4) How do you feel about your brother/sister?
5) How are you different from your brother/sister?
6) *If there were an awareness of the sibling's disability*- How would you describe your brother/sister's disability?
7) How does having a brother/sister with a disability make you feel?

B. *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) Can you think of any difficult parts or your day, week?
4) What are your favourite parts of the day, week?
5) Could you tell me what you mother and father (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?
6) What does your (Sibling with a disability) do during the day?
   Promt: Does he/she go to school?/ Who looks after him/her?

C. *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?
5) If you could change anything, what would you change?

Appendix I: Letter to Chairperson of APD

RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

PSYCHOLOGY CLINIC l Tel: (046) 603 8502 l Fax: (046) 603 7203 l e-mail:
y.scheepers@ru.ac.za

Dear Nobesotho, Fioana, Catherine and Francine

I am currently completing a master's degree in clinical psychology at Rhodes University under the supervision of Lisa Saville-Young.
The focus of my research is on developing an understanding of how children and adolescents who have siblings with a disability experience their lives. As I have a sister with a disability, who has worked for the APD in Port Elizabeth for 9 years, this matter is very close to my heart. One of my goals would be to try and assist the APD and the families they are affiliated with in offering support to children who have siblings with a disability in various ways.

I am therefore writing to request your assistance with my research project.
Briefly, it would entail making contact with a few families affiliated with the APD and obtaining their consent to interview one (or more) of their children who have a brother/sister with a disability. The identities of all the participants will be kept confidential.
As the interviews would have to be conducted in isXhosa, we were hoping to seek the assistance of Zuki, (whom we will reimburse for her time) to conduct the interviews for us. We would only need about 4 interviews (about an hour each) and a few hours to train her. We would be sure to arrange this at a time that would be convenient to her and not impose on your schedule either.

Francine has also mentioned that you have a counseling room at the APD, which may be very suitable for our purpose, as it is an environment the parents will be familiar with and will pose few interruptions during the interviews. Lastly, we would need to transport the children safely to the APD and home again, we wondered if it would it be possible to make use of the APD vehicle for this purpose if we cover all the costs of the petrol and gave sufficient notice?

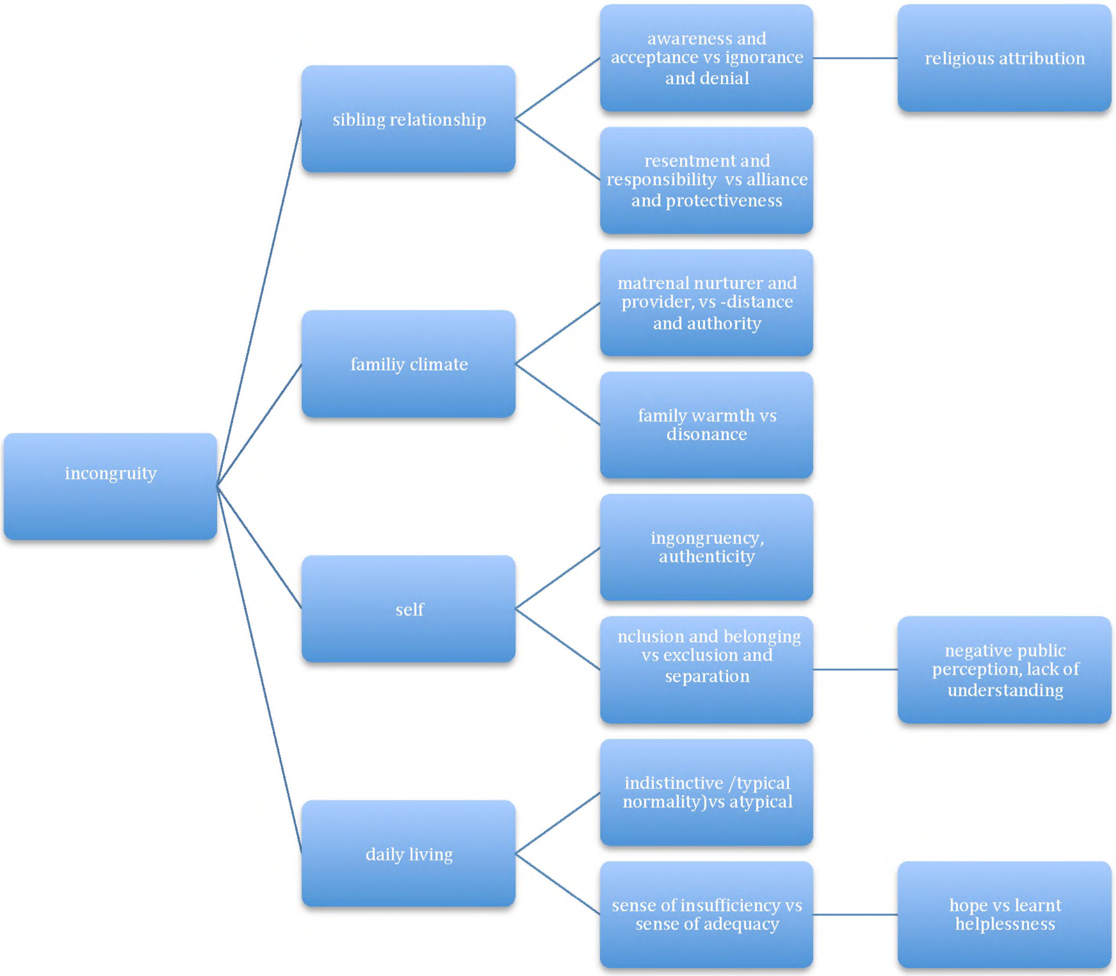
I am hoping that the information I get from the interviews will help me in providing you with some ideas on how we could support for children who have a sibling with a disability in the future as these children are often somewhat excluded or carry a great deal of responsibility in the caretaking of their siblings with a disability. We would greatly appreciate your assistance.

Thank you kindly for your time and consideration.
Tammy Foote
(Primary researcher)

Lisa Saville-Young
(Supervisor)

Appendix J: Examples of Themes and coding

	1. **Interviewer:** Could you tell me about the people in your family?	
Speaks positively about family. Sees entire family as a unit.	2. **Interviewee:** Okay I've got two brothers and then I have my two parents and my mother's sister who's a year older than me but we live as a family, we are a crazy family I would say. We are energetic, funny yah, we love each other more than anything.	**Inclusion "we"**
	3. **Interviewer:** Who do you think you are closest to?	
Closest to her father- again not mother?	4. **Interviewee:** I'd say my dad, we like one thing like boxing so we are very close.	**Maternal distance Alliance with father based on common interest**
	5. **Interviewer:** Could you tell me about your relationship with your mother?	
Respects mother	6. **Interviewee:** I have a strong relationship with my mother but it's not that strong enough compared to my father but we love each other that's one thing that I love about her. She's a strict person but I respect her because she knows what's right and what's wrong for me.	**Maternal distance Ambivalence Respect Strict=fear?**
	7. **Interviewer:** How do you feel about your brother?	
Doesn't like the fact that her brother is disabled, but can't change it. Fantasizes about him being typical. Independent. Sees him as friendly and supportive to her emotionally.	8. **Interviewee:** Honestly sometimes I don't like the matter that he's disabled but I can't change that. It's a fact that will always stay like that because sometimes I feel like I want a big brother who would be able to walk by himself, do his own things by himself but eventually I'll accept him whatever the circumstances are because I love that guy he's friendly, he's nice. Even when I'm sad he's always there, a shoulder to cry on so yah he's a nice person.	**Ambivalence Helpless Acceptance Resentment Alliance with brother- shoulder to cry on**


incongruity
sibling relationship
awareness and acceptance vs ignorance and denial
religious attribution
resentment and responsibility vs alliance and protectiveness
familiy climate
matrenal nurturer and provider, vs -distance and authority
family warmth vs disonance
self
ingongruency, authenticity
nclusion and belonging vs exclusion and separation
negative public perception, lack of understanding
daily living
indistinctive /typical normality)vs atypical
sense of insufficiency vs sense of adequacy
hope vs learnt helplessness

Theme Findings- Daily Living

- **To note:** All participants explain the reason their parents work as a means to support the family, but when asked about their own thoughts about future employment, these decisions seem to be 'passion/dream' based.

Participant A

Distinctive vs Typical	Deprivation
36 Day to day activities are not distinctive from that of a typical adolescents. 36 "Okay, when I wake up on weekdays, when schools are open, I wake up as usual and bath and prepare to go to school. When I go to school I either take a taxi or walk, it depends. When I come back from school if I have homework I do them late not when I come back from school. Maybe I have to do chores like cleaning. My mom cooks in the evening when she comes home then I wash dishes after that." **46 her favourite activities, include watching are not distinctive from typical adolescent 9 no sense of added burden or financial deprivation)** **60 After much prompting she lists Friday as being the most difficult for her as a result of the extra homework she is required to do.**	**40 When asked to describe her home, she does not refer to any deprivation or concrete examples... she describes it in terms of the inhabitant.** 40 "It's a good home, it has relaxed people who can talk, they don't keep things inside, if someone wants to say something they just tell you that it's like this and that." **44 when asked to describe any difficult aspects of her day, she has no examples to give, she does not experience her life as particularly challenging in terms of material deprivation or lack of access to resources, nor in terms of potential added burden/responsibility due to sibling.** **70 When asked why she thinks her parents work, after prompting acknowledged it is to support the family.** 70 "mmm to support us" **101 When asked about her thoughts for the future... she describes 2 vocations that seem interest based... although i wonder whether she wants to be a lawyer as it is high earning?** 102 "For now I am confused about what I want to be. I wanted to be an actor but I also want to be a lawyer so I dont know which one" **112 When asked if there is anything in the world she would change she highlights the fact that disabled people are often taken advantage of**

	as the carers want their grant. 112 "If there's anything I could change it's disabled people. With the people who are not disabled I could change the way they treat disabled people, like they dont treat them right and then ya, they dont treat them well and then like if there's a disabled person at their home who is old they dont take care of them but when they get grant money they want to be close to them and then leave them again. That's what I would change"

Participant C

Distinctive vs Typical	**Deprivation**
27 when asked how he feels about his sister, he explains his care for her by describing how he would miss school to take her to school when the bus left her. I wonder why nobody else in the family would assume this responsibility. Furthermore, if he didn't go to school there are seemingly no consequences… sense of neglect? **28 Interviewee:** I feel okay, with Asemhle even when I was still at school, sometimes I skipped school just so that I can take her to school 29 “ Sometimes her transport would leave her and she would cry to go to school whilst I'm also going to school. So I would choose to take her to school instead. 30 “And what would happen to you when you don't go to school? 31 “Nothing happens” **71 When asked to describe his average day, he describes a basic routine, which does not include added chores or responsibilities even though he no longer goes to school.** 75 I wake up and brush my teeth then bath 82 What do you do during the day 83 I don't do anything… 85 My friends come to my house early and then I go with them **93 he no longer goes to school as he claims he scared to return after someone he had fought with brought a knife to school. He wishes to return to a different school but claims he cannot. The school he went to mostly for street children or children who reside in shelters… I get the sense that perhaps he is unable to return due to monetary constraints.** **181 When asked if there were**	**123 When asked to describe challenging aspects of his week, he claims it is Wednesdays as this is a day they generally run out of food and debt collectors come to claim with his grandmother.** 125 “On Wednesday we can run out of food and then my grandmother gets into a lot of debt. So when people want their money they don't ask for it nicely.” **136 when asked about his favourite parts of the day he says it is Wednesday as he hget to spend time with his grandmother and go to church… further prompting from the interviewer also reveals tat the family generally cook food on Sundays.** 134 Is it better because at least there is a difference, you go to church? 135 “Yes Sister” 136 “ Do they cook at home on Sundays?' 137 “yes sister.” 138 “Is that why you like Sundays?” 139 *giggles* yes **147 when asked why he thinks his mother works he describes very basic needs that have to be met (less general then the other participants)** 147 To take care of us, so that we can eat and have clothes **164 When asked what he thinks about the future he claims he wished to work to provide for his sister.** 165 I think about working for my sibling

anything he wishes he could change about the world he initially says nothing and then says he wishes he could change schools.	

Participant D

Distinctive vs Typical	Deprivation
12 when asked about her bothers disability, one gets insight how this relationship differs from a typical sibling relationship as it require more patience and responsibility. 12 I'd describe it as a tough one because at sometimes when I'm angry and I have to do something for him he'd be like "Ayanda khayenze le nto" "do something like that" inside I'm angry with him but eventually I would do it because he doesn't know how to do it himself so I have to do it for himself you know and It's tough, It's challenging and anything that you can imagine that's hurtful so yah **22 her typical day does not seem distinctive from an average adolescents day..** 22 "**:** I usually walk to school by taxi or I walk by feet it depends on weather. My mother is the provider for anything I need during school time. When I'm at home or doing nothing I usually watch TV, sleep, eat, cook that's all. Besides school I like boxing that's my favourite sport, I'm usually a sit at home person who likes to chill especially with my family.	**32 both parents have skilled jobs= sense of financial stability** **44 when asked about what she thinks about the future… she is the only participant that shows interest in material wealth… she wants an expensive car BUT also she wants to provide for her parents…** 44 Yes, yooo every day, I dream, even when I look at things I'd be like I'm going to change that, I'm going to do this, I'm going to do that. I've always wanted to be a chartered accountant so when I look at myself in the future everyday I'd be like 'okay yah I see myself in a Jeep car' you know, providing for my parents anything like that. So every day I like see the future and I'm very excited about it.