

**The lived experiences of young mothers caring for  
disabled children in South Africa**

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## **Abstract**

A child's disability presents unique challenges and implications to a young mother. A mother's journey of motherhood has to be re-defined when the child is born. Using a phenomenological approach, the current research study attempted to study and look into the young mothers' lived experiences of caring for disabled children. For the interviewing process semi-structured interviews were conducted with three participants who meet the criteria of this research (young mothers/ female carers of disabled children). An idiographic interpretive phenomenological analysis (IPA) was useful in citing the common themes from the information gathered from the interviews. Findings of this research showed that young mothers are faced with compound challenges; as they tried to understand their children's atypical patterns of development. Participants recounted that this was a grieving process that involved mourning for the child they never had or were initially expecting and the motherhood they have imagined. These young mothers also communicated the fact that they have to make some life changes, such as in their professions or occupation and in relationships with family and with their typically developing children.

One billion people live with disability world-wide (ranging from mild to moderate and severe). Approximately 200 million are children and adolescents living with disabilities (20% of them are the youth), also approximately 80% of these children are underprivileged and are experiencing physical, developmental and psychological disabilities (UN Disability Fact sheet, 2006 as cited in UNICEF, 2007). Allied to this, more than 90 million children worldwide aged 0-15 years old have severe disabilities (WHO, 2011). Such disabilities are marked by severe limitations in activity, restrictions in performance and impairment.

With such high statistics, it is shocking how little attention is given to disability issues (Albert, 2004; WHO-Disabilities, 2011), especially where children are concerned. This is also evident when programs and events held for the disabled community tend to be uncoordinated, unsustainable and attended by a small group of people. Thus it is of certainty that making disability as part of the future developmental attempts has a long way to go. Yet the lack of attention given to disabled children is even more disturbing when considering the strong correlation between the child's disability and parental stress. Among parents of disabled children, those with severely disabled children are likely to be rejected and ignored by society and even by their own families (resulting in poor social networks).

To my understanding, South Africa has no dependable or consistent prevalence statistics related to child disability. However, the growing number of disabled children in South Africa suggests that there are numerous families confronted with the challenges of caring for such children. This is particularly the case for mothers- since they are, after all, traditionally the main caregivers for their children (Lutz, Patterson & Klein, 2012).

Having a child/ren with a disability or disabilities in many cases leads to mothers to be subjected to compound stressors relating to finances, lack of support from both the family and society, and limited personal time. This is due to the multiple responsibilities that accompany fulfilling the roles of being a wife or partner, taking care of the child or children with special needs and family, and trying to understand the child's disability (Parker, 2002). Added to this, mothers have to confront the stigmatization, myths and stereotypes that are associated with their child's disability. Consequently, such mothers lead challenging and stressful lives indeed. Thus it is of important to making certain that such mothers are heard

and their needs are met. Consequently of this , this research focussed on the mothers' distinctive experiences and opinions, and on the help that can be brought forward in order facilitate the challenges they are facing (Edwardraj et al., 2010).. According to Woodgate (1998), mothers of disabled children are often forgotten, especially in developing countries. As a result of this negligence, existing research heavily relies on quantitative methods to analyse the views and opinions of mothers caring for such children. These already existing studies were improved , nonetheless, by the use of qualitative research and methods, which provided explorations, descriptions and interpretations of the participants' individual and shared experiences (Fiese & Bickman, 1998).

### **Literature Review**

Previous research on childhood disability has provided evidence that mothers are traditionally the primary carers, and thus are likely to experience emotional stress and other psychosocial problems related to caring for the disabled child. These problems are (1) understanding the child's disability, (2) taking care of the physical and emotional needs of the disabled child, and (3) reducing the impact the disabled child has on the family, social life and occupation (Melnyk, 2000; Roberts & Magrab, 1991; Todaro & Smith, 2009).

### **Theoretical framework**

This literature review seeks to outline the mothers' lived experiences in light of Freud's psychoanalytic approach to parenting. Drawing on Freud's psychoanalytic approach and his "grief and bereavement model", the birth of a disabled child is regarded as a loss of a "perfect" child to the family, and most importantly to the mother of the child. Watermayer and McKenzie (2014) describe the grieving process as chronic distress that explains how a discord between the child the mother expected and the disabled child can lead the mother to be detached from motherhood, which can in turn lead the mother to experience negative feelings towards her child (Howe, 2005).

According to the "grief and bereavement model" a mother with a disabled child goes through 4 stages of grief. First, the mother experiences the presence and birth of the disabled child as a shock, then denial takes over, and then disbelief followed by acceptance of the child. Howe (2005) stated that the mother's progression or transition through this cycle sometimes disrupts family stability. Petterson (2010) discovered that the mother's response to having a disabled child varies. Some mothers experienced some episodic stress levels and despondency, whereas others advocated the importance of this cycle in strengthening their relationships. In a personal account by Crown (2009), mothers of children with disabilities described this transition as meaningful. Thus mothers believed that the psychoanalytic

perspective and its grief and bereavement model facilitated in the navigation of the on-going and multifaceted challenges of caring for a child with a disability. This process was described by Crown (2009) as a transformation from the mother's negative emotions associated with having a disabled child to more positive ones, thus finding balance in their lives. In general, Watermayer and McKenzie (2014) plead for an integrated point of view, valuing the contributions made by Freud's psychoanalytic perspective where feelings of the mothers were supported and understood, and both the material and contextual concerns of mothers regarding their child's development were addressed. The authors state that there is a need for a perspective that can challenge the effect of the disability on the child and the family, and the environmental barriers that they face together (Watermayer & McKenzie, 2014).

### **Effect on family**

When considering how a family deals with having a child with a disability, it seems that the focal point of the literature is on stress, adjustment, and the burden of caring for the child. Maul and Singer (2009) describe this as a "tragedy metaphor" that has always been the definition for the experience of a family caring for a disabled child. However, studies conducted on families with disabled children show that such families are capable of constructing sustainable routines that remark favourably on the 'natural ecology' of families, rather than disrupting it. Hastings and Taunt's (2002) research also recorded positive family experiences. Breitkreuz et al. (2014) suggested the question as to why it is that certain families, but not others, are able to show resilience. Data authorized by a research held by "contact a family" in the year 2003 established that caring for children with disability is likely to bring families together and cultivate stronger relations, but can also be a factor leading to parental separation, with normally the mothers left to be the only caretakers. The majority of these separations occurred because some partners felt overwhelmed with problems related to having a disabled child and separation occurred as a result of such problems. Contributing factors were classified as adjusting to new parental roles, adjusting emotionally, socially and financially. Another important contributing factor is the different coping techniques employed by the family. It is said that the different coping techniques influence the support partners have for each other. The study established that partners who support each other are able to protect each other from pressures and the risk of depression allied to caring for a disabled child.

The 'Social ecology of resilience' developed by Ungar (2011), is a framework that describes 'doing well' out of the ordinary. In a study done on families caring for disabled children, researchers established that a family that identifies itself as 'doing well', in general

feels strongly connected to other family members and thus has a strong sense of belonging to the community at large. In contrast in a family that is 'not doing well,' the research showed that the family's life revolves around the child's disability. Such a family is likely to be detached from each other, not have enough social support and have some financial struggles.

Interested in the adjustment of a single mother, Levine (2009) established a difference in the misleading public discussions on single mothers and disability, and individual experiences. The author recognized four main processes that encourage resilience in single mothers; reframing single parenting as an empowering choice; normalising the child's disability; being confident of one's own capabilities; and making conscious efforts to cultivate social networks.

### **Effect on siblings**

Researchers commonly agree on the fact that the birth or presence of a disabled sibling within a family affects the typically developing siblings. A study conducted by Hames (2008) showed that as early as 7 years of age, siblings already have come to develop a conceptual idea of disability. The amount of information they have gained affects their adjustment. Additional research done by Ferraoil and Harris (2008) on the phenomenon came to similar conclusions.

Throughout the adolescent years, siblings become aware of the causes and long-term effects of their sibling's disability, as well as their imminent individual responsibilities associated with taking care of the disabled sibling. Interviews conducted by Ramson (2009) with teenage siblings indicated that many had worries about future responsibilities associated with the disabled sibling and whether they were able to care and support their siblings the same ways their parents did. Further information from a study conducted by Lach et al (2009) raised issues related to a lack of parental attention. In the study siblings reported experiencing difficulty adjusting to new environments, often feeling isolated and not being given enough attention because of the little emotional support and discipline received.

A study conducted by Levine (2009) was based on the assumption that a family with a disabled sibling experiences more stress. However, their research findings were unforeseen, as they found that siblings of disabled children had a more positive self-concept than siblings of normally developing children. Such views however were significantly different from those of their parents; who had more negative views. This was the case because mothers were at all times concerned with the disabled child, and did not have a correct view of the other child/ren with varying developmental demands and needs. However, Wright and Kirby (1999) warned that even though having a disabled sibling may not be a risk factor in itself, when there are

compound demographic risk factors besieging the family it may possibly be more challenging for the normally developing sibling to deal with the disabled sibling.

### **Cultural Considerations**

Researchers appear to agree that it is of importance to focus on the mother's cultural background to be able to understand the mother's experience. Dempsey and Keen (2008) reviewed literature on families of disabled children and found that cultural responsiveness to disability is an important factor. A study conducted in Bangladesh by Begum (2007) showed that child disability has a significant effect on mothers, in terms of anger, embarrassment and extensive social disapproval and stigma. Exploring the views on 'black' African families, Lawrence (2014) established that acknowledging the child's disability and demands was embedded within religious systems, often with little or no understanding of the child's disability. According to the author such religious systems may act as stumbling blocks in the understanding, adjustment and management of the child's needs. Krause (2002) on the other hand has a different viewpoint, explaining one's culture as complex interactions of individual accounts that are consequent of opinions, emotions, and inspirations of individuals in a community. The author articulates the view that the human condition is free of culture, and thus all social systems are marked by a connection to one another (Krause, 2002).

### **Aims and Objectives of the Study**

The literature reviewed above demonstrates that the experience of mothers caring for disabled children is a complex one, influenced by a range of personal, psychological and social variables. Although there have been efforts made in exploring the mothers' experiences, much of the research has been done with older women (40 years and older) who are caring for or mothering disabled children, as opposed to studying young mothers (18 -30 years of age). Therefore our understanding of mothers' experience of caring for a disabled child is based on the ideas of older women, and younger mothers seem to have been overlooked (Wright & Kirby, 1999). Therefore, the aim of the proposed research study is to explore the lived experiences of mothers aged between 18 and 30 years, who are caring for disabled children. The proposed study further aims to do this by offering rich accounts of these women, by focusing not only on their descriptions and interpretations, but also on the complexities in their experiences. This methodology is in concordance with interpretive phenomenological analysis (see page 7), which views participants as experts in their own lives and thus can offer detailed accounts of their life events or experiences.

#### **Main research question:**

What are the lived experiences of mothers caring for disabled children?

### **Sub-questions:**

- How do mothers experience caring for a disabled child?
- What implications do these accounts of childhood disability have for experiences of motherhood?
- What impact does the child's condition have on other family members?
- In what ways are mothers of disabled children negotiating, managing and approaching their everyday lives?

## **Methodology**

### **Research Design**

#### **Significance of the study**

The research study is convinced to enhance value to the psychology discipline and other similar areas of study at both a theoretical and methodological level in the following ways:

1. The insights into the world of local, black women, who are caring for disabled children, will serve as a contribution to the country's knowledge of this phenomenon.
2. By applying qualitative research methods, this study will be an extension of the local work recently done in the field of child development and other related fields.
3. By generating knowledge of black women's experiences on mothering such children may build a frame to enable to improve these women's daily lives.
4. Possibly findings of the study will be able to inform future interventions within disability and health organisations that will help to provide a more supportive environment for the mothers of disabled children.

In the past two decades, researchers have seen an increase in the application of phenomenological research to qualitative studies, with its various approaches being embraced. Smith (2011) asserts that interpretive phenomenological analysis (IPA) has been the most employed qualitative approach in research, mainly because of its consistency with the epistemological position of the research enquiry. For example, 'IPA places attention on the participant's experience and how he/she understands or makes meaning of particular life events, which in the case of the present study is the investigation of the lived experiences of young mothers caring for disabled children. Interpretive phenomenological analysis assumes that the information or data produced from the research by the researcher shares something about the participants' involvement in the lived world. This approach is devoted to examining



how participants understand their major life events (Smith, 2011). Informed by three major debates within the philosophical knowledge, namely phenomenology, hermeneutics and idiographic, interpretive phenomenological analysis is believed to be appropriate in the achievement of the aims of the proposed study as it will enable the investigator to appreciate the different ways in which participants make sense of their major life experiences (Smith, Flowers & Larkin, 2009).

Built on the work of Husserl, Heidegger, Merleau-Ponty, and Sartre, phenomenology (the philosophical approach to the study of experience) particularly focuses on individual experience. Husserl stressed the importance of the person's own interpretations of his/her life experience by separating "*the what*", which is the phenomenon experienced, and "*the how*", the manner in which the phenomenon is experienced. In the present study, this will assist the researcher to find the essence of the phenomenon under investigation (Smith et al., 2009). This approach was further advanced by Heidegger through his Hermeneutic phenomenology approach- the theory of interpretations. Heidegger advocated that people's existence is not in isolation, but rather in a lived world, thus the meanings they attach to their experiences are influenced by their involvement in the lived world. Hence people can only be accurately understood as functions of their diverse associations with that world (Smith et al., 2009).

This form of analysis assumes that the researcher is interested to learn and understand the unique psychological worlds of participants. This manifests in the form of what Heidegger calls the *Double Hermeneutics* - the relationship between the investigator and those being investigated. Hermeneutics recognises that the interpretive accounts produced by the investigator from the research study are functions of the relationship between the investigator and her participants. Furthermore this approach highlights that such accounts are dependent on and can be complicated by the investigator's own assumptions, opinions, beliefs and biases.

With great influence on Interpretive phenomenological analysis is the final phenomenological approach - idiographic phenomenology. Different from the approaches discussed above, the idiographic approach is not interested in the generalizability of the findings; rather it is concerned with detailed lives and how the particular people under study make sense of their experiences. Thus, the approach is interested in understanding experiences from the perspectives of a small group of participants (Smith et al., 2009). My decision to select interpretive phenomenological analysis as a framework and its idiographic nature will allow me (the researcher) to be the "insider", to be able to hear my

participants' accounts and worries (Larkin et al, 2006) as it is relevant to the proposed study. The use of IPA will give voice to the mothers or women involved about how caring for a disabled child has impacted their lives.

This study adopted a qualitative approach. Qualitative research methods aim to gather in-depth understandings of the participants' lives and experiences. Instead of seeking to test a predetermined hypothesis on a large sample, qualitative research methods seek to understand the experiences of a fairly small sample. Thus the qualitative research approach is believed to be suitable for the proposed study (Creswell, 2009; Smith, 2008).

### **Sampling Strategy**

This research study employed a purposive sampling approach. Thus individual participants were carefully chosen according to the objectives of the study (Babbie & Mouton, 2007). This sampling approach was appropriate for the present research study mainly because it was interested in studying and exploring the distinctive lives and experiences of the individual participants (Riessman, 2008).

A non-governmental organization (children's disability centre) was used to recruit 10 participants for the research study. The NGO identified 10 potential participants who met the inclusion criteria and gave them information sheets inviting them to the study (see Appendix 1). On return of signed invitation letters, there were only three interested participants who were later contacted for interview schedules.

To guarantee a satisfactorily consistent sample, participants who met the following requirements:

1. Biological mother or a female guardian/carer aged between 18 and 30 years

Past research on parents caring for disabled children indicated that there were differences in the ways men and women respond (Reid, Flowers & Larking, 2005). As a result of such differences, the research study only recruited women (Smith et al., 2009).

2. Have a 4 to 10 year old disabled child
3. IsiXhosa speaking
4. Stay in Khayelitsha

### **Data Collection Materials and Procedure**

The research study has made use of semi-structured interviews. (see appendix 3) This form of interview is a commonly used data collection tool (Corbin, 2003). Recommended by Smith and Osborn (2008), semi-structured interviews enable the investigator to facilitate a

more casual conversation with those being studied, thus allowing for the exploration of particular areas of interest pertinent to the research question.

The semi-structured interview schedule developed for this study is provided in appendix 3. The schedule was meant to guide interviews rather than to dictate them; this allowed participants to tell their own stories using their own words. In the research study open-ended questions were employed or introduced as means to get closer to participants' interpretations. I (the interviewer) have followed all the interviews by recording and taking notes of the mothers' thoughts, feelings and impressions as well as kept a record of all the effects in the interviews, for example; disturbances or noticeable details about the environment in which the interview took place in.

Participants have been given an option to choose where they will be interviewed in. Estimated time for interviews was between 40 to 60 minutes per interview. Interviews were audio taped and then later transcribed. For reasons of confidentiality all the participants' identities and names were changed.

### **Data Analysis**

Data analysis was done through the application of interpretive phenomenological analysis as discussed above. Transcripts were analysed independently and sequentially. The process began by familiarising participants' accounts by reading and listening to the recordings repetitively, during which notes have been made on interesting things in the conversation. This included a summary of content, along with some comments on the connections and discrepancies between the personalised interpretations (Smith & Osborn, 2008).

Transcripts and notes made were then used for the documentation of emergent themes. These themes were listed sequentially, to create a group of themes (clusters). These grouped themes were then titled to create superordinate themes. During this process the researcher was continuously revisit the transcripts, to substantiate whether or not such themes reflect what has actually been said by the interviewee. A diagram consisting of themes with the exact transcription extracts was produced (Smith & Osborn, 2008).

The process was reiterated for all interviews. Although connections in themes were seen, caution was taken to acknowledge the issues that emerged in each transcript, therefore giving attention to the ways in which participants' stories are similar as well as different from each other. When all interviews have been analysed, the themes for all the interviews were evaluated and grouped for the creation of a master list of themes for all interviewees. The themes provided a comprehensible outline to understand the young mothers' lived

experiences of caring for disabled children. The themes were later translated into narrative accounts that expanded the analysis and explained the themes, illustrated with verbatim extracts. Measures were taken to make sure that there were discrepancies between what the interviewees said and my own interpretations (Smith & Osborn, 2008).

The employment of IPA in this study provided a different perspective on the lived experiences of mothers caring for disabled children by gaining knowledge from the people who are experiencing the phenomenon, rather than acquiring the knowledge from predetermined ideas in existing research studies (Shaw, 2001). The idiographic nature of the interpretive phenomenological analysis was appropriate for the study as it was interested in studying the detailed lives of small groups of individuals experiencing the phenomenon, rather than seeking to generalise its findings and ideas for larger groups of people (Smith & Osborn, 2008).

Indeed, Smith (2004) suggested that the interpretive phenomenological analysis is by nature enabling the researcher to learn about important generic themes along with the participants' individual stories/accounts. The opportunity to study the phenomenon from a different perspective by gaining knowledge from the people who are experiencing it, rather than from already existing ideas or information, matches well with the objectives of the current study (Reid, Flowers & Larking, 2005; Smith & Osborn, 2008). Furthermore, Interpretive Phenomenological Analysis was mostly convenient for exploring the complexity in mothers' accounts.

## **Ethical Issues**

**Informed consent:** three participants agreed to take part in the study; they were given information sheets which explicitly outlined the objectives of the research and ensured participant awareness (See appendix 2).

**Withdrawal:** I informed participants that their participation was strictly voluntary, and that should they wish to pull out from the research, they have the right to do so without any negative consequences (See appendices 1 and 2).

**Confidentiality:** Participants were informed that all identifying information were anonymised. Furthermore, any information they shared during the interview was not going to be disclosed to anyone or any organization (See appendix 1 and 2).

**Affiliation of study:** I made sure that participants were informed that the research was independent of the services from the children's disability centre and thus their decision to

participate was not going to affect any of the services they received from the organization (See appendix 1).

**Risk:** Although it was hoped that participants appreciated the opportunity to share their experiences, an ethical concern was the potential distress mothers have experience when asked about how caring for a disabled child/ren has had an impact in their lives. Measures were taken to minimise the risk of distress. The interviewees were informed in writing in the information sheets (see appendixes 1 and 2), and verbally before the interview, that they had the right to pull out from the research at any time and did not have to respond to questions they do not feel comfortable responding to. If it did happen that the interviewees felt distressed as a result of the study, I would have provided them with sources of referral (See appendix 2). I am an honour's psychology student with some experience of dealing with distressed people thus interviews were conducted as sensitively as possible.

### **Reflexivity**

According to Willig (2008), the meanings and findings generated from the study do not merely ascend from the data collected, but also from the investigator's own personal and subjective understanding of the research and the phenomena in question (England, 1994; Willig, 2001). Therefore, when conducting a qualitative research it is imperative for the investigator to be aware of her position in the meaning- making process. Failure to do so could undermine the validity of the research study (England, 1994; Willig, 2001).

Just because the research study and approach employed was sensitive to power imbalances, and tried to counteract inconsistencies as much as possible, it did not mean that they did not exist (England, 1994). Such inconsistencies were furthered by the difference in experience (Frith, 1998; Watts, 2006). The investigator is a 22 year old Honours student, with no children, thus allowed for the differences in life experiences of her and the persons she studied. The absence in common experiences acted as a stumbling block to the relationship and understanding of participants' experiences, which consequently had an effect on the interview relationship, and the content of the interview (Tang, 2002). Encouraged by the IPA, it was imperative for me to block out any assumptions and knowledge I held about the phenomena under study. This was achieved by keeping a reflective logbook.

### **Results**

This section includes a report on the findings of the IPA of three participants' life stories and experiences of caring for disabled children. Throughout the analysis of the research results, there emerged the two following super-ordinate themes:

- Making sense of life changing events
- Impact on family dynamics

These super-ordinate themes make up the potential interpretations or understanding of how young mothers' experience of caring for disabled children. Interpretive Phenomenological Analysis stresses that the process of establishing such themes is grounded on the investigator's ability to employ a double hermeneutic, where she (the investigator) tries to make meaning of the mothers seeking to make meaning of their own life events. Therefore, this interpretation is personal. The themes produced from the findings of this research study do not envelop or encompass each and every aspect of the mother's experiences but, the researcher has selected these themes for their applicability and significance to the research questions. The figure below shows the two super-ordinate themes and the sub-themes associated, which will each be discussed and explained with quotes from the transcript.

Super-ordinate Themes	Sub-Themes
Making sense of life changing events	The child I never had
	Uncertainties about the future
	Personal effects
Impact on family dynamics	Adjustment to family circumstances Changing roles of parenting

The researcher selected the order of the themes by beginning at the personal level experience of the mothers, and the impact of the children's disability on family dynamics. Initial questions of the current research study, which are the foundation for the initial discussions with the mothers (participants), have been grounded on delineations of care and management of the child's disability, as well as the recognition of individual growth. Personal effect is one of the most themes of mothers caring for disabled children. This theme feeds into the next theme about how each family of the participants adapts to the unexpected and unfamiliar experiences. For the objectives of this research study, changes to the text extracts have been made. To ensure privacy, the mothers in the current study have been given false names and all

Participant pseudonym	Age	Ethnicity	Marital status	Employment status	Relationship to the child
Bongi	27	Black	Single	employed	Biological mother
Yonela	29	Black	Married	unemployed	Biological mother
Lungi	24	Black	Single	unemployed	Biological mother

Table: 1 provides a brief summary of participant's particulars in order to simplify the reading of this section.

### **Theme 1: Making Sense of the Child's Disability**

Making sense of the child's disability is the process the participants went through subsequent to giving birth children with disabilities. Participants described their experiences and their responses. It seemed that their responses to their experiences were embedded in a wide-ranging absence of knowledge about why they are experiencing this.

The three mothers communicated this process as acknowledging the child's disability, which for some facilitated the ability to manage the challenging reactions linked with the child's disability. For the mothers in current research study, this process was already enabled by health experts and in addition sustained by the participants' parents and families. As their relations with their children advanced, one or two debated their awareness that the children's disability was stable, and they found it important to try to understand it. What appeared to follow was a necessity to cope with the interactions made with the children, whereby the participants can to live with their disabled children without making any major changes to their lives.

#### **1.1. The child I never had**

For all of the mothers, there appeared to be a sense of impact on their personal lives and an alteration from what the mothers envisaged for their motherhood. For Yonela, the shock began during the time she was pregnant (expecting twins), unfortunately losing one of the babies, the surviving baby being disabled. For Bongi and Lungi the recognition or knowledge of something not being right, and then a doctor's confirmation of those worries, was just as devastating.

Yonela describes the changes in her and her husband's life after her disabled child was born. Their parental roles were re-defined, and so do their views and meaning of life:

**Yonela:** *my husband and I went through so much ...It almost felt like a very..ehh.. dark period for us, the thought of our son being in a home one day... and not having grandchildren .. I mean what kind of a future is that??? Is there a future there?.. My husband and I were kinda confused as to our parental roles... I mean we questioned ourselves ..are we parents?, carers? Or what?*

Yonela defined the process as grieving the child she never heard.

**Yonela:** *like any other couple or parents out there, we had dreams of having a big family with children running around the house ...just us and our “children” and those dreams went down the drain, and it just felt like someone died and we were grieving.*

Bongi in the same way referred to this experience as an unsettling sense of loss.

Bongi's words provided a sense of the emotional effect. She as well experienced the difficulty in contemplating the future:

**Bongi:** *I cried a lot... The idea of having a child with a disability was too great for me – I won't lie.. I couldn't stop myself from crying.*

For Lungi, whose late brother had an intellectual disability, getting the information about her child's disability was nearly way too much handle. To the same degree with Yonela and Bongi's experiences, she articulated the sense of loss she had felt.

**Lungi:** *Gosh I don't ever want to feel like that again... I felt helpless and I felt not fit for that in my life... I just couldn't handle it anymore...I can't express how I felt at that moment ... umm.. It's just that no mother wishes for a child like that...it felt someone just threw a bombshell... and I just could not believe it*

Bombshell felt like the most suitable representation for explaining the reality for her, life will not ever be the same again. Such feelings can be applicable to the rest of the mothers in this research study. There were some intense and deep emotions communicated and expressed by all the mothers interviewed. Like most individuals going through a distressing and aggrieving phase time is a healer. Though, some mothers in this research study theirs is a continuous reminder of the child they never had. Such reminders continue with the disabled child's development. Yonela made use of a very expressive representation that possibly summed up all the young mothers experiences:



*Yonela: it was not until I saw my friend's three year old normal baby girl, and she was just doing everything... vocab.. Running around and playing ...and then I always get this sad feeling.. like. I mean that could have been my child.. Who's running around and playing but, you just have to carry on like it's no big deal..*

## **1.2. Uncertainties about the future**

All the mothers developed an understanding and awareness of how their children's disabilities would have permanent effect on their children's future. For Yonela, Lungi and Bongi, the questions concerning the future of their children seemed to be raising even more questions than responses. Such answers are unknown, as the mothers seemed to look into the distant future when they are no longer in the picture:

*Yonela: you know ..(pause) having a disabled child ..You need to be prepared for it whether you like it or not .. I mean it's not like he ..um.. caught a cold or something .. this is real .. it is like..he will never have a career like others ..Nor have children or get married .. I mean ..no woman would want to get married to him... if I die today .. who is going to stand in for me and take care of him?*

*Lungi: back in the days before I had my child.. I used to dream of him going to school, varsity and being successful, having his/her own family. All those dreams disappeared into thin air. Because I know he is not going to be any of that.*

*Bongi: Gosh, you know there isn't any place on this planet for people like her... I am struggling while I'm normal.. So I always think of what will happen to my baby when I'm no longer around'. You know..*

These mothers have to take care of their disabled children till they die. And there are uncertainties surrounding the question of who will look after their children when they are no more. Additionally to this the mothers experience despondency due to the fact that they will never see their children going through the normal developments

For Bongi, her major concern, especially as a single parent, is that as *Unathi* is growing older, she will end up in a home and this is not she would want for her child.

## **1.3. Personal effects.**

All three mothers described individual effects; how they had learned to adapt to their situations and new roles. Yonela described the life she had before the birth of her child as principled. Her whole life changed immediately after her child was born.

***Yonela:** I know that there is a lot changed in my life .. when I look back from who I was back before I had Samkele..i would say I envy the woman I have become.. I was the most selfish person you could ever meet.. I didn't care for no one but me.. I lived in my own little bubble.. The worst thing that could happen to me was if I broke a nail or lost my phone.. That is nothing when measured up with this..*

Both Bongi and Yonela used to work before having children. Bongi had continued, although with reduced working hours. Lungi had been denied to be a flexible worker that she is in the process to fight for. Yonela views herself as having gained self-confidence through raising her son and thus developed expertise that she never had:

***Yonela:** The experience of being a young mother of a disabled child has made me a stronger individual.. I know my worth. My experience has opened many opportunities for me .. I am a motivational speaker at disability centre.. I motivate other young mothers like myself .. I help them help themselves and see their children's disabilities in a different light.*

For Bongi, the impact was even more subjective. Bongi singled out the characteristics she believed to have made her a better mom and an even better individual giving her the ability to enjoy motherhood:

***Bongi...** I was, I'm ehh, am a lot more patient than before , I am very much more considerate, kind and complimentary. Um, I'm clearly resilient...i mean if can take care of my child as a single parent ..what else can't I defeat?*

Bongi goes on to say that if she never gave birth to a disabled child, she would have not been the incredible mother she is.

***Bongi;** you know, I've found that I often think that if he didn't have the special needs that he has, I probably wouldn't be the parent that I am now. I would probably have been you know, a little less patient with him, a little bit more nagging with him.*

Lungi's account differed from the other mothers. Lungi was of the opinion that her entire life was negative and that she failed to live up to her dreams.

*Lungi: I just know and feel like I don't anything to live for .. days with friends and parties have all gone .. I cant seem to do anything these days.. my life seems to have reached a dead stop...I had to let go of everything I loved and hold dearest to my heart ( my job, school, dreams) it just feels like I have sacrificed everything the day I had my child.. I know it sounds really bad but, that's the way I feel ...I tried going back to school to finish my teaching degree but it is just so impossible for me to do it .. especially when I used to work .. I worked 8 hours and then I would always have to work up midnight to make sure he was doing okay , cover him with a blanket .. make sure he is warm.. and then again in the early morning between 4 and 5 o'clock to change his nappies ..hhuh (sigh) it was just so impossible for me to do something with my life... im only 24 (laughs)and in many instances I feel like im way too old and I have failed myself.*

Although Lungi saw the academic direction as her only way to achieve freedom within her ethnic and cultural settings, to be a stay-at-home mom-looking after her child all day long, and attending to almost every needs, has shoved back in the more traditional role she was maybe attempting to get away from.

## **Theme 2: Impact on Family Dynamics**

This second theme is interested to knowing how families of disabled children adjust arrival of the disabled child to the family and how does such children within the family influence the relationships between family members.

### **2.1. Adjustment to family circumstances**

For all the participants (young mothers) in the current research study, the presence of a disabled child within the families made the participants to re-examine their situations and their families'. This examination led the young mothers to rely more on their parents.

Yonela (the married young mother) developed a huge reliance on her husband with her parents and other relatives offering very limited or no support. It is thought-provoking to reveal that for each of the families, there was an adjustment or alteration in relations.

The birth of a child with disability strengthens other family relations , and in others tend to be more of a weakness.

Physical and substantial expenses are made that wedged the families. All participants acknowledge the support from parents (and grand-parents). It appeared that all the participants' families, grandparents sacrificed their time to give assistance to their daughters.

For Bongi and Lungi, relations with, and their dependence on their parents had grown and excavated:

**Bongi:** *Clearly my mom and dad are very supportive of me and my son , they are always helpful and considerate of me*

**Lungi:** *currently I'm staying with my mom and dad ... they are both quite old (in the late sixties) my older sister also lives with us*

Bongi is in contact with mother and father almost every day, as they play an important role in both her and her daughter's life. Her mother and father take turns to bathe, feed and read books for the child.

Lungi, as a single parent also continued to stay by her parents' house with her 3 siblings and other young children in the house, and also with her being a member of the intergenerational household.

For both Bongi and Lungi, the relationships they have with their mothers are the most valued. As they always turn to their mothers for emotional support

**Bongi:** *my dadis really fond of Unathi, they are like buddies .. thus my father relates more to Unathi than to me... on the other hand my mother is my pillar of strength.. she is my support system.. when things go wrong I turn to her.. it just feels so nice when I have someone to talk to about everything that happens in my life. And my mom is just that person.*

**Lungi:** *...when I need a shoulder to cry on my family is always there for me .. we may not always see eye to eye but when it comes to helping me with the child everyone is on board especially mom and dad.*

It is clear from the discussion above that participants receive emotional support and validation from their mothers (or older female figures in their lives) Lungi communicated that her mother has faced some difficult time as a result of her experience. It can be projected that Bongi's mother experienced this too.

Grandparents use these opportunities to enhance their lives and roles. Such role are used as coping mechanisms and they bring new perception and drive in life.

Bongi's parents , especially her father seemed to have viewed the birth of his grandson as a blessing and thus a state that needs to be accepted and welcomed.

In two out of three mothers in the current study, two of them have two children , one disabled and one normal .These families are affected by the arrival of a disabled sibling. This seemed to result in discomfort around prioritising one child over the other, and attempting to treat each child equitably, however admitting the disabled child is demanding. Yonela articulated these obstructions:

***Yonela:** 'mommy can I sleep in your bed tonight, 'no, dear you can't you know there isn't any space for you in my room, unless you can ask to crash by daddies room.. and I hate myself for saying no to him, because my children are both equally loved. I am aware that sometimes she gets jealous because of all the attention given to the disabled one. This breaks my heart..*

Bongi, even though admitting to the additional burden she had rested upon her older son, she finds her older son lovely and very considerate of his sister. Bongi see her son as intensifying family values:

***Bongi:** there's only 4 years between them – so he's had to grow up. But it's made him into a really lovely person, but he's got that awareness that other children of his age don't really have, and probably aren't even going to have as adults. So it's been an eye opener for us having him. For Sibusiso (the typically developing child) that's his life – that's how it's always been. He's been through a lot, but he gives Unathi lots of love. That's how it's always been.*

For any sibling there is an adaptation in circumstances when a new baby is born, but for these siblings in particular there is the added knowledge of having to always come second, even if this is not what their mothers would choose, and even if they can see the qualities that have developed in their children as a result. Bongi sums up the essence of what all the families experienced in that the disabled child becomes central to how a family functions and has a day to day impact on the immediate family.

*Bongi: Unathi is the focus of the family .. she gets everything first.. and her needs are always attending to before others.. this is not because I love her more than my other child it is just she has a condition that needs special attention...however there are some days were I just get sense or the feeling that world revolves around her .. Our family depend on her mood...*

## **2.2 Changing role of parenting**

The birth of a disabled child seems to put parents under the spotlight, and not only focus on diverse prospects and coping techniques, but how gender roles turn out to be more delineated:

*Yonela: I am grateful that I have my husband to help me everything. And I mean everything that has to do with caring for our son. I have heard cases were there are some parents who do it all alone ...*

It is evident from the quote above that Yonela and her husband have a mutual understanding and thus support each other. They both work together in making the best decisions for their disabled son. Because of the shared roles they are able to make the right choices for the child:

*Yonela: my husband and I work together all the time to make sure that we are raising our son the best way we can. Because we have got pretty much the same parenting style, we are able to work as a team without getting into conflicts*

Yonela pointed out that she and her husband don't receive support from the community and other close relatives because they are regarded as a solid , thus needing no assistance or help from anyone. Be it a community of family.

Though Bongi is a single parent it is fascinating how her sister steps in the role of a carer.

*Bongi: for example .. my sister helps me with the child .. my child does not have a father , my sister has always been there for me all the time... and my daughter is aware of that*

Parental roles come to be demarcated between the female and male. In Yonela's household there appeared to exist a conventional dissection of responsibilities for both her and her mother, with the both of them assuming the roles associated to taking care of children and

doing house chores, despite the fact that the men are defined as having rights to making family decisions.

It is of the great interest of this research study to reveal the fact that in times of distress, such roles are significantly used as coping mechanisms, thus women fall naturally to these more passive roles of mothering and taking care of the child or children and the men take up the more active roles. This is the case in Yonela's shared responsibilities (co-parenting relationship) with her husband, in her opinion or outlook her husband's change in assuming the role of a stay-at-home dad is more sacrificial than hers, and in her Xhosa belief, her husband has thrown away some characteristics of his manhood.

In Yonela's relationship with her husband, it looks as if that these stereotypical roles were already outlined, and come to be strengthened Yonela's role was degraded much more to being the main parent. It might well be that there was also ethnic, racial and cultural defence of Yonela's role, that turn out to be more distinct because of the household settings.

### **Discussion**

The main research question for this study was: What are the lived experiences of mothers caring for disabled children? Sub-questions were:

- How do mothers experience caring for a disabled child?
- What implications do these accounts of childhood disability have for experiences of motherhood?
- What impact does the child's condition have on other family members?
- In what ways are mothers of disabled children negotiating, managing and approaching their everyday lives?

All three of the participants articulated or voiced out the impact to begin upon the self and then goes on to feeds on to other avenues. One participant described the initial impact as following the birth of her child (that is right after birth). For the rest of the participants it was through the concerns and the awareness that something was not right with their children. such emotions were compared to grief, furthermore the experience was considered overwhelming and has effects on the emotions. Lungi termed her experience as a bombshell. Both Yonela and Bongi described theirs' as a dark place

These shared accounts were revealed in the Crown (2009) and Constantine (2010) research studies. Both these authors connected their findings to the psychodynamic framework, which assisted in organising participants in terms of their experiences.

A shared account shared by the mothers in the current research study was embedded in future concerns. All the mothers seemed to fear the future and how their disabled children might be affected by it. The reality kicks on the fact that their children will never be able to have children, get married, and or get jobs or careers.

Yonela articulated her fears that she and her husband are already suffering – thus the future isn't promising the best for them and their disabled son. Lungi and Bongi had anxieties and concerns that they are not able to cope with the reality that their children might have to go into care.

All the mothers identified areas of personal growth. For Bongi and Yonela the improvement of parent qualities. They additionally acknowledged that the experience of having to care for a disabled child had allowed them to become adult. Yonela and Bongi acknowledged a new willpower. Levine (2009), even though recounting the experience of single parents, labelled characters such as resilience.

Lungi, is the only participants who had a different experience, articulated that the life she has now is the total opposite of what she envisioned for herself, Presently she sees her life as a process of sacrificing herself. Experiencing parallel events too is, Crown (2009) who also recognized periods of concern, hurt, rage, fault and isolation, however had the last period as hoping to see a transformation to the self.

### **Impact on Family Dynamics**

**All the mothers in the current study demonstrated a shift and alterations in family patterns. For Bongi and Lungi there was a development on the reliance to parents. This relationship is a natural process. For Lungi her parents offered her a place to stay, however the consequence was the fact that this placed a toll on the parents. For Bongi the parents became the most important part of both her life and her son's life**

In Yonela's interpretation, grandparents were barely stated, and surely not with the same regard as the other participants. Her relations seemed detached and did not seem to be supportive.

Two of the participants had two children. Uneasiness emerged about having to prioritise one child over another in terms of time and attention. Only Yonela highlighted any difficulties, acknowledging the responsibilities they had put on their older son, but also describing the positive qualities that had developed. He was within the age range of 7 - 11, which Hames (2008) described as being when a child was more able to describe the impact of having a disabled sibling, and also take more personal responsibility. Research literatures tend to advocate that siblings of disabled children can be additional stressors within the



household. Nonetheless, Yonela's older son seemed to have developed a positive self-view, a result also underlined by Aronson,(2009); Fisman et al., (2000); Ferraoi & Harris, (2009).

The effects of having disabled children was mostly experienced by the adjustment to the child's disability and the redefinition of roles between a man and a woman. Just in the case of Yonela and her husband , were they co-parented their disabled child , with the husband and wife assuming similar roles.

Yonela designated their corporation as teamwork. Brageil and Kanoik (2011) Acknowledged contribution from the father in the caring of a disabled child and the mother's gratification of that assistance contributes to the adaptation and caring. The authors emphasized that a father only get involved in the caring of a disabled child or children when he is in partnership with his wife. Some fathers find it challenging adjusting to unforeseen roles (Simmerman, Blacher and Baker, 2001).

### **Methodology: Strengths and weaknesses**

This research study has quite a few strengths, the first one is the employment of a qualitative research approach, which offered the young mothers the opportunity to tell their life stories and experiences in their own words, something that has been ignored by research studies done in the previous years. Making use of the interpretive phenomenological analysis seems to have fitted well with the objectives of this research, allowing for a fruitful and comprehensive analysis of the mothers' experiences. As the interpretive phenomenological analysis and its idiographic approach do not strive for finding conclusive answers, it is impossible to make assertions about the application of the findings to all young mothers caring for disabled children. Thus, even though other young mothers may share the same views and interpretations of the experience of caring for disabled children, it is of necessity to accept that the results from this study offer an in detail understanding into the most important themes of the mothers' experiences in the study. Similarly, even though efforts were made to be accurate and translucent during the exploration and analysis, it is vital to take note of the analysis and interpretation. When the investigator was interviewing the mothers, it became clear that it may possibly have been useful and advantageous to have interviewed the mothers multiple times in order to be able collect more in depth and meaningful interpretations. The investigator was conscious of her self being a stranger to the mothers and even though the mothers were keen to communicate and discuss their life stories, if only the investigator met the mothers many times prior the interview, perhaps this could have facilitated a relationship and made it easier for participants to communicate their experiences. Useful factors to consider would be the time and dedication needed from the participants to do this.

An additional factors that needed to be considered is the location or surroundings in which the interviews were taking place. All participants were interviewed in the comfort of their home and, although they were not in the same room as the participants, their parents and spouses were in the house in the next room. The presence of the other (not participating in the research study) could have had an effect on the mothers' interpretations of their experiences. Yet, conducting the interviews at the participants' homes presented a calm, easy and informal environment and possibly making the interviewing process less stressful for the participants than perhaps conducting the interviews within the disability centre.

Another important issue to be considered is the possibility of biasness among the mothers who chose to take part in the research study. It is important to note that the mothers voluntarily chose themselves to participate in the study furthermore all the mothers seemed to manage well. Thus, this means that there could be differences in experiences of caring for disabled children between the mothers who participated in this study and those who chose not to. Moreover, the participants in this research were all black (IsiXhosa speaking) women; which according to Williams (2000) could result in the problem of cultural-related disparities. With reference to William (2000) it is of likelihood that the mothers in this study could share different views and opinions with other mothers from different racial and cultural background and their experiences of caring disabled children

### **Suggestions for Further Research**

This research has showed us the significance in studying and exploring the lives and experiences of young mothers caring for children with disability, facilitating our understanding of the processes involved in learning and or adjusting to having a disabled child.

Even though research about the experiences of mothers caring for disabled children has increased, only a small amount of research studies have been exploring the processes that mothers go through as a result of having to care for such children and the general understandings around these processes are derived from older mothers' representations. The results from this research study imply that even though there are no significant differences between young and older mothers and the processes of learning to adjust and live with a disabled child, there are other areas which are overlooked (such as the role of grandparents). Thus more qualitative studies may possibly add on the results of the present research study, developing our understanding of young mothers' experiences of caring for such children. Particularly, as the present research study is centred on women, it would be of value to

explore young fathers' experiences of caring for disabled children, acknowledging the influence of gender related issues on the experience of caring for a child with a disability/ies.

Additionally, not much is known about the effects of culture on the mothers' experience of caring for disabled children and thus it is worthy of note to investigate such accounts from the viewpoints of young mothers from different ethnic and cultural groups. An additional avenue for further exploration is to study the contribution of grandparents in the adjustment to the child's disability.

### **Conclusion**

The objective of this research study was to employ an all-inclusive methodology to the experiences of young mothers/ female carers who are taking care of disabled children and by studying their life stories as an alternative to taking the position of a reductionist and attempt to determine the effect. Research done in the previous years has ignored and overlooked the views of young mothers taking care of disabled children and therefore understandings of the accounts of all mothers, including the young were based on older mothers or female carers' views and conceptions. The participants (young mothers) were able to offer and / give valuable and useful narratives of their experiences of caring for disabled children. Findings from this research study give emphasis to the compound and convoluted nature of caring for a disabled child stressing the difficulties young mothers are facing consequently to having to take care of disabled children. In line with developmental theories, the results from this study imply that from early adolescence to adulthood (18-30 years of age) individuals are in the process of establishing / developing identities and individuality from families and parent.

In this perspective, having to care for a disabled child can have detrimental effects to the young mothers' psychological and psychosocial health. However, these research findings offer some understanding to the various strategies employed by these mothers in efforts to manage these effects, making their children's disability more endurable and continue with their everyday lives. Furthermore, it draws attention to the valuable roles the parents of these young mothers can play in encouraging and supporting their daughters. Developing an understanding of this process from the young mothers themselves can facilitate direct attention to how young mothers of disabled children and their families can be supported.

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## **Appendix 1**

### **Information sheet**

**9 September 2017**



## **Department of Psychology**

Lived experiences of young mothers

caring for severely disabled children

Dear Parent

You are invited by Letu Kohlakali who is an Honours Psychology student at the University of Cape Town to take part in a research study about young mothers' lived experiences of caring for a disabled child.

Before you decide whether to participate or not, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully, or listen while the researcher reads it to you. Please let the researcher know if you would prefer her to explain the study in IsiXhosa rather than in English.

You are allowed to ask the researcher if there is anything that is not clear or if you would like to get more information about the study. Take time to decide whether or not you would like to participate.

Thank you for the time taken to read this.

### **What is the purpose of the study?**

Research shows that caring for a disabled child can have a big impact on the mother's life. There is also evidence that adjusting to life with a disabled child can be difficult for some mothers. However, there is very little known about the daily lives and adjustment of young mothers with disabled children. The present research study is concerned young mothers' experiences of raising a disabled child and how this has affected their lives in general.

The information gathered from this study may help organisations to improve the services and support that they offer to mothers of disabled children and their families.

### **Why have you been chosen?**

You have been chosen to take part because you are a mother or female carer for a child living with a disability.

### **Do you have to participate?**

It is up to you to decide whether or not to participate. If you decide to participate, a copy of this information sheet and a consent form (to sign) will be given to you. If you decide to participate you are still free to withdraw at any time without giving a reason. Your decision to withdraw from the study will not affect the standard of care your child receives at *Isibongile*.

### **What will happen if you participate and what will you have to do?**

I have arranged convenient time to meet with you, either at your home or at the *Isibongile* centre. Before the interview takes place you will be required to sign a consent form as proof that you have read and understood the processes and methods involved in the interview. You will be required to answer some questions related to the experience of being a young mother caring for a disabled child/ren. The estimated time to finish the interview is between one to two hours. For the purpose of this research study everything you say in the interview will be audio recorded and then transcribed word for word. With the certainty of removing any identifying information.

### **Risks**

Since the proposed research study requires you to describe your experience of caring for a disabled child/ren, there is a possibility that the interview might stimulate some emotions that you might find challenging to cope with or manage. If it happens that you suffer from psychological distress as a result of the interview, you can make use of the psychological support services offered by the organisations listed below.

### **Benefits**

Participants will not receive any direct benefits from participating in this study.

### **Privacy**



Rest assured that your identity and the answers you provide in the interview will be treated with strict confidentiality. The results and information published will not contain names of those who participated in the research; instead, I will use false names (Pseudonyms). To further ensure confidentiality, the tape recordings will be destroyed towards the end of the research study. The transcriptions will be kept safe on a password-protected computer.

You are more than welcome to refer any further queries you have about this study to the following people:

Researcher: Ms Kohlakali

Cell: 0814031911

Supervisor: Prof Wild

Tel: 021 650 4607

Research Ethics Committee secretary: Ms Adams

Tel: 021 650 3417

If it happens that your participation in the present research study triggered any unpleasant emotions that have lead you to experience distress , please make use of the counselling services offered by;

**SADAG Mental Health Line:** 011 2344837; 24hr Helpline 0800 12 13 14; SMS 31393 (and they will call you back)

**Lifeline telephone counselling services:** 021 461 1111

## Appendix 2

### Consent form

#### Lived experiences of young mothers caring for disabled children

You will receive a duplicate of the consent form and information sheet; please know that it is you are participating in this study voluntarily. This means that you have the right to pull out any time. Your decision to pull out from this research does not have any effects or influence to services you and your child get from the disability centre( *Isibongile*)

Has this information sheet been read to you or have you read the information sheet about this research study? Yes/No

Do you know what the research study is about? Yes/No

Have all your questions answered in the manner you wanted? Yes/No

Are you aware of your rights to withdraw from the study if you want to? Yes/No

Are you aware that the conversation you have with the interviewer during the interview are audiotaped? Yes/No

Are you pleased to participate? Yes/No

**If you do want to take part, please write your name below.**

\_\_\_\_\_  
Name of the participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of the researcher

\_\_\_\_\_  
Signature

Date

**Thank you for your help.**

## **Appendix 3**

### **Interview schedule**

Interview procedure: The lived experiences of mothers caring for disabled children

Date of interview:

Interviewer:

Interviewee:

List of questions:

- a) Can you please tell me about your experience of caring for a disabled child?
- b) How has your child's disability affected you personally?
- c) How has your child's disability affected you social life?
- d) How has your child's disability affected your work life?
- e) How has your role as a mother been affected by caring for a disabled child?
- f) What is your day to day life like?
- g) What are the positive and negative aspects of your child's disability?
- h) Do you ever worry about your child's future?
- i) Do you feel like there is something else important that needs to be shared ?
- j) How did you feel about the interview?