

EXPERIENCES OF PARENTS OF CHILDREN WITH CONGENITAL
ABNORMALITIES AT OSHAKATI INTERMEDIATE HOSPITAL,
OSHANA REGION

A THESIS SUBMITTED IN PARTIAL FULFULMENT
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DECLARATION

I, the undersigned, hereby declare that this study is a true reflection of my own work, and that this work has not been submitted for a degree examination at any other institution of higher education. All sources that were used or quoted have been acknowledged by means of complete references.

M.T. Sankombo

Date

DEDICATION

I dedicate this piece of work to my husband, Bravo and my children, Arens, Mabuku, Muselo, the twins: Sepo and Lilato. I fully appreciate your support and understanding during my studies.

I also wish to dedicate this work to the memories of my late brother (Eustace Sauzuo) and my late father. I know your spirits are celebrating this achievement, may your souls rest in eternal peace.

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LIST OF ABBREVIATIONS

CA	Congenital Abnormalities
CBR	Community Based Rehabilitation
CDH	Congenital Diaphragmatic Hernia
HSRC	Human Sciences Research Council
IHO	Intermediate Hospital Oshakati
MCA	Multiple Congenital Abnormalities
MCAC	Mother to Congenital Abnormal Child
MOHSS	Ministry of Health and Social Services
MOLRR	Ministry of Lands, Resettlement and Rehabilitation
N.D.	No Date
UNICEF	United Nations Children's Fund
WHO	World Health Organization

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ABSTRACT

The purpose of this study was to describe and explore the experiences of parents of children with congenital abnormalities and identify source of support such parents employ when dealing with the child born with congenital abnormalities. Congenital abnormalities, regardless of the type, pose a concern to the Government, society, immediate family members and individual parents. The expectations parents had for a normal child becomes a nightmare when the child they were expecting is born with a disability. Living with such a child can be stressful for parents and other family members. Therefore, exploring and describing the lived experiences of parents of children born with congenital abnormalities is important in the process of finding ways to assist or support parents to provide proper care for their children.

A qualitative, explorative, descriptive and a contextual study design using a phenomenological approach was used for this study. In-depth interviews were conducted with twelve purposefully selected participants from the population of parents of children born with congenital abnormalities. The study was conducted at Intermediate Hospital, Oshakati in Oshana region in north-central Namibia. Data analysis was done using content analysis and it was categorized into four categories with three sub-categories.

The study revealed psychological, emotional, social and economic challenges parents endure while raising a child with congenital abnormalities. Psychological and emotional challenges included being stressed by caring tasks and having

worries about the present and future life of their children. They were terrified and traumatized by the reactions of some spouses/family members and community who failed to comprehend with the child's condition. Social challenges were inadequate social services for their children, such as special schools, specialized health care services, stigma and burden of caring tasks. The economic challenges were poverty, child care interfering with various income generating activities and other extra expenses associated with the child's condition.

Keywords: Parents, Experiences, Children, Congenital abnormalities/Disability

CHAPTER 1

INTRODUCTION AND ORIENTATION OF THE STUDY

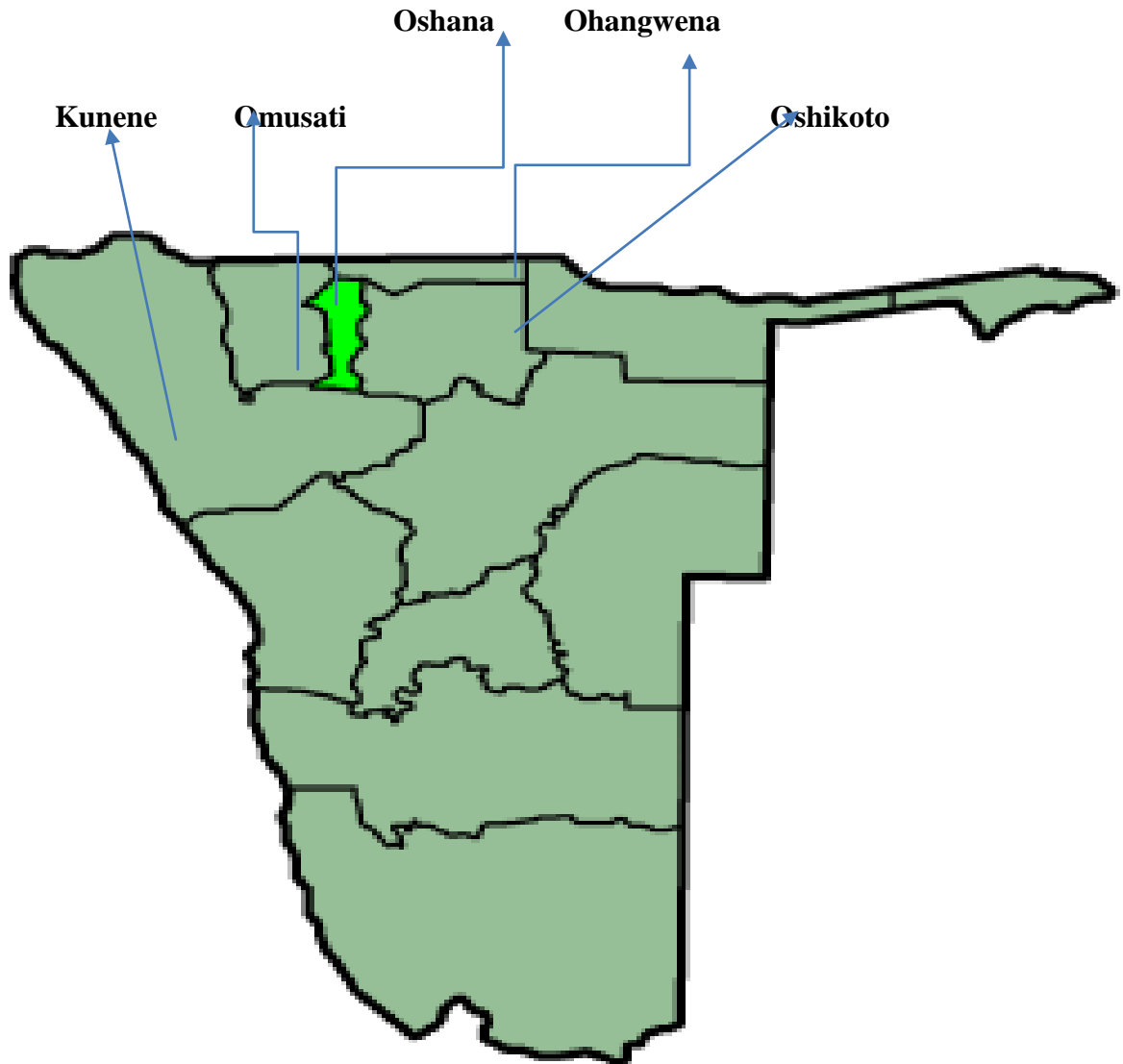
1.1 Introduction

This chapter introduces the orientation to the proposed study in which the following will be discussed: Background of the problem, statement of the problem, the overall objective of the study as well specific objectives and significance of the study.

1.2 Background of the problem

The main purpose of this study was to explore and describe the experiences of parents of children with congenital abnormalities at Intermediate Hospital, Oshakati (IHO), in northern Namibia. The hospital is one of the three Intermediate hospitals in Namibia and the only hospital in Oshana Region, and also serves as the main referral centre for the four Northern regions of Omusati, Ohangwena, Oshikoto and Kunene. Oshana is one of the densely populated regions in Namibia with a catchment population of 193,538 and population growth rate of 1.8% per year (National Population and Housing Survey, 2001). Approximately 32.1% of the total population is children under the age of 14 (National Population and Housing Survey, 2001). This implies that all cases of congenital abnormalities that require intervention from the above mentioned regions are referred to the IHO for further intervention.

Figure 1.1 Namibian Map showing four Northern regions, which are catered by IHO



The map above shows the four Northern regions which refer patients to Oshana region, the smallest and most densely populated region.

1.2.1 Global overview of congenital abnormalities

Congenital abnormality is a worldwide problem prevalent in all communities, both developing and developed worlds. They (congenital abnormalities) are the most prominent cause of disabilities in the world. Approximately 10 percent of the world's population have disabilities and about 30 percent of families lives with family members who have disabilities (Thoraya, n. d.).

These figures are increasing as a result of rapid population growth and advanced modern technologies that highly contribute to the survival of infants born with malformations. A high percentage of those cases require either surgical or medical interventions while others are life- long, posing an economic burden to both families and States.

According to the WHO report on congenital abnormalities, 1 in 33 infants are born with congenital abnormalities (also referred as birth defects) which result in approximately 3.2 million birth defect-related disabilities every year (WHO, 2012). An estimated 270 000 newborns die during the first 28 days of life every year from congenital abnormalities related conditions (WHO, 2012). Meanwhile, there are more than 4,000 different known birth defects, ranging from minor to serious, and although many can be treated or cured, they're the leading cause of death in the early years of life (Clark, 1995 in Ricci & Kyle, 2009) .

Mazer, Gischler, Koot, Tibboel, Van Dijk & Duivenvoorden (2008) state that about 2–3% of new-borns exhibit major anatomical congenital abnormalities

(CA). Most of these are life-threatening unless surgically corrected. Presentation may be isolated or as part of a spectrum of multiple congenital abnormalities (MCA). The following are examples of birth defects: intestinal atresia, abdominal wall defects, congenital diaphragmatic hernia (CDH), anorectal malformations and Hirschsprung's disease, cleft lip and palate, hydrocephalus, cerebral palsy and many more. Advances in surgery and pre-operative care have reduced mortality (apart from CDH) to approximately 10% (Mazer et al., 2008). This, however, has caused much morbidity, with effects, possibly extending into adulthood and placing a heavy burden on patients, parents and health-care system.

1.2.2 Burden of Congenital Abnormalities in Namibia

According to the 2001 population and housing census, the prevalence of disability in Namibia stood at 4.7%, which translates into approximately 85,000 people (National Health Policy Framework, 2010-2020). Only 5.6% of the disabilities are related to chronic mental illness and injuries, the rest are congenital abnormalities. A study from 2003 (SINTEF) revealed that only 0.48% of children with disability had attended school in comparison with 78% of all children, and out of 69% of the population employed only 1% are people with disability (Namibia National Population and Housing Survey, 2001).

About 4500 people with disability visited IHO during the period March 2011 to April 2012 and out of this number, 2475 (55%) were children below the age of fourteen years (IHO, 2012) who were accompanied by their parents to the hospital for follow-up either on a monthly or quarterly basis. Among those children who

visited IHO, the highest proportion of 15% were those with cerebral palsy while 10% were children born with Down syndrome, and the rest were other types of congenital abnormalities (IHO, 2012).

1.2.3 Parental burden

Congenital abnormality is one among the eminent problems in the society that affects the livelihood of the individual, communities and the health sector. It creates uncertainty among family members as they strive to identify ways and means to assist one another in the upbringing of these children born with congenital abnormalities. The serious consequences of CA may induce the process of parental mourning and victims are liable to suffer psychological stress which may eventually lead to life styles health conditions (Bouman, 2008).

Furthermore, CA is a complex societal problem characterized by social, psychological and economic implications requiring a collective multisectoral approach. The majority of CA requires surgical procedures, while some conditions require long hospitalization and multiple interventions especially with multiple congenital abnormalities. All such interventions are costly and at times they are not treated locally, and the government through the Ministry of Health and Social Services has to fund those activities especially if the cases are to be referred to hospitals in other countries.

Documented studies have shown that the majority of families with children living with disabilities resulting from anomalies lives under severe poverty, remote from information and therefore not covered by the world statistics (EUROCATE, 2005).

The burden of raising a child with CA in northern Namibia is manifested in the long distances that parents have to travel from their respective residences to IHO for follow-ups, the long waiting time in the hospital that they are subjected to, long hospitalization period as well as the cost involved and frequencies of follow-ups. While empirical research has evaluated parental burden experienced with the birth of a child with CA, little is known of parental adaptation or coping mechanism that these parents employ when dealing with CA (Hazebroek, Bouman & Tiboel, 2005).

The process of silent mourning that most parents experience at birth or when the final diagnosis of their child is made is not always evident to everyone. Instead, it is an inner process which is felt by the person who is directly affected by the birth of such a child. Based on this argument, this study seeks to explore more on the mourning, coping and adaptation processes that parents of children go through as they are caring for their disabled children.

1.2.4 The concept of congenital abnormalities

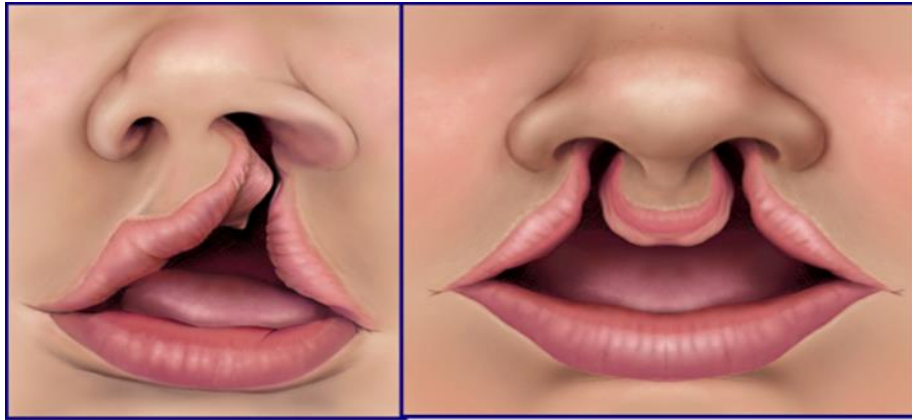
Congenital abnormalities are also referred to as birth defects, congenital disorders or congenital malformation and are defined as physical, metabolic or anatomic deviation from normal development that is apparent at birth or detected during the first year of life (Harry & Karpawich, 2007). Gross abnormalities are obvious at birth while many metabolic abnormalities are not apparent immediately and represent a significant and possibly preventable hazard to the well-being of a person. Guha (2008) stated that most of the birth defects present at birth can be

corrected while those present a year or more after birth are often impossible to be cured.

Abnormalities evident at birth can arise due to failure of development (for example, absent limb(s), *microcephaly*), failure of parts to unite (cleft lip and palate), failure of parts to divide (syndactyl- joined toes or fingers), failure of parts to canalize (atresia- no passage through some parts of the gut), excessive division (polydactyl- too many fingers or toes, duplication of kidneys. Chromosomal and gene mutation abnormalities take effect during all phases of pre- and post-natal life and can cause isolated or multiple congenital abnormalities (Cleveland clinic Children's Hospital, 2012). See figures 1.2, 1.3, and 1.4.

Below are some of the congenital abnormalities included in this study:

Figure 1.2: Baby born with a cleft lip and palate (Failure of organs to unite)



Source: <https://www.google.com.na/search?hl=en&site=img&tbn=isch&source=hp&biw=1242&bih=598&q=cleft+lip+and+palate&oq=cleft+lip+and+palate>.

Figure 1.3 Child with hydrocephalus



Source: <https://www.google.com.na/search?hl=en&site=img&tbn=isch&source=hp&biw=1242&bih=598&q=hydrocephalus+infant&oq=hydrocephalus&gs>.

Figure 1.4 Child with cerebral palsy



Source: <https://www.google.com.na/search?hl=en&site=imghp&tbm=isch&source=hp&biw=1242&bih=598&q=child+born+with+cerebral+palsy&oq=child+born+with+cerebral+palsy>.

1.2.5 Historical myths of congenital abnormalities

Historically, children born with congenital abnormalities and their families have been viewed in a stigmatized manner and every society had its own perception surrounding this fate. Kathy & Mike in Carsle, Mason, Watkins & Whitehead (2005) report that in Greek society, CA were seen as a sign of divine retribution, as a means of atonement for transgression at an earlier life. Likewise, in Roman civilization there is evidence that statutes were decreed which instructed the head of the family to kill the child born with a defect (Jon Aase, 2007).

Moreover, in Medieval times and Tudor age children with deformities were viewed as changelings, the devil's substitutes with the perception that deformed

children represented the parents' involvement with the black magic (Christianson, Howson & Modell, 2006). Kathy & Mike in Carsle, Mason, Watkins & Whitehead (2005) further explain that Martin Luther, the great Protestant reformer considered disabled children as the devil incarnate and recommended the killing of such children. Superstitious beliefs and attitudes towards the deformed children began to shift in the nineteenth century due to the increased awareness of the association of congenital abnormalities and environmental conditions.

1.2.6 Modern myths of congenital abnormalities

Although there is no confirmed evidence about some recent myths surrounding the causes of congenital abnormalities, some communities still believe that specific events during pregnancy would lead to specific defects, for example being frightened by a mouse would result in giving birth to a baby with mouth shaped birthmark (Lobo & Zhaurova, 2008).

Beside modern and ancient beliefs regarding congenital abnormalities, documented studies have linked congenital abnormalities to multiple factors. Lobo & Zhaurova (2008) explain that some birth defects are inherited while others are a product of harmful environmental factors known as teratogens, while others are multifactorial, resulting from a complex interaction of genetic and environmental influences. Meanwhile, most defects that can be traced to a single cause have a genetic origin. This does not necessarily mean that the parents suffer from the same defect. It may be that they are carriers of the condition, or that the genetic problem occurred for the first time in the cells that gave rise to the baby. Known

genetic causes account for about 25 percent of all congenital abnormalities (Children's Hospital Boston, n. d.).

1.3 Problem statement

Namibia, together with its developmental partners, has done more in terms of caring for people with disability as well as children with congenital abnormalities. National policies have been drafted and adopted. These policies are mainly concerned with removing the barrier that may stand in the way of people, including children with disabilities' full integration into the society so that they have the opportunity for a quality life equal to any other member of the society (MoLRR, 1997). Thus, the Government is responsible to ensure that all disability aspects are included in all relevant policy- making and national planning activities.

Moreover, guidelines and community based training manuals are in place to guide parents and rehabilitation service providers as they are the providers of care to the disabled members of the society. Social nets that give a positive socioeconomic support to families and disabled members are provided. However, the experience of parents with congenital abnormalities is not known. Given the hypothetical levels of stress envisaged among parents of congenitally abnormal children, the problem of psychological neglect of these people makes them vulnerable to stress outcome as they may not have any coping mechanism in place. It is against this background that a qualitative study on experiences of parents of children with congenital abnormalities at IHO was done as a prerequisite to the initiation of psychological coping mechanism for these parents.

1.4 Purpose of the study

The main purpose of this study was to explore and describe the experiences of parents of children under the age of 14 years who were born with congenital abnormalities at the IHO.

1.5 Specific objectives

- To describe and explore the experiences of parents of children with congenital abnormalities.
- To identify the source of support that parents employ when dealing with congenital abnormalities.

1.6 Paradigmatic perspective

The philosopher, Thomas Kuhn was the first to use the term “paradigm” for science, suggesting that scientific research does not progress towards truths, but is subject to dogma and clinging to old theories. The word, “Paradigm” like many scientific terms, comes from Greek, and means example (Shuttleworth, 2013). Since the publication of Kuhn’s *“The Structure of Scientific Revolution (1970)”*, the term paradigm has been used with increasing frequency in the scientific community and Kuhn has used the term in many ways. Among others, he defines paradigm as discipline’s specific structuring of reality (Brink, Van Der Walt & Van Rensburg, 2006).

Laundan in Brink et al. (2006) describes a paradigm as a set of assumption about the basic kinds of entities in the world, about how those entities should interact

and about the proper methods to be used for constructing and testing theories of these entities. In essence, a paradigm frames the way in which the discipline's concern is viewed and a direction that a project takes (Brink, et al., 2006).

A paradigm acts as a perspective that provides a rationale for the research and commits the researcher to a particular method of data collection, observation and interpretation. Moreover, Blanche, Durrheim & Painter (2006), explains that paradigms help people to understand the reality of a particular phenomenon of their interest and are the basis of belief that guides action. Meanwhile, qualitative researchers approach their studies with a certain paradigm or worldview of which they have to decide what paradigm should be used in their research and know the nature of their selected paradigm by which they will communicate to the reader (De Vos, Strydom, Fouche & Depolt, 2011).

1.7 Assumptions

Burns & Grove (2011) refer to assumptions as basic principles that we accept in faith or assume to be true without scientific proof or verification. In research assumptions are entrenched in the philosophical base of the framework, study design and interpretation of findings. Assumptions are so basic that, without them, the research problem itself could not exist. Equally, theories and research instruments are also developed on the basis of assumptions that may or not be recognized by the researcher (Burns & Grove, 2011).

The current study applied a phenomenological –interpretivist with a naturalist or qualitative approach. Phenomenology is based on a world that is constructed,

meaning people are creative agents in building up a social world; and inter-subjectivity experiences the world with and through others (O' Leary, 2004). Individuals are therefore central to phenomenological studies. In this current research, parents of children with congenital abnormalities are central, as they construct their world through lived experiences. Understanding human behavior or experience is central for the researcher - the researcher requires that the person (Parent of children with congenital abnormalities) interprets her/his experience to the researcher and the researcher must then interpret the explanation provided by a person (Burns & Grove, 2011).

Simon (2011) urges researchers to use assumptions when they want to elaborate more on the nature, limitation and delimitation of their studies.

In the current study, the researcher made use of assumptions that follows below:

1.7.1 Ontological

Polite & Beck (2013) submitted that, for the ontological assumption to be formulated, the following question needs to be asked: What is the nature of reality? According to an anti-positivist inquiry, the reality is multiple, subjective and mentally constructed by individuals and it exists only through construction. In this study reality is mentally constructed by parents of children born with disabilities.

Ontological assumptions are embedded in our understanding of human nature and society. Therefore, what is important to the researcher is to understand the reality as experienced by each parent in the real world.

1.7.2 Axiology

“What is the role of values in an inquiry? This is a question that is formulated for axiological assumption (Polit & Beck, 2004). Values are central to any human relationship. Parents of children with congenital abnormalities, primary caregivers and the researcher come together, each party with her/his own value system and these values are the foundation of interpersonal relationships. Values may have a negative or positive influence towards the person’s views on health. A traumatized parent of a child born with disability who visits the health center to obtain professional help expects the health workers to respect her human dignity. The parent becomes vulnerable if he/she is not fairly treated, respected and understood.

1.7.3 Epistemology

Epistemology is the reality of knowledge (Brink et al., 2006). This assumption has to do with how the researcher understands knowledge and how he/she acquires this knowledge. In the absence of knowledge about the experiences of parents of children with congenital abnormalities, the researcher conducted phenomenological, in-depth interviews to gain more insight into the lived experiences of these parents. In addition to that, truth lies in the constructed reality and in-depth interview is one of the techniques known to maximize

knowledge as it minimizes the number of participants as well as the distance between the researcher and participants.

1.7.4 Methodology

Kothari (2004) refers to methodology as a total strategy for the study that begins with problem identification to the final plans of data collection. In this context, it refers to the scientific methods according to which the researcher will conduct this study. Researchers who aim to explore more on the lived experiences to gain more understanding about the nature of reality of participants prefer to adopt interpretivist paradigm. The researcher believes that parents of children with congenital abnormalities become study participants to relate their own experience through qualitative, phenomenological approach.

Phenomenological studies tend to examine human experiences through the description provided by people themselves (Brink et al., 2006). This entails collecting life stories from participants as they experience the world. The approach may enhance the quality of research and ensure trustworthiness of the results (Burns & Grove, 2011). Methodological assumption therefore, focuses on analysis of the methods used for gaining the data.

1.8 Definition of Concepts

For this study the concept to be clarified are: parents, experiences, congenital abnormality/disability.

Parents: Becoming a parent, one of the most powerful of the human experiences, is often accompanied with feelings of celebration and relief, but it can also be a time of anxiety and stress (Lawoko & Soares, 2007). The term “parenting” is derived from the Latin *rootpario*, meaning life-giver, and encompasses much more than just the caregiving activities parents perform (Scher & Sharabany, 2005). Parenting frequently involves pleasure and joy and provides individuals with a sense of competence, but at times parenting can be confusing, frustrating, irritating, and stressful. In this study a parent will be referred to any person who fulfills the mentioned parenting roles, towards a child with congenital abnormalities.

Experiences: Experiences are defined as things that have happened to you that influences the way you think and behave (Oxford Advanced Learner’s Dictionary, 2006). Behaviors are the result of a person’s thoughts, feelings or perceptions resulting from a particular situation. Experiences, whether negative or positive helps to shape an individual, assist us to grow, accept and adapt to the reality of life. This can make a person adopt and adapt to new roles and responsibilities and may even change his life completely. For this particular study, experience will mean things that happened in the lives of parents of children born with congenital abnormalities.

Congenital abnormalities/Disability: Congenital abnormalities comprise a wide range of abnormalities of body structure or function that are present at birth and are of prenatal origin (WHO, 2014). Congenital abnormalities are often referred to as birth defects; they can be present both at birth or days or months after birth.

Birth defects that are present at birth can be corrected through surgery and those that are visible months or years after delivery are often incurable. Major structural abnormalities account for most of the deaths, morbidity and disability related to congenital abnormalities. A person born with congenital abnormalities may not be able to perform tasks that other normal person will do, thus this person may be referred as a person with disability. For this study, a child born with congenital abnormalities is one that meets the aforesaid explanation, while disability is that child born with congenital abnormalities that result in disability.

1.9 Significance of the study

The findings of this study will act as a baseline for the development of policy frameworks as well as the coping mechanism for psychological support to parents of children with congenital abnormalities. It was important to conduct such a study as it will contribute to the regional, national and global knowledge bank on the lived experiences of parents of children with congenital abnormalities. The information derived from this study may assist family members of parents of children with congenital abnormalities and the community to understand, assist and support these parents. They may also be able to know the type of support these parents need.

Future students who may want to conduct the research on the same or related topics may use the study to add to their knowledge. Hypothetically, the implementation of the study recommendations may minimize the stress levels experienced by mothers and other care-givers.

1.10 Division of chapters

The research is divided into the following chapters:

Chapter 1: Background and overview of the study

Chapter 2: Research design and methods

Chapter 3: Analysis, results and discussion

Chapter 4: Conclusions, limitations and recommendations

1.11 Summary

In this chapter, the orientation of the study was introduced stating the problem statement, purpose, specific objectives and research paradigm. The chapter also highlighted the various assumptions and definition of key terms used as well as the significance of the study. The chapter that follows (chapter 2) will focus on research design and methods.

CHAPTER 2

RESEARCH DESIGN AND METHODS

2.1. Introduction

This chapter presents a detailed discussion of the design and methods employed in this study. Data was collected by means of in-depth interviews with the participants, who are parents of children with congenital abnormalities. The data collected was analyzed using content data analysis process.

2.2 Description of the study setting

The study was conducted at Intermediate Hospital, Oshakati which is situated in Oshakati district in the Oshana region, north central Namibia. Oshakati is the main town in north central Namibia and the hospital serves as a referral hospital for five regions, namely Oshana, Ohangwena, Omusati, Oshikoto and Kunene regions. The hospital is a 750-bed hospital and has many specialist departments as well as General Outpatient Department. There were five hospital departments which participated in the study, namely, Physiotherapy department, Occupational Therapy, Orthopedic department as well as both Medical and Surgical Pediatric units. These are departments that are actively involved in care for children with congenital abnormalities. Maternity unit was among the departments which were earmarked for participating, but this was not possible as at the time of data collection as no baby was reported to be born with congenital abnormalities.

Parents of children with irreversible conditions such as Down syndrome, cerebral palsy and others normally bring their disabled children to the hospital for follow up on a quarterly basis while reversible conditions are admitted in the hospital for intervention. Once the CA has been corrected, the children are either discharged completely (for example, cleft lip) or given follow up for further intervention (for example, hydrocephalus and cardiac abnormalities).

Cohort register for parents of children with Down syndrome and cerebral palsy exists in the Occupational health therapy department, which includes the name of the parents, physical address and telephone numbers. Parents are reminded telephonically of their follow-up dates by staff members of the department. Follow-ups for parents of children with reversible CA depend mostly on the nature of the abnormality and the medical officer in charge of the child.

2.3 Research design

Research design refers to a “structural framework or blueprint of the study and it guides the researcher in the planning and implementation of the study while optimal control is achieved that could influence the study” (Burns & Grove, 2003, p. 195). It forms a plan that determines the methodology used by the researcher to obtain sources of information (Brink, et al., 2006) such as participants, data collection, analysis and interpretation of findings. A well planned design should have components that work harmoniously and promote efficiency and successful attainment of research goals. Moreover, this plan must be able to answer the research question or meet the objectives of the study.

The study was a qualitative, phenomenological, explorative, descriptive and contextual design in nature. The rationale for using the design was to meet the overall objective of the study, i.e. that of describing and exploring the lived experiences of parents of children with congenital abnormalities.

Pope, Ziebland & Mays (2008) consider qualitative research designs to be suitable for research that aims to explore health behaviors because qualitative studies place more emphasis on the lived experience of participants in an attempt to understand the phenomenon in its entirety rather than focusing on specific concepts.

2.3.1 Qualitative design

Qualitative research is a “systemic, subjective approach used to describe life experiences and gives them a meaning” (Burns & Grove, 2011, p.73). According to LoBiondo & Haber (2010), qualitative research encompasses several different methodologies that share similarity in the conduct of such research.

Characteristics of qualitative Research Design

Tappen (2011) cites Lincoln & Guba (1985), Patton (2002), van Manen (1990) & Denzin & Lincoln (2005) and refers to the following characteristics:

Qualitative research begins with the conscious notion of avoiding preconceived ideas referred to as “bracketing”. In other words, the researcher begins his/her study without a supposition about what he/she is going to discover.

It is assumed that qualitative research is neither context nor value free. Instead, the perspectives of the researcher are important to consider, as is the context in which the study is done.

During data collection, the researcher becomes the instrument, instead of using the external means of collecting data such as questionnaires or physical measures used in quantitative studies; the researcher employs her/himself as an observer and interviewer.

Qualitative researchers study things in natural settings. Natural settings are referred to as settings where people live (LoBiondo-Wood & Haber, 2010) other than classrooms or laboratories. This is called field work and no control or manipulation is involved. Moreover, qualitative researchers assume that things can be understood better if they take place in their natural settings. Qualitative research is generally inductive leading from specific to general, meaning drawing conclusion from a particular fact (developing theory from results).

A holistic perspective is adopted and fragmentation is avoided in qualitative research. There should be a dynamic interaction between the researcher and participants. Qualitative research is discovery oriented. It is explanatory, descriptive in nature, it uses words other than numbers to explain a phenomena and it allows researchers to see the world through others. The researcher therefore utilized this design to gain empirical knowledge into the lived experiences of parents of children with congenital abnormalities.

2.3.2 Exploratory study design

Exploratory designs aim at gaining insight into phenomena. Moreover, the design enables greater openness from participant and allows greater flexibility in data collection by giving participants room to give more information. This is confirmed by Baum (2008, p.180) who asserts that “explorative research design is best suited for studies that aim at exploring health behaviors and gives an understanding of how people interpret health and diseases and make sense of their experiences as well as a systematic review of the research question that cannot be answered by quantitative methods”.

Similarly, Blanche et al. (2006, p. 44) also affirm that “explorative design provides more insight about the nature of the phenomena as it facilitates greater openness from participants and allows for flexibility in data collection, giving room for participants to give more information that was previously unknown.”

The researcher employed explorative research design to examine the lived experiences of parents of children with congenital abnormalities upon receiving news about the condition of their child. During the data collection procedure, open-ended questions and probes were used to explore more in-depth information from participants. This allowed the participants to narrate their lived stories in their own words about their lived experiences when they learnt about their child’s condition.

2.3.3 Descriptive study design

Descriptive design is the description of the phenomenon in a real life. It provides accurate account of characteristics of particular individuals, groups and situations. Through descriptive studies, researchers discover new meanings, determine what exists, determine the frequency with which something occurs and categorize information. Thus, its purpose is to provide a picture of a situation as it naturally occurs (Burns & Grove, 2005). In this study, descriptive design was used to have an understanding of what parents of children born with congenital experience.

2.3.4 Contextual study design

Silverman (2010) reports that “the basic message that qualitative researchers convey is that whatever the spheres in which the data are collected, we can understand events only in a wider social and historical context. Thus, contextual study design allows the researcher to systematically conduct the research in the real life situation.

Phenomenologists believe that a person’s behavior and experiences cannot be understood without appreciating the context in which she/he lives. In this study the lived experiences of parents of children with congenital abnormalities were described within the context in which they occurred.

2.3.5 Phenomenological study design

Phenomenology approach is a qualitative research design that studies phenomena. Phenomenologists examine human experiences through the description that are

provided by the people involved (Brink et al., 2006). Therefore the researcher that employs this method describes experiences as they are lived by the study participants.

The lived experiences include what people experience with regard to a certain phenomenon as well as how they interpret experiences or what meaning the experiences holds for them. In other words, Phenomenology is an approach that concentrates on a subject's experience rather than on the person as a subject or object (De Vos, Strydom, Fouche & Depolt, 2005).

In this study, the researcher used in- depth interviews to probe more on the individual experiences of parents of children with congenital abnormalities, for instance, what is happening in their real world (Brink et al., 2006), what is important about their experiences and what changes can be made.

The researcher interviewed the participants in the real world, mainly where participants lived with such experiences i.e. during admission and follow-ups in the health facility and in the community.

The central question asked was:

What are your experiences in raising a child with congenital abnormalities?

During the interview the researcher was conscious about the effects of bracketing. Bracketing involves identifying and setting aside of preconceived beliefs and opinion, which the researcher might have about the phenomena under

investigation and by doing so, the trustworthiness of the study is maintained (Denzin & Lincoln, 2005).

2.4 Research methods

Research methods are the tools used when conducting a research. This includes the procedures and instruments used by the researcher to investigate and generate information, including the technique used (Locke, 2010).

In this study, the researcher used methods and procedures that follow to obtain the lived experiences of the parents of children born with congenital abnormalities.

2.4.2 Sample and Sampling method

De Vos et al. (2005) describe sample as an element of the population considered for actual inclusion in the study, while sampling is the actual process of selecting a sample from the total population in order to obtain information regarding a phenomenon in a way that represents the population of interest.

According to Bassett (2004), qualitative research does not require a large random sample because qualitative studies seek to describe a range of experiences rather than collect numbers for statistical analysis. In qualitative research, the sample size depends on the purpose of inquiry. Therefore, the situations, persons and events most likely to yield information-rich data about the problems are selectively chosen (Holloway & Wheeler, 2005). This type of sampling is known as non probability “purposive” sampling and in some instances sampling might

continue until data saturation has been achieved. Data saturation refers to the point at which new data no longer emerge during the data collection process (Brink et al., 2006).

After explaining the purpose of the study to the health workers in all six participating hospital units, the study participants were selected with their assistance. The cohort register was used in this regard to identify some of the study participants. The participants who were admitted in the hospital and from the cohort register were selected purposively according to the type of congenital abnormality. This was done in order to obtain views of parents of children born with different types of congenital abnormalities.

The following criteria were used to select study participants:

- Parents of children from the four northern regions of Oshana, Omusati, Ohangwena and Kunene regions.
- Parents of children under the age of 14 years who were admitted in both surgical and medical pediatric units with reversible condition or irreversible. This criterion further included mothers of children who were waiting for intervention and those that were assisted already.
- Parents who brought their children for follow-up at physiotherapy department, Occupational therapy as well as orthopedic department.
- Parents whose follow-up were not due at the time of data collection, such as those parents of children with cerebral palsy and Down syndrome were

identified from the cohort register and were contacted telephonically, those who were interested volunteered to come to the occupational therapy department where they were interviewed after a detailed explanation of the purpose of the study.

- Parents of children with CA who were admitted to the Pediatric surgery unit were grouped together, the purpose of the study was explained and those who agreed to take part in the study were interviewed individually.
- After the explanation and before the in-depth interview, participants were requested to read and sign the provided consent form and parents who accepted to take part were interviewed after signing the consent form.

The main eligibility criteria were: parents of children under the age of fourteen years born with any type of congenital abnormalities. The parents should be admitted with their children in the hospital or should be met with their children at any of the participating hospital units.

A total of twelve participants were interviewed and participants comprised of parents of children with reversible conditions, irreversible condition, long hospitalization, more frequent follow ups and those waiting for surgery. Participants were selected to represent, as far as wide range of experiences of parents of children with CA.

2.4.1 Population

Polit & Hungler (1995) in Brink et al. (2006, p.123) describe population as an entire group of persons or objects that is of interest to the researcher or that meet the criteria which the researcher is interested in studying. This is supported by Parahoo (2014, p. 259) who refers to the population as “the total number of units from which data can be collected”, such as individuals, artifacts, events or organizations.

In this study the population is referred to as all parents of children under the age of 14 years born with congenital abnormalities who were either admitted in IHO or has been visiting the hospital on a monthly or quarterly basis for reasons pertaining to the condition of their child.

2.4.3 Data collection

The process of data collection is of importance to the success of the study (Brink et al., 2006). Without high quality data-collection techniques, the accuracy of the research conclusion is easily challenged. According to Burns & Groove (2005) data collection is the precise and systematic gathering of information relevant to a research problem using instruments which can be in the form of questionnaires, interview schedules and guides, field notes and records and/or artifacts. In a qualitative study, the most common data collection methods used are: interviews, observation, and examination of written texts, field notes and artifacts.

In this study, an interview schedule was developed and piloted to test its feasibility. In-depth interview was the data collection method used in order to gain more insight into the phenomenon under review. The detailed description of the method will follow.

- **In-depth interview**

The primary source of data collection for this study was in-depth interview. Bowling (2014) considers in- depth interview as a relevant tool to use when seeking to learn about people's feelings and experiences. Similarly Boyce & Neal (2006) describe in depth interview as one of the best data collection methods as it provides more detailed information than what is available through other data collection methods, such as surveys. They also provide a more relaxed atmosphere in which to collect information.

The researcher conducted a face to face interview with the twelve participants in the language of their choice which was Oshiwambo. Since the researcher is not much conversant with the participant's choice of language, a field worker was appointed and trained to assist in the translation from English to Oshiwambo and vice versa. Meanwhile, the interview guide was also translated from the English version to Oshiwambo and back translated to English to ensure accuracy prior to the data collection procedure.

- **2.4.3.2 Data collection procedure**

In-depth interviews were conducted with twelve study participants. During the interview sessions, the researcher with the assistance of a field worker wrote verbatim notes (real words from participants) to capture key issues and noted the non-verbal language of study participants. Furthermore the interviews were recorded to assist the researcher not to miss any valuable information for the study. The voice recorder was used with the participant's permission, meaning permission to use voice recorder was obtained prior to data collection (Annexure 1).

- **Field work assistance**

According to Patton (2014), the credibility of the researcher is important in qualitative research as it is the person who is the major instrument of data collection and analysis.

In his study, Shenton (2004) emphasizes the importance of trustworthy information and refers to the scrutinizer's trust in the researcher as of equally relevant to the adequacy of the procedures. In this study, the researcher is not conversant enough with the language spoken by most of the study participants which is Oshiwambo. Therefore, in order to ensure that the research findings are credible to both study participants and readers of this research, the researcher appointed a field work assistant who was a first year pupil enrolled nurse at the Oshakati Health Training Center who is fluent in Oshiwambo and English language to assist in the data collection process.

The main responsibility of the field worker was to translate the questions asked by the researcher to participants from the English version to Oshiwambo which was the vernacular preferred by most of the participants. However, participants who could understand English, interviews were carried out without translation.

During the interview sessions, the field work assistant assisted in taking field notes together with the researcher and at the end of each day's session data triangulation was done where comparison was made between field notes of the researcher and field work assistant. Data triangulation is one among the strategies highlighted by LoBiondo & Haber (2010) to ensure trustworthy information.

- **Field notes**

LoBiondo-Wood & Haber (2010) refer to field notes as a short summary of observation made during data collection. In other words, they are written accounts of things which the researcher sees, hears, thinks and experiences during the course of the interview which should include empirical interpretation. They supplement recorded interviews as non-verbal language cannot be captured by voice recording (Morse, 2013). Moreover, field notes are not restricted to a particular behavior, rather they represent a narrative set of written notes intended to paint the picture of the social situation in a more general way.

In this study, interviews were conducted with the assistance of the field worker who was translating from English language to Oshiwambo and vice versa. Both the researcher and field worker assumed the responsibility of taking field notes. The field worker jotted her narratives in vernacular while the researcher's

narratives were in English and this was done during and after the interview with each participant for cross-referencing with the recorded interview. Field notes were treated as valuable material as they would serve as a source of information for the analysis of collected data (Morse, 2013). For this reason the researcher together with the field worker had to meet after each session to compare and summarize the field notes.

The field notes comprised mainly of facial expressions, voice tones, gestures, questions from participants, the researcher's thought (this statement were indicated with double quotation marks) and were written in a summary form. During transcription of recorded interviews, field notes were incorporated in the transcript.

2.5 Data analysis

Data analysis is the interpretation and organization of data collected during fieldwork for the purpose of discovering important dimensions and patterns of relationships (Polit & Beck 2006). According to Henning, Van Ransburg & Smit (2004), qualitative research data analysis is an ongoing, emerging and interactive non-linear process. Similarly, in this study data analysis continued simultaneously with data collection. In-depth interviews with the participants were recorded and transcribed verbatim to ensure that no information was lost prior to data analysis. In this study, data analysis commenced as soon as the recorded interviews were transcribed and the data were read through over and over to identify emerging categories. Qualitative data analysis needs to be conducted with rigor and care

(Coffey, Atkinson & Delmont, 2004). The phenomenological research analysis starts as soon as the first data are collected and prior to data analysis the researcher has to clarify personal preconceptions about the phenomenon under study. This is known as 'bracketing', suspending the researcher's meaning and interpretations as much as possible and entering into the world of the individual interviewed (Tesch, 2004). In this study bracketing and reflexivity was applied during data analysis.

The transcribed interviews were coded into seven main categories and there were no sub-categories emanated from the emerged categories. This was because of the nature of information gathered. Some researchers prefer to use the term theme, but for this research the researcher preferred to use the term category. (See chapter three).

2.6 Literature Control

The aim of literature control is to uncover facts on what is published about the topic to be researched with the motive of gaining better insight into dimensions of the research. In addition to that, it aims at identifying gaps in knowledge, establish the significance of the study and situate the study within the current body of knowledge (Burns & Grove, 2010).

To achieve the above, the researcher verified the lived experiences of parents of children with congenital abnormalities with the existing literature to build a body of knowledge on the topic as well as facilitating better insight to the consumers of

the researcher. Similarities and contrast were uncovered during the verification process (refer to chapter 3).

2.7 Measures to ensure trustworthiness of information

When conducting qualitative research, it is of utmost importance to ensure that results and interpretations are trustworthy. The quality of any qualitative study is measured by its trustworthiness. Thus, the researcher should demonstrate a sense of fairness and truthfulness in her/his study. According to Pope et al. (2008), the basic approach to ensure rigor is systematic and self-conscious research design, data collection, interpretation and communication of findings.

Some qualitative researchers use the terms reliability and validity to define rigor, but others have rejected them since the underlying philosophy and the criteria are different, so they thought different terms should be used. The best alternative terms suggested to define trustworthiness were those proposed by Denzin & Lincoln (2011): credibility, dependability, transferability and conformability.

Trustworthiness or rigor of any qualitative study is a concern to consumers of the research and it is what persuades readers that the findings reported are worth paying attention to, that they are credible, dependable, conformable and transferable to other situation (Tappen, 2011). To ensure trustworthy or rigor, the researcher made a judgment and employed the four criteria:

2.7.1 Credibility

Marshall & Rossman (2011) describe credibility as a process of demonstrating that an inquiry is conducted in a manner that ensures the accuracy of how subjects were identified and how the experiences were described. Credibility is equivalent to internal validity in quantitative research. To ensure validity, the researcher must first determine the extent to which conclusions effectively reflect reality, and assess whether constructs devised represent the human experience that occurred. To ensure credibility and authenticity in qualitative research, researchers should ascertain whether the findings of the study are credible to the study participants and consumers as well as the truthfulness in the information under review (Brink et al., 2006).

Credibility and authenticity may be established, though the following measures:

- **Prolonged engagement and persistent observation**

Credibility can be established by context-rich and meaningful or thick description (Denzin, in Brink, et al., 2006). A superficial description of human experience may result in superficial conclusion and may limit understanding on the subject matter of interest. Therefore, prolonged engagement and persistence observation is of utmost importance to gain more insight into the subject under discussion. To gain more insight through prolonged engagement, the researcher may need to probe more, if possible with in-depth interviews.

Meanwhile, Conrad, Garret, Cooksley Dunes et al. (2006) in Tappen (2011) recommended the following ways in which to address trustworthiness and rigors:

- Individual or in-depth interview- Provides richer description than focus group discussion.
- Maintenance of an audit trail – Ensures authenticity of information.
- Verification of findings with participants.

To establish rich and meaningful description from participants, the researcher used individual interview, which is more in depth than a focus group discussion. This affirms the writings of Tappen (2011) who once said “being there matters most when conducting qualitative research”. Maintenance of an audit trail and verification of the findings were achieved through peer debriefing and member checking as discussed below.

- **Member checking**

Member checking is among the interesting approach to establish credibility of the study finding in qualitative studies. It involves information sharing with either the participants in the study, members of the culture or subculture under study or representatives of the community in a work setting. Information to share includes field notes, or transcription with the member of the community, most common and appropriate information to share is the preliminary findings with the study participants. Findings should be phrased in such a way that participants

understand them and give feedback whether or not these findings resonate with them (Tappen, 2011).

To ensure trustworthiness through member checking, the researcher made some follow-up interviews with participants who were still in the hospital shortly after the data collection was completed.

- **Peer debriefing**

Peer debriefing, unlike member checking, seeks evaluative feedback from expertise. It involves the researcher discussing the research process and findings with impartial colleagues who have experience with qualitative methods. Krefting (2004) asserts that colleagues can increase credibility by checking themes or categories developed from data collected.

To ensure credibility through peer debriefing in this current study, data were coded by the researcher and verified by an experienced data coder, and findings were shared with the two supervisors mainly to check the authenticity of the categories that were developed.

- **Triangulation**

“Triangulation is the expansion of research methods in a single study to enhance diversity, enrich understanding and accomplish specific goals” (LoBiondo & Haber, 2006, p.19). In research, triangulation allows cross-checking of both data and preliminary conclusions (this includes testing for consistency and inconsistency). It also provides for multiple perspectives which are valuable when

addressing a complex subject where no one method or source can provide explanation for. Patterson, Dobouloz, Chevrier, Hull, et al. (2009) report the following ways of data triangulation in research:

- Methodological triangulation which uses multiple methods to collect data, for example: interviews and observation.
- Source triangulation that involves obtaining different viewpoints, such as interviewing families, patients and care-giving staff.
- Analyst (investigator) triangulation. This is an independent analysis by more than one investigator, such as where two researchers develop coding schemes independently and then compares the codes produced.

According to LoBiondo-Wood & Haber (2006, p. 119), it is important to know what triangulation is and what it is not as it is frequently misused; it is not asking someone her diagnosis and then confirming it with the diagnosis in the medical record but rather using two pieces of information to find a third unique finding.

The researcher employed source triangulation method where the finding from one participant was triangulated with the caregiver in one of the participating departments.

2.7.2 Transferability

Transferability refers to the extent to which the results of the study can be applied to other similar contexts (Tappen, 2011). Unlike quantitative studies where samples are randomly selected and statistics applied to estimate the extent to

which findings can be generalized, qualitative research aims at describing a phenomenon/sample and the context in which the study was conducted and decide whether the findings can be used in other similar studies (Tappen, 2011).

Purposive sampling method was done and detailed description of study participants (demographic data) and the context in which the study was conducted were elaborated to allow for the possibility of transferability of findings to other similar context.

2.7.3 Dependability

Dependability is another criterion referred to by Denzin & Lincoln (2011) that can be used for establishing rigor of a study. Dependability requires an audit trail, which involves an inquiry auditor who follows the whole process and procedure used by the researcher and decide whether they are dependable.

In qualitative research, it is advisable to use audit trail as it helps the researcher ensure transparency of the study and it also allows the reader to judge the rigor of the study as well the trustworthiness of the findings. Audit trail includes revising collected raw data, data analysis, data synthesis, findings and recommendations to determine whether they are acceptable.

To ensure transparency, the researcher provided a detailed description of the whole research process and procedures. A clear description of research methodology was provided to make it easy for other researchers to follow the research process.

2.7.4 Conformability

Tappen (2011) relates conformability to efforts of maintaining objectivity in quantitative studies. Conformability in qualitative studies guarantees that the findings, conclusions and recommendations are supported by the data collected. This is also achieved through incorporating an audit trail (Brink et al., 2006). When conducting a qualitative study, it is important for researchers to keep a record of expectations and preliminary ideas about what is going to be studied and what is expected to come out from the study. This is extremely important as the researcher will want to reflect on those preconceived ideas to confirm whether they are corresponding with the initial findings.

To achieve conformability, the researcher kept a record of all personal experiences and feelings throughout the research process.

2.8 Ethical considerations

Researchers have an obligation to observe and respect all fundamental ethical principles throughout their studies. Tappen (2011) refers to research ethics as “norms for conduct that distinguish acceptable and non-acceptable behavior”, in other words, the standard of conduct when doing research. These principles are based on human rights that need to be protected in research. These are: rights to self-determination, privacy, anonymity, confidentiality, fair treatment and to be protected from harm.

The section that follows discusses the three ethical principles and their application to the conduct of the current research.

2.8.1 Principle of respect for person

This principle is based on the premise “individuals are autonomous, meaning that individuals are having rights to self-determination i.e. rights to decide whether or not to take part in the research without fear of victimization by the researcher. Lack of respect for a person is shown when a person is denied freedom in his or her decision, for instance, when a person is forced to take part or respond to questions that she is not comfortable with (Tappen, 2011).

The researcher presented the much needed information about the study, which included the study purpose, the voluntary participation of all participants, meaning they could withdraw their participation if they so wished without any consequences in future. Furthermore, the researcher made sure that all aspects of the study were handled in a way which was respectful of the human rights and the needs of the participants (HRC, 2009).

2.8.2 The principle of beneficence

The principle of beneficence is based on the notion of “right to protection from harm and discomfort “which emphasizes that one should do well and above all, do no harm. In qualitative studies researchers often enter the participants’ lives. This happens during exploration of living experiences of participants where researchers might encounter unresolved issues that might upset the participant.

Therefore, qualitative researchers should always use good clinical judgment as well as organizing support from caregivers prior to the end of an interview. Furthermore discomfort and harm can be prevented through the use of carefully structured and continuous monitoring of participants for any sign of distress (Brink et al. 2006).

Unresolved issues that triggered emotions were discovered in this study and the researcher had to refer the participants to the caregiver/health workers for clarity.

2.8.3 Principle of justice

According to Brink et al. (2006), the principle of justice includes the subjects' rights to the fair selection and treatment and rights to privacy. The right to fair selection and treatment is maintained through a fair selection of study participants and giving credit where it is due, meaning participants should receive what is owed to them and equally. Participants should be selected for reasons directly related to the problem of the study and not merely to suit the researcher's preference, nor availability of the participants.

Right to privacy entails the right to determine the extent and circumstances under which the participant may divulge or withhold the information. Moreover, a researcher who gathers information from subjects without their knowledge, it may be through voice recordings, using hidden cameras and microphones invades the privacy of a person.

The principles of justice in this study were maintained through the following measures:

- The participants were resting assured that the information derived from the study will not be shared with anybody who is not directly involved with the study and that field notes and voice recorder used will be kept in a safe place.
- Personal details e.g. names of all participants were not recorded. Participants were further rest assured that the research findings will be published in such a way that participants will remain anonymous.
- To ensure confidentiality transcribed interviews were captured personally by the researcher on a personal computer; the researcher has sole access to these data.
- An information sheet was provided to all participants, which contained information about the researcher's intention to use voice recorder if permitted to do so by the participants.
- The interviews were conducted in different private rooms available at IHO to ensure privacy of the participants.
- **Informed consent**

Informed consent is one among the procedure and mechanism which the researcher employed to ensure human rights protection. The ethical principles of voluntary participation and protection from harm are formalized in the concept of "informed consent." Burns & Grove (2011, p. 122) refer to informed consent as a "prospective agreement to participate in a study as a subject and emphasizes that

every participant depending on the degree that she is capable, should be given an opportunity to decide whether to participate”. The author further elaborates on the four elements of informed consent, namely:

- Disclosure of the participant information to the subjects.
- Comprehension of this information by subjects.
- The competence of the subjects to give consent and.
- Voluntary consent of the subject to participate (Burns & Grove, 2011).

Written consent was obtained from participants prior to the data collection process (see ANNEXURE 1). The purpose of the informed consent was to ensure that the participants understood what was expected of them and that they agreed to take part in the research (Blanche et al., 2006). During data collection, renegotiation of informed consent was implemented when respondents became emotional (interviews had to be stopped for a while).

- **Application for approval**

Permission to conduct research was obtained from the University of Namibia’s Research Committee (ANNEXURE 2), the Ministry of Health and Social Sciences (ANNEXURE 3), Regional Health Director of Oshana Region through the Medical Superintendent of Oshakati Intermediate Hospital (ANNEXURE 4). The approval letter from The Medical Superintendent was then circulated to the participating departments in the hospital.

2.9 Pilot study

A pilot study is sometimes referred to as a 'preliminary study'. This is a small-scale study conducted prior to the main study on a limited number of subjects from the population at hand (Brink et al., 2006). The main aim of conducting a pilot study is to investigate the feasibility of the proposed study and to identify possible obstacles that might hinder the progression of the actual study. This might be obstacles related to data collection tool such as ambiguous questions or inadequate time limits. In addition to that, pitfalls and errors that may prove costly in the actual study can be simply detected and avoided.

For this study, the researcher conducted a pilot study mainly to test the feasibility of the data collection instrument and this was done prior to the initial data collection procedure of the main study. Although the researcher planned to use a voice recorder, the pilot study was conducted without the voice recorder and this is where shortcomings were discovered. To prevent this, the researcher had to acquire a voice recorder prior to the actual data collection.

2.10 Summary

In this chapter, the research design and methods used in the study were fully explained, these included: Qualitative design, phenomenological research design, explorative and contextual research design. Finally, population, sample and sampling methods, data collection procedures as well as measures to ensure trustworthiness and ethical consideration were discussed.

The following chapter (chapter 3) will focus on research results and discussion of the findings.

CHAPTER 3

DATA ANALYSIS AND LITERATURE CONTROL

3.1 Introduction

In this study the parenting and family experiences of mothers of children with congenital disabilities, aged from less than one year to 14 years, are explored. The research sought to identify the commonalities and variations in families' experiences. Key questions for the research were: What are your experiences in raising a child with congenital abnormalities? What challenges have you faced ever since giving birth to a child with congenital abnormalities? What are some of the coping strategies you use to deal with your current situation?

This chapter presents the analysis, findings and discussion of the study findings together with reference to relevant literature. The findings of the study revealed various psychological, social and economic challenges that parents experienced in raising a child born with a disability. Some of the key themes found in the peer literature review with respect to experiences and needs of families of individuals with disabled child also emerged in this study.

3.2 Characteristics of Participants

A total of 12 respondents (identified as MCAC1 to MCAC12) were interviewed and their age range was 17 to 45 years with a mean age of 33 years. The participants were mothers of children with congenital abnormalities, ranging from cerebral palsy, Down syndrome, cleft palate and hydrocephalus. On average, the

participants had 1 child with congenital abnormality except one participant with 2. The highest level of education attained ranged from grade 7 to grade 12 with grade 9 being the average highest educational grade achieved. Three of the participants were employed, 7 were unemployed and 2 had small businesses. Also 4 of the participants were married, 7 were single mothers and one was a widow. The table below illustrates a summarized description or characteristics of the participants.

Table 3.1 Characteristics of participants

Age Group	No.	Highest level of Education	Employment status			Marital status	
			Unemployed	Employed	Small business	Single	Married
17-21	3	Grade 7, 9,12	3	-	-	3	-
22- 35	4	Grade 9,10 x2, 12	3	1	-	3	1
36+		Grade 7, 8 9 x2 10	2	2	2	1	3 1widow

3.3 Data analysis and findings

The data generated from the in-depth interviews were subjected to content analysis and categorized. Four categories of description reflecting key variations of meaning emerged from the analysis. The commonalities and variations in mothers' descriptions are illustrated with excerpts from the transcripts. The quotes provide illustrative examples of the category that supplement the excerpts description. There are three sub-categories under category 1 and the remaining three categories had no sub-categories. This was because of the nature of information gathered.

Two key words, i.e. parents/mothers and congenital abnormalities/disability will be used interchangeably. This is due to the fact most of the parents interviewed in this study were mothers in exception of one interview where the father together with the aunt accompanied the child to the hospital for follow-up. Moreover, it is well documented in many studies that mothers carry the disproportionate burden of raising the child with CA, thereby being more inclined to experience stress related to child care (Johnston, Hessel, Blasey, Eliez et al., 2004). Congenital abnormalities and disability are two related terms, (see Chapter one of this study), as congenital abnormalities can result in disability. For this reason the concepts will also be used interchangeably.

The seven categories derived from mothers' experiences are illustrated in the table below:

Table 3.2 Categories

Category	Sub-category
1.The emotional experiences of parents of children with congenital abnormalities	Experiences with family relationships
	Parenting expectations and practices
	Role changing of family daily life
2.Social Support	None
3.Formal Services	None
4.Community acceptance	None

3.3.1 Category 1: The emotional experiences of parents of children with congenital abnormalities

This core category describes the initial impact of the birth of a child with congenital abnormality on the mother. The circumstances under which this news is received, is clearly recalled by the mothers because this is a significant event that is maintained as a part of the on-going family narrative.

The impact of this experience is evaluated and re-evaluated over time, as mothers consider the changes that the event has brought to their lives. The timing of the event provides variable within this category, similar to the time when the knowledge is shared with others. This category and its three sub-categories clearly

indicate the emotional, psychological and economic challenges endured by the parents when raising a child born with CA. This includes the parents' immediate reaction when they learnt about the child's CA, parents' experiences with family members when they revealed the news about the CA, parents' expectation and practices after learning about their child's condition and push and shifts that the mothers have to undergo to reposition themselves to better care and understanding of the congenital abnormalities.

For MCAC1-MCAC9 and MCAC10, the knowledge that their child had congenital abnormalities came when the child was born. For MCAC8, the knowledge was acquired 9 months after birth, for MCAC11 it was 6 months after birth that she learnt of the congenital abnormalities, whilst MCAC12 learnt of the congenital abnormality after 2years. For all the mothers, this knowledge brought trepidation and apprehension because they possessed little knowledge about congenital abnormalities. The majority (9) of the mothers were uneducated with either grade 10 or lower as the highest passed grade.

This coincides with the writings of Harry (2007) who differentiated the congenital abnormalities into two groups, the first group are gross abnormalities which are obvious at birth while the second group are metabolic abnormalities that are not apparent immediately and represent a significant and possibly preventable hazard to the well-being of a person. Thus, those participants who learnt about the congenital abnormalities of their children immediately after birth are falling under the group of gross abnormalities whilst the ones that learnt about the congenital abnormalities later are falling under metabolic abnormalities. Guha (2008)

emphasizes that most of the birth defects present at birth can be corrected while those present a year or more after birth are often impossible to be cured or corrected, which is also evident in this study.

The level of education among the participants of the current study reflect the findings of other studies which revealed that the majority of those families living with disabilities resulting from anomalies live under severe poverty, remote from information and thereby not covered by the world statistics (EUROCATE, 2005).

In this category, the emphasis was mainly on the parental reaction and impact of such reaction upon learning about their child's disabilities. Carsle, Mason, Watkins & Whitehead (2005) referred to the birth of the baby as a major event in the life cycle of the family and a source of great expectations, so giving birth to a baby who manifests with a different appearance or who presents with life threatening conditions triggers a series of reactions. Variations in reaction and its impact were observed in the excerpts that follow:

A 36 year old mother whose child has a cleft lip and palate said (MCAC1):

“I was shocked, I became sick and I developed high blood pressure. I started thinking a lot of things asking myself what I did wrong to my God, what did I do to deserve this?”

A 17 year old mother whose child has a cleft lip and palate said (MCAC2):

“I was afraid and I kept asking myself will there be any help for the baby or it was the end of everything, it affected me so much that I do not feel good about it.”

A mother whose child has hydrocephalus said (MCAC3):

“I was worried, I was worried (repeating herself) and I started asking myself why, what has caused this problem what have I done, my Lord?”

Another mother whose child has hydrocephalus had this to say (MCAC5):

“I first did not believe what they told me because the child’s head was just normal at birth, I did not expect to be like that (Referring to the big head now), I am not sure how I felt!!!” (She becomes emotional).

All along, as she spoke these words, MCAC1 was trying hard to hold back her tears and her voice was quivering as she wanted to cry. Sajjad (2010) cites Vijesh & Sukumaran (2007), that parents may experience periods of panic, anxiety and helplessness, periods of indifference and anger, depression, apathy and bitterness.

This agrees to the feelings of MCAC1 and MCAC2.

The feeling of guilt and denial by MCAC2 and MCAC3 was also reported by Reichman, Corman & Noonan (2008) that stress may be associated with guilt, blame or reduced self-esteem and may divert attention from other aspects of family functioning.

The situation was slightly different with MCAC6, a 42-year old mother whose child has a Down syndrome and congenital heart disease who had this to say:

“When the doctor told me that my child has Down syndrome and heart problem, I accepted it because I could also see that the child does not look like others, I accepted the condition, it is God’s creation.”

Whereas MCAC7 a 45 year old mother whose child has Down syndrome did not say anything when the news was given to her by the doctor, her response shows a crushed and despaired heart as stated below:

“I did not say anything or do anything, the doctor told me first that your child is Down syndrome and we are going to refer you to the rehabilitation centre, then I just said it’s ok, it is fine so long I am having my son.”

At times responses like this show a personality trapped between hope and despair and this is reflected in her subsequent response to the question how do you feel deep inside you about the condition of your child:

“Oh!!!! (Takes a deep sigh) I always feel bad, and sometimes I always cry because of my son.”

Some mothers had the same experience when they discovered that their child had a congenital abnormality, they felt bad, angry and abandoned by their God or as if they were the cause of their child’s disability. Some of them always ask themselves and their God, “why them”? Some of them still feel bitter in their hearts and physically cry when they reflect on and see their children. Having a child with congenital abnormality is shocking and emotionally traumatizing to a mother as revealed by some of these mothers. These feelings are a reflection of a battle within the parent in grasping and accepting the difference between expectations and the real disabled child. Matthew, Modrcin & Robinson (2006) reinforce this experience and they state that the initial diagnosis of a child’s disability confronts the family with the discrepancy between their hopes for the

child and the child's actual abilities. This discrepancy between their child's developmental capabilities and the child's peers increases a sense of being isolated from other families.

Mothers describe the feelings and emotions they experienced with the disabled child's birth with great suffering and grief. An abrupt disturbance strikes their emotional balance. They live a unique and non-transferable experience, permeated by crying, loneliness, helplessness and a great anxiety to escape this situation. Therefore, the mother lives a great emotional and existential conflict, feeling abandoned and powerless to continue living. She wishes to give up the struggle, which, at that moment, feels too painful. She shows herself vulnerable in the face of the situation, not being able to comprehend the reality of having a disabled child. The mother feels unhappy, showing feelings of disbelief and hopelessness. Having a disabled child brings great suffering, reported by her as death.

The category illustrates the initial and on-going effect that the birth of the child with congenital abnormality had with the mother, as well as the significant impact of the event on other family members. Sajjad (2010) acknowledges that when parents are told about having a child with disability, they generally progress through six emotional stages: disbelief, guilt, rejection, shame, denial and a feeling of helplessness. This observation concurs with the findings of this current study, as reflected by responses given above.

There are several reasons for parents to have such psychological and emotional, bitter feelings: one being that this baby is something the mother was carrying for

nine months, hoping to have a normal child who will assist her in the near future and eventually become a productive citizen of the country. All of a sudden this dream becomes a tormenter to these parents as they see themselves in the spheres of not knowing how to face the reality of living with this child. They are occupied with fear, wondering whether there will be any help for this child. Furthermore, this is something that is not transferable or something that one can throw away, nor change, but is something that parents themselves have to cope with, in most cases throughout their lifetime.

The psychological and emotional challenges experienced by parents in this current study differs to what was found in the Tanzanian study, where mothers of disabled children had concerns about the future of their children due to the special needs, erratic and long term consequences (Ambikile & Outwater, 2012). Thus the cause of bitter feelings in these parents was mainly emanating from the long term consequences of their disabled children. However, the emotional experience of sadness, inner pain or bitterness in this current study is similar to the previous study done in the United States where emotional strain was expressed by mothers as having fear, frustration and guilt (Scharer, Colon, Moneyham, Hussey et al., 2009).

Moses (2004), summarizes his experience in treating parents with disabled children by acknowledging that parents attach to children through core-level dreams, fantasies, illusions, and projections into the future. Disability dashes these cherished dreams. The impairment, not the child, irreversibly spoils a parent's fundamental, heart-felt yearning. Disability shatters the dreams, fantasies,

illusions, and projections into the future that parents generate as part of their struggle to accomplish basic life missions. Parents of impaired children grieve for the loss of dreams that are key to the meaning of their existence and to their sense of being.

i. Sub-category 1: Experiences with family relationships

This sub-category is complex, related to the subsystems in family relationships: the marital relationship, sibling relationships and relationships with the extended family. It identifies how the child's condition has affected the cohesion of the immediate and extended family. It includes individuals' relationships with the congenitally abnormal child and the nature of the relationships between family members that do not include the child but which are affected by the presence of the child. It also reflects the degree of acceptance of the child by family members.

Some parents described their family relationships as normal and supportive of all families, as highlighted by a few extracts from the interviews below:

A 42-year old mother of a child with cerebral palsy had this to say about family relationships (MCA12):

“My family and husband's family are fine with the child, like now the child stays with my mother in-law and I know she treats the child well, immmm!!!! The problem is that she is too old. I once decided to take the child to Windhoek, but I thought again that the child was still small to be sent to Windhoek.”

Responding to the question, what was the father's reaction when he saw the child for the first time? MCAC12 had this to say:

“Like the other people were saying he encouraged me to take the child to the church and hospital. He felt pain, but he accepted the condition of the child”

MCAC7, a 45-year old widow and mother of a child with Down syndrome echoed the same sentiments about her family:

“The family is fine when it comes to the child, they have assisted me so much with money to buy medicine, my cousin put him on her medical aid, and a lot of other support. Even now if I tell them that the child is sick, I want to take him to the hospital they will assist.”

MCAC6, a 42-year old mother of a 7-year old child with Down syndrome expressed gratitude to the relationship she has with her family as highlighted by the following extracts from her interview:

“I did not observe any change from both my husband’s and my family. The only thing I observed is that they feel sorry for the child, because every time and then the child had to be taken to Windhoek, came back and went back, until the child was finally referred to South Africa.”

Asked about the reaction and relationship she has with her husband, MCAC6 had this to say:

“No change, the relationship remained the same. He also accepted the child because he could see that the child does not look like other children.”

All the above participants highlighted the importance of support from their partners and family members. The in-laws were very supportive as well as the

mother's family. Extended family members as aunts and cousins had good relationships with all the four participants. This is confirmed by Rosenweig & Huffutter (2005) who asserted that families with children born with CA tend to function more successfully with effective family support system because these are people available at all times and may render assistance any time the need arise.

However, two of the participating mothers had mixed relationships with their families - that is some family members accepted their congenitally abnormal children, while others did not accept them.

Though MCAC5, a 32-year old mother of a hydrocephalus child had this to say pertaining family relationships:

“My husband also told me the child will be operated, he used to call to find out the condition of his child.”

Despite this revelation by this mother, there are still some casts of doubt whether the spouse really supports and accepts this child as expressed in the subsequent answer to the question, whether her spouse has ever seen the child ever since it was born. She had this to say:

“No, he used to call to find out the condition of the baby, if he can assist with money to buy milk and nappies and to come and see the child.”

It clearly shows that mothers with children that are congenitally disabled are at times the only load bearers, who at times are rejected indirectly by their spouses.

MCAC8, a 31-year old mother of a child with cerebral palsy, had a fair share of mixed experiences with family relationships. When asked about the father of the child and if he knew about the child's disability, she had this to say:

"Yes (she lowers her voice), I told him at a later stage, he just asked where did he get the abnormality. I said I don't know also (still speaking in a low voice)."

Asked how she felt about the spouse's response MCAC8 responded with difficulty:

"I felt very bad since I did not know how to explain it to him (Her voice is breaking as she wants to cry), but latter he accepted the child."

Asked about her relationship with her mother, MCAC8 had this to say:

"She accepted the child because sometimes I leave the child with her when I go somewhere."

Some of the participants had really emotionally traumatizing family relationships which compounded the burden of looking after the congenitally disabled child. Some of these mothers were emotionally drained and throughout the interviews, crying was experienced and mostly came when the question of acceptance of the child among family members was posed. In the family support and direct character assignation by the people who are supposed to be pillars of strength of the mother, the mother is vulnerable emotionally and mentally. What follows below are some of these experiences that the participants went through.

MCAC11, a 33 year old mother of a congenitally disabled child has a good relationship with her husband, but the relatives of the husband have traumatized them so much as expressed below:

“My husband is depressed because his family did not accept the child up to now. They used to tell him bad words like he is stupid, he is having a disabled child. One time this year (2013) in May he was on leave at home and one of his uncles (grandfather) asked him to take him to the cattle post and he responded that he is busy because he is taking child to the hospital for measurement of the wheelchair. The uncle said for what purpose if the person is disabled, what it is going to help, for what reason, so he is always depressed.”

Sajjad (2010), concludes in his study on the impact of disability that anger, sense of loneliness and depression faced by mothers of children with intellectual disability has a negative impact on their family life. Reichman et al. (2008), acknowledges that living with a disabled child can have profound effects on the entire family—parents, siblings, and extended family members. The authors further state that it is a unique shared experience for families and can affect all aspects of family functioning. On the positive side, it can broaden horizons, increase family members’ awareness of their inner strength, enhance family cohesion and encourage connections to community groups or religious institutions.

On the negative side, the time and financial costs, physical and emotional demands, and logistical complexities associated with raising a child with disability can have far-reaching effects as described below. The impact will likely

depend on the type of condition and severity, as well as the physical, emotional, and financial wherewithal of the family and the resources that are available. Holmes & Deb (2008) stress that disabilities and illnesses come in many forms and so do families' experiences with them. An unpredictable, hard-to-manage health condition can contribute to anxiety, conflict, and depression in a family, drain financial resources, and leave the children without adequate parental care. In addition, a progressive, terminal condition can bring feelings of grief, powerlessness, and loss of structure to the family environment.

In the African culture, the extended family is the shoulder to cry on and a pillar of strength. Failure of the extended family to take up this role has devastating results. For some relatives a disabled child is nothing and a father must have better things to do than baby-sitting a disabled child. This, coupled with the stress of having a congenitally disabled child is psychologically draining. The social safety net of family members then becomes fragile, dismantled and feedback into the stress cycle, which is why the husband of MCAC11 is in depression.

As MCAC11 explained tears are dripping down her cheeks and she is crying almost every second, this is an enormous emotional despair as she realizes that the child is not wanted by the people who are supposed to be mentors of this child. Furthermore, the husband who is supposed to be protecting her is emotionally depressed making this mother emotionally vulnerable.

Beresford, Rabiee & Sloper (2007), found in their study that parents were concerned about the strain imposed on their relationship with their partner. Doing something to support or preserve the relationship was often a high priority for

these parents. Ways to support the mother-father relationship included: meeting fathers' emotional needs, greater involvement of fathers in consultations with professionals, short-term care and domiciliary support to release parents from the caring role and domestic tasks, and help with the disabled child's sleep problems. Unlike their study, parents interviewed in this current study did not report any effort being done to restore relationships with their spouses.

MCAC3, a 38 year old mother of a hydrocephalus child narrated her experience with her family members and had this to say when asked about family support:

“He (referring to her husband and crying) did not accept the condition of the baby because in their family there is no one born with defects.”

“.....the situation has changed” (crying) referring to her relationship with her husband.

Asked if she ever communicates and gets support from her husband, she said:

“Just a little bit..... No support from my spouse” (She starts crying).

This is her husband and father of her four children who abandoned her after the birth of the hydrocephalus child. The way this mother was crying shows the pain she is going through, the pain of being rejected and abandoned by someone she has been with as they raised their normal children. The reason of rejection is even very painful, just because in the husband's family, there isn't someone with that congenital abnormality, it automatically implies that the wife is responsible and this is traumatic to this mother.

This mother (MCAC3) was in emotional trauma as most of the times she was just continuously crying and the interview had to be stopped for a while as her cry was worse. When asked later if she gets any support from any family members she again burst into tears and then she managed to calm down and had this to say:

“..... *No support from other family members*” and continues crying.

Family conflicts emerge as a source of concern for the mother, which is experienced due to the difficulty in perceiving the child as a being with capabilities and in accepting its disability. As she goes through this intense suffering, the mother feels lonely and distanced from the real situation and from her family members. This distancing and loneliness makes it difficult for her to become involved in the situation and consequently impairs her understanding or attribution of the meaning of her existence.

She experiences the guilt of having generated a disabled child and of having feelings and attitudes of rejection towards that child. This guilt comes with suffering, as the mother perceives herself as being the only person with feelings of rejection and non-acceptance.

MCAC9, a 21 year old mother of a baby born with cerebral palsy, stays with her grandmother and has gone through a great ordeal with her baby's condition. She says although she gets little support from her spouse, she is encouraged by her aunt who has become her support system. The worry she has is, she cannot stay with her aunt but her grandmother. Asked about her family, relationships, especially with her aunt, MCAC9 had this to say:

“The father of my child is in Windhoek, he is the one encouraging me to bring the child to the hospital; he will also send transport money to bring the child to the hospital. My grandmother hmmm..... is there but she does not regard me as part of her family, she does not seem to have concerns with the child even when I tell her anything about the child. Even when I was pregnant, I was always in the same situation. She will throw bad words at me, maybe it is because of this situation of my grandmother that is why I gave birth to such a child. When the pregnancy was big, I had to leave her house and went to my aunt and that is where I stayed until delivery.”

“.....I always cry at certain times, it makes me feel very bad and stressed”(speaking in a very low voice).

MCAC1 had the torture of her life when she returned home with a congenitally abnormal child soon after her discharge from the hospital. She was even accused by her mother in-law of having done something to the baby. At times family members showed no remorse to an already traumatized mother. This mother in-law has already another abnormal child in the family, but she had the audacity to tell her daughter- in -law that she did something to the baby. MCAC1 response to the question about family challenges is highlighted below:

“After I was discharged from the hospital, when I reached home, my mother in-law said that I did something wrong that is why I gave birth to a child with congenital abnormality. She also said that the child must not be taken outside among the people; it must be kept in the house. But my husband when he heard

that I gave birth to a child with a congenital abnormality, he called and told me not to worry because there is someone in their family with such a condition.”

MCAC10 is a unique case; she is an aunt of a child with hydrocephalus, club foot and meningo-myocle. The child is in her custody together with its father; the mother of the child has abandoned the child and has moved to a coastal town. Even though she doesn't work, she has stayed there for over two years. Although the mother calls frequently to hear about the child's wellbeing she doesn't visit. This is a mother torn between fear and self-denial, the part of being a mother reaches out to the child through phone calls, but the fear of facing the congenitally abnormal child and the despair of not being able to take care of this child shuts the mind of the mother leaving her hiding within her uncertainty. To her, being with this child isn't an option, for in herself, she is convinced she is a disgrace to motherhood as she has given birth to what society has labelled "not a child." Coupled with her ill prepared psychological framework and hibernation becomes the only alternative.

If one looks at the other perspective, you would really also see the dilemma of a mother who has been subjected to stigmatization and also labelled with various connotations associated with giving birth to a disabled child. Sometimes the physical and emotional pressure becomes unbearable and a mother is left with no option except to run away.

It is evident from the extracts above that parents who reported revolting and traumatizing relationships were emotionally drained and throughout the interview,

tears were visible from the eyes of some of them. The tears demonstrated feelings of sadness, anxiety, loneliness and fear. One mother's husband is depressed, "a positive sign of mental disorder" simply because his character was assassinated by people who were supposed to be his strength or pillar to lean on during this difficult moment.

The above findings coincide with the writings of Albrecht (2010) who stated that a supportive relationship is an important part of keeping us healthy and may reduce the chances of developing poor physical and mental health. In addition to that, Uchino, Cacioppo & Kiecolt-Glaser (2007) revealed that having a strong network of friends and family who provide social support is linked to good health.

A particularly strong correlation was found between anxiety and low number of friends. Individuals with good social support are less likely to react to negative life events with depression, anxiety, and health problems and the magnitude of reaction to stress is considerably less for individuals with good social support from close friends and family members than for individuals with inadequate social support (Lahey, 2004).

ii. Sub-category 2: Parenting expectations and practices

This sub-category represents parenting expectations and the practices in which they engaged to support their child's learning and development. In other words the sub-category elaborates what the parents expected from the Government, family members and community. Whilst much is known about the difficulties and

challenges parents with a disabled child face, and what parents want for their children, very little is known about how parents want their own lives to be.

This current study agrees with the findings of Beresford et al. (2007) in that some mothers were aware of the importance of optimal learning experiences for their child to achieve his or her potential. There was also a recognition that a major goal in parenting is to ensure that the child becomes independent irrespective of any physical or intellectual disability. Based on this notion, some mothers acknowledged the need for a special school to cater for their children's needs as the current school scope of practice in the region is limited to blind and deaf children and many other forms of disability.

When MCAC10 was asked what else she wanted government to help her, she had this to say:

“We want them to help us with paying fees for kindergarten for the disabled children and we want a special school for our disabled children. They must also attend to the foot of the child so that he must be able to walk.”

“.....maybe to increase the fund to N\$500.” This refers to the disability grant provided to the children by the government.

(Father interjects) *“No, it's not enough because the kindergarten only is costing N\$600 per month, so N\$200 is not enough.”*

MCAC2 and MCAC3 had this to say pertaining caring for a child with congenital abnormality who is unable to feed and relieve himself.

MCAC2 had this to say: “...*They must give me money to buy milk for the child, even to repair the abnormality.*”

MCAC3 voiced the same sentiments: “...*to help us with food, money to help us raise our children.*”

Most mothers experienced increased costs of caring for the child with congenital abnormalities and these costs were related to buying disposable nappies, milk and transport to the hospital for monthly follow ups. MCAC12 acknowledged this:

“They must provide the child with shoes, at least if the child can walk, although she is not talking, it is better and I think once they will provide her with shoes things will be better. The child is growing bigger and the time she will be five years no one will be able to carry that child”

“Yes, yes, she is receiving N\$200. Ooh, is too small. If you think you are buying milk and disposable nappies, the money is just too little. Now if I could not be working who could provide the child with nappies? She is also not getting food”

“They must provide milk and nappies, these things are very expensive, you know how much they cost.”

Various studies have documented that financial burden is one of the stresses of parenting children with disabilities. Braeuner (2014) made an observation that families of children with special needs face a different monetary burden than other families. Furthermore, Braeuner (2014) states that medical care, therapy and special equipment may be covered by insurance, but some companies limit the

benefits. Parents may still have additional out-of-pocket expenses. In addition, most families of children with special needs have greater financial need, nearly a third of these families lose one parent's income to provide the child with needed care. This combines to create a recipe for stress. Understandably, families without access or with limited access to these types of supports have additional challenges and subsequent increased levels of stress than those with such resources (Browne & Talmni, 2008).

MCAC11 has high expectations of government and had all this to say:

"....Yes, my child is receiving the grant, there are two categories, those who are eighteen years and above, they are receiving N\$500 while those who are below 18 years are getting N\$200. He has received this grant for three months, because when I used to go to the councillor to register the child for the fund, I was always told that I must be able to help that child like other children who are not disabled" (starts crying again).

Asked if the N\$200 is helping her?

"Yes, it can help because N\$200 is better than nothing, but they must try to pay all of them the same amount with the ones above 18 years, it is when you can be able to buy something, although we are being told to support them the way we are supporting the normal children" (continues crying).

"We want a school for our disabled children. We are having an Eluwa School for deaf and visually impaired children, I once wanted to take my child there but I was told they cannot assist me because of the type of disability that my child is

having. They were willing to assist but because of the shortage of staff and the type of disability they were unable to assist. Now why can't the Government increase the number of staffs at Eluwa if they cannot provide us with school for disabled children in the North?"

MCAC8 echoed the same feelings about nappies being expensive:

Ahhhhh!!!, this pension (Referring to disability grant) you can say thank you because you are receiving something, the other time you don't have anything if you receive it then you can buy soaps and nappies only. We are asking the Government to assist us to subsidize nappies, for instance, maybe you come and pay N\$10. 00 to the hospital and you are given nappies that will last you for the whole month. Because these children need to be in nappies at all time and they are very expensive.

Canam (2011) concurs with these financial woes that confront parents with disabled children, and the author further stresses that parents of children with special needs require additional resources and support from outside the family to manage the ongoing care of their child and family life. This support includes competent medical, educational and rehabilitative services for the child, information, respite care, and emotional support from friends and groups outside the family. Parents may have support in one area and not enough in another. For example, parents may have a lot of friends who provide emotional support, but they may not have anyone who can look after their child so that they can get a weekend of respite. It is important for parents to recognize the strengths and limitations of

their support network and develop new resources to address the gaps. Parents need to be reminded that doing their best does not mean doing everything themselves.

MCAC4's expectations were more on the construction of the hospital facility, and she was advocating for a physical barrier to seclude her and her baby from other patients. She felt vulnerable to emotional torture by other mothers with normal children and she expresses it in the following way:

“The Ministry should assist us not to share rooms with other people, because those coming in the room they keep observing my child or our children with deformity and once they go home or out they start spreading stories about such abnormalities. Even may be to put doors that can be closed because others will just come in the door and start observing what you are doing with your child and I feel bad about it.”

“It is affecting me because our children are not having the same deformity, and sometimes when her visitors come to visit her they start discussing about Forgive's (Name of the child) condition which is not good to me.”

These are clear pronouncement of a mother who is only seeing the abnormality in her child and surely with no room that there is more this child can do. The inferiority complex is tied right around her and even any discussion by roommate or relatives is perceived as vindictive of her child's condition.

A family does not anticipate the onset of a severe emotional disorder in one of its children. This occurrence is non-normative in that it is unexpected. Normative events allow a family to anticipate change and make the necessary arrangements

that will allow the family to adjust to the new set of family demands. Families with children and adolescents who have serious emotional disabilities do not anticipate raising a child who is disabled. The event is involuntary in that it is not chosen, anticipated or expected to be part of the family life-cycle (*Matthew et al., 2006*). It has been documented with adults who are mentally ill that “the onset of mental illness in a family member produces a state of crisis in the family” (Hatfield & Lefley, 2004). This upheaval and state of crisis for parents with children who are diagnosed as having a serious emotional disorder disrupts communication patterns, family roles, and living patterns for the family. The marital unit, sibling and parental relationships are all affected by the needs and behaviours of the child. How these variables are influenced will vary from family to family. How the family organizes around this crisis situation can, and often does determine the future course for family adaptation and development.

In this current study mothers advocated for the provision of special schools as they wanted their children to at least learn something, though not for the purpose of securing employment. This differs from the findings of Ambikile & Outwater (2012) where parents interviewed were advocating for special boarding schools and Day Care Centre, as they believed this could save time which can be utilized for other productive activities.

Some parents in this study also expressed the desire for special treatment, they wished their disabled children be given specialized health care. These wishes were basically brought because of stigmatization experienced by some mothers. According to Kourkoutas, Langher, Caldin, & Fountoulaki (2012) dismissal of

parental expectations by health care workers often leads to intense emotional frustrations. Some authors interpret the parents' tendency to put the blame on others as a coping mechanism that relieves feelings of guilt (Seligman, 2011), for instance, parents may perceive having certain problems is a result of children who are not in school. It may also be a defense mechanism to cope with painful or depressive feelings.

There are more reasons to believe that most of the parents interviewed in this study are economically challenged as most of them are single and unemployed parents. This observation on the economic status of the parents concurs with the findings of Ambikile & Walter (2012) who revealed that the total cost of bringing up a child with a disability is three times higher than for a non-disabled child.

Instead of devoting most of their time in income generating activities, parents interviewed in this current study are engaged more in caring responsibilities which makes them more vulnerable to poverty. Parents in this study wished government disability grant to be increased in order to cater for the daily needs of their disabled children. They are burdened by exorbitant fees charged by kindergartens and high price of nappies for most of these children were either bedridden or wheelchair bound. Similarly, the challenges of poverty among parents of disabled children was also found in a study by Ambikile & Walter (2012) where parents expressed their agony and suffering resulting from poverty; they said poverty was responsible for their inability to meet the needs of their disabled children.

Unlike what was found in this current study, Ambikile & Walter (2012) found that parents in his study were overburdened with medical costs as they had to buy medication for their disabled children. The fact that one prescription had more than one medication and at times these medications could not be sourced at one pharmacy and they had to travel from one place to the other placed them in a complex position.

iii. Sub-category 3: Role changing of family daily life

This Sub-category exposes the push and shifts that the family undergoes as they reposition themselves to better the care and understanding of the congenital abnormal child. Suddenly the mother finds herself in a position where she has to adjust the family daily life and enter a new path, sometimes in a different direction and at times within the same direction.

The family's ways are transformed with the child's disability, initially showing vulnerability to everyday activities and in other moments, re-organizing themselves and showing a disposition based on what is to come. The mother feels the need of family support and the attitude of listening as emotional and practical support for her acquaintanceship and care for the disabled child.

According to Contact a Family (2013) relationships matter and when they work well, they are a vital source of support and protection against life's stresses and strains. The author furthers stresses that relationships go through periods of change and challenge, hence acknowledgement that parents caring for a disabled child have to adjust to new roles, and may have different expectations about their

child. They also have to cope with significant emotional, social, physical and financial pressures. Many parents find that these experiences bring them closer to each other and make their relationship stronger. Some of the mothers interviewed in this study went through emotional trauma which worsened their relationships with their spouse and extended family.

When living with the disabled child, the family discovers that there are no formulas or specific ways for the relationship with him or her, unless that it is necessary to be patient, strong, persistent and affectionate. Through the daily routines with the child, the family members discover new ways, learning in the self-discoveries a way to live together as a family. Hence, the acceptance of the family members is reached by allowing themselves the dignity of experiencing and expressing strengths and personal limitations, respecting themselves and their individual potentials. The mother understands that the emotional situation generated by the child's disability also affects the closest family members and that such experience cooperates with the family union, which mobilizes itself towards helping to provide care. The mother perceives this fact, as a facilitating integration and attitude toward the disabled child in the family unit.

The mother of a congenitally abnormal child has to make a number of adjustments in her life so as to fit herself in the requirements of her child. She has to re-adjust her schedule since the condition of the child cannot be adjusted to suit the mother's schedule that she had before giving birth to the congenital abnormal child. Most of the mothers interviewed in this study reported one or more changes in their lives, of which some of the changes have even cost their income.

MCAC2 has a child with cleft lip and palate and instead of normal breastfeeding, she had to express her milk first then feed the baby. This may appear to be a small change, but this has emotional strain on the mother, as breastfeeding is regarded as the pillar of motherhood, failure of which a mother disqualifies herself. MCAC2 had this to say:

“...It is difficult, I experienced difficulties with the feeding of the child, so I have to express milk from the breast and feed the child.”

What else?

“Whenever I could feed the baby, the milk could come out through the nose. Sometimes the baby could vomit after feeding.”

Heiman (2009) cites Marvin & Pianta (1996) and concurs with the expression of MCAC2 that because of disability she has to change her routine breastfeeding. Heiman (ibid.) emphasizes that changes of life routines are necessary in order to provide for the child’s care, which has been found to have significant effects on family functioning.

MCAC3 has a hydrocephalus child and has 6 other normal children, and her lifestyle changed with the birth of the congenitally abnormal child. She has to go to the hospital every month and because of the size of the child’s head, she admits it is difficult to carry the child.

“...It is difficult to carry the child.”

“...Many times, every month for five month.”

“.....I feel very bad about it.”

MCAC9 had to change her life style now that she is expected to be at the hospital often and she stays very far from the hospital and had this to say:

“It is very difficult. I am staying at Okalongo and it is very far from here. I always struggle with transport money because sometimes the father of the child is not around to give me transport money since most of the time he travels.”

Some of these congenital abnormalities require prolonged hospitalization and this completely alters daily routine of the mothers. Some of these congenitally disabled children need special care which most of the time, the mother is the only person, patient and competent to execute care. This in turn ties the mother to the baby and she is left with no freedom to be away from this child.

“Since February this year I have been in the hospital, I was never discharged.

I learnt a lot of things. At first I had problems with the feeding, because the baby is fed through the tube that goes directly in the stomach, sometimes this tube could block and I did not know—how to unblock it. The other thing, it is really difficult to take care of this child because you should stay with the child at all times, you cannot leave him with anyone else because she won't know how to handle him or feed him,” says MCAC4.

Heiman (2009) had similar findings, some of the parents interviewed in his study reported, the challenge of carrying the child everywhere as seen in this extract from his study: “I can never leave him alone” or “I have to take her with me

everywhere”. Most of the parents spoke about the various difficulties they themselves have to cope with, while others mentioned never-ending emotional and/or physical fatigue, social isolation, and the feeling of a lack of freedom.

MCAC5 a mother of a Down syndrome child went through a lot of changes in her daily lifestyle as revealed by the following excerpts from the interview:

“I learnt a lot of things in raising this child. I learnt to give special care, to be doubly careful when I speak to him. I cannot shout at this child, immediately you shout the child will stop whatever she wanted to do and she will be demoralized and stay quiet for a long time. You need to treat her like other children, keep him clean and dress him properly and so on. The other thing is that the child is not talking so, I always try hard to teach him at least how to say a few things.

The strength is coming from the beginning, because at birth I accepted the condition of the child, I stayed three months in ICU with this child, so I left everything in the hands of God, I thought he was the one who created the child if he takes him away, he can do that but if he heals him, we will always have hopes for the better through prayers.

It affected me because you leave your house and nobody is doing your work. Like the other time when I went to Windhoek I was forced to remove my child who is followed by this disabled child from attending a kinder-garden and took him to my mother because I could not leave him with the father. Of course it was difficult for me to leave my house and business unattended; I could not do anything about

it. I have to remove my child from school; I was not having any choice” (Becomes slightly emotional).

Asked how giving birth to a Down syndrome child has changed her daily lifestyle MCAC7 had this to say:

“Yes, it affects me very much. Like now I don’t go to my business in the morning because of the child, I go in the afternoon when the school is out for the sisters to stay with him when I am gone. I used to take him but I failed, if you go with him there he will play with people’s things and they often become upset with him. I was also having a business at open-market. I dropped the business because there is no one to look after the child.”

MCAC7 had to change her business location.

“My business is now at my neighbour’s place. I cannot operate from my house because of him, he will spoil everything, look all this stuff you see here they are broken by him, and my windows are all broken because of him”, MCAC7 explains.

Changes are also brought about by the hyperactive child and the complications of abnormality.

“There are a lot of problems with this child because he does not stay in one place; you cannot leave him with another person other than his sisters. He cannot play with other children sometimes he beats them. Even when you tell him not to do something or not go out he just do it or go, he does not take orders. With the

diet, he is having an allergic reaction to certain food, like fatty foods. The other time he took the whole year without opening his eyes, there were some sores in the eyes, until one of my cousins put him on her medical aid; we took him to the specialists for treatment and after that, his condition improved,” stated MCAC7.

The findings of this current study are similar to what was found by Cousino & Hazen (2013) when they explored the factors in the child care that contributed most to the added strain. Their findings revealed that the demands for caring create greater stress than the severity of the disability.

Buying pampers and watching over the congenitally abnormal child becomes part of the mother's life:

“Every time you need to wash the child and change nappies; you have to buy nappies every time. You must feed the child every time she needs food, every second she needs food.”

“You know, you cannot leave the child behind; anyway you can leave her with other people or at kindergarten but it is not good” said MCAC10.

MCAC11 is confronted with a growing child who is immobile and has to carry her to the hospital for follow up visits and elaborates her experiences in life style changes as follows:

“My dear, the child is growing; he is also gaining weight like other children, so when you carry him, he is even taller than you, when you carry him, his legs are disturbing your legs (meaning she does not move properly). The other thing, the

child had a wheelchair in the beginning, so as the child was growing this wheelchair became smaller and I had to bring him to the hospital to come and order a new wheelchair of his age. I had to wait for two to three years before the new wheelchair arrived. During this period when I was waiting for the new wheelchair, I suffered a lot, imagine you are carrying this child every time for immunization; it was not easy for me.”

“The challenges are more (many), let us start with feeding; the child cannot feed himself, somebody has to feed him. Like now, I am at work, the child is with my mother, she is the only one to feed this child, bath and so on. I am having sisters but most of the time they are at school. The child cannot do anything or help himself, he is just there not walking. I have been buying expensive disposable nappies from birth up to now, he is a big boy so I always buy the largest size of those nappies which is XX large. Now I really don't know where I will get disposable nappies of his size.”

The mother sees herself in face of the need to leave her job and daily life to meet the demands of the disabled child's care, and due to the initial difficulty in dealing with the feelings and conflicts. She feels incapable of leading a life as the one she had before her child arrived and therefore, she launches herself to the demands imposed by the situation experienced in the family regarding the child's care.

Daily life and activities of all parents in this study were affected by the presence of a disabled child. Much time was spent looking after the child and as a result,

they were not able to do other important activities such as business and caring role of other siblings.

3.3.2 Category 2: Social support

This category represents the mothers' experiences with the social support services outside the family. It focused on mothers' experiences with existing social networks which included among others meeting other parents who had a child with congenital abnormalities.

Social support is important for health and stress relief; it increases resilience, multiplies joy, and softens sorrow (Scott, 2007). An important resource for coping with stress is social support; the presence of others in whom one can confide and from whom one can expect help and concern. In their study, Burton, Westen & Kowalski (2009) concluded that social support is important in strengthening acceptance and resilience of reality.

Mothers interviewed in this study confirm the findings of Burton et al. (2009) and related how social support systems such as religion, peers and formal services available in their community have assisted them to accept their children as illustrated by the following extract from one of the mothers:

MCAC1 comments illustrate this category:

“The words from the pastor and my husband assisted me to accept the situation because after that, I did not even consider what my mother in –law was accusing me of doing something to my child. After birth it was hard to accept, but the

hospital Pastor came and advised me to pray every day, because at least I gave birth to a live child, I should thank God for that and accept what God has given me, so I accepted. Then by that time I was relieved from worries. The other thing when my husband told me about one of his family members with the same condition and after seeing this cousin of my husband, I became much better and I accepted my child.”

Pastors and other religious leaders play a critical role in building self-belief among their members who have social problems, by proclaiming divine help from the almighty, as members take it by faith and belief in their God. They will then start to accept their situation, especially when they know they are not alone in the battle but God is with them. God becomes the shoulder to cry on and replaces the emotional void in their hearts and suddenly they have someone to talk to, who has all the time in the world to listen to them. So when things are not fine, when the stress levels are high they turn to their God and all the burdens and sorrows, they cast them on him and they feel much better. This in the long run, gives them the strength and willpower to soldier on.

At times the social support fabric can be torn by other members of the fabric who are not supportive, but usually social recovery is a function of health worker impact and the strength of the positive support network as highlighted by MCAC2:

“Hopes that the child’s lips will be fixed keeps me strong. People who feel sorry for the baby, they make me feel bad. The assurance from my mother and health

workers about the possibility to restore my child's image (lips and palate) assisted me to cope and accept the condition. The other thing is my sister who is having the same condition like my child."

Hope that the medical intervention will change the child's condition for the better is also very important social support system as indicated by MCAC4:

"The fact that I am waiting for the operation of my child to be done, I am hoping that the child will be fine one day, my sister and spouse's support."

Mothers MCAC2 and MCAC4 demonstrate another coping mechanism which is hope centred on professional advice, i.e. the possibility for restoration of the child's congenital disability. The fact that the condition of the child can be restored gives hope to the mother and takes away all the emotional agony in the mother's life. This then can be utilized by health care workers, especially on those congenital disabilities that are repairable, to inform the parents at first contact.

The mother's affliction and experience bring out the need to look for answers to her questions from a spiritual point of view. In religion, they find the help needed to understand, face and accept the child's disability. The mother wins over the disability gradually, trying to build the bases of a relationship in which the disability is not the child's existence axis. The mother shows the feeling of love and affection flourished in the overcoming of pain and suffering.

Spirituality and divine intervention are important social support structures in society and so is the acceptance of the child's condition as from the beginning.

This is highlighted by MCAC6:

“The strength is coming from the beginning, because at birth I accepted the condition of the child, I stayed three months in ICU with this child, so I left everything in the hands of God, I thought he was the one who created the child if he takes him away, he can do that but if He heals him, we will always have hopes for the better through prayers.”

Gupta & Singhal (2004) reveal that there is research evidence that families, instead of totally depending on external agencies for rehabilitation, the parents take charge of the situation and educate and train themselves. A remark by MCAC6 demonstrates self-dependency brought about by an acceptance of the situation from the beginning. However MCAC6 emphasizes another coping strategy, i.e. spiritual support. Many studies have demonstrated that most parents resort to spiritual and social support as a coping strategy, as concluded by Sajjad (2010), that the social support system in Pakistan resulted in less stress in parents because of joint family system. Common therapies used by mothers include offering prayers.

MCAC7 described how she developed her own support group with other parents who had a child with congenital abnormalities:

“As I said, it was an initiative for parents of children with Down syndrome who came together to find ways how to assist our children, they started these lectures in 2007, that time I was in Windhoek for follow-up, when I came back from Windhoek I heard about it then I decided to join. Basically, we are taught what is Down syndrome, how to handle these children and how to ask for assistance from

the Ministry of Health. Sometimes we used to go there to discuss how we can go about taking care of children, we have tried!!!! We discuss a lot of things like the need to get a school for our children, the need to take care of those children ourselves, not leaving the child with anybody you see because the child might beat that person or the person beating your child because the child is not used to that person. There was a time when we were visited by a Member of Parliament, we gave all our problems to her to take to the parliament, mostly was the issue of school, we want a school where we can take our children. It does not matter where the school is built whether in Ondangwa or Oshakati what we want is school.”

This concurs with the writings of Vijesh & Sukumaran (2007) who acknowledge that formulation of small mothers’ groups in the special schools, can provide the mothers a needed platform for expressing their difficulties, sharing their experiences, solving their problems and more importantly, to develop a mutual help system.

A social support system may include meeting other mothers going through the same condition and this encourages mothers with congenital abnormality children as expressed by MCAC8:

“What gives me, courage is that whenever I bring my child to the hospital, I will see that we are many parents who are having disabled children and when we are here, we normally share ideas on how to care for our children.”

Considering that other mothers are experiencing a similar situation, or maybe worse, and comparing herself to them, the mother launches herself into living and doing things for the disabled child. She perceives herself as having to adopt the characteristics of the perfect, ideal mother and for that, she acts towards accepting all the requirements of the outside world, coping with the situations she experiences with resignation.

By doing so, she establishes an affectionate relationship of helpfulness and patience, surrendering to the child's care. These actions, however, reveal the idea, already conceived by the mother, that the child care is her responsibility, considering herself the main provider of his or her needs. This way, she perceives herself living the experience of being a mother in different and adverse situations, which demand constant mobilization to provide the child and the family with the necessary conditions for acquaintanceship and development. The mother has quite a diverse area of social support of which family members especially spouse, mother and sisters form the core of this support. Some, if not most, of the mothers reported seeking spiritual divine support through their pastors and some had themselves beliefs and convictions as support framework.

3.3.3 Category 3: Formal services

Families of children with disabilities deal with formal services. This category represents the mothers' experiences with health care services primarily. It focused on mothers' experiences with professionals. They had mixed responses about the quality of information and support received. Most of the interviewed mothers

were furious about health care workers' failure to disclose the condition of their children as well as failure to give as much information about the condition as reported by MCAC1:

“In the beginning if the nurses see that you have given birth to a baby with congenital abnormalities, aren't they used to ask and show the sex of the baby immediately, but now since they keep the child away from you for a while after birth, when they bring the baby, they don't even tell you anything about the abnormality of the baby, the nurse just gives you the baby and off she goes, without even telling you or counsel you. At least once they bring the baby they must be able to tell you that the baby is having such a problem or when they are showing you the sex of the baby they must also inform you about the abnormalities of the baby and how you should handle it. Not just to give you the child without saying anything. Like with my baby, I just saw the defect myself and it was only after the baby started crying is when I saw that even this was open (holding the palate). That is what bothered me because I knew only of the defect on the lip, but when the child cried I saw the big opening inside. They should tell us in advance so that when they are bringing the baby to you, you already know that the child is like this” (speaking in a crying voice).

The earlier the mother knows about the disability of her child, the better she will be prepared to cope with the disability. As long as the mother has been psychologically prepared and has accepted the condition of her child, then she is prepared to seek as much information. MCAC1 acknowledges that she was never told about the disability of her child and this affected her emotionally as she only

learnt about the child's cleft palate when the child cried. Therefore, this demonstrates negligence or incompetence on the part of the health workers. However, there is a thin line between times for disclosure of the disability to the mother, since disclosing soon after birth ensures early coping for the mother, but the strains and stress of giving birth leaves the mother emotionally unstable for breaking the news of a disabled child.

MCAC9 had this to say:

"I think they need to improve!! You know last month I brought my child they took X-ray and they told me to come to this center (Occupational therapy) where I was told to play with the child, I was given a follow-up date, but still when I came back I am told to play with the child, I can play with the child even at home. If they can tell me the problem of the child and try to change, then maybe things could be better."

Failure to disclose and explain the condition of the child to the mother has negative implications on the treatment plan of the child. Although the health care workers were correct to ask the mother to play with the child using the ball, it was meaningless to the mother as she could not link it to the condition of the child which she did not know. To foster coordinated treatment strategies between the mother and health care workers, disclosure and explanation of the condition for the mother should be mandatory to enhance good treatment outcomes.

When a patient decides to go to the press, it really shows that she has tried all avenues in vain. This reflects the desperation of the mothers in her question to

know the truth and possible solution to her child's condition, MCAC6 reports her ordeal with the health care workers:

“Starting from 2007 Oh!! The nurses and doctors were tired because I was in and out of the hospital and the condition of the child was not improving. In 2007 the child had a heart surgery and after the surgery, I thought that the child will be better but it was not the case. I continued within and out from the hospital without any improvement. I became tired and also fed up also because you are admitted in the hospital, nobody is telling what is wrong with the child, and the child is not getting better.

They discharge you on medication which does not help the child. If you tell them (health workers) that the medication is not helping, they will tell you that the child is a Down syndrome he will be like that for the rest of his life. But yet the child continued with feeding problems of not sucking well and vomiting after a feed. Then I started thinking why are they not referring the child to Windhoek? You ask them about that nobody answers (mother becomes emotional, starts crying). Until when I decided to go to the Namibian Newspaper to put my child in the newspaper for people to assist me with funds so that I can take my child to Windhoek on my own, is where I was given a letter which I brought to the Medical Superintendent of Oshakati Hospital. I told the Medical Superintendent that I am tired, if there is nothing to be done this time I will leave this child in your office so that you see how I always suffer with this child, then I will go to the police and tell them that I left my child with the Medical Superintendent because I

am very tired, I am in and out from the hospital but they are not telling whether the child will be fine or not.

It's only after that letter is when they referred my child to Windhoek. Windhoek was almost the same story; doctors failed to do something, you stay in the ward for more than a week and nothing is done to the child, again nobody is telling you what is happening with the child. The child is on a drip and nasogastric tube at all the time you go there, and you come back without any help for many times (from 2005 to 2009). It was only when Doctors from South Africa came, they are the one who identified the problem of my child and was referred to RSA for surgery. Fortunate enough after the surgery the child was well."

Similar sentiments were shared by mothers in the study on the experiences of parents of children with autism (Kourkoutas et al., 2012). Parents from this study had this to say:

"The problem is that they don't know or they don't want to tell you about how the child will develop in the future...will he be able to go to school? Will he be able to work or to get married?"

The second mother had this to say:

"You don't know which way to turn...how to find the strength to accept this illness."

In concurrence with Sajjad (2010), most parents in his study who visited professionals for help in the diagnosis or treatment of children suspected of being intellectually disabled, have reported frustrations and disappointments.

The lack of a precise and clear prognosis is an additional stressor for the families. Consequently, the way in which a diagnosis is communicated to the parents is considered an essential step in helping parents engage in an early intervention program and secure the maximum professional support available for their child (Kourkoutas & Georgiadi, 2011).

According to Bumin, Gunal & Tukul (2006), practitioners must be willing to discuss openly with families what is known about their child's handicap. Parents need this information in order to make sense of what is happening to their child and to enhance their ability to cope with this situation. In their study, Barlow, Harrison & Shaw (2004) revealed that lack of opportunity to discuss the condition of the child and delay in obtaining treatment may result in high stress levels in parents of children with CA.

If practitioners do not have the information or are not clear themselves about the diagnosis or appropriate interventions, then they must be willing to discuss this openly with the family. In these situations it will require that the practitioner either refer the family for additional help, search for additional resources, or consult with experts in the field to secure and provide this information to the family.

Communicating a diagnosis of a serious developmental disorder is not an easy task. Kourkoutas & Georgiadi (2009) stress the need for professionals to be trained to do it in a structured manner and be sensitive to the needs of parents, thereby providing families with the emotional support they need and helping them to make the best choice and decisions for their child in the long term. One mother interviewed in this current study shared her experience on how lack of information has resulted in wrong decision making for her child and had this to say (MCAC12):

“Yes and the doctor did not tell me what was wrong with the child. Then I saw that the baby was fine, no problem and I decided to take the child to South Africa. If they could tell me earlier that there is something wrong with the child I could have not done that” (she starts crying).

In similar studies, Skotko (2005) found that mothers who learned of the diagnosis shortly after birth felt they would have preferred being informed earlier, as soon as the diagnosis was confirmed. Study respondents who reported a delay of more than 24 hours from the diagnosis to disclosure stated that they had previously noticed the health care team avoiding them.

The parents’ notion, perception and the manner in which the news is conveyed at the initial time of notification of disability by the health care workers play a major role in the family’s perception of the child and their long-term adjustment to the child’s disability (Ahmed Abdelmuktader & Elhamed, 2012).

Incompetence and wrong diagnosis is frustrating to an already emotionally traumatized mother who is looking for a permanent solution. MCAC8 went through these inaccurate diagnoses and had this to say:

“Like in Onandjokwe hospital, I did not get much help. I remembered the other time when my child could not breathe properly, I took him there and I was told the child was having asthma by the doctor, I was given a pump for asthma while the child was not asthmatic and one nurse advised me to take the child to the doctor at Oshakati hospital where they examined the child and discovered that the child was having something growing that was blocking the airway. The child went for surgery, after that the child was fine. The operation was done three times from 2009 to 2011.”

Sometimes health care workers fail to provide information about where to access milk and even knowing very well the mother is admitted and have no source of income as highlighted by MCAC4:

“They must look on the issue of milk, they should provide us with milk. The milk is at the hospital pharmacy but they just observe you suffering (struggle) with the milk while you are in the hospital, I am not working and I am in the hospital, there is no time to go out and look for money to buy milk, my relatives are staying at Outapi. The other problem is nappies we are just given one nappy for the whole day.”

Though most mothers interviewed were furious about the health care workers, some felt health care workers helped them so much, as alluded to by MCAC5:

“They are assisting me because every time they come and ask the child’s condition, and if they find a problem they inform the doctor. They are assisting us much because even when you are sleeping they could come and ask you the condition of your child.”

MCAC10 agrees also that health care workers help them a lot:

“They help the children with their exercise; they take their weight, to see if they are malnourished. They take their height to see whether the child is still growing, they check x-ray to see if the muscles are still working properly and also the stomach. They are teaching us how to massage the child, they are also encouraging us to play with the child and make the child laugh.”

Following her path in this experience, the mother faces the fact that she does not know and does not have information about her child’s disability. The lack of information means not knowing how to act. She perceives in the professional’s attitude the lack of involvement and support necessary for her adaptation to the situation and for the adoption of actions regarding child care. For the mother, it is disturbing to find a discrepancy between her own emotional turmoil and the insensibility of the professionals.

Although the mother searches for sources of support from health care professionals to face this moment and to be able to take care of her child with more safety, she does not find any. For the mother, not receiving the necessary information regarding the child’s disability means not being seen and respected as a person and as a human being, not being respected in her feelings. This in turn

leads to experiencing feelings of disbelief and hopelessness. The mother looks for some kind of explanation for why this happened to her, worrying about the exact cause of the disability. This fact is frustrating, since it is not always possible to determine the reason for the child's disability.

3.3.4 Category 4: Societal and community acceptance

Throughout the interviews, mothers referred often in the broader societal context in which they lived and their awareness of the possibilities of social exclusion for them and their child. The mother is launched in a world of uncertainties and insecurities, which leads her to feel without possibilities of relations with herself and the world she leaves.

She faces the impact and the rejection from people regarding the child's disability and suffers with the curiosity manifested by the looks, comments and attitudes in the presence of her and her child in the different environments she visits. When she notices that society does not accept and does not offer space for the different, the mother adopts the same attitudes found and the imposed standard of normality, reinforcing her own feelings of shame of the child's differences and thus, preferring to ostracize the child.

MCAC1 was not comfortable to walk around with her child because of the staring of people, but with counselling she became comfortable, and had this to say:

“The people were shocked and scared when they first saw the child since such conditions are not very common in their community. Yes, when you are among them everyone will be looking at the child, most of the time they do not talk to you

or greet you. But my husband told me while I was still in the hospital not to worry, because his cousin was also born with such defect. Because I was told that is God's creation, for the child to be like, I don't always care much even when they look at the child".

The birth of a disabled child also has an emotional impact on the community not only to the mother. This is the reason why MCAC1 acknowledges that at the first sight of the child, the members of the community were shocked. The staring and muteness of the community is a state of despair and sympathy for the mother, whilst at the same time the community is not sure whether discussing the disability will not cause more harm than good to the already traumatized mother. But to the mother, meeting other community members bring a flare of hope as she anticipates verbal communication, which unfortunately she doesn't get. The mother ascribes a meaning to this reaction and concludes that the society is mocking her and her child, which might not be the case, but it might be the disability has overwhelmed the society to the extent that they do not even know what to say to the mother.

MCAC8 had a bad experience with part of her community and they could even call her names and she reveals what she went through:

"They also accepted the child, but not fully. When I am with the child people used to ask me a lot of questions like why are you not sending the child to your grandmother? Is she not alive? I used to respond that I will stay with my child. Sometimes you will hear someone say you people with your disabilities (One no

maulema eni in the vernacular) then you feel very bad about it and think that you need to stay with your own child. Sometimes I used to go to the village to visit my grandfather, because every time I go there, sometimes I will bring food, but when it will be time for the hospital follow up, I have to come back and take my child to the hospital. No one wants to help me to take the child to follow up.”

People may not fully accept the child in the sense that they are not prepared to give their time towards the caring of this disabled child as revealed by MCAC8 above, that no relative is prepared to help her take the child for follow-up. The community in which MCAC8 lives sees being with the disabled child as a sign of social misfit. To them, a disabled child should be sent to the village away from the people. This reaction portrays disability as a shame which should be hidden to peers, which transcends to the social exclusion of disabled children. These reactions could have been made with positive connotations where the community is sympathetic with the mother in telling her to send the child to the village. In their endeavour not to accept the disabled child, the community can end even calling names of the mother. This name calling constantly reminds the mother of her disabled child, even when she moves around the community in search of free space.

Too much sympathy from society at times makes mothers feel bad, and most of the times society does not realize this effect. MCAC2 and MCAC9 explain respectively how they felt bad when they brought their children to the community:

“After discharge when I went home, people felt very sorry for me (they were sympathetic). I always feel bad when they feel sorry for me or the child,...I always feel very bad (when they stare at my child).....I don't always think of anything but it is just bad” (to stare at my child).

“They always talk about the child saying the child is not well, he needs to be taken to the hospital, some of them sympathizing with me but they always make me feel bad.”

At times, unknowingly the community always complicates issues by over sympathizing with the parents of disabled children. The community has the notion that over sympathizing ascribes the meaning of being there for someone in problems not knowing that it increases stress vulnerability to the mother of the disabled child. The community is not able to distinguish between sympathy and empathy.

Sometimes the community intrudes the mother's privacy by trying to discuss the child's condition with other members of the community and as MCAC4 puts it is disheartening, as she prefers she does it herself:

“...Like I said I have been in the hospital since February, visitors show as if they are sympathetic, especially my room-mate's visitors, but yet I don't feel well when they discuss the condition of my child without even asking me as a mother. They will come in the room and will start explaining my baby's condition to each other. No, I don't want, the way they are discussing the condition of my child.”

MCAC11 had this to say about her community which she felt was a mixture of good and bad experiences:

“Some are sympathetic, but some of them they do not care” (still crying as the interview is stopped for while).

The community is also an important source of social support and their coming to visit and play with the congenitally abnormal child helps the mother emotionally as MCAC5 explains about how her community helps her:

“They don’t say anything; sometimes they may come at our place to visit the child. They will take the child and play with him.”

The sentiments of MCAC5 shows support from the community and it really goes a long way to relieve stress to the mother of the disabled child.

MCAC6 had similar experience with her community and she had this to say:

“I did not observe any bad reaction or talks from the community. For me, I think they love him because he makes them to laugh when he does those funny things, people enjoy them.”

The sentiments of MCAC6 above contradicts the findings of Brown (2010), which revealed that in western culture, the major cause of high levels of stress faced by mothers of children with intellectual disability is the inappropriate behaviour of such children. On the contrary, in MCAC6’s case, it is the inappropriate behaviour of her child, which makes the community like the child and so reduces stress on the parent.

The primary need of all human beings is to be liked and accepted by other human beings and nothing is more painful than watching your child being isolated and rejected by others. The community's attitudes and practices have a much bearing on the emotional engagement and recovery of the mother with a congenitally abnormal child and effective community support framework helps the mother to cope with her child's condition (Lavoie, 2014).

The findings of the current study revealed how crucial community/societal support has been in moulding the coping mechanism and reducing stress levels of parents with disabled children. Most of the parents who encountered community members who showed some form of negative reaction created feelings of anxiety and anger. For instance, mothers reported sympathy, staring at the child without saying a word and discussing the condition of the child without consulting the mother as some of the actions that induced stress in these mothers.

The above findings concur with what was found in the study done in Pakistan, where lack of social interaction of their children with society was among the primary causes of stress in parents with disabled children (Sajjad, 2010).

UNICEF (2013) concludes that in many countries, responses to the situation of children with disabilities are largely limited to institutionalization, abandonment or neglect. These responses are the problem and are rooted in negative or paternalistic assumptions of incapacity, dependency and difference that are perpetuated by ignorance. What is needed is a commitment to these children's rights and their futures, giving priority to the most disadvantaged as a matter of

equity and for the benefit of all. UNICEF (2013) states further that children with disabilities encounter different forms of exclusion and are affected by them to varying degrees depending on the type of disability they have, where they live and the culture or class to which they belong. Gender is also a crucial factor: Girls with disabilities are also less likely to get an education, receive vocational training or find employment than are boys with disabilities or girls without disabilities. Children with disabilities are often regarded as inferior, and this exposes them to increased vulnerability: Discrimination based on disability has manifested itself in marginalization from resources and decision making and even in infanticide. Exclusion often stems from invisibility.

At policy and national levels, UNICEF (2013) concludes that a few countries have reliable information on how many of their citizens are children with disabilities, what disabilities they have or how these disabilities affect their lives. Children thus excluded are unknown to, and therefore cut off from public services to which they are entitled. These deprivations can have lasting effects by limiting access to gainful employment or participation in civic affairs later in life, for example.

3.3 Summary

This chapter presented four categories that emerged from the data analysis of the interviews conducted with parents of children with congenital abnormalities. The chapter highlighted the emotional, psychological, social and financial stresses that parents, especially mothers of children with congenital abnormalities experience

in the day to day care for these children from birth. Research findings were discussed with relevant literature control and these study findings contributed to the already existing knowledge bank.

Conclusions based on the study findings, recommendation and limitations will follow in the next chapter.

CHAPTER 4

CONCLUSION, LIMITATION AND RECOMMENDATIONS

4.1 Introduction

In the previous chapter, the results on the experience of parents of children with congenital abnormalities were analysed and seven main categories that have emerged from the analysis were discussed with literature control. In this chapter conclusion, recommendations and limitations of the study will be discussed.

The main purpose of this study was to explore and describe the experiences of parents of children under the age of 14 years who are born with congenital abnormalities at the Oshakati Intermediate hospital.

4.2 Conclusions

The conclusions of this study are drawn from the findings and are discussed as per study objectives:

4.2.1 Objective1. Exploration and description of the experiences of parents of children with congenital abnormalities

The study concludes that parents of children with congenital abnormalities suffer an emotional and physical trauma through rejection and stigmatization by family members/spouses. They were terrified and traumatized by the reactions of family

members and spouses who failed to comprehend with the condition of the child which resulted in bitter feelings, anger and self-blame.

Parents were emotionally disturbed by delays and the failure by the health workers in disclosing the information about the congenital abnormality. The lack of information resulted in parents taking wrong decisions and compromised the provision of health care as mothers could not understand the reasons for certain instruction from health care workers. This led to feelings of shame and disappointment as they expected health workers to inform them immediately after the diagnosis was made.

The study further concludes that parents of children with congenital abnormalities' socio-economic needs were never fully considered by policy makers. The imposed Government grant of N\$200 per month is seen as a proof of lack of consultation on part of the Government. Parents indicated clearly that the N\$200 grant is not responsive to the needs of the disabled child because disabilities like Down syndrome and cerebral palsy are associated with other complications which need more financial resources. They (parents) have to find means to support their children financially, even though they don't have free time to engage in income generating activities. Therefore, parents are emotionally traumatized because of the economic challenges, given an extra financial demand of a child with congenital abnormality.

Parents, especially mothers have to go through a lot of challenges and they have to adjust their lifestyle to fit the situation of this new baby and this has resulted in

increased levels of stress. The following adjustments were reported; a transition from an independent working mother to a full time caregiver, rescheduling of activities and relocation of workplaces to suit the child with disability, frequent hospital visits and long hospitalization leaving out other important family matters like care of other sibling, and finally, changing from a breastfeeding mother to a bottle feeding and yet breastfeeding is regarded as a pillar of motherhood.

The study further concludes that, the emotional dilemma endured by the parents was compounded by indecision to leave the child at home and go for work (formal / informal) or take care of the child and not to go for work. This challenge is emanating from lack of special schools and day care centres for the disabled children where parents could take their children during the day while attending to other activities.

Finally, sympathising with the parents and starrng at the child with congenital abnormality without talking to the mothers are some of the actions that the community do without knowing that they are infringing on the rights of other human beings.

4.2.2 Objective 2: Identification of the source of support that parents employ when dealing with congenital abnormalities

The study concludes that there is no formal coping mechanism framework designed specifically for mothers of children born with disability. Parents felt being left out because all intervention and strategies that are in place are directed to the children or people with disability without considering the care-takers or

mothers. Mothers interviewed in this study felt that they were more disabled than the people they were caring.

In the absence of formal coping mechanism framework, parents engage in various activities that assist them cope with their child. Research has shown that families with children born with congenital abnormalities tend to function more successfully with strong support system (Rosenweig & Huffutter, 2005).

Hence, the study concludes that, the support system available in the community played a role in helping the parents of children born with disability to come to terms with the disability. These supportive systems included: Church pastors, supportive family and community members and parents' belief and trust in God.

Finally, the study further concludes that the availability of formal services in the community also played a role in alleviating stress to some parents of children with disability. While some parents suffered emotional stress resulting from the treatment they received from formal services, others appreciated the care especially the reassurance by some health workers that the congenital abnormality will be treated. Meeting other parents with similar conditions at the hospital during follow- ups or hospitalization assisted them to cope and accept their children, as they could compare conditions and find solace.

4.3 Recommendations

The following recommendations are made based on the findings of this study:

4.3.1 Policy recommendation

The implication for public policy is that the only way to equitably and efficiently provide services to disabled children and their families may be through a national coordinating system. There is a need for a coordinating body where parents of children with congenital abnormalities should be referred after the final diagnosis is made to give appropriate direction to these parents. There are few policies that Government ministries use to provide services to children and adolescents with disabilities. Unfortunately, these policies are not made public enough. Hence, parents and other interested parties do not know them. Once the child has been identified by the medical doctors as having a disability, there are no clear-cut policies on what happens next. Caregivers seemed to grope in the dark and shop around for assistance without guidance.

The current Policy on Disability is not comprehensive and is non-committal. There is a need to revise the policy so that it clearly spells out who is responsible for what immediately when the final diagnosis is made of a child with congenital abnormality. Furthermore, the current policy is concentrating on children with disabilities ignoring the fact that parents taking care of such children are more disabled than the people they are caring as they are emotionally, psychologically and physically drained by the presence of a disabled child in the family. There are no specific programs available to provide counselling services for parents especially mothers of disabled children. Efforts exist in terms of health, education and social welfare, but no counselling services are available to prepare these mothers to take up the caring responsibilities. Therefore, there is a need for

counselling services to be provided to these mothers as soon as possible after the final diagnosis.

The issue of poverty as a basic factor that triggered other problems ran throughout this research. Programs that empower caregivers to generate independent financial resources to be able to care for their disabled children are extremely few or are not in existence in most cases. Throughout the interviews, respondents raised financial implications related to kindergarten fees, buying disposable nappies, food, walking devices and transport costs. The current disability grants have been proven not responsive to the needs of the children born with disabilities. Hence the need for the Government to adjust the grant from the current N\$200 to N\$500 or more, as some mother argued that there is a need to adjust the grant for children below the age of eighteen as there are more challenges during childhood stage than adulthood.

It is of utmost importance for decision makers to consider stress reducing factors when funding disability related programs. Factors that are known to induce stress, such as those related to establishments of specialized schools for disabled children, specialized health care and day-care centres should be identified at different developmental stages of children with disabilities and be addressed. Day care centres have been proven to reduce stress related to care giving responsibilities as parents may place their disabled children at these centres during the day and attend to other activities such as engaging in income generating activities to bring food on the table.

In conclusion, a coordinating body is highly recommended to give directions to parents of children with disability immediately after the final diagnosis is made. The current Disability Policy needs to be revised to include compulsory counselling services to all parents of children born with disability and the current grant of N\$200 should be adjusted to N\$500 or more. Finally, the Government needs to establish more specialized services such as specialized schools, specialized health care services and day care centres as measures to assist parents to cope with the caring with disability.

4.3.2 Health care system

The most important recommendation of this current study is that professionals who work with children with disabilities must recognize the resources and concerns of the entire family. Professionals working in medical and educational settings “historically developed a kind of tunnel vision that is, they focused exclusively on the child as patient, student, or client and ignored the world within which the child lived. Evidence from contemporary research indicates that “the most effective and meaningful practices are those that promote an ecosystem and partnership vision; include the parents in the treatment process; enhance family resources and are relationship-focused” (Seligman & Darling, 2008, p. 376).

The general message for clinicians is that, to be able to provide comprehensive care to parents of children with disability, they must be aware of the complex needs of families with disabled children, which start from the moment they

receive a diagnosis or impairment is suspected. Parents should be told about the diagnosis as soon as possible, even if it is suspected but not yet confirmed.

The diagnosis should be communicated in person, by a health care professional with sufficient knowledge of the condition. Health care providers should coordinate the message to ensure consistency in the information provided to the family.

Communication with parents of children who have birth defects is vitally important. Healthcare professionals need to take every opportunity to leave the lines of communication open with parents and to help them along their journey from the initial diagnosis to essential educational information and finally to the future needs and issues for that child.

Clinicians should inform parents that their children will need a range of services and that the system may be extremely difficult to navigate. Whenever possible, they should provide referrals to local support and advocacy groups, national organizations focusing on specific conditions and websites where families can source information about congenital abnormalities.

Furthermore, there is a need for health professionals, especially clinicians to be trained in delivering bad news to parents so as to do it in a more professional manner without causing further harm to parents. Various studies have indicated that there is a lack of proper training to develop skills to communicate well in both pre-graduate and postgraduate education (Loaisa & Arroyave, 2009).

Different approaches can be incorporated during medical school training to develop such skills.

Nursing interventions designed to meet parents' needs are important to reduce stress in parents of children with congenital abnormalities. Interventions such as providing emotional support in the form of counseling, listening to parents' views, dissemination of proper and accurate information about the current situation and expectations for parents of children with congenital abnormalities may yield the best results thereby reducing stress levels.

Psychologists are among the cadres of professionals that are lacking in all public health institutions in the country. These professionals are known for possessing expertise in helping people deal with crisis, trauma and loss. Based on the findings of the current study, this position should be initiated in public health institutions to take up the responsibility of providing counseling services to clients with psychological problems including parents of children with congenital abnormalities. Once the final diagnosis is made about the disability, the clinician may refer parents to a psychologist for professional counseling before discharging the child from the hospital.

In summary, there is a need for health workers/clinicians to deliver the message about the presence of disability to parents as soon as possible, to prepare them psychologically and the message should be delivered in person by a professional who is trained in delivering bad news. Hence, such training is crucial to develop skills to communicate well with parents of children with disability.

4.3.3 Parents

When a child has a chronic condition, parents and professionals play different but equally valuable roles in meeting the child's special needs. Parents are the experts on their child. They know best about how their child responds to different situations, and they notice changes that the professionals may not pick up. Their expert knowledge of their child is what they bring to the partnership. The professionals have specialized training and many years of experience in caring for multiple children with similar conditions so they bring a broad knowledge of the condition, common responses, and effective treatments.

Parents who are able to build an effective partnership with professionals can ultimately improve the well-being of the child. But many parents feel intimidated by professionals, which can create a power imbalance. To overcome feelings of intimidation, parents may need to learn assertiveness skills – how to communicate clearly and directly and to express their feelings and needs honestly and appropriately. If parents are not able to stand up for their rights they may feel taken advantage of, which can create resentment and mistrust that poses a barrier to an effective partnership with medical professionals.

Parents also need to develop their skills in obtaining information about their child's condition, because having appropriate and sufficient information can help parents to cope better. They will feel more in control of their situation, will be able to manage their child's condition better on a day-to-day basis, can come to terms with the diagnosis, make informed decisions about their child's care,

confidently answer their child's questions and teach others including grandparents, friends, and neighbors about the child's health condition.

Finally, there is a need for mothers to have awareness as to how they can overcome their stress and accept their children with congenital abnormalities. Therapies that can be used by the mothers to overcome stress include; Music therapy, aromatherapy, massage and yoga therapy and controlling diets, e.g. avoiding alcohol, caffeine and sugar. Exercises, entertainment, and mediation can improve physical and mental health of these mothers. Formation of a small group of mothers of children in special schools can provide the mothers a needed platform for expressing their difficulties, sharing their experiences, solving their problems and more importantly, to develop a mutual help system.

4.3.4 Community/society

Community or public awareness is very important in reducing stress levels among parents of children with congenital abnormalities. Communities should be made aware that congenital abnormalities are real and they do exist in all societies, therefore seeing them in the society should not be a strange phenomenon, instead they should join hands and support parents of such children.

Sympathizing and staring at the child silently by the society/community members were identified as reactions that induced stress among mothers of children born with disabilities. Therefore, public education is needed to educate the public to be able to distinguish between the two terms i.e. sympathy and empathy. In most cases, the community usually sympathizes with these mothers without knowing

that they are causing more harm than good. The community should rather be empathetic than sympathetic.

Instead of sympathizing with these mothers, communities should be encouraged to organize themselves to form support groups where these mothers may be referred by health professionals upon the discharge of a child with congenital abnormalities from the hospital/rehabilitation centres.

Community-based rehabilitation (CBR) programs, which seek to ensure that people with disabilities have equal access to services and opportunities relating to health, education and livelihoods are some of strategies that can be designed and run by local communities to assist parents of children with disabilities.

4.3.5 Research

Sibling issues need attention. Parents and professionals often lose sight of the need to help siblings understand the problem that is affecting their brother or sister with disability. Then there is a challenge of trying to reduce the jealousy that results when so much attention is focused on one child as well as the frequent limitations on doing common family activities by their mother. It is clear that siblings need an opportunity to voice their questions, concerns and feelings.

Siblings could offer a different view of the way individual family members experience their sibling's congenital abnormalities. Further research should include members of the extended family, including siblings and use different methodologies that could offer a more comprehensive view on the way congenital

abnormalities affects family functioning and the particular coping strategies that families developed to deal with this type of disability.

Secondly, there is a need for future researchers to develop a policy on the coping mechanism framework that stretches from the day the initial diagnosis is made up to the day the mother or parents will be referred to various support groups in the society.

4.4 Limitations of the study

The limitations of the study are those characteristics of design or methodology that can impact or influence the application or interpretation of the results of the study (Simon, 2011). In addition to that, those characteristics are uncontrollable and can restrict or decrease the generalizability of the study findings. Like any other studies, this study had the following limitations:

The current study described and explored the experiences of parents in the given setting and concentrated on different types of child's disorder at IHO. It is at the reader's discretion to see how the results can be applied in other similar settings and circumstances.

The researcher experienced difficulties in locating study participants as at the time of data collection, follow up dates of most of the participants had already passed. Therefore, researcher had to use a cohort register available in the participating hospital departments to trace those parents. Participants who were reachable telephonically, some reported to have moved to other places, so the time frame for

data collection had to be extended to allow those parents whose follow-up visits were approaching to take part in the study.

Some of the participants had unresolved issues either with the family, health workers or society, so the interviews reminded them of those bitter experiences as a result, they became emotional and could not respond to some of the questions and valuable information might have been missed.

Finally, the researcher conducted the interviews with the assistance of a field worker who had to act as a translator from English to Oshiwambo and Oshiwambo to English, so this was time consuming and tiresome to participants and may have resulted in missing some of the valuable information.

4.5 Final conclusion

Parents attach to their children through dreams, fantasies, illusions, and projections into the future. Children are our second chance, our ultimate “life products,” the reflection and extension of our very being. To know that a human life exists that grows from our genes, our bodies that is a result of our existence, brings a measure of spirituality into the most hardened individual. Something basic to our sense of being is stirred when we witness the miracle of the continuity of our lives. What happens when this core experience is marred irreversibly by disability? How does a parent survive the devastation of a handicap in their child that shatters their heartfelt dream? How do they go on? How can they help their child, their other children, themselves?

This current study arose from the above statement, the researcher being a midwife had come into contact with a number of children or babies born with congenital abnormalities. It was observed that most of these mothers giving birth to congenitally abnormal children are usually silent upon receiving or noticing the abnormalities of their child. What goes on in their minds is always not known to most of the health care professionals. They are often discharged into the community or referred to the rehabilitation centres or other advanced institutions for further interventions with or without counselling and without knowing what happens to them when they join their families and society. In some instances, they are often seen with their disabled children admitted or visiting the hospital for follow-ups. This has impelled the researcher to conduct a scientific inquiry into the lived experiences of parents of children with congenital abnormalities.

In conclusion, the study has contributed to the existing body of knowledge on the experiences of parents of children with congenital abnormalities. Similarities and contrasts of the current researched information and existing knowledge were identified. The current study revealed that, the society is still turning a blind eye to people born with disability, for such people, assisting children born with disability is a waste of time and resources. Therefore, there is a necessity for continuous public education and policy reform to mitigate the significance of this phenomenon. Moreover, to be sympathetic to parents of children with congenital abnormalities and stare at the child with congenital abnormality without talking or greeting the mother are stress-inducing actions that were uncovered by this study as new knowledge.

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ANNEXURE 1:**CONSENT FROM AND RESEARCH QUESTIONS POSED****Consent Form**

Dear parents

My name is Sankombo Marian Tusano, a final year Masters of Public Health student at the University of Namibia's faculty of Health Sciences, under the supervision of Dr. L. Lukolo and I am conducting a research on the following topic:

- A study on the Experiences of Parents of children born with congenital abnormalities at Oshakati Intermediate Hospital.

The study seeks to explore the lived experiences of parents caring for their children who are born with congenital abnormalities. You are being requested to attend a face to face interview with the researcher and respond to questions that you will be asked. Your participation in this research is voluntary, you may withdraw from the interview at any time without any consequences. The researcher with your permission will use a tape (voice recorder) to assist her not to forget valuable information. However, this may be withdrawn if you are not comfortable with it.

The results of the study may be published but your name will not be revealed and no individual identification information will be provided. Although there may be

no direct or immediate benefit derived from the study, the result of the study may generate new perceptions about your lived experiences to law makers, Health workers and others.

May I thank you for your participation

Consent

I have read the above informed consent, the nature, demands and benefits of the study.

I understand that I may withdraw my consent and discontinue participation during interview without any penalty or loss of benefit to myself.

Signature of the Participant: Date.....

I certify that I have explained to the above participant the nature, purpose, and potential benefits and risks associated with participation in this study.

Signature of the researcherDate.....

Interview Guide for Parents of Children with Congenital Abnormality

1. Demographic Data.

Age: -----

Marital Status: -----

Number of children: -----

Number of Children with Congenital Abnormalities: -----

Occupation: -----

Highest grade Passed: -----

2. When did you learn about the disability of your child?-----

- How did you feel when you first saw or learn that your child had congenital abnormalities?-----

- Can you tell me what are your experiences raising a child with congenital abnormalities?-----

- What challenges did you face since then?-----

- How did it affect your life?-----

- In case of working parents, how does caring for this disabled child affect your work life?-----

3. Can you tell me more about your child's disability?-----

- Are you aware of any factor that might have contributed to the child's condition? -----

4. How do you view your family or your spouse's attitude towards you since the birth of this child?-----

- What kind of support are you getting from your family or spouse?----

- In your own opinion, how would you want family members to assist you?-----

5. How do you experience the people in the community since the birth of this child?-----

6. Based on your experience, what factors do you think might have contributed or is contributing to your negative or positive experience raising the child?----

7. What helps you cope with this child?-----

8. How do you experience coming for follow-up to the hospital on a monthly basis?-----

- How would you view the assistance you are receiving from the health care providers? -----

- In your own view how do you want the health care providers to assist you?-----

- Do you have anything to say about health care providers?-----

9. I am aware of the social benefits from Government that your child is entitled too, how do you view this kind of support?-----

- How would you want the Government to assist you specifically?---

10. Any other comment or something that you want to say?-----

The end

ANNEXURE 2

**PERMISSION LETTER FROM THE UNIVERSITY OF NAMIBIA TO
CONDUCT RESARCH**

(+264 61) 206 3111
Website: www.unam.na



340 Mandume Ndemufayo Avenue
Private bag 13301
Windhoek
NAMIBIA

Inspiring minds & shaping the future

Enquiries: Dr. H. J. Amukugo
Private Bag 13301
Mandume Ndemufayo
Windhoek

Tel. No.: 061-2064617
Fax No.: 061-
e-mail: hamukugo@unam.na

All correspondence must be addressed to the Office of the Associate Dean

**Letter of permission:
Post graduate students**

Date: 08 January 2013

Dear Student: Sankombo Marian Tusano (890122)

The post graduate studies committee has approved your research proposal.

EXPERIENCES OF PARENTS OF CHILDREN WITH CONGENITAL ABNORMALITIES AT OSHAKATI INTERMEDIATE HOSPITAL, OSHANA REGION.

It may be required that you need to apply for additional permission to utilize your target population. If so, please submit this letter to the relevant organizations involved. It is stressed that you should not proceed with data collection and fieldwork before you have received this letter and got permission from the other institutions to conduct the study. It may also be expected that these organizations may require additional information from you.

Please contact your supervisors on a regular basis

Deputy Associate Dean (SoNPH)
Mrs. L. van der Westhuizen

ANNEXURE 3

APPROVAL LETTER FROM THE PERMANENT SECRETARY IN
MOHSS



REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Private Bag 13198
Windhoek
Namibia

Ministerial Building
Harvey Street
Windhoek

Tel: (061) 2032125
Fax: (061) 272286
E-mail: msimasiku@mhss.gov.na
Date: 16 July 2013

Enquiries: Mr.M.Simasiku

Ref.: 17/3/3

OFFICE OF THE PERMANENT SECRETARY

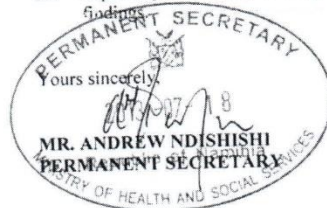
Ms. Marian T. Sankombo
P. O. Box 2003
Ngweze
Namibia

Dear Ms. Sankombo

Re: Experiences of parents of children with congenital abnormalities at Oshakati Intermediate Hospital, Oshana region.

1. Reference is made to your application to conduct the above-mentioned study.
2. The request has been evaluated and found to have merit.
3. **Kindly be informed that permission to conduct the study has been granted under the following conditions:**
 - 3.1 The data collected must only be used for purpose stated in the proposal and the permission requesting letter;
 - 3.2 No other data should be collected other than the data stated in the proposal;
 - 3.3 A quarterly report to be submitted to the Ministry's Research Unit;
 - 3.4 Preliminary findings to be submitted upon completion of study;
 - 3.5 Final report to be submitted upon completion of the study;
 - 3.6 Separate permission to be sought from the Ministry for the Publication of the findings.

Yours sincerely,



"Health for All"

ANNEXURE 4

**LETTER FROM THE MEDICAL SUPERINTENDENT GRANTING
PERMISSION TO CONDUCT RESEARCH**



REPUBLIC OF NAMIBIA
 MINISTRY OF HEALTH & SOCIAL SERVICES
 OSHANA REGION DIRECTORATE OF HEALTH

INTERMEDIATE HOSPITAL OSHAKATI

Private Bag X5501
 Oshakati

Phones: +264(65)2233000
 +264(65) 221 380
 Faxes: +264(65) 224564
 +264(65) 221 390
 E-mail: supt.ihosh@ivay.na

Enquiries:

Ref:

**TO: MS. MARIAN T. SANKOMBO
 P.O. BOX 2003
 NGWEZE
 NAMIBIA**



EXPERIENCES OF PARENTS OF CHILDREN WITH CONGENITAL ABNORMALITIES AT INTERMEDIATE HOSPITAL OSHAKATI, OSHANA REGION.

Your approval to do the above refers.

We are hereby informing you that we have received your approval from the Permanent Secretary and you can go ahead with research at this hospital.

Yours faithfully

**DR. P. NAKANGOMBE
 CHIEF MEDICAL OFFICER—PROFESSIONAL SERVICES**

ANNEXURE 5**EXTRACT FROM THE IN-DEPTH INTERVIEW****Interview Guide for Parents of Children with Congenital Abnormality****Down Syndrome; Out patient**

1. Demographic Data.

Age: 45

Marital Status: Widow

Number of children: five

Number of Children with Congenital Abnormalities: one

Occupation: unemployed having small business

Highest grade Passed: -Grade 10

When did you learn about the disability of your child? **Immediately after birth the doctor told me that the baby is a down syndrome.**

After the doctor told you that your baby is a Down syndrome what was your immediate reaction? **I did not say anything or do anything, the doctor told me first that your child is down syndrome and we are going to refer you to the rehabilitation center, then I just said ok it is fine so long I am having my son.**

This time when they were explaining to you that the baby is a down syndrome, did they explain to you what might have caused the child to be like that? **They did not tell me anything.**

According to your own experience what are the causes of congenital abnormalities, there are different types of congenital abnormalities around us what might be the causes? I don't know.

Can you tell me what are your experiences raising a child with congenital abnormalities or what problems you are currently facing or you encountered before? Hmmm!!! I stayed with Lopez (the name of the Down syndrome child) for four year without walking or sitting just lying down. The baby developed some skin problems, his skin was like a bubble gum. Since my husband died 7 year ago, I have been struggling to get medication for the skin problems and other medication for calming his mind, my family has assisted me a lot with money to buy those medications. I went to Onandjokwe hospital several times, where I was once told to buy some materials to put on his legs since he was having problems with walking. He was once burn by hot water, so again it was another problem adding to the existing problem that the child was having. It is only when he was five years is when he started walking and I took him to Kindergarten. He stayed two years at kinder then I decided to take him to school.

What other challenges are you facing with your child Lopez? The main problem is with my neighbors, they are complaining about my child some of them does not want to see him at their houses, they talk," this down syndrome is troubling us, go out". Others are even locking their houses for my child not to go there, like one neighbor, the first house on your right, he always beats Lopez, and she does not want Lopez to play with her child. This lady, I am not talking to her, she makes me feel bad.

How do you feel about this deep inside you? OHH!!!! I always feel bad, sometimes I always cry because of my son.

You said you are not working but you own a small business? How does raising a child with Down syndrome affect you small business? Yes, it affects me very much. Like now I don't go to my business in the morning because of Lopez, I go in the afternoon when the school is out for the sisters to stay with him when I am gone. I used to take him but I failed, if you go with him there he will play with people things and they often become upset with him. I was also having a business at open-market. I dropped the business because there is no one to look after Lopez.

Now where are you operating your business from? At my neighbor's place. I cannot operate from my house because of Lopez, he will spoil everything, look all this stuff you see here they are broken by Lopez, and my windows are all broken because of him.

Can you tell me more about your child's disability apart from the appearance and behavior. There is a lot of problems with Lopez because Lopez does not stay at one place, you cannot leave him with other person other than his sisters. He cannot play with other children sometimes he beats them. Even when you tell him not do something or not go out. He just do or go, he does not take orders. With the diet, he is having allergic reaction to certain food, like fatty foods. The other time he took the whole year without opening his eyes, there was some sores in eyes,

until one of my cousins put him on her medical aid; we took him to the specialists for treatment after that his condition improved.

How do you view your family attitude towards you since the birth of this child?

The family, are fine when it comes to Lopez, they have assisted me so much with money to buy medicines my cousin had put him on her medical aid, and a lot of other support. Even now if I tell them that Lopez is sick I want to take him to the hospital they will assist

I am aware of the fact that your husband is no more, do you mind if I ask one question about him? You can ask.

What was his reaction when you told him about the problem of his child? He also did not say anything, he kept quiet.

Based on your experience, what factors do you think might have contributed or is contributing to your negative or positive experience raising the child (Not asked)

What helps you cope with this child?-To cope with Lopez is something which is very difficult, he does not stay at home every time you have to know where he is and what he is doing , you cannot leave him alone. If you miss him at home he is already at the road then you have to follow him. Is somebody you have to handle

with care you cannot beat him, scare him otherwise he is upset he can cry the whole day.

So what is giving you courage to cope with all what you have just spoken? Myself
I do those things on my own, sometimes my family too, they always encourage me to take care of my child.

How do you experience coming for follow-up to the hospital on a monthly basis? -
Oh I suffered a lot every time you are at Onandjokwe hospital ,they will refer you again to Oshakati, you are in between those two hospitals at all times. It is really bad sometimes my mind went very far and I ended up asking myself why god gave me such a child. If I think about it deeply, I used to crying –but then the other side you have to accept pray to God and the child

How would you view the assistance you are receiving from the health care providers, you have said you were just between the two hospitals all the time?
Like in Onandjokwe hospital I did not get much help. I remember the other time when my child could not breathe properly, I took him there and I was told the child was having asthma by the doctor, I was given a pump for asthma while the child was not asthmatic and one nurse advised me to take the child to the doctor at Oshakati hospital where they examined the child and discovered that the child was having something growing that was blocking the airway. The child went for surgery, after that the child was fine. The operation was done three times from 2009 to 2011.

In your own view how do you want GRN to assist you or where can they improve?-they must improve in the way they are treating our children with Down syndrome. If you take the child to the hospital when the child is having fever, you will find different nurses, the others may sympathize with you while the other one will only look at you child and tell you to go there with your child. But those who sympathize with us they always give us advices

I am aware of the social benefits from Government that your child is entitled too, how do you view this kind of support?- My child is not receiving disability assistance. i went to the hospital to register him, so that he can receive the disability pension but i was told that the child is not qualified because he is receiving money for orphans. I was told to stop the money for being an orphan first before they can register for disability.

How would you want the Government to assist you specifically? Mostly we want school for our children, the school where we used to take our children-is not conducive for them, teachers they don't have time to take care about them, sometimes Lopez may leave the teacher inside teaching and go and play outside. Sometimes they are being beaten by other children. So we really want a school especially in the North. In Windhoek and Katima Mulilo there is a school for disabled but it is very difficult for me to send him there. Even if we don't get much benefits from the school but at least the child is not at home for the whole day, it is better to be kept busy at school.- Like Lopez, he can speak English- he can sing with others. I feel if he is taken to a special school he can do more.

Apart from school, what other things do you want the government to do for you, especially you parents who are caring for these children, you are going through difficult times, sometimes you are stressed, and some of you cannot even sleep because of your disabled children. What can you tell me? Yes, as we are having children like these ones, the government should try to give us employment to be able to help our children or they can build school for down syndromes where we as parents of those children can work and be paid even small amount of money to help our children or the government can assist us to start up with income generating projects for example we can plough even maize and sell, so as to help children. Like in my case I am having children who completed school but they are not having decent jobs to be able to assist me.

I am aware of the lectures that you always attend at Rehabilitation center at Oshakati hospital, what can you tell me about that, is it helping you in coping with your disabled child or what benefits are you getting from there? Sometimes we used to go there to discuss how we can go about taking care of children, we have tried!!!! We discuss a lot of things like the need to get school for our children. The need to take care of those children ourselves, not leaving the child with anybody you see because the child might beat that person or the person beating your child because the child is not used to that person. There was a time when we were visited by the member of parliament, we gave all our problems to her to take to the parliament, mostly was the issue of school, we want school where we can take our children. It does not matter where school is built whether in Ondangwa or Oshakati what we want is school.

Now what really is the lady teaching you at the Rehabilitation center? **Mostly we just go there to discuss about how to take our children, especially with school.**

Any other comment or something that you want to say? **None**

The end