

**INVESTIGATING THE NEED FOR A HOME-BASED HEALTH
CARE PROGRAMME IN SUPPORT OF THE
PARENTS/CAREGIVERS OF CHILDREN DIAGNOSED WITH
HEART DISEASE IN THE RURAL AREAS OF NAMIBIA**

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PROGRAMME IN SUPPORT OF THE PARENTS/CAREGIVERS OF CHILDREN
DIAGNOSED WITH HEART DISEASE IN THE RURAL AREAS OF NAMIBIA**

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**BY
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ABSTRACT

The incidence of congenital heart disease (CHD) has been reported to be 8 out of 1000 live born infants worldwide. Accordingly, congenital heart defects and rheumatic heart diseases contribute to approximately ten percent (10%) of all paediatric admissions to health care facilities in Namibia as compared to the proportion of diarrheal (3%) and acute respiratory infection (3%). Congenital heart diseases account for 9% of neonatal deaths in Namibia (WHO 2006; WHO 2009). Clearly, the situation in Namibia is grave as regard to profile of heart diseases among children. The majority of children with heart disease are from the rural areas. If they are not acute sick, the majority of these children often receive treatment as outpatients and their parents/caregivers are expected to cope with the demands of caring for these children at home. Taking care of a child with a heart disease at home is daunting task for the parents and the caregivers as extreme vigilance on their part is required. However, this degree of vigilance cannot be realized by the parents of children with heart diseases who are from the rural areas in Namibia, because there is no support system in place to enable them to cope with the demands of caring at home.

The aim of this study was to explore and describe the lived experiences of their parents/caregivers as regard caring for a child with a heart disease at home and the experience of living with heart diseases by the children with the purpose to identify the needs for facilitation of coping with the demands of caring and to develop a home-based health care programme to facilitate coping with such a situation.

A qualitative, exploratory, descriptive, contextual and phenomenological study was conducted to describe the participants' experiences, identify need for assistance and assess the possibility of remedial actions to help parents and caregivers cope with caring at home. The study was performed in three sequential research phases.

Phase I involved the situational analysis through the description of the participants experiences of caring for a child with a heart disease and of living with a heart disease respectively. Phenomenological data was collected from a purposefully selected sample of 5 multiple cases of parents/caregivers and children with heart disease from the rural areas in Namibia. The data was collected by means of in-depth interviews, field note and the pictorial naïve drawings by the child participants until data saturation was reached. The data were analysed using the Tesch method of qualitative data analysis. The findings revealed that the parents/caregivers were struggling to cope with the demands of care and, hence, there was a clear need to empower them so as to facilitate their coping.

Phase II involved the conceptualisation of the research and the development of a home-based health care programme. Accordingly, a home-based, health care programme, which encompassed multi-component interventions to facilitate coping, was developed for the parents/caregivers and the children concerned.

Phase III involved the implementation and evaluation of the programme at the households of the study participants. A two-day workshop was facilitated at each household in order to implement the programme interventions. The programme outcome evaluation was conducted three months after the programme implementation with the

findings of the evaluation indicating that the programme interventions has, indeed, empowered the parents/caregivers to cope with the demands of care.

In conclusion, the experiences of poor coping on the part of the caregivers of children with heart diseases from the rural areas in Namibia calls for innovations from both health care providers and other social systems to support the caregivers and enable them to cope in providing home care to their children with heart disease. In this regard, the recommendations were made with regard to health care providers to implement contextualised health education to the parents/caregivers of children with heart disease to enable parents/caregivers to continue with palliative care at home, the inclusion of interventions contained in this programme in the health care programmes at the district level of health care delivery and the provision of social grant to children diagnosed with heart diseases whose parents/caregivers are economically vulnerable.

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To the Almighty God: “For a bruised reed He will not break, and a smoking flax, He will not quench, till He sends forth justice to victory” (Matthew 12: 20).

DEDICATION

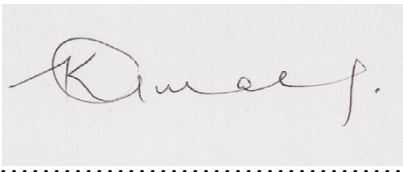
This study is dedicated to the parents, the caregivers and the children with heart diseases from the rural areas in Namibia. It is hoped that the study will contribute to facilitating the parents'/caregivers' coping with the demands of caring for these children and the children's coping with the burden of their diseases at home. In addition, it is anticipated that the frontline health care providers within the clinical health care setting and at the district level of health care delivery may use the guidelines of the home-based health care programme, as suggested in this study, to help them to cope with the demands of home care facing the parents and caregivers of children who are diagnosed with heart disease and who are from the rural areas in Namibia.

DECLARATION

I, Kristofina Amakali, hereby declare that this study is a true reflection of my own research and all the sources used have been acknowledged in the text and the bibliography. This study is an original work and has not previously been submitted in its part or in its entirety for a degree at any other institution of higher education.

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Date: 21/02/2013

CHAPTER 1

ORIENTATION AND OVERVIEW OF THE STUDY

1.1 BACKGROUND

Heart disease in children refers to problems experienced with the structure and functions of the heart. The types of heart diseases vary but, essentially, heart diseases include failure of the foetal openings in the heart to close (referred to as congenital heart defects) and the incompetence of the heart valves, which is often a result of rheumatic fever. The most common congenital heart diseases include, inter alia, the septal defects, patent ductus arteriosus and the coarctation of the aorta (Coovadia & Wittenberg, 2007).

The incidence of congenital heart disease (CHD) has been reported to be 8 out of 1000 live born infants worldwide (Opie, Bongani & Mayosi, 2005; Clay, 2004). In Namibia, heart diseases contribute to approximately ten percent (10%) of all paediatric admissions to health care facilities (WHO, 2009). Congenital heart defects and rheumatic fever (infection) are the main causes of these heart diseases, accounting for sixty percent (60%) and forty percent (40%) respectively of all paediatric patients with heart disease in Namibia. It is, therefore, clear that a significant number of children in Namibia are currently in need of cardiac (heart) surgery for congenital and rheumatic heart diseases and approximately all (90%) of these children are from the rural areas.

Heart defects, whether congenital defects or rheumatic heart diseases, are disabling disorders that interfere with the most basic human requirement, namely, the need for a continuous supply of well oxygenated blood to the body systems. The circulation of

blood and, thus, the oxygen supply to the new born or the child, is adversely affected (Coovadia & Wittenberg, 2007; Potts & Mandleco, 2002).

Physiologically, heart disease is accompanied by system derangements and the children with heart disease experience poor quality of life as regards vitality. Patients with either congenital heart defect(s) or rheumatic heart disease are subjected to a chronic state of deranged cardiac output, poor blood circulation, and a sustained state of hypoxia as the blood with optimum oxygen no longer being delivered to the body systems to enable sufficient body metabolism. As a result, children with heart disease experience symptoms which range from fatigue to low weight for age and lowered intellectual functioning (Coovadia & Wittenberg, 2007; Mogotlane, Mokoena & Chauke, 2005).

Psychologically, children with heart disease are likely to experience negative emotions such as perceptions of “prolonged suffering” and fear of death, often evoked by their experience of the symptoms. Furthermore, they also experience a loss of self-esteem as a result of loss of control of their developmental functions (McKhann, Drachman, Folstein, Katzman, Price & Stadlan, 2008; Arafa, Zaher, EI-Dowaty, & Moneeb, 2008).

In addition to the child’s own experiences, the parents and caregivers may also experience psychological trauma as they witness their child suffering from the illness, when a clinical condition becomes worse or, at worst, when the child dies. Although they are often promised that, in most cases, curative treatment is available, the treatment may be delayed and the child’s condition may deteriorate or else, the treatment may not be successful.

The increased expense involved in the treatment of their diseased children may also evoke feelings of guilt and inadequacy on the part of the parents/caregivers as caring for these children require extra resources to meet the demands of caring at home and to facilitate surgery to restore their health (Du Toit, 2008; Arafa et al., 2008).

In addition, as the parents/caregivers spend time providing care to their sick children, they may experience poor coping in other areas of their lives as they may not have time for recreation and, as a result, they may become distressed (Reinhard, Given, Pelick, & Bemis, 2008).

The changes that occur in the physiology of the heart as a result of the pathological effects of heart disease and the accompanying psychological trauma demonstrate that the quality of life for these children is compromised and vigilant palliative care is required to prevent complications.

The experience of either living with a heart disease or else providing care to a child with a heart disease is, therefore, an extremely significant life event for both the children and their parents/caregivers as heart disease adversely affects the quality of life of both the child and his/her caregiver(s) in all dimensions of their lives (Arafa et al., 2008).

Collins, Bronte-Tinkew, and Logan (2008) and Rogers (2003) are of the opinion that people who live in rural areas are not only disadvantaged socio-economically, with limited access to health care and social services, but they may experience extreme poverty as they are not able to provide for even their basic needs. Therefore, coming from an average to poor socio-economic background in Namibia, some of the parents

and caregivers of children with heart diseases are not able to provide the required palliative care at home because of their poor overall socioeconomic status. In particular, these families are likely to lack resources, not only because of their own socioeconomic status, but also because other members of their role set (e.g. relatives and friends) tend to be in the same position as regards limited resources. Life modifications that are required for palliative care in order to improve the quality of life for these children constitute challenges for their parents and caregivers (Du Toit, 2008; Coovadia & Wittenberg, 2007 & Ipinge & Botes, 2002).

In line with evidence from the literature, during the transition from hospitalization to home, there is a probability of a breakdown in care which, in turn, often results in negative outcomes because the aftercare needs for the children are not adequately determined before they are discharged (Naylor, Brooten & Campbell, 2004; Ipinge & Botes 2002). Approximately 5% of paediatric patients in Namibia experience post-heart surgery setbacks, including the recurrence of respiratory infection, endocarditis, growth retardation, poor school performances as well as psychological problems such as aggression and depression (Du Toit, 2008).

Poor coping on the part of these parents and caregivers is a call for professional innovation with a holistic approach to care, which is driven by the needs of the child and the caregivers and aimed at helping the parents/caregivers to cope with home care for their children concerned. One way in which to enhance coping on the part of these families is to empower them.

Proponents of health promotion through behavioural change are of the opinion that learning how to meet challenges is a process – it does not happen immediately. Accordingly, it is essential that those who are affected by illnesses come to understand more about their condition and play their part in managing the illness (Glanz, Rimer & Viswanath, 2008). Therefore research-based evidence indicates that many people find that being empowered to take an active part either in managing their own health care or in managing the care of their significant others with chronic health conditions enables them to feel stronger and better equipped to deal with life's trials and tribulations. This, in turn, helps them to confront the health challenges they encounter. With proper management, a person suffering from a chronic illness, such as heart disease, may feel in control and even healthy for much of the time. In other words, those who are willing to learn seek support from others and participate actively either in their own care or in the care of their significant others, usually cope (Glanz, Rimer & Viswanath, 2008).

Furthermore, the findings from studies on parents/caregivers coping with caring for their children with chronic disease at home reveal that being empowered with the capacity to make decisions and having a supportive environment, are some of the factors that contribute to the ability of the parents/caregivers to provide the care that is required. As a result, the parents/caregivers are more likely to cope and to develop a feeling of confidence as regards providing care for their children (Stajduhar, Leigh Martin, Barwich, & Fyles, 2008; Brosig, Kupst, Pierucci & Leuthner, 2007). These findings may,

therefore, be used as a reference in providing a home-based health care approach to the parents or caregivers of children with heart diseases from the rural areas in Namibia to facilitating their coping within their own contexts.

In agreement with the view of Beck and Wiencek-Kurek (2007), the researcher is of the opinion that, instead of passing judgment on people because of their socio-economic situation, a well-meaning helper should rather acknowledge that these parents/caregivers are good-hearted individuals with strength who are trying to cope with a difficult situation and they would appreciate any help offered to them.

1.2 PROBLEM STATEMENT

The introduction indicated the scope of heart disease among children in Namibia with these children needing palliative or symptomatic care to improve their quality of life. In addition, the poor socio-economic status of the parents/caregivers may adversely affect their coping and their providing care for their children at home (Du Toit, 2008).

Caring for a child with a heart disease can be a daunting task and requires vigilance for the parents and caregivers as the type and depth of caring usually increase exponentially as a result of the complicated nature of heart diseases, their interrelatedness with the organ systems and the fact that surgery is often necessary (Du Toit, 2008; Coovadia & Wittenberg, 2007).

Vigilance and the provision of the required care assumes that the parents and caregivers possess the necessary knowledge, skills and financial means and also that supportive systems are in place (Beck & Wiencek–Kurek, 2007). Therefore, certain skills and knowledge, as well as the financial means to provide for the material needs, are required. However, to date, there have been no studies conducted within the Namibian context on the parents/caregivers' experiences of providing care to a child with a heart disease or else of living with heart disease by the children. Accordingly, there is little known about the way in which the parents/caregivers experience and cope with the demands of caring for their children with heart diseases, or whether the parents/caregivers are adequately prepared as regards providing such care. In addition, there is little known about how these children cope with the experience of the disease burden. Knowledge about caregivers' experience of caring for a child with a heart disease at home would assist to identify mechanisms that can assist the caregivers to cope with the demands of providing care at home. Likewise, the knowledge of the children's experiences of living with heart disease would assist in identifying methods that would assist these children cope with the burden of the disease and which in return would help caregivers cope with the demands of care at home. It therefore appears that there is a need for research which focuses on exploring the need for support of parents/caregivers as an integral part of the care plan which is aimed at ensuring the quality of life of these children (Reinhard et al., 2008).

While it is necessary to assist these parents and caregivers in their caring in order to facilitate coping, it is essential that their assistance be based on both the holistic

experience of their coping and caring for their children as well as the children's own experiences of living with heart diseases.

1.2.1 Research question

Based on the discussion of the problem and problem statement and in keeping with the principles of phenomenological inquiry, as proposed by Streubert Speziale and Carpenter (2007), the following research question was formulated. The aim of the research question is to enable the participants to describe their experiences holistically.

How do the parents/caregivers of children living with heart disease experience caring for these children and how do the children themselves experience living with heart diseases?

The abovementioned research question gives rise to the statement of the purpose of the study.

1.3 PURPOSE AND OBJECTIVES OF THE STUDY

Beck and Wiencek-Kurek (2007) concur with Asandi-Lari, Packham and Gray (2003) and recommend that, in order to meet the health care needs of those suffering from chronic illnesses and to improve their quality of life, there is a need to explore and describe the cultural, socioeconomic and environmental factors that impact on their health care, to identify their health care needs and to put in place a support system to facilitate their coping with their situation.

1.3.1 Purpose of the study

The purpose of this study is, therefore, firstly, to explore and describe the experiences of both the parents/caregivers in caring for their children with heart diseases at home as well as the children's experiences of living with heart diseases in order to interpret the way in which the parents/caregivers cope with the situation at home and identify the need for assistance.

1.3.2 Objectives of the study

The objectives are as follows:

- to explore and describe the experiences of the rural parents/caregivers as regards caring for children who are diagnosed with a heart disease.
- to explore and describe the children's own experiences of living with a heart disease.

- to develop health care programme aimed at providing support to the rural parents/caregivers of children living with a heart disease.

1.4 THE SIGNIFICANCE OF THE STUDY

An understanding of the experiences of the parents/caregivers of children living with heart diseases as well as the experiences of living with a heart disease by the children will provide the insight that is necessary to conceptualise the need for assistance in order to facilitate coping with the demands for care. The conceptualisation of the need for assistance will serve as a basis for the development of a home-based health care programme aimed at supporting these parents/caregivers in their coping with the demands of care at home. It is envisaged that such a programme will improve the quality of life for these sick children.

A home-based health care programme which is aimed at providing support to the parents and caregivers of children with heart disease is a prerequisite to facilitating optimum health care for these children. According to the George (2008)'s assumption, the goal of such a programme is to devise positive or desired adaptive modes of mastery and coping for the parents/caregivers and survival and growth for the children. The positive adaptive modes to be realised for these children include the physiological mode which encompasses the sustainment of sufficient oxygenation, adequate nutrition metabolism, balanced body fluids and electrolytes and activity tolerance (Roy, 1991, as quoted by George, (2008). In addition, a home-based health care programme may facilitate these children's attainment of a positive self-concept mode as a result of their experiencing

positive body sensations and psychic integrity as opposed to experiencing symptoms of systems derangement and fear of death (George, 2008).

As regards the parents and caregivers, the purpose of the home-based health care programme is to facilitate the attainment of the role function mode with parents and caregivers being enabled to master the knowledge and skills required to care for their children at home. In addition, they are empowered to function socially and to restore their social relations as opposed to their having insufficient time for recreation as a result of needing to care for their sick children (Reinhard et al., 2012; Arafa et al., 2008; George, 2008).

In conclusion, this study will provide for the health promotion approach adopted in Namibia and also globally which advocates for the empowerment and/or rehabilitation of individuals in terms of promoting and sustaining their own health through a process of enabling these individuals to utilise their potentials (Munodawafa, 2006 & Iiping & Botes, 2002).

1.5 PARADIGMATIC PERSPECTIVES/ASSUMPTIONS

A paradigm is a framework which encompasses assumptions about the study participants, the details of structure of the research direction and the research methods to be adopted (Shuttleworth, 2008). Three types of assumptions were applied in this study, namely, meta-theoretical assumptions about the research subjects (the study participants) as human beings in society requiring health care, theoretical assumptions or the

researcher's tentative belief system regarding the way in which the research subjects experience the phenomenon which is being investigated and methodological assumptions about the nature or type and structure of the study. These assumptions are discussed below.

1.5.1 Meta-theoretical assumptions

A meta- theoretical assumption refers to the pattern according to which a researcher perceives the subjects of the research or the beliefs that the researcher has about the subjects of the study (the participants) (De Vos, Strydom, Fouche, and Delport (2007). Orem's philosophical assumptions about health, human beings and society in relation to providing care to those who are in need as quote by George (2008) were applied to this study.

Health

Orem defines health as a state of comprehensive contentment of physical, psychological and social well-being. If an individual is not able to provide the self-care required to achieve that goal, then it is incumbent on others to provide the necessary care for the individual concerned (George, 2008). Based on this assumption, the researcher deemed it necessary to develop and implement home-based health care interventions in order to negate the negative experiences of the parents/caregivers and the children with heart diseases as they struggle either to meet the demands for care or to come to terms with the experience of living with heart disease. In addition to the benefits for the

parents/caregivers as a result of their empowerment, the children would receive better care and this, in turn, would improve their quality of life.

Human beings

Both Orem (1991) and Wiedenbac, (1970) as quoted by George, (2008) assert that human beings are endowed with the unique potential to develop both themselves and the resources that enable them to maintain and sustain themselves, and if exposed to an environment which is conducive for learning, human beings will operate as open systems and make the best use of their abilities as well as realise their self-worth. Therefore, these instincts enable human beings to strive towards self-direction and relative independence in making the best possible use of their potentialities and fulfilling their responsibilities. Based on these assumptions, the researcher acknowledges that the parents/caregivers of children with heart diseases have the ability to learn and make use of knowledge to cope with the demands of caring at home. It is therefore necessary to develop a health care programme to facilitate the parents and caregivers' learning and develop their potential to provide care to their children at home.

Society

Orem (1991) (as cited by George 2008) is of the opinion that society values both self-help and help to others. As a result, adults are expected to be self-reliant and to take responsibility for both themselves and for the well-being of their dependents. However, the theorist argues that society accepts that those individuals who are helpless should be helped in their immediate distress to attain responsibility within the limits of their capacity (George, 2008). Based on this assumption, the researcher deemed it necessary to address the need for support and to develop a home-based health care programme aimed at empowering the parents/caregivers of children with heart diseases from poor rural backgrounds in order to facilitate their coping with the demands of home care.

1.5.2 Theoretical assumptions

Theoretical assumptions were employed as terms of reference in this study to refer on the situation of children with heart disease and to that of their parents/caregivers. A theory defines the relationship between the concepts relevant to a phenomenon and, therefore, the relevant theory provides a direction in terms of understanding the phenomenon and also serves as a basis for considering the way in which the new knowledge about the phenomenon may be organised (Silverman, 2010). In terms of this study, the theoretical assumptions comprise the tentative belief systems of the researcher regarding the way in which children experience being afflicted with a heart disease, and how their parents/caregivers experience and cope with caring for these children at home.

1.5.2.1 The Transactional Model of Stress and Coping

The theoretical assumptions applied in this study are *related* to the theoretical framework of the “*transactional model of stress and coping*.” This model predicts people’s appraisals of challenging life experiences and the way in which these appraisals influence the strategies they employ to cope with such challenges (Glanz, Rimer, & Viswanath, 2008).

However, the researcher departs from the notion that a theoretical framework in a qualitative study, like in this study is only briefly described as part of the developmental phase, a sensitizing framework that provides orientation to the study and, helps guide the investigation (Polit & Beck, 2012). Accordingly, all “ideas” and assumptions from the transactional theory were “bracketed” in order to avoid preconception on the findings arising from this qualitative study. As a result the theoretical assumptions in this study were utilised only as references for the discussion of the study findings in chapter 4 and in phase II and phase III of the study for the development of the programme interventions and the implementation and evaluation of the programme interventions.

1.5.3 Methodological assumptions

The methodological assumptions explain the method used to investigate the research problem. It refers to the choice of the approach for the study, methods of data gathering, form of data analysis in planning and executing a research study (Silverman, 2010). In this study a qualitative study was chosen to provide the data on the experiences of the

parents and caregivers as regards providing care to a child with a heart disease and on the experiences of the children with heart disease as regards living with heart a disease.

The qualitative approach capitalises on the subjective claims of the study participants while taking into consideration the context in which such experiences take place as a way of understanding and interpreting human experiences. A qualitative, phenomenological and contextual approach was deemed a suitable method for this study to explore and describe the participants' lived experiences in relation to the context in which the experiences take place (Polit & Beck, 2012; Polit & Hungler, 1995). The research design and research methods are discussed in chapter 2 of the study.

1.6 RESEARCH DESIGN AND RESEARCH METHODS

Planning the research design and research methods to be adopted constitutes an organising principle that ensures the logical execution of the research activities. Research methods refer to the steps and procedure for gathering and analysing the data in a study (Polit & Beck 2012). A detailed discussion of the research design and research methods is provided in chapter 2. However, in the interests of a comprehensive presentation of the overview and orientation of the study, a brief discussion of the research design and research methods together with the measures taken to ensure the trustworthiness of the study will follow below.

1.6.1 Research design

The research design for this study was qualitative, descriptive, exploratory, contextual and reductive phenomenological in nature (Streubert, Speziale & Carpenter, 2007). The study explored and described the lived experiences of the parents or caregivers as regards caring for children with heart disease and also the lived experiences of the children with heart disease as regards their living with heart diseases. The study is aligned to the research methods which provided for a reductive approach to the study.

In line with the reductive orientation of a phenomenological study, the conclusions drawn in respect of the experiences of the study participants and the development of the programme interventions are the result of the reduction process which was applied to the data provided by the study participants.

1.6.2 Research method

This study was carried out in three phases, namely, description of the participants' experiences, development of the conceptual framework, the development and implementation of the programme. These phases are briefly explained below.

1.6.2.1 Phase 1: Description of participants' experiences

Phase one of the study involved the description of the parents'/caregivers' experiences of caring for children with heart diseases and the children's experiences of living with heart diseases.

1.6.2.2 Phase 2: Conceptual framework and the programme development

Phase two involves the development of a conceptual framework and also the resultant development, in accordance to the conceptual framework, of the home-based health care programme aimed at facilitating parents'/caregivers' coping with the challenges of caring for their children with heart disease.

1.6.2.3 Phase 3: Programme implementation and evaluation

Phase three involves the implementation of the programme interventions aimed at facilitating the participants' coping and the evaluation of the outcomes of the programme interventions.

The programme evaluation is aimed at validating whether the programme interventions are likely to bring about the desired change within the participants and whether it would be possible to transfer the interventions to another situation within a similar context (De Vos et al., 2007; Mouton, 2004; Henning, Van Rensburg, & Smit, 2004).

1.7 ETHICAL MEASURES

Ethical measures are codes of conduct that are developed to guard against any violation of human rights in the conducting of research (Streubert Speziale & Carpenter, 2007; Parahoo, 2006). The ethical measures that were adopted in this study included approval of the research by the Post Graduate Study Committee of the University of Namibia and obtaining permission from the Research and Ethical Committee of the Namibian Ministry of Health and Social Services to conduct the research study among the clients

of the health services. The informed consent and assent from the participants were obtained while participation in the study was voluntary. In addition, the anonymity and confidentiality of the participants were ensured. Chapter 2 contains a detailed description of the ethical measures adopted in the study.

1.8 PHILOSOPHICAL APPROACH TO THE STUDY

A paradigm is a way of looking at a natural phenomenon, and it encompasses a set of philosophical assumptions that guide the researcher's approach to inquiry (Polit & Beck, 2012; Polit & Hungler, 1995). The philosophical approach applied in this study was based on the naturalistic paradigm, also referred to as the phenomenological paradigm or constructivism.

The naturalistic paradigm argues that reality is not a fixed entity, but rather a construction or a phenomenon derived from the subjective claims of the individual concerned, within which context several constructions of the reality are possible (Polit & Beck, 2012; Polit & Hungler, 1995). This study is based on the following major philosophical assumptions of the naturalistic or the constructivism paradigm:

Epistemological assumption: The epistemological assumption emphasises that it is important for the researcher to interact with the research participants if the researcher is to maximise the knowledge arising from the study (Polit & Beck, 2012; Polit & Hungler, 1995). The findings of this study are, therefore, the result of the vigorous interaction of

the researcher with the study participants through in-depth interviews, field notes, member checking by the study participants and the peer debriefing of the researcher.

Ontological assumption: The ontological assumption asserts that reality is multiple and subjective and, as such, reality is mentally constructed by the individuals participating in the study (Polit & Beck, 2012; Polit & Hungler, 1995 & Henning et al., 2004). The reality or the findings of this study are both multiple and subjective as the findings are constructed according to the perceptions of the various individuals who participated in the study – the parents'/caregivers' perceptions of providing care to a child with a heart disease and the children's perceptions of living with a heart disease.

Axiological assumptions: The axiological assumption acknowledges that, because reality is mentally constructed by the study participants, subjectivity and value are both inevitable and desirable (Polit & Beck, 2012; Polit & Hungler, 1995). As a result, the conclusions that were arrived at in this study are based on what the participants regarded as the most important experiences to them as regards providing care for their children with heart diseases, or else living with heart diseases.

Methodological assumption: The methodological assumption of the naturalistic paradigm emphasises that it is desirable to present the entire narrative information as emerged from the participants and also to contextualise the entire phenomenon (Polit & Beck, 2012; Polit & Hungler, 1995). Accordingly, this study utilised an inductive

process and also interpreted the narrative information provided by the parents/caregivers and the children as the study participants. The findings were qualitatively analysed and conclusions were drawn about the need to provide support to the parents/caregivers in order for them to cope with the demands of care at home.

The subsequent development and implementation of the programme activities were aligned to the context of the participants because the activities were implemented both to and by the parents/caregivers and the children with the heart disease in their households. The researcher is of the opinion that the findings regarding the experience of caring for a child who is living with a heart disease as well as the programme activities designed to facilitate coping may be transferred to any relevant context.

1.9 DEFINITION OF CONCEPTS

According to De Vos et al., (2007), a definition refers to the description and clarification of the key terms that require particular attention in the scientific study under review. In this study, the following key terms are important.

Home-based care

Home-based care refers to the provision of basic health care needs to people in their own homes by either formal or informal caregivers with the aim of enabling the recipient to achieve the best possible quality of life through the restoration and maintenance of the individual's maximum level of comfort, function and health (WHO, 2002). For the

purposes of this study, home-based care refers to the provision of planned activities to be implemented to and by the parents/caregivers of children with heart diseases as well as by the children themselves to facilitate coping with their situation at home.

Health care programme

A programme refers to a series of planned combinations of activities, with a set of instructions designed to achieve specified goals and needs, both material and human (Kozier & Erb, 2008). In the context of this study, a programme refers to a series of health care activities to be implemented to and by the parents/caregivers of children with heart diseases as well as by the children with heart diseases in order to facilitate coping with the situation.

Parents/caregivers

A parent/caregiver is a father or a mother, one who begets or one who gave birth to, or one who nurtures and raises the child concerned. A caregiver may also be a relative who acts as guardian to a child (Baiham, 2007). In this study the term “parents/caregivers” refers to either, the biological parents, legal guardians or family members who are responsible for the care and maintenance of a child with a heart disease.

Children

According to the United Nations (Baiham, 2007) and Gouws, Kruger and Burger (2008), a child is a human being of age from birth until the age of 18 years and who is, therefore, dependent on care by others (UNHCR, 2009). For this study, the United Nations

definition of a child is adopted and a child is someone from the age of 11 to 18 years with a heart disease and who was able to participate in this study.

Heart diseases

Heart diseases refer to any disease of the heart structure and the central blood vessels. The most common heart diseases among children are congenital heart diseases that develop during foetal life as a result of interplay between genetic and environmental factors and also rheumatic valvular heart diseases (Coovadia & Wittenberg, 2007; Opie, Bongani & Mayosi 2005; Potts & Mandleco, 2002).

Facilitate

The term facilitate refers to a process or actions that are taken to ensure smooth and effective functioning. For the purposes of this study, “to facilitate” refers to the process by means of which the parents and caregivers of children with heart disease are enabled to provide necessary care and to cope with the demands of providing of such care at home.

Coping

Coping refers to renegotiating ways of thinking and feeling and being able to adjust to the challenges of life. In other words coping is the process and actions involved in restoring balance in the demands imposed by both the internal and the external environment (Webb, 2009; Glanz et al., 2008; Ulvik, Hanestad, Wentzel-Larsen, & Wahl, 2008). For the purposes of this study, coping refers to the process and actions

taken by the parents and caregivers to maintain a balance between the demands of caring for their children with heart diseases and the maintenance of their own psychosocial well-being. In this regard, coping refers to the climate in which the parents and caregivers deal with their workload, maintain family routines and take the opportunities to socialise and recreate without restricting their social lives (Reinhard et al., 2008; Arafa et al., 2008; Shu-Fan, Pei-Fan & Kai-Sheng, 2007). Finally, coping refers to the ability of parents and caregivers to employ a positive, emotionally focused coping effort and to ensure their own emotional wellbeing (Glanz et al., 2008). As regards the children, coping refers to their ability to attain a physiological integrity, optimal functional status and vitality (George, 2008).

1.10 DIVISION OF CHAPTERS

The content of this dissertation is presented in three phases and corresponding chapters. Phase one involves the description of the parents/caregivers experiences of caring for a child with the heart diseases and the children's experiences of living with heart diseases for situational analysis. The content of the situational analysis is described in the chapters as follows:

Chapter 1 presents the orientation and overview of the study. The chapter also provides background information about the reasons which prompted the researcher to conduct the study.

Chapter 2 discusses the research design and research methods adopted in conducting the study the study. Chapter 3 presents the research findings in accordance with the

phenomenological approach. Chapter 4 contains a discussion and literature control of the research findings in relation to the existing body of knowledge relevant to the phenomenon under study.

Phase two of the study is concerned with the formulation of a conceptual framework and the development of the resultant home-based health care programme in accordance with the conceptual framework. The home-based health care programme is aimed at facilitating the parents'/caregivers' coping with the challenges of providing care to their children with heart diseases. The contents of this phase are discussed in the following chapters.

Chapter 5 covers the conceptual framework which emanates from the research data. The conceptual framework served as guideline for the development of the programme interventions. Chapter 6 discusses the development of a home-based health care programme with the programme interventions designed to empower the parents and caregivers to cope with the demands of care at home being presented.

Phase three covers both the implementation of the programme interventions designed to facilitate coping on the part of the participants and the evaluation of outcomes of the programme interventions. The programme outcomes evaluation is aimed at validating whether the programme interventions are likely to bring about the desired change in the participants, the findings of which can guide whether it would be possible to transfers

the interventions to another situation in similar context (De Vos et al., 2007; Mouton, 2004; Henning et al., 2004).

Chapter 7 discusses the implementation and evaluation of the programme interventions. As such, the chapter presents the process of programme implementation and the findings of the programme outcomes evaluation. Chapter 8 presents the summary, limitations of the study and recommendations and the conclusions on the study.

1.11 SUMMARY

Chapter 1 illustrated the magnitude of heart diseases among children globally and, in particular, in Namibia. The effects of heart disease on the quality of life of both the children who have heart disease and their parents or caregivers were discussed. Based on the presumed negative effects on the quality of life for both the children and their caregivers, the problem statement pertaining to the study was formulated. The goals and specific objectives of the study were described as was the significance of the study. The paradigmatic perspective or assumptions with regard to the research subject, theoretical assumptions and methodological assumptions as a point of departure for the study were explained and the philosophical approach to the study were discussed. The key concepts of the study were defined and the division of chapters were outlined.

In view of the fact that this is a qualitative study, the next chapter describes the research design and research methods which were adopted to provide an answer to the research question about the way in which the parents and caregivers of children with heart disease, as well as the children concerned, cope with their situation at home.

CHAPTER 2

RESEARCH DESIGN AND RESEARCH METHODS

2.1 INTRODUCTION

Chapter one presented an overview of the study, including the background to the study and the rationale behind the study. It is, therefore, necessary to establish scientific data in order to provide an answer to the research question and to justify potential solution to be provided. Scientific data arises from a scientifically validated method – the research design (De Vos et al., 2007). Accordingly, this chapter discusses the research methodology-the research design and methods of data collection for the study.

2.2 RESEARCH DESIGN AND RESEARCH METHODS

The research design refers the way in which the researcher goes about studying a particular phenomenon or the planning and execution of the study activities. In addition, the research design explains the type of the study that is conducted in accordance with the type of the results at which the researcher is aiming, methods of data collection and the forms of data analysis used in order to provide an answer to the research question (Silverman, 2010). Consequently, the research method refers to the procedures that were followed in conducting the study (Henning et al., 2004; Babbie & Mouton, 2001).

2.3 Research design.

This study is qualitative, explorative, descriptive, contextual and phenomenological in design. The study made use of case studies for the in-depth exploration and understanding of the lived experiences of caring for a child with a heart disease on the part of the parents/caregivers and of the children's experiences of living with heart disease, in relation to the socio-economic context which may play a role in influencing the participants' experiences. For the purposes of this study a case study refers to a unit comprising a parent/caregiver and the child with a heart disease. The purpose of the study was to explore and describe the participants' experiences and perceptions or their personally constructed meaning about caring for a child with a heart disease or else living with a heart disease (Henning et al., 2004). The characteristics of a qualitative study as applied to this study are described below.

2.3.1 Qualitative

Qualitative research refers to the collection, analysis and interpretation of thick narrative and visual data so as to enable the researcher to gain insights into the phenomenon of interest (Polit & Beck, 2012; Gay, Mills, & Airasian, 2009). Qualitative research is, therefore, a naturalistic inquiry aimed at gathering data based on the perspectives of the participants. Qualitative research enables the researcher to understand the meaning of events from the participants' perspective and within a specific context (De Vos et al., 2007).

This study is in line with the view of Hardy and Bryman (2004) and of Streubert Speziale and Carpenter (2007), when they state that qualitative researchers explore the complex life histories of everyday and life experiences of the study participants. The participants are regarded as the insiders who are the best based on the premises to describe their situation or the phenomenon and, as such, they constitute the primary sources of data. It is, therefore, essential for preservation of objectivity towards the data that the researcher either remains free from or bracket preconceived notions about the phenomenon under investigation (Silverman, 2010; Streubert Speziale & Carpenter, 2007; Hardy & Bryman, 2004; Holloway & Wheeler, 1995). This study is, therefore, qualitative because it presents the self-constructed meanings of the parents' and caregivers' experiences of caring for children with heart diseases as well as the children's experiences of living with the heart diseases.

2.3.2 Explorative

The purpose of qualitative explorative studies is to explore unknown areas pertaining to the study participants in order to gain insights into the phenomenon under investigation (Streubert Speziale & Carpenter, 2007; De Vos et al., 2007; Holloway & Wheeler, 1996). This study may be regarded as an explorative study because it explores the unknown experiences of the parents/caregivers from the rural areas in Namibia in regard to providing care to a child with a heart disease and of living with heart disease (children). In view of the fact that there is currently no information available in Namibia on either the parents'/caregivers' experiences in respect of the demands of care, or on the

children's experiences of living with a heart disease, the researcher assumed that insights into the phenomenon would be of assistance to identify mechanisms that can assist the caregivers to cope with the demands of providing care at home.

2.3.3 Descriptive

A descriptive study aims at presenting a detailed representation of a specific situation (De Vos et al., 2007). Accordingly, this study provides a “thick”, detailed description and interpretation of the parents'/caregivers' experiences of providing care for their children with heart diseases at home and the children's experience of living with heart diseases (Holloway & Wheeler, 1996). In view of the fact that it is also necessary to provide evidence of the trustworthiness of the data, verbatim or narrative reports of the individuals' account of their experiences, events recounted and the perceptions and ideas of the participants are quoted verbatim. In addition, the “heart drawings” or naïve drawings of some of the child participants are presented and described (Mitchell, 2011; Silverman, 2010).

2.3.4 Contextual

A contextual approach advocates that people be studied within their cultural, social and personal historical context in order to attach meaning to the life activities and experiences taking place in their daily lives. In other words, a contextual study explains

people's experiences in relation to their cultural and economic backgrounds or the world which determine people's experiences and their responses to illness or challenges (Burns & Grove, 2004). Hence a contextual study purposefully focuses on human beings within their cultural context, thus acknowledging that human beings are more than merely bodily systems or diagnostic cases. This perspective is embedded in the understanding that health and illness is a multidimensional experience as it is related to the physical, emotional, spiritual and socio-economic aspects of the individual concerned (Streubert Speziale & Carpenter, 2007; Holloway & Wheeler, 1996).

Accordingly, this study describes the rural parents/caregivers' experiences of caring for the child with a heart disease and the children's experiences of living with the heart disease in relation to the socio-economic contexts that influence the parents'/caregivers coping with the demands of providing care at home. In other words, this study is a contextual in the sense that it focuses on those children with heart disease and their parents/caregivers who are from the poor, rural areas with limited resources in Namibia. As such, this context may negatively affect their ability to cope (Collins et al., 2008; Rogers, 2003,). Insights into these contextual variables play an important role in determining the various components of the health care interventions which are aimed at facilitating coping with the demands of care on the part of the parents/caregivers.

In view of the fact that the study was contextual in nature, with the emphasis on rural areas, the context of this study was the rural areas of Namibia. The main, rural areas of

Namibia comprise the four northern regions (Oshikoto, Oshana, and Ohangwena & Omusati), two north-eastern regions (Kavango and Caprivi), the north western region of Kunene as well as some areas in the southern regions. The rural areas in these regions are characterised by a high level of poverty. As the literature claims that the life of children who grow up in poverty is none other than “feet that are cold and wet” (Levy & Sidel, 2011, pp.779), this situation predisposes children to rheumatic heart disease in the rural areas in Namibia. Concurrently, of the children with heart diseases who are being treated at the health care facilities in Namibia, almost all those who are diagnosed with rheumatic heart disease are from the rural areas in one of the abovementioned regions and, in fact, three of the child participants in this study are suffering from rheumatic heart disease. For the purposes of data collection, it was decided to select parents/caregivers and children with heart diseases from the rural areas in various regions and from different cultural orientations in Namibia in order to verify the role played by socio-economic factors in coping with the experiences of the same phenomenon across cultural differences in rural areas of Namibia (Streubert Speziale & Carpenter, 2007; Wåhlin, Ek, & Idval, 2006). The next section will discuss the phenomenological characteristics of the study.

2.3.5 Phenomenological

The purpose of phenomenological studies is to define the personally constructed meaning of human experiences. Accordingly, the central focus of a phenomenological inquiry is on describing the meaning of lived experiences of those experiencing the issue

under investigation in the belief that the truth about reality is grounded in the lived experience of those individuals who experience such reality at first hand (Polit & Beck, 2012; Streubert Speziale & Carpenter, 2007; De Vos et al., 2007; Burns & Grove, 2004).

In view of the fact that this study is a phenomenological of nature, its research design falls within the ambit of the phenomenological approach. This study is a phenomenological research as it aims to capture and describe the “lived experiences” of both the parents/caregivers as regards providing palliative care at home to their children with heart diseases and the children’s experiences of living with heart disease.

The study is based on a naturalistic methodological assumption which advocates the maintenance of openness, thoroughness and consideration of all the subjective data as it emerges from the participants. In other words, the researcher’s own assumptions about the phenomenon under investigation were not allowed to come into play in describing the data which originated from the participants (Polit & Beck, 2012; Burns & Grove, 2004). Instead, the naturalistic, axiological assumption was adopted to enable the researcher to understand and describe issues which were of importance to the participants (Polit & Beck, 2012; Polit & Hungler, 1995).

Furthermore, the literature indicates that the phenomenological approach is dynamic in nature and offers a variety of options from which to choose although the choice is guided by the phenomenon that is being studied (Streubert Speziale & Carpenter, 2007).

The study is, thus, inductive in nature and it commenced with the description of the participants' experiences as a situational analysis. In line with the reductive orientation of phenomenological study, conclusions were drawn based on the participants' experiences and the central concept related to the participants' experience was identified. The reduction arising from the situational analysis enabled the researcher to formulate a conceptual framework encompassing the central concept about poor coping with the demands of care, hence the needs to facilitate support to the parents/caregivers to enable them coping with the demands of care at home (see table 2.2).

2.4 Research method

A research method refers to the systematic procedures followed by a researcher and the specific techniques, for example, interviewing, field note, audio recording and pictorial naïve drawings, that may be utilised when collecting and analysing the data, depending on the suitability of such techniques to the research design (Silverman, 2010). Appropriate and effective research methods ensure the reliability of the data in order for the researcher to arrive at an appropriate solution to the research problem (Gay et al., 2009; Creswell, 2008; Babbie & Mouton, 2001).

The research activities in this study were carried out in the following three phases, namely, the description of participants' experiences for situational analysis purposes, conceptualisation of the parents'/caregivers need for support and the development of the health care programme. The study was concluded with the implementation and evaluation of the programme interventions. The summary, limitations, recommendations

and conclusions, conclude the research activities. The phases of the study design are presented in table 2.1.

2.4.1 Phase 1: Description of participants' (parents/caregivers and the children)'s experiences.

The description of participants' (parents/caregivers and the children's experiences was carried out for situational analysis purpose. Situational analysis involves the identification of the needs relevant to an intervention programme (De Vos et al., 2007). Phase one comprised the situational analysis and the parents'/caregivers' experiences of caring for a child with heart disease and the children's experiences of living with heart disease were explored and described by means of a phenomenological analysis. In accordance with the procedure inherent in a phenomenological study, during this phase, the caregivers lived experiences and the challenges of providing care to a child with a heart disease and the children's experiences of living with heart disease as well as the way in which the parents/caregivers cope were explored and described (Silverman, 2010).

2.4.2 Population and sampling (used in phase one)

A study population refers to all members of a specific group of people who possess the attributes that the researcher aspires to study and about whom the researcher draws conclusions with regard to the findings of the study (Babbie & Mouton, 2001 & De Vos et al., (2007). For the purposes of this study, the study population comprised approximately 500 children who were identified with the assistance of the Ministry of Health and Social Services (MoHSS) and who were being treated for congenital and rheumatic heart diseases at the state health facilities in Namibia and to whom the research findings and the home-based health care interventions to facilitate coping could be applied.

2.4.3 Sample and sampling method

Sampling is a procedure for selecting a set of individuals, who possess the same characteristics as the members of the study population, to serve as a representative of the targeted research population and in respect of whom the research findings may be applied to the targeted study population (De Vos et al., 2007). Appropriate sampling enhances the transferability of the study results to a situation with a similar context (Brink, 2007 & Henning et al., 2004).

Streubert Speziale and Carpenter (2007) concur with Joubert and Enhrlich (2007) when they state that, in qualitative studies, non-probability sampling methods are the most appropriate methods to use as a qualitative study focuses on those individuals or group

of people who possess the specific characteristics that are relevant to the study concerned.

Therefore, in view of the fact that this study is both qualitative and phenomenological, a purposeful sampling method was used to deliberately choose the most eligible participants, that is, those individuals who possess all the possible characteristics of interest and are, therefore, likely to provide an abundance of the pertinent information that is being sought (Polit & Beck 2012; Joubert & Enhrlich, 2007; Burns & Grove, 2004). Accordingly, five multiple cases of parents/caregivers and their children with heart disease from the rural areas of Namibia were purposefully selected to participate in the study. A multiple case refers to a unit of the parent/caregiver and the child with a heart disease and who is being cared for. Multiple cases were preferred because the evidence from a greater number of cases is more compelling (Perry, 2004) and would enable the researcher in this study to draw inferences in order to explain the lived experiences of the parents/caregivers and their children in respect of the research question.

2.4.4 Sampling criteria

The proponents of qualitative research argue that, in qualitative studies, sample size is statistically insignificant because sampling is based on data saturation, even if the data is derived from few cases, (Polit & Beck, 2012). The sampling criteria that were important in this study include the context, language of communication and age, considering the ability of the participants to express themselves (De Vos et al., 2007 & Patton, 1990).

The list of names of potential participants was drawn from the register of the paediatric cardiac clinic at Windhoek Central Hospital. Five multiple cases from the rural areas of a female parent/caregiver and the child for whom she was providing care were purposefully selected from the register at the paediatric cardiac clinic at Windhoek Central hospital. These five multiple cases were characterised by a poor socio-economic status, that is, from rural households and headed by a subsistence agricultural farmer, as these characteristics implied that the parents/caregivers would be at risk of poor coping (Collins et al., 2008). Those households with children between the ages of 12 and 17 (see the definition of child in chapter 1) only, were selected because such children would be able to understand the meaning of the interview questions and the degree of the details required. In addition, children in this age bracket would be able to apply formal and operational thinking to provide either thoughtful, substantive responses or complete and accurate information (Mack, Giarelli, & Bernhardt, 2009). In other words, they would be able to communicate and explain their experiences of living with a heart disease effectively. Another criterion for sampling was the language proficiency.

Language involves the communication of one individual's mental representation of reality. As such, it is recommended that a language, through which the participants would be able to compose thorough self-expression be used (Botes, 1991). Two of the multiple cases were from the Omusati region, two were from the Oshana region, while one was from the Caprivi region (see figure 2.1). The participants from Oshana and

Omusati were interviewed in their mother tongue, Oshiwambo, to enable them to communicate fluently, after which the data were translated by the researcher in English for analysis (A sample of the transcribed data is attached in annexes 5 for trustworthiness of the data). The participants from the Caprivi region were, interviewed in English and the data from this case were acquired in English, as English was the medium that facilitated fluent communication between the research and the participants and there was no need for translation of the data. As regards the programme implementation, the Oshiwambo language was used as the programme was implemented in the Omusati region only. A detailed discussion of the programme implementation is provided in chapter 7).

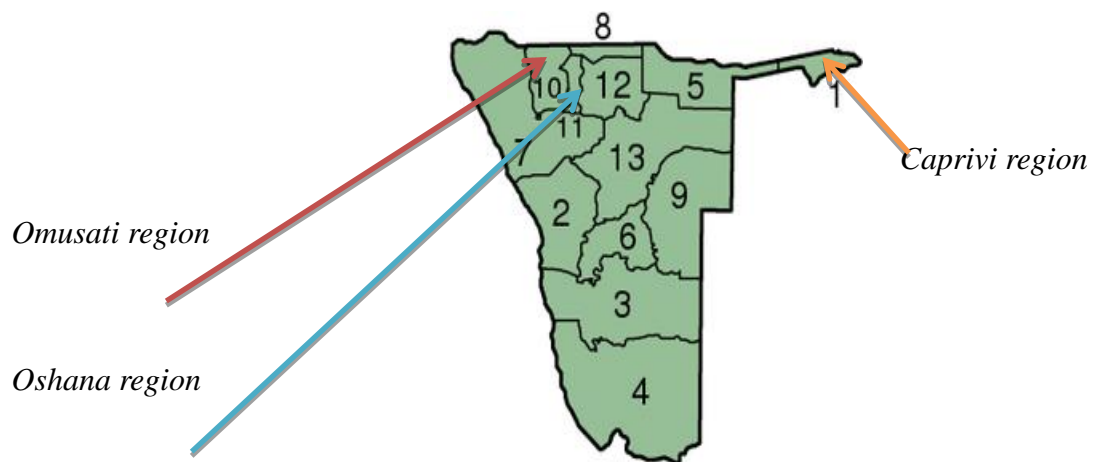


Figure 2.1: Map of Namibia

The study participants were from Caprivi, Omusati and Oshana region.

2.5 Data collection

2.5.1 Data collection instruments

In view of the fact that this study was qualitative and phenomenological in nature, the need for the participants to structure their responses was borne in mind. Semi-structured interview comprising an open-ended question to allow the participants to structure their responses about their experiences of caring for a child with a heart disease at home and of living with a heart disease was prepared for the purposes of data collection from the parents/caregivers and the children respectively (Silverman, 2010).

Interview question

All the parents/caregivers who participated in the study were asked the following single, open-ended question:

How do you experience caring for a child with a heart disease?

The child participants, on the other hand, were asked the following open-ended question:

How do you experience living with a heart disease? Draw a picture and tell the story about the picture.

The interview questions were pilot tested in order to assess if the research question is appropriate to elicit appropriate responses from the participants (Creswell, 2008).

2.5.2 Pilot testing

According to Bless and Higson-Smith (2000), a pilot study is a small study, which is conducted prior to the main study, among the respondents who are homogenous to the participants of the main study. The purpose of pilot testing is to determine the appropriateness of the data collection instrument and the probability that the participants in the main study will provide the required information. In addition, pilot testing allows the researcher to pre-empt any problems that may arise during the main study. The ultimate aim of pilot testing is to effect the necessary modifications to the data collection instrument in order to ensure the trustworthiness of the data collected during the main study (De Vos et al., 2007). For the purposes of this study, the research questions were pilot tested for the relevance of the interview content and the appropriateness of the interview process. As regards the content, the research questions were pilot tested for relevance on one registered nurse at the paediatric cardiac clinic in order to obtain the “experience of the expert” in the discipline (De Vos et al., 2007).

As regards the interview process, the research questions were pilot tested on the two parents/caregivers and their children with heart disease at the paediatric cardiac clinic where they are readily available, to determine the respondents’ ability both to participate and to provide appropriate information, hence to assess the feasibility of the study. These parents/caregivers and the children were excluded from participating in the main study.

The pilot testing enabled the researcher to identify the need to appreciate the practical aspects of establishing access to and making contact with the participants, conducting interviews and becoming aware of her own level of interviewing skills. Where necessary, wordings of the research questions were amended for appropriateness to ensure the trustworthiness of the data to be collected from the respondents of the main study (De Vos et al., 2007).

2.5.3 Methods of data collection

Data collection refers to the process of gathering information from the participants. In view of the fact that this study was both qualitative and phenomenological in nature, methods of data collection that are appropriate to phenomenological or interpretive inquiry, including interviews, taking of field notes and pictorial naïve drawings were employed to collect the data from the five multiple cases of rural parents/caregivers and their children with heart disease who required care (Henning et al., 2004). The data was collected at the paediatric ward of the Katutura Reference Hospital at the time of follow up treatment.

Semi-structured interviews were conducted for the five multiple cases, which include the parent or caregiver and the child, between June and August 2010. A total of ten interviews, with two interviews per one multiple case, were conducted. All the parent/caregiver participants were females. Four of the parents/ caregivers were mothers of the children and the one remaining caregiver was a family member who was playing

the role of caregiver. A one-day session of data collection was allocated for two multiple cases with the data collection process being completed over a period of three days – see following paragraphs.

Interviews

An in-depth, face-to-face interview was conducted for each of the five (5) multiple cases. A one-on-one, unstructured interview was conducted with each participant from each multiple cases and each interview lasted for approximately 60 to 80 minutes. During the interviews the parent/caregiver participants described their experiences of providing care to the child with heart disease and the child participants described their experiences of living with heart disease. The information gathered from the interviews was recorded on a tape recorder and subsequently transcribed (Streubert Speziale & Carpenter, 2007; Joubert & Enhrlich, 2007).

Pictorial naïve drawings

The child participants were also asked to communicate their feeling about how suffering from a heart disease affected their lives through the “heart drawings” or naïve drawings. Accordingly, through the medium of the naïve drawings, two of the children explored their feelings about the illness and about how living with heart disease had affected them (Mitchell, 2011; Creswell, 2008; Brosig et al., 2007).

The data was collected until data saturation was reached, that is, when the parents/caregivers had exhaustively described their experiences of caring for a child with heart disease and the children described their experience of living with heart disease, until the participants were almost repeating themselves and there was no new information emerging from subsequent interviews (Polit & Beck 2012). This yardstick meant that sufficient and valid data which reflected the participants' experiences had been gathered (Streubert Speziale & Carpenter, 2007; Mack et al., 2009; Joubert & Enhrlich, 2007; Morse, 1994).

2.5.4 The use of communication skills for the data collection

Communication skills, as discussed in the next paragraph, were used during the interviews to enhance the participants' self-expression in order to enrich the data collected (De Vos et al., 2007).

Probing: Probing was employed to elicit more detailed information than that was volunteered, and, to provide clues to the participants about the level of response that was expected of them, while at the same time, encouraging the participants to pursue their lines of thought (Polit & Beck 2012; Mack et al., 2009; Brink, 2007).

Paraphrasing: The participants' words were restated in another form with the same meaning to enhance the participants' meaning and understanding.

Reflection: As regards reflection important statements from the participants were reflected back in order to obtain the participants' consensus on the opinion being preferred.

Clarification and minimal response: Clarity and expansion in respect of unclear statements were requested in order to draw out the meaning, understanding and the beliefs that the interviewees attributed to the various experiences they went through as the caregivers for their children with heart disease. In addition, minimal responses were reflected to demonstrate interest in what the respondents were alluding to.

Member checking or reflective summary: Preliminary interpretation of the data were shared with the participants to check at once on the researcher's understanding of the meaning of the information provided and, therefore, to ensure the validity of the data (Polit & Beck 2012; Gay et al., 2009; Mack et al., 2009; De Vos et al., 2007; Joubert & Enhrlich, 2007).

2.5.5 Field notes

In addition to the interview and pictorial naïve drawings, field reflective notes about the participants' non-verbal responses or the researcher's personal thoughts on the participants' nonverbal responses and reactions and *hunches* were recorded (Creswell, 2008).

The data from the interviews of all categories of participants was tape-recorded, transcribed at the end of each interview. The children's pictorial naïve drawings were described and interpreted by the children. Field notes were interpreted by the researcher. Tape recorded information and all field notes were stored safely for confidentiality until the data analysis had been completed, after which they were discarded. The pictorial naïve drawings are annexed in the study report (Creswell, 2008; Streubert Speziale & Carpenter, 2007).

2.6 Data analysis

Data analysis refers to a descriptive examination of the participants' narrative so as to enable the researcher to become familiar with the nature of the data (Polit & Beck, 2012 & De Vos et al., 2007). Subsequent to the data analysis process is the interpretation of the data and the construction of the meaning ascribed to the participants' experiences, with the researcher allowing the results of the data analysis to reflect an in-depth picture of the relationship within and among the various aspects of the problems identified (Burns & Grove, 2004; Holloway & Wheeler, 1996).

For the purpose of this study, the data from the parents/caregivers were handled as the main focus for the exploration and description of the experiences of the demands for caring and the identification of the needs for facilitation of coping with the demands to care. The data from the children on the other hand were used to employ triangulation in order to ensure credibility of the data.

In this study the data analysis was based on the eight steps (8) of Tesch method of qualitative data analysis as proposed by Creswell (2008). In terms of this method, the researcher examined the verbatim transcripts from the interviews, the data from the field notes and familiarised herself with the data and obtained a global understanding of the research results. Thereafter, the transcripts were analysed one by one until all the transcripts had been analysed. Code words or phrases were allocated to the data that described the main ideas about the participants' experiences. The main ideas or topics which were to be found in all the transcripts were coded. After coding, the data from all the transcripts which contained similar codes was grouped together into categories, and redundant codes were eliminated. In this way the list of codes was reduced to a smaller number of codes. Themes were then identified from each category of the codes. The themes which the participants had frequently discussed and which were unique or surprising, or which were supported by the most evidence were identified from the codes (Creswell, 2008). These themes were then layered or reduced into sub-themes. A recoding of the data was performed by means of an audit trail or by a co-coder on the data collection, data analysis and data interpretation in order to ensure the reliability of the data (Creswell, 2008; Silverman, 2010). Member checking for the purposes of data confirmation were also carried out for the participant to confirm the data and peer debriefing was maintained to refine the data and to promote the researcher's insight into the study (Gay et al., 2009; Creswell, 2008; Streubert Speziale & Carpenter, 2007; Joubert & Enhrlich, 2007).

In addition to the analysis of data from the interview and field notes, the pictorial naïve drawings from the children participants were described by the researcher and interpreted by the children. Theme that raised from the children pictorial naïve drawings supported one of the themes identified from the interview and field notes.

As outlined in chapter 3 on the findings of the study, the data are presented under the corresponding theme and sub-theme. The themes and sub-themes are discussed and verified with the literature control which is presented in chapter 4 of the study.

2.7. Literature control

The purpose of a literature control is to position the research findings within the context of the existing body of knowledge and current trends applicable to the phenomenon in question in order either to confirm or contradict the information contained in the existing literature or to gain new insights from the current study that may contribute to the existing literature (De Vos et al., 2007).

Streubert Speziale and Carpenter (2007) propose that, in phenomenological studies, the literature review should follow the data analysis to avoid influences of conceptualization of the findings, so as to enable the researcher to achieve a pure self-constructed description of the phenomenon under investigation. By so doing, the researcher is less likely to influence the findings with biases based on preconceived knowledge of the phenomenon (Polit & Beck, 2012; Streubert Speziale & Carpenter, 2007). Therefore, in line with this postulation, a literature control of the themes that had been formulated was

conducted after the data analysis was completed and the findings were established to avoid the researcher's influence on the research findings and to ensure the validity and reliability of the data. Chapter 4 contains a discussion of the research findings. Following the discussion of the findings, a conceptualisation of the research was formulated and is presented in chapter 5 of the study.

2.8 Phase two: Conceptualisation of the research and programme development

Conceptualisation refers to an abstract interpretation and categorisation of the data (De Vos et al., 2007). In phase two of the study, a conceptual framework relating to the study findings was formulated. As regards this qualitative research study, conceptualisation refers to the researcher's organised image of both the parents or caregivers' experiences of caring for their children with heart diseases and the children's experiences of suffering from heart disease. Concepts, both central and relevant to the findings of the study in respect of coping were described. In addition, home-based health care programme interventions to facilitate coping on the part of the parents and the caregivers were also identified and described. Chapter 5 contains more details on the conceptualisation, while chapter 6 contains the development of the home-based health care programme interventions.

2.9 Phase three: Programme implementation and programme evaluation

Phase three of the study involves the implementation of the home-based health care programme for the parents/caregivers of children with heart disease. This programme consists of a series of planned combinations of activities to be implemented to and by the parents and caregivers of children with heart diseases in order to facilitate coping on the part of the parents/caregivers and to improve the children's quality of life. The programme was implemented at the household level to facilitate learning the methods of coping on the part of the parents/caregivers and also the children with heart disease.

Chapter 7 presents a description of the implementation of the programme activities contained in the home-based health care programme.

This phase concluded with an outcomes evaluation of the programme interventions to assess the relevance and effectiveness of the programme interventions (De Vos et al., 2007; Mouton, 2004; Henning et al., 2004). The outcomes evaluation of the parents'/caregivers' self-concept of their ability to cope with their role function and behavioural performances and the children's perception of empowerment was based on the perspectives of the Transactional Model of Stress and Coping as proposed by Glanz et al. (2008). (See chapter 6 on programme implementation and programme evaluation). Table 2.1 presents a summary of the three phases of the study.

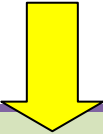
Table 2.1 Research design for phases 1, 2 and 3

Phase	Design	Population	Sample	Data collection	Data analysis	Results
1. Description of participants' experiences	Qualitative, exploratory, contextual, phenomenological and descriptive	Two populations from the rural areas: 1. Parents/caregivers caring for children with heart diseases and from the Oshana, Omusati and Caprivi regions. 2. The children with heart diseases being cared for	Purposive sampling	Pilot interviews In-depth individual interviews of multiple cases Field notes Literature control Pictorial naïve drawings	Tesch's method of qualitative data analysis Description and reductions Descriptions and interpretations of the pictorial naïve drawings by the children.	Experiences of parents/caregivers as regards the demands of caring for a child with a heart disease Experiences of children as regards living with a heart disease Identify contextual factors that hinder parents/caregivers' coping with the demands of care. Identify the need for support to facilitate coping for the parents/caregivers
2. Development of conceptual framework	Development of a conceptual framework Development of educational programme interventions			Results from phase one of the study		Educational programme interventions developed to empower the parents/caregivers
3. Programme implementation and programme evaluation	One day workshop for each household	Rural parents or caregivers from Omusati region	Purposive sampling	Interviews Observations Testimonials from the participants Field notes		Facilitation of parents/caregivers' and children's participation in the home-based health care programme interventions.

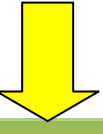
Table 2.2 on the next page presents a summary of the phenomenological reductive approach to the study.

Table: 2.2 Phenomenological reductionist approaches to the study

Phase 1:		
Description of the participants experiences	Data collections	Data analysis
1.1 Explore and describe the lived experiences of the parents/caregivers as regards providing care to a child with a heart disease and the lived experiences of children living with a heart disease respectively in order to identify the parents/caregivers' need support to facilitate their coping and the children's need for the facilitation of empowerment so as to enable them to cope with the disease.	<ul style="list-style-type: none"> - In-depth interview with individuals from each multiple case. - Observations of non-verbal responses of the participants - Field notes - Pictorial naïve drawings 	<ul style="list-style-type: none"> - The Tesch method of open coding during data analysis and reduction was applied - Description and interpretation of the pictorial naïve drawings



Phase 2	
Developmental phase	Activities
2.1 Development of researcher's reasoning map 2.2 Programme development based on the concepts of "adult learning" and "experiential learning". 2.3 Develop a home-based health care programme interventions to facilitate the parents' /caregivers' coping with the demands of providing care at home.	<ul style="list-style-type: none"> - Development of conceptual framework - Programme interventions described



Phase 3		
Implementation phase	Activities	Outcomes
3.1 Programme implementation	Two-day workshops for each multiple case, at the two households of the participants.	Active participation of the parents/caregivers and the children in the activities of home-based health care programme interventions.
Programme evaluation	Session evaluation Post workshop evaluation Outcomes evaluation after one month	Recommendations

2.10 Measures to ensure trustworthiness

Both Gay et al. (2009) and Morse (1994) maintain that it is essential that research findings be as trustworthy as possible. The trustworthiness of the data refers to the degree to which the data reflect what the researcher is endeavouring to measure. Thus, the trustworthiness of the data should be demonstrated by descriptive validity, interpretive validity, theoretical validity and evaluative validity – all of which were adhered to in this study.

In this study the descriptive validity of the data demonstrated the factual accuracy of the accounts of the parents/caregivers and the children about the phenomenon under investigation, without any distortion of the information by the researcher. Interpretive validity refers to the accurate interpretation of the verbal and non-verbal responses of the participants while theoretical validity refers to the relevance of the findings in respect of the phenomenon under study to the body of existing theory. On the other hand, evaluative validity refers to the maintenance of objectivity by the researcher in reporting the data in an unbiased way (Gay et al., 2009; Morse, 1994).

The literature further suggests that trustworthiness of the data may be established through the application of credibility or truth value, confirmability or neutrality as well as the transferability or applicability as appropriate criteria to ensure the validity of the data (Gay et al., 2009). These criteria were, therefore, applied to the data in this study and the next sessions describe how each criterion was applied to ensure trustworthiness of the data of this study.

2.10.1 Credibility or truth value

As regards a phenomenological study, the credibility of the data from a qualitative study refers to the truth, value or believability of the findings that have been established by the researcher as a “cumulative knowing” and “lived experience” of the participants (Morse, 1994).

Prolonged engagement with the participants, field notes on the participants’ non-verbal reactions, triangulation and member checking and peer debriefing, constitute some of the activities that enhance the credibility of the data with all these activities being carried out in this study. In particular, prolonged engagement with the participants minimised the risk of data distortions which could result from the researcher’s limited engagement with the participants (Streubert Speziale & Carpenter, 2007).

Persistent field notes during interview were critical to identify the participants’ reactions and feelings and non-verbal responses, thus, to enhance the interpretive validity of the data. Triangulation facilitated the collection of data through the use of different methods of data collection – interviews, field notes and pictorial naïve drawings and from different levels of persons – the parents/caregivers and the children to ensure data saturation (Polit & Beck, 2012). Member checking was utilised for the purposes of the confirmation of the data by the participants (Ware & Raval, 2007; Gay et al., 2009). The transcription of the interviews immediately after they had been conducted reduced the risk of misunderstanding and misinterpreting the data and, therefore enhanced the trustworthiness of the data (Sjöström-Strand & Fridlund, 2008). In addition, the quotations and submissions in respect of similar experiences of the respondents from different cultures in the various regions of Namibia also enhanced the trustworthiness of the data. Peer debriefing was performed to test the researcher’s growing

insights into the phenomenon under investigation. The confirmation of the trustworthiness of the data demonstrates confidence in the truth of the findings of this study in regard to the participants' responses and the context in which the research study was carried out. Table 2.3 depicts the application of the criterion pertaining to the credibility of the data.

Table 2.3: Credibility or trust value

Criterion	
Truth value or credibility	Method of application
Prolonged engagement with the participants	<ul style="list-style-type: none"> - Sufficient time for the in-depth interview with each participant from each multiple case ensured prolonged engagement with the participants.
Triangulation (method and person triangulation)	<ul style="list-style-type: none"> - Different methods of data collection were used to collect the data, namely, in-depth interviews, filed notes and pictorial, naïve drawings. - The data were obtained from different sources – two categories of interviewees as sources of the data, namely, the parents/caregiver as the main focus and the child to validate the data through multiple perspective on the phenomenon under investigation. - The resources for the literature control also served as sources of data.
Consistent field notes on the participants' nonverbal responses	<ul style="list-style-type: none"> - Persistent field notes on the participants non-verbal responses was carried out in order to identify pervasive characteristics among the participants. - Non-verbal reactions were identified and interpreted.
Member checking for data confirmation	<ul style="list-style-type: none"> - The results of the interviews were confirmed with the participants. - The tape recorded data were replayed to the participants for their confirmation - The participants were given opportunity to confirm the data, correct misinterpretations and provide additional information.
Peer group debriefing	<ul style="list-style-type: none"> - The researcher maintained consultations with other professionals to refine the data and to promote her own growing insight into the phenomenon under investigation.

2.10.2 Confirmability or neutrality

Confirmability refers to the objective acquisition of direct, repeated, subjective data (what the researcher has heard, seen or observed) from the study participants as regards the phenomenon under study. The researcher maintained objectivity toward the data obtained from the study participants. This included confirmation of the information obtained with the participants, a full description of the data that were collected and analysed and objective analysis of the field notes – all criteria in respect of the confirmability or neutrality of data (Gay et al., 2009; Streubert Speziale & Carpenter, 2007; Morse, 1994).

In addition, a referential adequacy was performed with the data being controlled for adequate analysis, accurate interpretation of the findings and appropriate synthesis of the themes and sub-themes (Gay et al., 2009; Streubert Speziale & Carpenter, 2007).

Consequently, the data obtained in this study demonstrated confirmability by providing evidence on which the conclusions of the research study were based (Kobus, 2007).

Table 2.4 presents a summary of the application of confirmability or neutrality of the study.

Table 2.4: Confirmability or neutrality

Criterion	
Confirmability/neutrality	Method of application
Confirmability/neutrality	<ul style="list-style-type: none"> - The data from the interviews were tape-recorded in the interests of descriptive validity. - Field notes were taken – for the purpose of interpretive validity. - Objective analysis of field notes was performed. - Interpretation of the pictorial naïve drawings by the participants. - Referential adequacy or recoding of the data was performed to confirm neutrality. - A programme was developed and implemented in accordance with the conceptual framework.

2.10.3 Transferability/applicability

Transferability is a criterion that guarantees the applicability of the data. The applicability of the data from qualitative research implies that the data are context relevant and, as such, the data are specific to a setting and are context bound. Therefore, it is possible to identify the data with the relevant setting (Gay et al., 2009). By implication, transferability refers to the fact that it is possible to transfer specific findings from a qualitative study to a situation within a similar context, and still preserve the same meaning and interpretations as with the initial study (Morse, 1994).

Against this background, the findings in respect of the participants' experiences and the subsequent home-based health care programme interventions may, when appropriate, be transferred to parents/caregivers and children with heart disease who are from similar socio-economic backgrounds as those of the study participants (Henning et al., 2004). Moreover, the data for the situational analysis and collected from the participants who are from different cultural backgrounds demonstrated similar trends as regards the experiences of the phenomenon under study across different cultural groups in different (3) regions of Namibia. It is, therefore, possible to generalise experiences pertaining coping with the demands to care for a child with a heart disease and the interventions of the home-based health care programme which was developed to facilitate coping with the demands of caring for the parents/caregivers of children diagnosed with heart diseases from the rural areas in Namibia.

Table: 2. 5 Applicability/transferability

Criterion	
Applicability/transferability	Method of application
Sample	<ul style="list-style-type: none"> - Rural parents or caregivers of children with heart disease. - Children with heart disease aged 12 to 17 years from the rural areas of Namibia. - Purposive sampling and voluntary participation on the part of the participants. - Selection of participants from rural areas in different regions and from different cultures in Namibia to verify the notion that socio-economic factors play a role in coping with the experiences of the same phenomenon in rural areas across cultural differences.
Research design and research method	<ul style="list-style-type: none"> - The research study comprised the following three reductive phases, namely, the situational analysis through description of the participants' experiences, conceptualization and programme development, and programme implementation and evaluation.

2.11 Ethical measures

Ethical measures refer to codes of conduct that should direct the researcher's actions and ensure that all actions are in the best interests of the study participants (Parahoo, 2006; Richards & Schwartz, 2002; White, 2001). The literature recommends a strict observation of ethical principles in all research to protect the research participants from harm and risks and, therefore, the rights of the participant to refuse to participate in the study or to withdraw, if they so wish, are to be respected (Streubert Speziale & Carpenter, 2007; Holloway & Wheeler, 1996). Four ethical principles, namely, the principles of autonomy, non-maleficence, beneficence and justice, as outlined by Parahoo (2006), White (2001) and Beauchamp and Childress (1994) in Holloway & Wheeler (1996) were applied to this research study to protect the participants from exploitation in context of qualitative research, ensure participants' right to self-determination and anonymity.

Therefore a permission to conduct the study for academic purpose was granted by the Post Graduate Committee of the University of Namibia. The data for this study were collected according to the procedures that are approved of by the Research and Ethical Committee of the Namibian Ministry of Health and Social Services and which are intended to protect the subjects of research activities in the health domain. During the course of the research activities conducted in this study, the following ethical principles were applied.

2.11.1 Autonomy

Autonomy refers to the right of self-determination, as based on the possession of adequate information and, therefore, on the individual's ability to act on that information (Streubert Speziale & Carpenter, 2007; Parahoo, 2006; White 2001). In this study, the autonomy of the study participants was respected at all times while the purpose for which the information was being sought from them was clarified. The informed consent was sought from the participants. The informed consent of the parents/caregivers to participate in the interviews and programme activities was obtained, as well as their consent to allow the researcher to approach and obtain an informed assent from the child participants. In other words, informed, written consent was secured from the caregivers allowing the researcher to interview the child participants. The participants in this study were, thus, allowed to make a free, independent choice to participate without coercion. In addition, the participants were assured of their right to withdraw from the study at any time.

2.11.2 The principle of non-maleficence

The good to be derived from the research was weighed against any potential harm which could be occasioned by the study. During the interview, the participants were protected from psychological harm with questions that were intrusive, sensitive and which may have elicited adverse emotional reactions from the participants being avoided. When necessary, an immediate renegotiation of consent was considered during the interviews (Parahoo, 2006; Mack et al., 2009; White, 2001). Thus, the dignity of the participants was therefore respected.

2.11.3 The principle of beneficence

Care was taken that the benefit derived from the respondents' participation in the study was not countered by any risk for either the individual participants or for the broader society (Streubert Speziale & Carpenter, 2007 & Parahoo, 2006). It was hoped that the study would pave the way for a solution to be found for their need to cope with the demands of care at home.

2.11.4 The principle of justice

Justice refers to fair treatment. The research methods and procedures adopted in the study were in accordance with the approved procedures that are in place to protect study participants (White, 2001; Holloway & Wheeler, 1996). The data were collected only after permission to do so was granted by the Research and Ethical Committee of the Namibian Ministry of Health and Social Services. Anonymity was maintained, as no participant is identified with the data.

In conclusion regarding observation of ethical principles and, as recommended, a “scientific soundness” of the data was ensured through obtain of informed consent as a process through the course of fieldwork, assurance of confidentiality and a reflexive stance taken toward data analysis and interpretation. The researcher’s role boundary was also clarified in order to minimize expectations and potential for distress to the participants (Richard & Schwartz, 2002, p.135 &137).

2.12 SUMMARY

This chapter discussed the research design and research methods adopted in the study. The characteristics of qualitative research and their applicability to the study were described. In addition, the research procedures were explained and the sampling methods used to select the study participants as well as the sampling criteria in respect of the eligibility of the study participants were clarified.

The process of data collection by means of interviews, field notes and pictorial, naïve drawings was described and the data analysis process, which was carried out in accordance with Tech’s method of qualitative data analysis, was discussed. The measures taken to ensure trustworthiness (credibility, confirmability and applicability) were discussed as they related to the research activities undertaken in this study while the application of ethical principles to the study was explained. The next chapter (chapter 3) presents the findings of the study in a phenomenological outline.

CHAPTER 3

DATA ANALYSIS AND RESEARCH FINDINGS

3.1 INTRODUCTION

The previous chapter discussed the research design and the research methods. This chapter focuses on the phenomenological presentation of the research findings.

The purpose of this study was to explore and describe the lived experiences of parents/caregivers as regards caring for a child with a heart disease as well as the children's own experiences of living with a heart disease. The resultant findings then were formulated into themes and sub-themes.

The data were collected at the paediatric ward at the Katutura State Hospital, after a purposeful selection of the participants at the time of follow-up treatment. Semi-structured interviews on the experiences of caring for the child with a heart disease at home and of living with a heart disease were conducted between June and August 2010 with the five multiple cases of a parent/caregiver and the child with a heart disease. A total of ten interviews were conducted. All the parent/caregiver participants were females. Four of the parents/caregivers were the mothers of the children, while one was a caregiver.

The gender make-up of the parent/caregiver participants in this study was not predetermined and was rather a reflection of the cultural stereotype which dictates that caring for children is the preserve of women. In addition, in contrast to men, women usually accord priority to concern for the family and feel that it is impossible for them to delegate their responsibility for the family to

anyone else (Sjöström-Strand & Fridlund, 2008). This is in accordance with the views of Ware and Raval (2007) and other researchers to the effect mothers are the ones who often assume the responsibility for caring at the family level. They are the ones who spend extra time caring for their sick children and, as a result, they are the ones who will probably accompany the children to treatment (Shu-Fan et al., 2007; Evangelista, Dracup, Doering, Westlake, Hamilton, & Fonarow, 2002).

It may, therefore, be inferred that, in Namibia, and specifically at the family level, more than any other members of the family, mothers and female caregivers are the ones who take care of a child with heart disease. Consequently, the sample of participants for this study appears to be congruent with the accepted practice at the household level. This also helped with the identification of the focal person for the home-based health care programme aimed at facilitating coping.

The average age of the parents/caregivers was approximately 39 years (between 29 and 49 years old). All the parents/caregivers were from the rural areas and were living the lifestyle of agricultural subsistence farmers. One only of the parents had attended school up to the level of grade twelve. On the other hand the average age of the child participants was approximately 14 years (between 12 and 17). One of the children had been diagnosed with the Tetralogy of Fallot; three had been diagnosed with post-rheumatic valvular heart disease of the stenosed mitral valves while one had been diagnosed with a ventricular septal defect.

Three of the child participants were male and two were female. Three of the child participants were still at school, while two (both male) were no longer attending school because of ill-health as a result of heart disease.

Table 3.1 Demographic information of the participants

Case	Participant	Age	Gender	Level of schooling	Diagnosis
1	Parent	38 years	F	Grade 10	
	Child	17 years	M	Grade 10	VSD
2	Parent	44 years	F	Grade 7	
	Child	12 years	F	Grade 8	RHD
3	Parent	44 years	F	Grade 12	
	Child	12 years	M	Grade 7	RHD
4	Parent	49 years	F	Grade 5	
	Child	12 years	M	Grade 6	RHD
5	Caregiver	29 years	F	Grade 10	
	Child	12 years	F	Grade 7	Tetralogy-Fallot

3.1.1 Types of data collected:

Phenomenological data were collected from five multiple cases of a parent/caregiver and a child with a heart disease by means of in-depth, face-to-face semi-structured interviews, field notes on the participants' nonverbal responses and hesitations and the pictorial, naïve drawings by two of the child participants depicting the way in which being afflicted with a heart disease was affecting their lives (Mitchell, 2012; Creswell, 2008; Streubert Speziale & Carpenter, 2007; Joubert & Enhrlich, 2007; Brosig et al., 2007).

3.1.2 Organisation of the data analysis process

Qualitative data analysis refers to the organization and interpretation of narrative data for the purpose of discovering underlying themes, categories and patterns of relationship of themes (Polit & Beck, 2012). The data from the interview and field notes were manually analysed, organised and interpreted according to the Tesch method of qualitative data analysis (Creswell, 2008). In terms of this method, the researcher examined the verbatim transcripts from the interviews and the data from the field notes so as to familiarise herself with the data and obtain a global understanding of the research results. Thereafter, the transcripts were analysed one by one until all the transcripts had been analysed. Code words or phrases were allocated to the data that described the main ideas about the participants' experiences. The main ideas or topics which were to be found in all the transcripts were coded. After coding, the data from all the transcripts which contained similar codes was grouped together into categories, and redundant codes were eliminated. In this way the list of codes was reduced to a smaller number of codes. Themes were then identified from each category of the data. These themes were then layered or reduced into sub-themes. A recoding of the data was performed by means of an audit trail or by a co-coder on

the data collection, data analysis and data interpretation in order to ensure the reliability of the data. Member checking for the purposes of data confirmation were also carried out for the participant to confirm the data. Peer debriefing was maintained to refine the data and to promote the researcher's insight into the study (Silverman, 2010; Gay et al., 2009; Creswell, 2008; Streubert Speziale & Carpenter, 2007; Joubert & Ehrlich, 2007).

The pictorial naïve drawings from the children participants were described in relation to their interpretations by the child/participants. A common theme raised from the pictorial naïve drawings of both children and which supported one of the themes identified from the interview, observation and field notes.

Four main themes emerged as a result of analysis of the data from the interviews field notes and the description of the pictorial, naïve drawings by two of the child participants. In regard to the findings, the interview data under each theme were presented in a subjective format, with relevant quotes or verbatim transcripts, while those from the pictorial naïve drawings are presented through representations of the pictorial, naïve drawings by the participants, all to demonstrate the "voices" of the participants in describing their lived experience about the phenomenon being investigated (Creswell, 2008; Streubert Speziale & Carpenter, 2007) regarding caring for a child with a heart disease at home and else living with a heart disease.

3.2 RESEARCH FINDINGS

3.2.1. Themes and sub-themes

The findings which emerged from the data analysis in this study were of three interrelated type, namely, the experiences, affects and behaviours. Experiences refer to the narratives describing what the individuals perceived had happened to them (Egan, 1998). The participants described their experiences as if they perceived that they had been adversely affected by both the immediate societal settings, for example, their families, and by the broader societal organisations, for example, the health system, which did not appear to be assisting them to cope with the demands of caring for their children at home.

Affects refer to the feelings and emotions that accompany the individual's experiences and behaviours (Egan, 1998). With regard to this study, the affects refer to the shock, disbelief, fear, depression and anxiety experienced by both the parents/caregivers and the children with regard to caring for a child with heart disease and living with a heart disease respectively.

Behaviours refer to the individual's actions which may assist in achieving a goal or the omission of which may result into failure (Egan, 1998). For the purpose of this study, behaviours refer to the actions which the parents and caregivers could perform in order to meet the demands of caring for their children, or those actions which they were not able to accomplish, either because of lack of means to do so or because of the limitations imposed by the demands of providing constant care for their children with heart disease. In addition, the behavioural findings refer to the experiences of loss of vitality on the part of the children as a result of their illness. These findings were then organized under the themes.

In this study four themes were identified from the data analysis. The first theme is related to emotional experiences of both categories of participants while the second theme is related to both categories of the participants' experiences of social functioning as parent/caregiver or as a child with heart disease. The third theme, is of an economic nature, is exclusive to the parents/caregivers and is related to their experiencing financial difficulties in regard to providing care for the children concerned. The fourth theme is exclusive to the children and relates to the experience of the symptoms of deranged physical functioning.

In view of the fact that this study is phenomenological in nature, a reductive process in respect of the data was performed and themes were developed. The themes were then further layered into the sub-themes (Streubert Speziale & Carpenter, 2007).

3.2.2 Themes arising from the parents/caregivers

Themes from the parents/caregivers were arrived at from the interview and field notes as described in the next sessions.

3.2.2.1 Themes arising from the interviews with the parent/caregivers

All the themes that were discerned from the analysis of the data arising from the interviews with the parents/caregivers were of either an emotional or an experiential nature. The first theme that emerged from the interviews with the parents/caregivers related to **emotions or feelings** as indicated by the parent/caregiver participants' experiences of the emotional challenges they encountered. The first theme therefore reads as: The participants (parents/ caregivers and children) experience challenging emotions. This theme is further supported by the following sub-themes:

- The parents experience shock and disbelief as a result of the child's diagnosis and they were afraid that the child may die while the children experienced depression and anxiety.
- The parents/caregivers experience "sadness" about the child's illness and blame themselves for the child's condition.
- The parents/caregivers experience feelings of inadequacy, helplessness and hopelessness as regards caring for a child with heart disease.

The second theme that emerged from the interviews with the parents/caregivers was of an **experiential nature**, as related to disrupted social functioning and social relations. The second theme read as: The participants (parents/caregivers and children) experience disrupted social functioning. This theme is further supported by the following sub-themes:

- The condition of the child affects the social functioning and social relations of the parent/caregiver /Life was no longer the same.
- The child's condition deprives the children of opportunities for socialisation and social achievement and causes them loneliness.
- The condition of the child implies the loss of a future support system which the child would have provided.

The third theme that emerged from the parents'/caregivers' interviews is also of an **experiential nature** and is related to a lack of support from the families and societal organisations as regards caring for these children with heart disease. The third theme read as: Parents/caregivers experience a lack of support from the family, as well as a lack of any form of organised support from social systems. This theme is supported by the following sub-themes:

- The parents/caregivers experience both a lack of family support and/or a lack of any form of organised support from social systems.
- The parents/caregivers experience financial difficulties related to providing for the special needs of the children.
- The parents/caregivers experience a lack of knowledge about the child's disease and the treatment outcomes.

3.2.3 Themes arising from the filed notes about the parents/caregivers

In addition to the emotional experiences that the participants stated verbally, the data from the field notes about the parents/caregivers also revealed a less constructive attitude of the parents/caregivers towards the child with a heart disease as manifested in a tendency for overprotection of the child by the parent/caregivers.

3.2.4 Themes arising from the child participants

The themes from the child participants were also arrived at from the interview, field notes and pictorial naïve drawing by two of the child participants and the data arising from the interviews, field notes and pictorial naïve drawings of the child-participants also manifested a functional aspect to their experiences. Three themes emerged from the interviews, field notes and the pictorial, naïve drawings of the child participants.

3.2.4.1 Themes arising from the interviews with the child participants

The first theme which emerged from the interviews with the children was of a **functional or behavioural nature** and was related to the children's experience of decreased vitality. This theme is supported by the following sub-theme:

- The children experience physical dysfunction.

3.2.4.2 Theme arising from the pictorial naïve drawings of the child-participants

The second theme which arose from the data that emerged from the pictorial, naïve drawing by some of the child participants was **experiential in nature**. As in the case of the parents and caregivers, this theme related to disrupted and restrictive social functioning, and is supported by the following sub-theme:

- The child's condition deprives the child of opportunities for socialisation and social achievement and causes them loneliness.

3.2.4.3 Theme arising from the field notes of the children participants

The third theme that emerged from the child-participants was derived from the field notes on the children and was of **emotional or feeling in nature**. As in the case of the parents or caregivers, this theme involves challenging emotions/feelings and is supported by the following sub-theme:

- The children experience depression and anxiety.

The themes and sub-themes which were common to all the categories of the participants were collapsed into one theme and were discussed as common themes. The next session deals with the presentation of themes and sub-themes.

3.3 PRESENTATION OF THEMES AND SUB-THEMES

The themes and sub-themes that were derived from the data are presented in phenomenological narrative from the parents/caregivers and the children.

According to Streubert Speziale and Carpenter (2007), in a phenomenological study, the data are described directly and presented with maximum quotations in order to display the richness and depth of the participants' experiences of the phenomenon under investigation. In view of the fact that this study is both qualitative and phenomenological, a dense, description – to give “voice” to the participants – of the data arising from each multiple case – the parent/caregiver participants' recounting of their lived experiences of providing care to a child with heart disease and the child participants' recounting of their experiences of living with heart disease – is presented in terms of themes and sub-themes (Streubert Speziale & Carpenter, 2007) to enable the reader to gain insights into the participants' experiences with regard to a specific theme or sub-theme. It is also important to note that, while all four (4) of the main themes apply to all the multiple cases, not all the sub-themes apply to all the multiple cases.

3.3.1 THEME 1: THE PARTICIPANTS (PARENTS/CAREGIVERS AND CHILDREN)

EXPERIENCE CHALLENGING EMOTIONS

This theme emerged strongly from all the participants' (parents/caregivers as well as the children) accounts. The theme reflects the perceived "unexpected and irrevocable" changes which occurred in the participants' lives. The parents/caregivers appeared to feel that their children were in danger and they (parents/ caregivers) felt uncertain and, therefore, out of control and fearful. Following are phenomenological presentation of the parents/caregivers' responses on the question about their experiences of caring for a child with a heart diseases and the children's response on the question about their experiences of living with a heart disease.

Open-ended questions to the participants were as follows:

To the parents/caregivers: How do you experience caring for a child with a heart disease?

To the Child: How do you experience living with a heart disease? Draw a picture and tell the story about the picture.

3.3.1.1 Sub-theme: The parents/caregivers experience shock and disbelief as a result of the child's diagnosis and they were afraid that the child may die while the children experienced depression and anxiety.

The parents/caregivers:

Case 1

The first parent interviewee provided sufficient evidence of challenging emotions when she stated:

"I am afraid that my child may die because the illness is incurable."

"I am really looking at my child with pain in my heart, because I imagine he will die from this disease one day."

Case 2

The mother looked sad as she said these words: *"I feel frightened because I feel that my child may die because of this illness."*

Case 3

As in the case of the caregiver from the previous multiple cases, the participant from this case expressed her experiences of emotional challenges as follows:

In accordance with the parent/caregiver' perception of their children as vulnerable, she made the following sympathetic statements:

“I always feel afraid that may be the child is seriously sick while I am away from home.”

“As a mother, you need to take care of the child all the time. You cannot go away, because he is sick all the time; he cannot stay alone. I cannot go away from home. As a mother all your heart is at home with him.”

“When I am at work, I am only away the body, but all my mind is with him – the child.”

Case 4

This parent did not make any allusion in support of this sub-theme.

Case 5

The caregiver from this case concurred with the emotional experiences expressed by the parents/caregiver of the previous cases when she stated:

“We were shocked at the diagnosis, because this is the first time for us to have someone diagnosed with a heart disease in our family.”

“The heart is the one that keeps people alive. So I perceive the illness of my child as being of a high degree. Therefore, I feel that my child can die of this disease.”

The children’s response about their experiences of living with a heart disease also provided information in support of experiences of challenged emotions as follows:

The children

Case 1

It appeared that the child from case 1 understood the progress of his disease and, therefore, he seemed not to be comfortable discussing his feelings. He stated: *“I am concern about my illness because I do not get better.”* When requested to draw a picture to explain how he felt about being afflicted with heart disease, the child responded: *“No.”* It also emerged from the field note that the child *appeared* to be *shy*, and, therefore, he does not appear comfortable explaining his experience of the illness although he did seem to understand the nature of his illness.

Case 2

The child stated that *“I feel bad because I am sick.”* However, from the field note point of view, *the child appeared irritated by her condition* and conveyed a feeling that she had to endure her suffering.

Case 3

The child appeared to be in agreement with the parent/caregiver’s assertion and also, expressively and implicitly, demonstrated his being emotionally traumatised:

“I do not feel OK.” Then he kept quiet. From the field note, the child appeared to be sad because of his illness.

Case 4

As in the case of the parent the child did not make any allusions with regard to this sub-theme.

Case 5

As opposed to the other child respondents who were sad and depressed, this child, notwithstanding the Tetralogy of Fallot, appeared to be resilient and was sufficiently assertive to explain the issues around her condition as she stated:

“The people say I am sick, but I say I am not sick. This is all I say. I do not feel anything.”



Figure 3.1 Representation of parents'/caregivers' and the children's emotional responses to the child's illness

When the symptoms intensify or the child's condition deteriorates, the parents/caregivers experience more, severe emotional challenges.

3.3.1.2 Sub-theme: The parents/caregivers experience sadness about the child's illness and blame themselves for the child's condition

The parent/caregiver

Case 1

With regard to this sub-theme, this parent stated:

“When I was told that my child has a heart disease, I felt bad.” She then said: “It is painful that the illness is incurable.” So I have to care for this child [with the illness] like this for the rest of the child's life”!

Case 2

With regard to this sub-theme, this parent had the following to say:

“When I was told that my child has a heart disease I felt bad.”

“Sometimes I put myself in the shoes of my child. I mean to take over and bear the pain she goes through, for example, when she experiences shortness of breath if she laughs, plays or becomes excited; and she lives a restricted lifestyle because of these symptoms. I imagine the pain she goes through.”

“All these make me hurt. I will never forget how I suffer for the health of my child.”

“Sometimes I ask myself, what did I do wrong before God for my child to be sick of a disease of a high intensity and which is incurable.”

Case 3

As in the case of the previous cases, this parent also expressed experiencing emotional trauma about her child's condition when she said:

“Sometimes I feel like crying when such symptoms remind me that the illness is severe”

Case 4

Once again, the feelings of sadness about the child's situation were simplistically stated by the parent.

“I feel bad because the child used to be normal” and “I feel sorry for my child because he has a disease of high gravity.”

“You cannot also leave him alone at home. If I am not there; nobody may notice that the child does not feel well.”

Case 5

With regard to this sub-theme, the caregiver had this to say:

“I am sorry for my child that she has the disease of such a high gravity.”

The caregiver then burst into tears.

The children**Case 1**

The child also shared similar feelings and stated:

“I feel bad because I am sick. I feel bad because my life is not normal. I wish I could get a cure.”

Case 2

Similar to her mother’s emotions, the child stated:

“I feel bad because I am sick: I do not feel OK, because others are at school and I am sick”.

“At school when I see other children playing, I feel like crying.”

Case 3

The child did not describe feeling sadness about his illness. However, his silence did indicate that he, too, was emotionally traumatised.

Case 4

“I feel bad, because I am sick.” Then silence.

Case 5

This child appeared to be resilient and, therefore, she did not express any feelings of sadness as a result of her illness.

3.3.1.3 Sub-theme: The parents/caregivers experience feelings of inadequacy, helplessness and hopelessness as regards caring for the child with heart disease.

The parent/caregiver

Case 1

To illustrate a sense of hopelessness and helplessness, the parent had this to say:

“I have no option, but to accept the situation. I have accepted that, this is what God has given me. I was told that the child is to get surgery for the treatment, but years passed. I am hopeless that the child cannot be cured.”

“Now I lost hope, because my child once went to Cape Town [for treatment]. But he came back untreated.”

Case 2

It is obvious that the experience of the negative emotions may result in the inevitable feelings of inadequacy, helplessness and hopelessness. With regard to this sub-theme the parent in this case study repeated some of the perceptions of the other parents/caregivers when she said:

“I have no option but to accept the situation. I have accepted that this is what God has given me.”

“When I cannot afford the foods that my child tolerates because of the illness, I feel helpless because I cannot provide for the necessity of my child.”

“..... And we stay like that, there is no help.”

“Having gone through all that, I surrendered myself in the hands of God, for Him to do what He can do.”

Case 3

The parent/caregiver did not reveal any feeling which support the sentiments expressed in this sub-theme.

Case 4

With regard to this sub-theme, the parent shared the sentiments of some of the parents/caregivers in the preceding cases. She said:

“I feel hopeless, because there is no help to solve the food problem”.

Case 5

As is the case of the preceding cases, this caregiver echoed similar expressions of hopelessness and helplessness when she stated:

“But we try to accept it that this is what God gave us. We, the family, accept it, because in this world who else cares about you. You just encourage yourself to accept it that this is what nature gave you.”

The children**Case 1**

The child did not voice his feelings with regard to this sub-theme. However, the child had made remark the about the effect that his illness had had on his schooling, and that echoed his hopelessness.

Case 2

The child did not make any remark that reflected this sub-theme. However, the remark that the child had made about the effect of the illness on her physical activities, the child had implied that she was feeling hopeless.

Case 3

Similar to the parent/caregiver, the child did not express any feelings related to this sub-theme.

Case 4

The child did not state any opinions related to this sub-theme.

Case 5

This child did not also provide information related feelings of hopelessness.

3.3.2 THEME 2: THE PARTICIPANTS (PARENTS/CAREGIVERS AND THE CHILDREN) EXPERIENCE DISRUPTED SOCIAL FUNCTIONING AND RELATIONS.

This theme is also substantiated by the following sub-themes with the data from the participants' experiences falling into these sub-themes.

3.3.2.1 Sub-theme: The child's condition affected the social functioning and social relations of the parents/caregivers/Life is no longer the same.

The parent/caregiver:

Case 1

With regard to the effect that the child's illness has on parents/caregivers' social life, the parent had this to say:

"Sometimes we have to stay in Windhoek temporarily, so the child can attend two consecutive follow up treatments before we go back to the north (Omusati region)."

Case 2

The parent of this multiple case alluded to concern regarding the child's schooling and said:

"The child stays out of school too often because of hospitalisation."

Case 3

With regard to this sub-theme, this parent made substantial claims that the demands of caring for the child was adversely affecting her other social roles and her social relations. In this regard she stated:

“It is not easier as a mother. You need to take care of the child all the time. You cannot go anywhere because the child is sick most of the time. He cannot stay alone. One does not also have time for other things. All the time you are on the road – every second month to Windhoek for a check-up.”

“As a cashier, I cannot stay at work settled because I think of him at home. And if I stay away from work, no money to take care of him.”

Case 4

In line with the previous cases, the parent from this multiple case made the following remarks with regard to this sub-theme:

“Another problem is the restriction on the social life of the family. The child cannot stay alone at home. So, for example, parents, especially me as a mother, I cannot go away from home. I have to stay at home to observe any change in the child’s condition and take him to the hospital.”

“You cannot also leave him alone at home because, if I am not there, nobody may notice that the child does not feel well.”

Case 5

Despite the fact that she was a caregiver and not the mother, the child's illness did affect her opportunity for social functioning. In this regard the caregiver recalled:

“Another thing is that one has to take extra care for the child because she gets tired easily. So, one ought to be available every time so that when she is tired you let her rest.”

The children**Case 1**

The child also indicated experiencing disruption in his schooling. He said:

“If there could be a school near the hospital so I can go to school.”

Case 2

As the one who has bear the physiological effect of the disease and the subsequent physical limitations imposed by illness, the child expressed the following concerns:

“At school, when other children play. I have to sit quietly, because I have to be seated and be quiet. It hurts because I cannot play.”

When requested to draw a picture to explain how she felt about being afflicted with a heart disease, the child responded: “Yes.” She subsequently drew a picture which illustrated her being socially isolated from the other children at school.

Case 3

Similar to the previous cases, the child participant from this multiple case was also concerned that the illness was adversely affecting his socialisation as he was not able to join in playing games with the other children at school. He stated:

“Others are at school and I cannot go to school. Other children do things like soccer at school but I cannot do it.”

When requested to draw a picture to explain how he felt about being sick with heart disease, the child responded *“No, I cannot.”*

Case 4

The child did not provide information relating to this sub-theme.

Case 5

As in the case of the child participant from multiple case 2, when requested to draw a picture to explain how she felt about being ill of heart disease, the child responded *“Yes.”* She subsequently drew a picture which indicated her staying behind on the way to school as she needed to rest.

3.3.2.2 Sub-theme: The condition of the child deprives the child of opportunities for socialisation and social achievement and causes them loneliness

The parent/caregiver

Case 1

With regard to this point, the parent/caregiver said:

“The child is often out of school because of hospitalisation. I am concerned because this affects his opportunity for education negatively. Now, I am concerned.”

She further stated:

“The illness has affected his opportunity for education negatively. I am really worried about the negative effect on the child’s school performance.”

Case 2

Concerns about lost opportunities for socialisation and social achievement and loneliness were raised by both the parent and the child

“She is a gifted child. She usually does not fail. However, the illness affects the child’s schooling negatively. Right now she was out of school for two years. She is now behind with school. She is now deprived of the chance to progress and complete her education.”

Case 3

As if she read the minds of the other respondents, the parent/caregiver in case 3 stated concerns similar to those of the other respondents.

“The child is often out of school, because of hospitalisation. I am concerned because this affects his opportunity for education. The illness has affected his opportunity for education negatively. I am really worried about the negative effects on the child’s school performances.”

She continued:

“As a result, he stays out of school often for too long. I am worried, because I wish him to complete school. Like now, he will repeat grade 7 when he could pass because he is a brilliant child.”

Case 4

The parent in this case was also concern about the limitation that the illness causes on the child’s socialization. In this regard, she stated: *“The child cannot play with other kids”*.

Case 5

Unlike the mothers in the previous cases, the caregiver did not offer any information about the effects of her illness on the child’s opportunity for socialisation. However, it is possible that, as she is the caregiver and not the mother, she may not necessarily be able to “put herself in the shoes of the child” as the biological mothers in the previous cases had been able to do.

The children**Case 1**

With regard to this point, the child expressed mixed feelings. As regards the likely outcomes of his treatments he said:

“I wish I get a cure so I can continue with schooling. Like now, I feel better, but I am just at home; I cannot go to school.” I wish there could be a school near the hospital so I can go to school.”

Case 2

The child was concerned that the illness was affecting her socialisation as she could not join in with the other children’s games. She said:

“I cannot also play, for example, run or jump with other children. At school when others play, I have to sit quietly.”

Case 3

The child also stated his concern over the adverse effect of his illness on his education. He stated:

“I do not feel OK because others are going to school and I cannot go to school. Other children do things like soccer, but I cannot do it

Case 4

Unlike his mother, the child made a brief statement and said:

“I am no more schooling, I am just sick.”

Case 5

As in the previous cases, the child also indicated the negative effects which the illness had had on her socialisation. She stated:

“I cannot also run, play with other children at school, because I get tired easily.” So I have to walk slowly. Then other kids pass by, while I sit and I will arrive late at home.”

Figure 3.2 below provided a representative summary of experiences of loneliness by the child participants.



The limitation which heart disease places on physical activities causes isolation and loneliness for the child.



The child with a heart disease is not able to keep pace with other children when playing or running to and from school.

Figure 3.2 Representation of the children’s naïve drawings of their experiences of social isolation as a result of heart disease (See Annexure 7).

**3.3.2.3 Sub-theme: The condition of the child implies the loss of a future support system
which the child would have provided**

The parent/caregiver

Case 1

In addition to feeling hopeless as regards meeting the demands of caring for the child, the parent/caregivers had also lost hope that the child would ever be able to contribute to the family system as a result of his illness. She stated:

“I counted on him as someone to help me in future.”

Case 2

While not stated implicitly, it was possible to infer from the following statement that the parent was feeling that she had been robbed of support because of the child’s illness:

“I count on her as someone to help me in future— for her to help me, her siblings and herself.”

Case 3

The parent did not reveal any feeling which provided evidence of the sentiments expressed in this sub-theme.

Case 4

The parent from this multiple case also explained how the illness would make it difficult for the child to contribute productively towards sustaining the family system. With regard to this point, the parent/caregiver stated:

“The child is disabled by the illness. He can no longer participate in domestic chores, like fetching water, and also supervising his siblings”.

Case 5

The caregiver from this multiple case did not provide any data pertaining to this sub-theme.

The children

Case 1

The child did not comment on this sub-theme.

Case 2

There was no comment from the child in respect of this sub-theme.

Case 3

As in the case of the parent, the child did not also state any feelings pertaining to this sub-theme.

Case 4

The child stated a brief concern about the effect that the illness has on his schooling. In this regard he stated:

“I am no more schooling. I am just sick.”

Case 5

Like her caregiver, the child from this multiple case did not provided any data pertaining to this sub-theme.

3.3.3 THEME 3: THE PARENTS/CAREGIVERS EXPERIENCE A LACK OF FAMILY SUPPORT AS WELL AS A LACK OF ANY ORGANISED FORM OF SUPPORT FROM THE SOCIAL SYSTEMS

3.3.3.1 Sub-theme: The parents/caregivers experience a lack of family support and/or a lack of any organised support from the social systems

The parent/caregiver:

Case 1

There were no concerns raised by the parents/caregiver with regard to this sub-theme.

Case 2

The parent/caregiver of this case expressed concern about the lack of support from immediate family members as well as from the social system when she stated:

“I also do not get assistance, neither from my family, because my family is not well off.”

“To make things worse, the child’s father does not assist in any way. He acts as if it is not his child. If you talk to him about the child, his response would be something one does not expect.”

Case 3

The parent/caregiver:

With regard to this sub-theme, the parent revealed that the child’s illness had affected the family relationships negatively. She stated:

“When the family and friends heard that my child’s illness is for life, they became tired and start staying away from us. It is like they condemned us, because the illness is continuous.”

Case 4

With regard to this sub-theme the parent/caregiver did express some concerns.

“We also need extra facilities to care for the child; for example, the child needs extra pillows to ease his breathing.”

“Another issue is extra care that the child needs. The child is disabled by the illness. He cannot meet some his basic needs. For example, the child has to be bathed every day.”

Case 5

With regard to this sub-theme, the caregiver had this to say:

“Nobody, not even the neighbours, will come to advise you how to care for this child.”

“We feel that our child needs help to get treatment.”

“I would like to ask you that, like in our case, we are orphans; all our parents died. Now we have this child who is sick. Can we get assistance for the care of our child”?

The children

Case 1

Despite the fact that the parent/caregiver had not raised any concerns with regard to this sub-theme the child had this to say:

“I wish to stay next to the hospital, like here in Windhoek, for my treatment.”

Case 2

The child did not express any concerns with regard to this point, probably because of her age. In fact, she appeared to be content with the care she was receiving from her mother. She also did not express concern regarding any other source of help.

Case 3

The child did not offer any information with regard to this sub-theme. However, as he is a minor, he appeared to be content or at peace with the care he was receiving from his primary caregiver, his mother.

Case 4

The child did not express anything with regard to this sub-theme.

Case 5:

The child did not provide any information in support of this sub-theme.

3.3.3.2 Sub-theme: The parents/caregivers experience financial difficulties related to providing for the special needs of the children

In view of the fact that it is the parents/caregivers who bear the responsibility for providing the necessary finance, they were the ones who stated concerns related to the expenses which they incur as a result of the demands of caring for the children.

The parent/caregiver

Case 1

Money needed to provide a special diet for the child

Concerns were raised about the money needed to provide a special diet for the child as well as for travelling to hospital and for the expenses involved in surgery for the child.

The following statements were made by the parent in connection with this sub-theme:

“Another thing is the money we need to fulfil the requirements of care for the child.”

“At the hospital, the nurse and doctors do tell us that we should provide the child with foods that are nutritious and with vitamins, like fruits, but I cannot afford it. Even milk, sometimes I cannot afford it.”

“Sometimes the child does not want to eat the foods which the rest of the family eats. I cannot afford the foods that the child prefers, such as macaroni and rice.”

She concluded:

“I just think if there could be a provision for the heart patients to receive food supplements, such as the case of People Living with AIDS (PLWA), and the foods for drought relief; if only the hospital services can refer us to the appropriate authority for food supply. The only thing they do

is to tell us to provide the child with foods that are nutritious and with vitamins, something we cannot afford.”

Money required for the expenses related to travelling to hospital and the expenses surgery for the child.

Money is also required for the expenses related to travelling to hospital as well as the expenses involved in surgery for the child.

“It needs money to take the child to the hospital for follow ups, and I do not work. That is why sometimes we have to stay in Windhoek temporarily, so the child can attend two consecutive follow up visits before we go back to the north (Omusati region).”

“Also one gets a short notice to bring the child to the hospital for follow up treatment”, which implies short time notice would not give her a chance to borrow money from other people.

Case 2

Money needed to provide a special diet for the child

Again, the parent expressed the difficulties she experiences with regard to this issue.

“To look after this child, I need money to buy the foods which the child tolerates. There are also those foods which I was told by the hospital staff to provide for the child; and most of the time I cannot afford these foods. I also do not get support, neither from my family, because my family is not well off.”

“Because I do not have money to buy foods for my child, I consulted our counsellor for my child to get a food allowance. The counsellor requested me to provide the doctor’s certificate which indicates that the child needs special foods. But the doctor said that the child is not disabled.

Having gone through all that, I surrender myself in the hands of God for Him to do what He can do.”

Money needed for travelling expenses to hospital and the expenses involved in surgery for the child

In this regard the parent stated:

“I cannot also afford money to take the child to the hospital, as sometimes one gets a notice at short time to take the child back to the hospital.”

“Because of travelling to hospital, I spent all the money I had. So, I had to borrow money from other people. Now I have debts to other people.”

“And, as a result, there is no money to pay for the school development fund. Sometimes you explain and ask the teacher to exempt the child from paying a school fee, but the teacher would reply back that the child cannot get education free.”

Case 3

Concerns about the money needed for special food for the child and for travelling to hospital were also raised by the parent/caregiver in this multiple case.

Money needed to provide a special diet for the child

In this regard, the parent explained how she struggles to make ends meet with the little income she earns. She said:

“The foods he eats differ from what the rest of the family eats. There are foods prescribed by the doctors, such as bananas and fruit juices. Sometimes I cannot afford, because I do not have all the money to buy the necessary foods as I have to put some money aside to travel to hospital.”

Money needed for expenses related to travelling to hospital and the expenses involved in surgery for the child

With regard to this point, the parent had this to say:

“One cannot do without money, because I spend more to take him to the hospital in Windhoek for follow up, or when all of a sudden he is sick. I also have to repeat paying school fee, as he has to repeat the grade.”

Case 4

With regard to this sub-theme, the parent had much to say about the money needed either to provide special food for the child, for the expenses related to travelling to hospital and the expenses involved in the child's surgery.

Money needed to provide special diet for the child

“The problem is food. The foods that I have to give to the child are not available in the household. You need to buy them, but there is no money because I do not earn money. Even those foods that the doctor told us to buy, we simply do not buy them, because we have got no money. We only give foods that are available at the household level, such as cow’s milk, pumpkins and fish. The child eats that for every meal. So there is no variation of food at home. This year, because of the flood, we did not harvest pumpkins.”

She went on to say:

“To look after this child, we need money to buy the foods that the child tolerates. There are also those foods that we were told by the hospital staff to provide for the child but, most of the time, we cannot afford these foods.”

“Well, sometimes you get some foods like a chicken to slaughter from the neighbours.”

Money needed for the expenses related to travelling to hospital and the expenses involved in surgery for the child.

Once again, the parent/caregiver had much to say. She stated:

“Another problem is attending a follow up treatment, which needs money. We do not have money to take the child to the hospital. Because whenever we have to take the child to the hospital, we have to hire someone’s car as the child cannot use public transport because he is fragile (gets tired). So we pay more and sometimes we cannot afford it.”

Then she added:

“We also need extra facilities to care for the child, for example, the child needs extra pillows to ease his breathing.”

Case 5

As was the case with the previous parents/caregivers, the caregiver in this case had much to say.

She stated:

Money needed for providing special foods for the child

“We need money to give her the correct and enough foods and vitamins and all the care she needs to be healthy until she gets the treatment for cure.”

“From the money we borrow from the neighbours (to take the child to the hospital), we also buy some foods for the child.”

“I am appealing for the assistance in the form of money and foods that we cannot afford. If only the government or a good Samaritan can help us in this regard! Sometimes we do not even know the foods that we are to give to the child.”

Money needed for expenses related to travelling to hospital and expenses involved in surgery for the child

“Taking care of this child is financially demanding. One needs money to take the child to the hospital. Nobody in the family works or even earns a salary to rely on. So, when it comes to taking the child to the hospital for the follow up treatment, we actually go around borrowing money from the neighbour to pay for the transport so we can take the child to the hospital.”

“Also for him to get treatment, it needs money, but we do not have money. Therefore, we cannot afford the money that is needed for his (curative) treatment.”

The children

Case 1

The child:

On further probing about the need for the special food that he prefers, the child confirmed his mother’s statement about the lack of finances when he said:

“I only like some foods, but my mother cannot always afford to buy them.”

Case 2

In view of the fact that the child is dependent on the parent, the child did not state any concerns with regard to this sub-theme.

Case 3

The child from this multiple case did not also state any concerns with regard to financial issue

Case 4

The child did not make any comment with regard to finances as he is dependent on his parent/caregiver.

Case 5:

The child did not mention anything with regard to either aspect of this sub-theme as he is dependent on his parent/caregiver.

3.3.3.3 Sub-theme: The parents/caregivers experience a lack of knowledge about the children's disease and the treatment outcomes

The parent/caregiver

Case 1

A lack of knowledge about the child's disease and treatment outcomes was reflected indirectly in some of the mixed responses offered by both the parent/caregiver and the child in this multiple case. The child's heart disease has already advanced, with a multiple system effect, and, as surgical treatment is no longer viable, the only solution is palliative treatment. However, the parents had this to say:

"I wish he could attend school to be successful. I wish there could be a special school near the hospital, in order for him to attend school, because I have a dream and I wish him to succeed at school."

Case 2

A lack of knowledge of the disease was implicit in the following statements made by the parent/caregiver and the child.

"At the beginning I was told that the child cannot be cured. Therefore, I tried to take the child to a private doctor in the North."

Case 3

The parents/caregiver did not make any contributions as regards this sub-theme

Case 4

The parent/caregiver did not also mention any concerns in respect of this sub-theme.

Case 5

In common with the first two cases, the caregiver from this multiple case indicated that neither she nor other members of the family had any proper knowledge about the child's condition and appropriate diet for the child. In addition, she appeared not to have any proper information about the waiting time before the child could undergo corrective surgery. In this regard, she said:

“We were shock because this is the first time someone is diagnosed with a heart disease in our family”, perceiving the child's condition as a family phenomenon which implies a lack of proper information about the cause of the heart disease for the child.

Furthermore she stated: *“In fact, we, as a family, sometimes we really do not know what are all the foods that have those stuffs that the child is not supposed to eat.”*

“Like now, we only have to go for follow up treatment and we do not know when the child will be corrected. I cannot wait for the time my child will be successfully treated.”

The children**Case 1**

“I wish to get a cure, so that I can be treated to heal, so I can continue with schooling.”

Case 2

The child also indicated a lack of understanding of her illness and the importance of healthy food choices, despite her age. She stated:

“Because of the illness, I am not allowed to eat sugar, salt, chocolate and soft drinks. I feel like crying when I see other kids eating attractive foods.”

Case 3

As was the case with his parent/caregiver, the child did not mention anything with regard to this sub-theme.

Case 4

As was the case with his parent/caregiver, the child did not mention anything with regard to this sub-theme.

Case 5

Like the previous case the child from this multiple case did not also mention anything with regard to this sub-theme.

3.3.4 THEME 4: THE CHILDREN EXPERIENCE DECREASED VITALITY

The disease affected the child directly but the parents/caregivers were also affected by the demands of care that resulted from the fact that the child's physical functions were limited by the disease.

3.3.4.1 Sub-theme: The children experience physical dysfunction.

In accordance with this sub-theme, the decreased vitality experienced by patients with heart disease was also alluded to by both the parents/caregivers and the children.

The parent/caregiver:

Case 1

Unlike the child, the parent/caregiver did not express any concerns in respect of this sub-theme, probably because the physical effects of the disease are confined to the child.

Case 2

Both the parent/caregiver and the child appeared resentful when they related incidences where the child had experienced physical dysfunction:

Parent/caregiver:

"The child cannot walk to school because she gets tired. She cannot walk long distance. She can only walk, like 15 minutes, then, she is tired already. So I have to carry her to school."

Case 3

The parent/caregiver also expressed concern about the child's decreased vitality when she stated:

The parent/caregiver:

"These days, the child cannot walk up to school. He cannot walk a distance. He cannot also carry his school bag to school. He becomes tired and gets difficulty in breathing."

CASE 4

With regard to this theme, the parent/caregiver had the following to say:

"Because he gets tired, he cannot meet some of his basic needs easily. That is why the child has to be bathed every day." "The child gets tired and experiences difficulty in breathing."

CASE 5

With regard to the child's experience of physical dysfunctions, the parent/caregiver had the following to say:

"The child gets tired and she experiences difficulty with breathing after playing or walking a distance." When she plays, she needs someone to help her as she may get tired or she may faint"

Figure 3.3 depicts the parents/caregivers experience of providing home care for their children with heart disease.

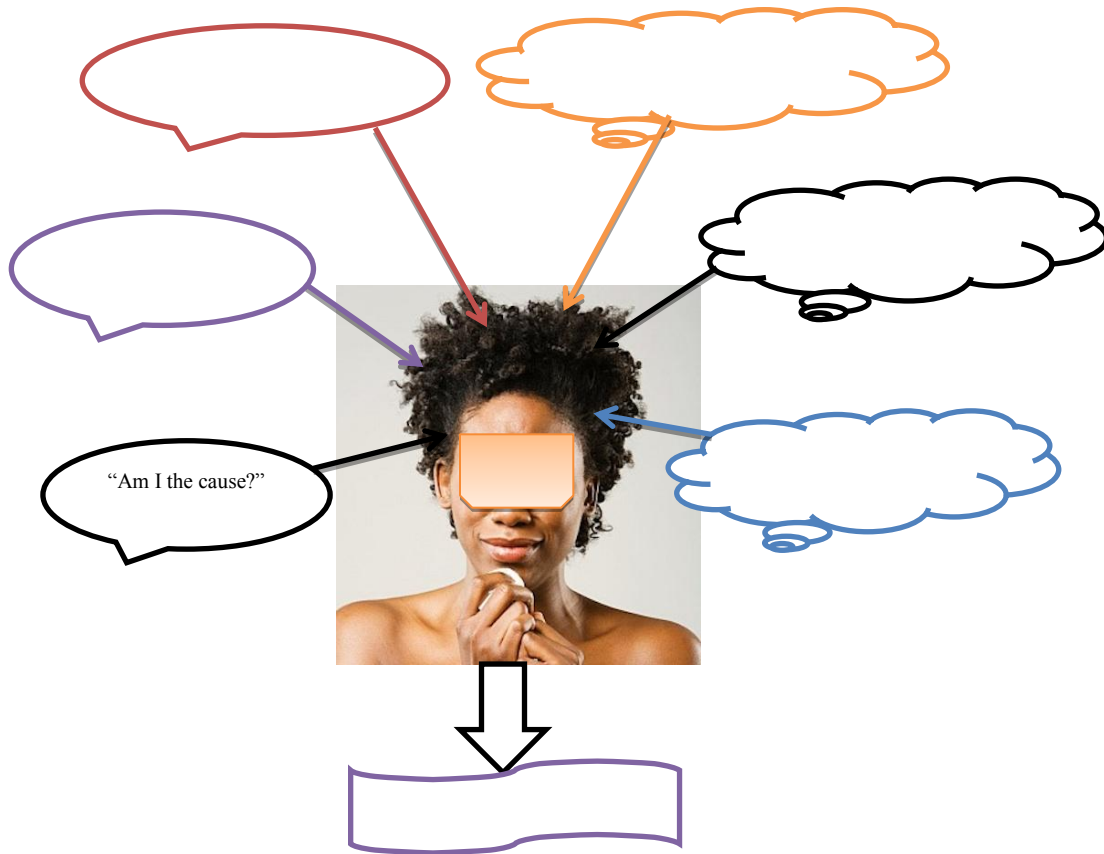


Figure 3.3 Representation of the parents'/caregivers' experience of the challenges regarding caring for their children with heart disease. "Things fall apart!"

The way in which challenges are experienced depends on the way the challenges are perceived and appraised by the person confronting the challenges. A perception of a heightened vulnerability results into poor coping (Glanz et al., 2008).

The children

The children's responses on their experience of living with heart disease reflect experiences of decreased vitality as demonstrated in the quotes from the children.

Case 1

"I also do not like some of the experiences I have, because of my illness, such as, stomach distension and discomfort and getting tired easily, especially after running."

Case 2

The child endorsed her mother's perception of her experience of physical dysfunction when she stated:

"I do not sleep restful at night because I feel chest pain"

Case 3

The child did not provide any information in respect of this sub-theme.

Case 4

The child did not mention his experiences with regard to physiological dysfunction. However, it was observed that the child spoke extremely softly because of his laboured breathing.

Case 5

"I am troubled by the symptoms. When I run, my heart beats so hard, making a sound that I can hear, and then I get tired. When walking from school, the heart starts beating and I get tired, then I sit down to rest. So when I arrive at home I am tired."

3.4 SUMMARY

This chapter presented the different themes and sub-themes which emerged from the findings in respect of the lived experiences of parents/caregivers as regards caring for a child with a heart disease as well as the lived experiences of the children themselves. Four main themes of an interrelated nature, about the experiences, affect and behaviours and their sub-themes were identified.

The themes that emerged from both the interviews with the parents and caregivers and also the from field notes on the parents and caregivers with regard to providing care for children with heart disease include the following experiences: emotional challenges, disrupted social functioning and social relations, a lack of support from families and the broader social systems in terms of providing the financial and material assistance needed to provide care for their children with heart disease and decreased vitality for the children. Each caregiver provided the information which reflects to all themes that were later established.

In line with the experiences of their parents and caregivers, the themes that emerged from the children's experiences of living with heart disease, as derived from the interviews, field notes and pictorial, naïve drawings of the child participants with heart disease include the following experiences: challenging emotions, disruption and restrictions as regards social functioning and social relations and decreased vitality. Furthermore, except one, each child stated the experience of decreased vitality and which was also asserted by all the caregivers.

The experiences of challenging emotions and disrupted and restricted social functioning and social relations on the part of both the parent/caregiver participants and the child participants were presented as common themes, while the themes in respect of experiences pertaining to a

lack of support on the part of the parents/caregivers and experiences of decreased vitality on the part of the children were presented as separate themes. Therefore, four main themes were identified and each theme was segmented into sub-themes. The data under each theme and sub-theme were presented in the form of quotes from the participants in order to give “voice” to the participants.

The next chapter presents a discussion of the research findings. The findings are supported by the literature control (cross validation) in order to relate the findings of this study to the existing body of knowledge and also to the current trends in respect of experiences of caregivers and the patients with heart disease.

CHAPTER 4

DISCUSSION OF THEMES AND SUB-THEMES AND THE LITERATURE CONTROL

4.1 INTRODUCTION

In the previous chapter, the lived experiences of the parents/caregivers as regards caring for a child with a heart disease and the children's experiences of living with a heart disease were described. This chapter presents a discussion of the research findings and the literature control pertaining to the findings. In qualitative research a literature control serves the purpose of placing the research findings in the context of the existing body of knowledge in respect of the phenomenon which is under investigation (De Vos et al., 2007). Hence, the literature control enables the researcher both to compare the study findings with the existing body of knowledge and to determine the way in which the findings from the study in question may contribute to the existing body of knowledge (Forrester, 2008; Streubert Speziale & Carpenter, 2007).

In view of the fact that this study is a qualitative study and the purpose of the study was to capture the "lived experiences" of the participants, the study findings were cross validated in order to relate them to the existing body of knowledge on children's experiences of living with heart disease and their parents'/caregivers' experiences of providing care to their family members with heart disease. As a result of the limited literature which is relevant to the experiences of caring for a child with a heart disease or of living with heart disease from an African perspective, the researcher made an effort to cross validate the study findings with relevant literature from a global perspective.

This chapter presents a discussion of the themes and sub-themes which arose from the participants' experiences in relation to the existing body of knowledge (Forrester, 2008). In

keeping with process of cross validation, the themes which had been identified served either as a confirmation or a contradiction of the existing literature or as emerging new knowledge that would contribute to the existing literature. Those themes which were alluded to by both the parents/caregivers and the children are discussed as common themes, while those themes that were exclusive to either of the categories of participants were discussed as such. The conclusions that were drawn from the discussions of the findings were used to guide the development of a conceptual framework. Table 4.1 presents the themes and sub-themes on which the discussion of the findings was based.

Table 4.1: Main themes and sub-themes

Main themes	Sub-themes
The participants (parents/caregivers and the children) experience challenging emotions (Affects/feelings)	Various emotions were experienced as a result of the diagnosis of heart disease and the prognosis: <ul style="list-style-type: none"> • The parents/caregivers experience shock and disbelief as a result of the children’s diagnosis and they were afraid that the child may die while the children experienced depression, and anxiety. • The parents/caregivers experience “sadness” about the child’s illness and blame themselves for the child’s condition. • The parents/caregivers experience feelings of inadequacy, helplessness and hopelessness as regards caring for a child with a heart disease.
The participants (parents/caregivers) and children were experience disrupted social functioning (Behaviours/action)	The participants reported various experiences in respect of their social functioning and social relations: <ul style="list-style-type: none"> • The condition of the child affects the social functioning and social relations of the parents and caregivers /Life is no longer the same. • The children’s condition deprivee the

	<p>children of opportunities for socialisation and social achievement and causes them loneliness.</p> <ul style="list-style-type: none"> • The condition of the child results in the loss of a future support system which the child would have provided.
<p>The parents/caregivers experience a lack of support from the family as well as a lack of any form of organised support from the social organisations (Experience)</p>	<p>Various experiences which were exclusive to the parents/caregivers with regard to the issue of support were recounted:</p> <ul style="list-style-type: none"> • The parents/caregivers experience both a lack of family support and/or a lack of any form of organised support from the social systems. • The parents/caregivers experience financial difficulties related to providing for the special needs of the children. • The parents/caregivers experience a lack of knowledge about the children's illness and treatment outcomes.
<p>The children experienced decreased vitality (Functional/behaviours)</p>	<p>As regards this issue, the children alluded to certain exclusive experiences:</p> <ul style="list-style-type: none"> • The children experience physical dysfunction.

4.2 THEME 1: THE PARTICIPANTS (PARENTS/ CAREGIVERS AND THE CHILDREN) EXPERIENCE CHALLENGING EMOTIONS

The first theme that emerged from both the interviews and the field notes on both the parents/caregivers and the children was of an emotional nature and is related to the experience of challenging emotions. This theme is further supported by several sub-themes.

Both the parent/caregiver and the child participants disclosed that they had experienced challenging emotions related to caring for a child with a heart disease and living with the heart disease, respectively. In the following discussions, the main theme and the subsequent sub-themes are related to the applicable literature in the context of the parents/caregivers and the children, respectively.

4.2.1. Sub-theme: The parents/caregivers experience shock and disbelief as a result of the child's diagnosis and they were afraid that the child may die while the children experience depression and anxiety.

4.2.1.1 Parents/caregivers

Literature has shown that, upon diagnosis of a living child's condition, the parents or caregivers often experience emotional challenges (Webb, 2009). The majority of children with heart diseases in Namibia, after diagnosis, they often receive treatments as outpatients. This, in turn, means that the parents/caregivers have to cope with the child's symptomatic care, carry out complex caring tasks and face fear and uncertainty about the treatment outcomes in an

environment which is away from health care experts (Ågren, 2010; De Geest & Sabaté, 2003). The parent/caregiver participants talked movingly about their initial and continuing emotional responses to their children's illnesses.

The findings of this study revealed that some of the parents and caregivers of children with heart diseases who had participated in this study reported that, at the initial diagnosis, the whole family had experienced shock, presumably as a result of their perception that the heart is the most vital organ as regards the survival of an individual. Existing literature has indicated that providing care to family members with heart disease is associated with emotional stress and the eroding of psychological health on the part of the caregivers (Pinquart & Sörensen, 2003 & Evangelista, Dracup, Doering, Westlake, Hamilton & Fonarow, 2002). As demonstrated by the simplistic and implicit statements of some of the parents, it also appeared that the parents/caregivers who participated in this study were shocked by their perception of the severity of their children's heart disease as well as by the heightened vulnerability of their children.

It also emerged that, while these parents and caregivers expected their children to succumb to the occasional minor childhood illness, they typically may not have anticipated their children develop heart diseases – serious illnesses which require adaptation as a result of compromised bodily functioning and for which there may not even be a cure. Hence, they felt that their children may have been in danger and, as a result, they felt uncertain, out of control and fearful. In other words, the parents/caregivers were grieving the loss of good health in their children's lives.

The findings are congruent with the findings of a study on the emotional experiences of patients with heart disease. This study found that a heart disease is often perceived as either a crisis or a

life-threatening experience as it is associated with poor prognosis (Ågren, 2010; Deyirmenjian, Karam, & Salameh, 2005). In addition, the emotional challenges experienced by the parents and caregivers in this study are consistent with the findings of studies by Shu-Fan, et al., (2007) and Brosig, et al., (2007) on “maternal experiences of caring for an infant with a heart disease” and on “the infant-end-of-life care”, respectively. These studies concluded that a diagnosis of a heart disease is indeed perceived as lethal and, therefore, when family members learn about the child’s diagnosis or, in cases where the symptoms intensify, these family members of children with heart diseases are likely to experience shock, disbelief or denial and become puzzled, confused and hopeless.

In addition to the experiences of shock and fears, the impact of heart disease on the interrelationship between the child and the parent/caregiver was also mentioned revealed in field notes. The findings of this study revealed an overprotective relationship between the parents/caregivers and the children with heart disease. This overprotective relationship was demonstrated by some of the implicit, non-verbal responses/reactions from the parents/caregivers in the form of attitudes and behaviours. All the parent/caregiver participants implied an increased feeling of love towards their ill children and wanting to make the most of their chances to spend time with their children and provide all the care that they (the children) needed.

The findings of this study also revealed that the majority of the parents and caregivers, or more so the mothers and less so the caregivers, were overwhelmed by a fear of the child’s imminent death as a result of heart disease. The literature supports this finding in suggesting that a close relationship between the caregiver and the recipient of care is often associated with a perception

of the heightened vulnerability of the person being cared for. However, the resultant poor emotional health outcomes of the caregiver may adversely affect the outcomes of the caregiving situation (Ågren, 2010; Creswell, 2008; Raina, O'Donnel, Rosenbaum et al., 2005).

Overprotection of a sick child within a family is, of course, a common phenomenon and is further substantiated by the literature on previous studies. In their findings on the psychopathological implications for the families of children either with heart diseases or with chronic diseases, Brovedani, Masi and Gabrielle (1999) as well as Ware and Raval (2007) assert that, based on their uncertainty and fear, the parents and caregivers often perceive a child with a heart disease as being extremely fragile and vulnerable and in need of protection. Hence these parents/caregivers often indicate a heightened love toward the child and they are often inclined to indulge in emotional overinvestment and to display an overprotective attitude towards the "sick" child in an effort to save the child. However, failure to save the child may result in feelings of sadness and self-blame about the child's illness (Brovedani et al., 1999; Ware & Raval, 2007). However, as it is essential for the duo to cope with the situation, Webb (2009) suggests that the parent/caregivers should not act in accordance with the child's response to the illness as the child's own coping efforts depend on the parent/caregivers coping.

It may, therefore, be concluded that the emotional reactions of the parents and caregivers in this study clearly demonstrate that parents/caregivers were overwhelmingly concerned about their children's suffering and, as a result, they were not coping well. It is, therefore, suggested that these parents/caregivers and/or families need appropriate support and interventions to help them manage their emotional experiences and, in this way, to facilitate positive health outcomes for the children concerned (Shu-Fan et al., 2007).

4.2.1.2 The children

Furthermore, the findings of this study indicate that it was not only the parents/caregivers who were manifesting negative emotions and feelings as a result of the condition of their children. The data from the field notes on the children with heart disease who participated in the study revealed that they, too, were experiencing emotional challenges as a result of the fact that they were suffering from heart disease. Of course, and in accordance with the literature, the children's responses as regards their emotional experiences are based on the ultimate meaning of a diagnosis of heart disease to a child (Webb, 2009).

Within the context of the children, the emotional challenges they were experiencing manifested in a range of emotional reactions, including irritability and mood swings. The fact that the participants in this study were struggling to accept the limitations imposed by their condition may be reflected by either their non-responses, a turning away from responding to the question or their statements that they felt that their lives were no longer normal as a result of their illness and they wanted to be cured.

These findings support the claims of previous researchers to the effect that the depression and anxiety, loneliness, low self-esteem and feelings of inadequacy which arise from the physical dysfunctions which are, in turn, caused by the effects of heart disease on the various bodily systems, are found frequently among patients with heart disease (Uzark, Jones, Slusher, Limbers, Burwinkle, & Varni, 2008; Ulvik et al., 2008; Deyirmenjian et al., 2005; Brovedani et al., 1999). In conclusion, it is obvious that the children's emotional reactions increase the demands of care and intensify their parents' emotional reactions and, as a result, cause poor coping.

4.2.2 Subtheme: The parents/caregivers experienced “sadness” about the child’s illness and blame themselves for the child’s condition

4.2.2.1 The parents/caregivers

The findings of this study indicated that the parents and caregivers feel extremely distressed about the children’s condition and they also feel guilty when they see their children experiencing symptoms such as problems with breathing and exhaustion, all as a result of the heart disease. As a result, the parents’/caregivers’ emotional responses to the children’s condition are sympathetic instead of empathic, a phenomenon that requires bereavement counselling that is directed towards increasing the parents’/caregivers’ feeling of self-control (Dracup, Evangelista, Doering, Tullman, Moser & Hamilton, 2004).

In addition, the parents/caregivers who participated in this study tended to employ a causal focus appraisal approach, i.e. trying to understand who is responsible for their children to acquire heart disease. As a result, they blamed themselves for their children’s conditions and used religious beliefs to explain why their children had developed heart disease. The findings of this study validated the claim made in the previous paragraph that an excess of sympathy may translate into self-blame on the part of the parents/caregivers, hence one of the parents/caregivers stated her fear that her child may die, especially when the child’s symptoms intensify, and such fear leads to her becoming puzzled and questioning why her child has to suffer these symptoms.

Likewise, existing literature explains that, when a stressor such as illness is perceived as intensifying, a causal appraisal may be applied as the individual tries to understand who is responsible for situation (Glanz et al., 2008). The literature further states that a causal appraisal towards the loved one’s condition may even result into self-blame on the part of the caregivers

with the caregivers perceiving themselves as having failed to do what they could have done for their loved one who is sick. As a result, caregivers may hold themselves accountable for the illness and potential treatment outcomes for the sick person (Forrester, 2008).

Moreover, the findings from this study support the conclusions of Van Tilburg, Denesh, Chitkara et al (2009) in their study on the “parental worries and beliefs about the children’s illness.” They claim that, when the parents or caregivers have interpreted the seriousness of the child’s symptoms as extremely grave, they are likely to respond with sympathy as a part of nurturing (Van Tilburg, Denesh, Olfur, Palsson, Levy & Whitehead, 2009). Nevertheless, the authors further caution that, while sympathy and empathy are important and nurturing to the child, a surfeit may result in the parents/caregivers feeling guilty and blaming themselves for the child’s illness and, thus, inadvertently reinforcing illness behaviours in the child and the subsequent poor coping for the caregiver (Van Tilburg et al., 2009).

Accordingly, Webb (2009) cautions that, while it is natural for the parents and caregivers to look for a reason behind the diagnosis of the child’s medical condition, either viewing the illness as form of punishment for wrongdoing, believing that someone is to blame or maintaining that the condition should not have happened to the child, creates maladaptation and poor coping (Webb, 2009).

In addition, other studies with a similar focus on the pattern of coping among caregivers have found that factors such as a lack of knowledge of the illness, a lack of a definitive medical confirmation of the cause of the illness as well as a lack of knowledge about the resources that may be of assistance in their caregiving roles, may also cause families to find all sorts of reasons

for the causes for the illness. This type of behaviour may be responsible for the negative appraisals of such families (Shu-Fan et al., 2007; Arafa et al., 2008).

As regard the parents/caregivers, the findings of this study substantiate the claims in existing literature that, although the progress of the illness or a debilitating disease is confined to the body of the affected person, it is not only the sick person who experiences the impact of the disease- the impact of the illness on the family system is often understated. The literature further argues that an illness may also impact on the entire family and, conversely, the family's response may impact negatively on the caregivers' coping effort, the course of the disease and the health outcomes for the family member who is sick. It may, therefore, be concluded that the parents and caregivers' emotional reactions to the diagnosis and the anticipated treatment outcomes affect the coping on the part of both the patient and caregiver (Forrester, 2008; Ågren, 2010).

However, the literature has provided evidence that these negative responses constitute reactive approaches to challenges and that they tend to hold the parents/caregivers within a circle of concern, thus decreasing their chances to be proactive and engage more with the circle of influences which may help them cope with their situation. As a result of persistently focusing on concerns, the parents/caregivers may experience feelings of inadequacy, helplessness and the hopelessness as regards providing home care for their children with heart disease (Covey, 2005).

4.2.2.2 The children

In common with the parents'/caregivers' feelings of sadness, the children also feel sad. In line with the children who participated in this study, Deyirmenjjan et al. (2005) concur with Dekker, Peden, Lennie, Schooler, and Moser (2009) in maintaining that patients with heart disease are likely to present with both overt and covert manifestations of emotional challenges (Dekker et al., 2009; Deyirmenjjan et al., 2005).

4.2.3 Sub-theme: The parents/caregivers experience feelings of inadequacy, helplessness and hopelessness as regards caring for a child with a heart disease

4.2.3.1 The parents/caregivers

Lowes and Lyne (2000) argue that, when a child is diagnosed with an illness that is of a life-threatening nature, not only do the parents or caregivers lose a healthy child, but they also lose self-confidence as regards their ability to meet the demands of caring for the child concerned (Lowes & Lyne, 2009). These feelings of inadequacy and hopelessness on the part of caregivers may be perceived as the negative reactions to the demands of providing care. In this regard, the literature has provided evidence that feelings of inadequacy and, hopelessness are the most common negative reactions to providing care for an individual with a severe illness (Jepson, McCorkle, Adler et al., 1999; Given, Given, Stommel et al., 1999).

It also emerged from the simplistic statements which signified helplessness on the part of the parents/caregivers that the parents/caregivers were experiencing intense feelings of powerlessness and, as a result, they appeared to have developed a feeling of inadequacy or

helplessness as regards providing care for these children at home. In fact, almost half of all the parent/caregiver participants in this study, more so those who were mothers, demonstrated a sense of hopelessness which appeared to have originated from their negative appraisals of the psychological, social and economic experiences of caring for their children with heart disease. All their hopes, expectations and plans seemed no longer to have any validity.

These findings support the claims by previous researchers in regard to caregivers coping with the demands of care at home indicating that, in the caring relationship between the parents/caregivers and the children, the task of providing care is, mainly the preserve of the parents or caregivers. As a result, it is the parents/caregivers who shoulder the burden of care and suffer the resultant emotional effects (Webb, 2009).

It may, therefore, be concluded that people's negative emotional responses to the changes and demands, for example, of providing constant care to a child with a heart disease, may result into maladaptation on the part of the caregiver as is characterised by feelings of inadequacy, helplessness and hopelessness, if no counteraction to restore the balance is instituted (Higgison & Gao, 2008; Glanz et al., 2008).

In addition, as demonstrated in several of the assertions made by the parents and caregivers in this study, when they experienced feelings of helplessness and hopelessness, they adopted a meaning based coping approach by using religion and spirituality as coping mechanisms/methods. These findings support theoretical claims made in previous studies on coping on the part of both the patients with heart disease and their caregivers. The findings from these studies postulate that, if a secondary appraisal of a situation is employed and the individuals perceive their inability to manage the situation or they realise that there is little help

forthcoming from other people, they may adopt either escape-avoidance behaviours or meaning based coping approaches (Ulvik et al., 2008; Covey 2005).

Furthermore, and as indicated by the findings of this study, when faced with the challenges of care or when experiencing a lack of the resources necessary to meet the demands of care, the parents and caregivers may then engage with negative thoughts, including thoughts of self-worthlessness. As a result, and without any counter measures, persistent feelings of inadequacy and helplessness may result in hopelessness as a maladaptation (Glanz et al., 2008; Cox, Docherty, Brandton et al., 2009; Van Tilburg et al., 2009).

The parents and caregivers of children with heart disease who participated in this study indicated significant experiences of helplessness and hopelessness. Accordingly, with regard to this sub-theme, the findings of this study support the claims made in the relevant literature that the parents and caregivers of patients with diseases that are perceived to be of a life-threatening nature, including heart disease, are likely to experience feelings of both helplessness and hopelessness and this, in turn, may result in poor coping (Dekker et al., 2009; Brovedani et al., 1999). In other words, the parents and caregivers' experiences of emotional challenges may translate in the poor coping on their part and this, in turn, may impact negatively on the quality of care provided to the child (Chung, Moser, Lennie, & Rayens, 2009).

However, the literature argues that dwelling on negative experiences is associated with poor coping as both options are likely both to diminish any seeking of positive influences and to lessen the adherence to any positive actions, including seeking information and connecting with others which may promote a sense of purpose in life as well as coping and positive health

outcomes for the beneficiaries of the caring effort (Vollman, LaMontagne, & Walston, 2009; Glanz et al., 2008). It is, therefore, recommended that the parents and caregivers should be provided with both appropriate medical and social assistance to help them cope with the course of heart disease and to carry out the prescribed therapeutic and rehabilitative measure effectively as options that may help them to cope with the demands of care (George, 2008).

In concluding this theme, the findings from this study, which provide strong evidence of emotional challenges being experienced by the parents and caregivers and also the children with heart disease who participated in this study, are strongly supported by the literature. Experiences of emotional turmoil are also linked to the second theme – the experience of disrupted social functioning and social relations.

4.3 THEME 2: THE PARTICIPANTS (PARENTS, CAREGIVERS AND THE CHILDREN) EXPERIENCE DISRUPTED SOCIAL FUNCTIONING AND SOCIAL RELATIONS

The second theme that emerged from the interviews is related to the social functioning and social relations in respect of both the parents/caregivers and the children, as well as to the children's experience of lost opportunities for social achievement. These outcomes are the result of demands of care in respect of the parents/caregivers and the impact which the disease may have on the children. This theme is further supported by the following sub-themes:

- The condition of the children influences the social functioning and social relations of the parents/caregivers.
- The children's condition deprives them of opportunities for socialisation and social achievement and causes them intense loneliness.
- The condition of the children implies the loss of a future support system which the children may have provided.

It is, therefore, suggested that there is a need to alleviate the burden of caring in order to prevent any overtaxing of the caregivers' coping resources and, thus, to enable them to be of greater assistance to their loved ones who are sick (Mitchell, 2011; Forrester, 2008).

4.3.1 Sub-theme: The condition of the children influences the social functioning and social relations of the parents and caregivers

4.3.1.1 The parents/caregivers

The parent and caregiver participants in this study expressly stated that the demands of caring for their children with heart disease affected the degree to which they were able to fulfil their social responsibilities as the need for them to stay at home to supervise the sick child limited the degree to which they were able to engage with their other social roles. The experience of role conflict with unresolved psychological preoccupations with the sick child came to the fore. It may, therefore, be assumed that there is a vicious circle of psychological preoccupation with the thoughts of the sick child and the less meaningful fulfilment of other social roles among these primary caregivers (Major, 2003). These claims about the restrictions on their social life were also explicitly stated by some of the parents. Finally, all the parent/caregiver participants indicated that short notice they received to bring the children to Windhoek for follow up treatments also adversely affected their other social responsibilities.

These findings correlate with the findings from other studies on the quality of life of the parents/caregivers of children with heart disease elsewhere. In this regard, the reports indicate that the parents or caregivers submitted that the caring load reduces the time and opportunity they have to socialise and “recreate”, restricts their social lives and imposes changes on family lifestyle (Arafa et al., 2008). In addition, and as indicated in the literature, the more the child’s functional status is deranged, the more the need for constant parental or caregiver supervision and less opportunity for socialization (Reinhard et al., 2008).

These findings are also in line with the findings of Ågren (2010) and Pressler, Gradus-Pizlo, Chumbiski, Smith (2009) when they say that a severe illness of a member of the family is likely to cause changes in the family dynamics and disruptions in the family roles, operations and activities of the caregivers because providing care to a relative requires the caregivers to change and adjust their daily schedule, including their having to limit their personal freedom in order to accommodate the need to provide care for their loved one. Of course, this shift is likely to result in disequilibrium in the daily activities of the caregiver as well as in the family dynamics, while it may also alter the family's ability as regards self-management (Pressler et al., 2009; Ågren, 2010; Aldred, Gott, & Garriballa, 2005).

In conclusion, Mitchell (2011) concurs with Ware and Raval (2007) in indicating that long-term illnesses impose changes in the routine of family dynamics, requiring the reassigning of roles and, indeed, imposing demand on the adults' time. In line with the postulations in literature, the evidence from this study also indicates that, unlike the fathers, the mothers, as the ones who are more involved in providing care to these children at home, are responsible for much of the caring role and, therefore, they spend extra time with the child and are the most affected by the changes in family dynamics. To that end, it is the mothers and female caregivers who require support to improve their self-management and coping and this, in turn, may enhance the quality of life of their children concerned (Sayers, Riegel, Pawlowksi, Coyne, & Samaha, 2008; Chung et al., 2009; Rohrbaugh, Shoham, Coyne, Cranford, Sonnega & Niklas, 2006).

4.3.2 Sub-theme: The condition of the children deprives the children of the opportunity for social achievement and socialisation and causes them loneliness

4.3.2.1 The parents/caregivers

The findings from this study revealed that the parents/caregivers were concerned that the disease would have a negative impact on the children's opportunity for education. In other words, the parent/caregiver participants, more so those who were the parents, were concerned that their children would be deprived of the opportunity to complete their education as some of the children either had an erratic school attendance record or they were not able to attend school at all as a result of ill-health and frequent hospitalisation.

4.3.2.2 The children

As was the case with their parents/caregivers, the children with heart disease also appeared to employ a motivational relevance appraisal, i.e. trying to explain the effect of their ill-health on their future as they indicated that their illness was depriving them of the opportunity for educational achievement. The evidence from the children's responses indicated that they, too, employed a motivational relevance appraisal of the effects of their illness.

In addition to the children's verbally expressed perception that they were being deprived of the opportunity for socialisation, the child participants were asked to draw and interpret pictorial naïve drawings about their feelings and experiences as regards living with heart diseases. The inferences that were made from these pictorial, naïve drawings by some of the child-participants

gave rise to the insight that these children were experiencing confinement, social isolation and loneliness as a result of their being sick.

Furthermore, and unlike other studies which had indicated that, when feeling depressed, the patients with heart disease engaged in activities such as reading and exercises (Dekker et al., 2009), these children indicated that, as they were deprived of the opportunity to socialise, they experienced loneliness, therefore implying that they had difficulty in carrying out behaviours that could moderate emotional distress (Ågren, 2010).

The children's own appraisal of the limitations which their illness imposed on their socialisation is in agreement with the assertions in the existing literature that those illnesses which involve repeated hospitalisation and which restrict activities also impose restrictions on the patients' social lives, restrict future opportunities and minimise any opportunities for achievement and, as such, may be regarded as dehumanising (Webb, 2009)

In conclusion, a heart disease may be regarded as having a negative impact on the social achievements of children. This may be inferred from the parents'/caregivers' assertions that their children's illnesses has deprived them of the opportunity to be able to work and contribute to their own living while the children, on the other hand, had indicated the wish to make up for the time lost to illness and to live their life to the fullest (Dekker et al., 2009; Brovedani et al., 1999).

It would appear that the concern over lost opportunities as a result of illness and which was alluded to by both the parent/caregiver and the child participants in this study is less prevalent in the literature and, this evidence presents new insights that may contribute to the existing body of knowledge on the experiences of children living with heart disease and their parents'/caregivers' perceptions of their children's futures.

Not only were these parents/caregivers concerned about the potential loss of opportunities for social achievement on the part of their children but a concern about the loss of a future support system (which would have been provided by the children) because of the children's condition was also strongly alluded to by some of the parents/caregivers.

4.3.3 Sub-themes: The condition of the child implies the loss of a future support system which the child would have provided.

4.3.3.1 The parents/caregivers

Nadakavukaren (1995) indicates that in an African context, children are regarded as social security for their parents, because as young as they are, their labors are needed on the farm and around the house. In that regard, children are additional pairs of hands to gather woods, haul water and tend to life stocks. Additionally, children are also expected to contribute to the family's well-being through their own socio-economic success. As a result, they are regarded as future investments for their parent (Nadakavukaren, 1995).

In support of the above assertion, there was evidence from this study that the parents/caregivers harboured the assumption that being afflicted with heart disease meant that their children would be deprived of a chance to succeed in life and would, therefore, not be able to contribute to the family system. The parents and caregivers are overwhelmingly concerned that the incapacitating effects of the diseases on the child may result in the child's inability to contribute to the family system, both at that time and in the future. These parents/caregivers implied they depend on their growing children for economic support in their old age.

These findings are furthermore consistent with the evidence from literature to the effect that, if the children, because of sickness or permanent disability, are not able to contribute to the customary roles as regards the sustenance of the family then the parents' dreams about the child are shattered (Forrester, 2008).

In concluding this theme, it may be inferred that the caring role imposes extra responsibilities on the parents/caregivers as the main caregivers, probably because they do not get the necessary support for them to cope with the demands of care. Disrupted social functioning and disrupted social relationships are also associated with minimal chances to access the necessary support while the needs of caring impose an economic burden on the families. Accordingly, the following theme encompasses the findings about both the social support and economic implications for the families of children with heart disease as they were recounted by the parents and caregivers.

4.4 THEME 3: THE PARENTS/CAREGIVERS EXPERIENCE A LACK OF SUPPORT FROM THE FAMILY AS WELL AS A LACK OF ANY FORM OF ORGANISED SUPPORT FROM THE SOCIAL ORGANISATIONS

The literature indicates that, in many situations, caregivers may not always have the resources at their disposal to respond to the demands of care effectively. Among others, the support from other family members in the form of emotional support or in a form of carrying out caring activities for the sick person and, therefore, providing relief for the focal caregiver, is necessary for effective responses to the demands of home care. Support may also include material and financial assistance from social organisations as genuine gestures of care which are directed to

the caregiver to facilitate coping with the demands of care at home (Forrester, 2008; Deyirmenjian et al, 2005).

The third theme that emerged from the participants' responses in this study and which is exclusive to the parents/caregivers is related to a lack of support from both the family and from social systems in terms of providing the financial and material assistance which the parents/caregivers urgently require to facilitate the care they provide to their children, as regards not only home-based care but also the health services. Almost all of the mothers and the caregivers who participated in the study indicated that they were in dire need of financial resources to enable them to provide home care to their children with heart disease. In addition, more than half of the parents/caregivers indicated that they needed to understand the nature of their children's illness and to acquire the skills necessary for them to carry out the activities of care at home. This theme was further supported by the following sub-themes as discussed in the following sessions.

4.4.1 Sub-theme: The parents/caregivers experience a lack of family support or any form of organised support from the social systems

Raina, O'Donnel, Rosenbaum et al. (2004) indicated that, although caregiving is a normal part of being a parent to a young child, the caring role may take on an entirely different significance, especially when a child experiences functional limitations in self-care functions such as feeding, bathing and dressing. Potential long term dependence with long term care would far exceed the usual needs involved in providing care for such a child (Raina et al, 2004). Therefore, one of the most important forms of assistance that may be rendered to a family that is faced with providing care to their loved one with a long term illness is to reaching out to the family and to provide

either material, practical or emotional support to such families (Forrester, 2008; Glanz et al., 2008). However, the findings from this study indicated that the opposite is true with the primary caregivers of children with heart disease from the rural areas in Namibia experiencing severe role overload.

4.4.1.1 The parents/caregivers

As may be inferred from the assertions of the parents/caregivers, it would appear that a lack of support from the families and social systems amplified the experience of poor coping on the part of these parents/caregivers. Some of the parent/caregiver participants in this study indicated that they receive scarcely any support from their families and nor do they receive any form of organised support from social systems to help them cope with the demands of care and the expectations of their children. Their relatives and friends were clearly failing to provide them with the on-going support for which they had hoped and, as a result, these parents caregivers felt betrayed by their families, friends and by society at large.

Almost all the mothers and the one caregiver who participated in the study reiterated that they needed some form of social support to enable them to provide the day-to-day care for their children with heart disease. One of the participants even made an appeal to the government to provide a home/hospice for these children with heart diseases where they could be cared for by trained health care workers and trained volunteers, thus supporting an explanation by the Health Care Online (2011) to the effect that, in the event of heart disease, the parents and caregivers may become so devastated by the demands of caring for their ill children that they experience coping difficulties. As a result, they would prefer the responsibility to be taken away from them.

The need for a hospice programme, as expressed by the parents/caregivers in this study, is supported by the suggestion of Pervan, Cohen, and Jeftha (1995), (as cited in Forrester, 2008, p.144), as well as by Webb (2009), who argue that the ideal care situation for children with special heart illnesses requires coordinated, on-going, comprehensive care in a medical home to provide relieve for the families. The assistance of a hospice programme is recommended in order to provide symptomatic care when the caregivers are not able to or else to provide the family members with the opportunity to take a break from their caregiving functions for a while.

These findings are further in line with the findings of Brosig, Pierruci, Kupst and Leuthner (2007) and Deyirmenjian et al (2005) who, in their parallel studies, argue that, when faced with the care of their loved ones who are suffering from serious illnesses, the caregivers are sometimes neglected and avoided by those from whom they hoped they would receive support to enable them to cope better. However, their expectations of support are not met (Brosig, Pierruci, Kupst and Leuthner 2007). As a result of their perception of being abandoned by families and friends, it is likely that the parents or caregivers may be intensely disappointed which, in turn, may result in poor coping (Stajduhar et al., 2008).

Indeed, Webb (2009) is correct when he asserts that it is essential that other family members ought to recognise that the “new” life for the child and his/her parents or caregiver is not a passing freak or a chance occurrence. Therefore, caregivers/parents cannot be denied assistance from members of the extended family to help balance the responsibilities of providing care to the sick child (Sittner, Hudson & Defrain 2007; Webb, 2009).

4.4.2 Sub-theme: The parents/caregivers experience financial difficulties related to providing for special needs of their children

Webb (2009) is of opinion that children with chronic health conditions that necessitate long-term care are of special concern with their health and well-being already being compromised by physical limitations and the experiences of emotional turmoil. Restricted access to health care services and a lack of material facilities and adequate nutrition to facilitate the required care at home because of financial limitations may threaten the ability and potential of these children (Webb, 2009).

The children with heart disease from the rural areas in Namibia are no exemption to a lack of material facilities and adequate nutrition to facilitate the required care at home. All but one of the parents and caregivers indicated their vulnerability in this regard when they related that they were experiencing financial hardship in providing for the two perspectives of care, namely, the provision of special diet for their children-with heart disease and for the expenses incurred by the cost of transport for the child to attend follow up treatment. This is discussed in the next sections. In addition, of the cases that participated in this study, the majority of the children were from a single parent, female household, a factor that exacerbates both the poverty of these families and the vulnerability to financial crisis and which in return contributes to poor coping with the demands of care. Indeed, the view of Iipingge and Botes (2002) is maintained as they states that rural communities in Namibia are expected to provide home-based health care to their significant ones while without essential facilities to provide such services.

4.4.2.1 Money required for providing a special diet for the children with heart disease

Research has proved that nutrition and diet are important aspects of the lifestyle of cardiac patients. In that regard, cardiac patients or their parents/caregivers make healthy food choices and, specifically, foods with reduced fat, reduced cholesterol and, reduced sodium intake and sufficient fluid and fibres. Therefore, a healthy cardiac diet especially for a growing child should comprise fish, beans and legumes, eggs and little red meat, although this requires financial planning (Smeltzer, Bare, Hinkle, & Cheever, 2010; Pretorius, Sliwa, Ruf, Walker & Stewart, 2012).

However, the evidence from this study revealed that it would appear that the parents/caregivers of the children with heart diseases who are from poor socio-economic backgrounds are not economically able to acquire the types of foods that are recommended for a patient with heart disease. In addition, most of these foods are not routinely available at their households, but are to be bought from the market. Hence, these parents/caregivers are not able to follow the recommendations with regard to the necessary diet simply because they cannot afford to. In line with the evidence from studies on the inability of families to meet the demands for special diets for their loved ones with heart diseases, the parent/caregiver participants in this study also indicated that they were experiencing difficulties related to the acquisition of special foods – nutritious and with vitamins, such as fruits and vegetables – as recommended by the health care workers for their children as cardiac patients (Webb, 2009; Beck & Wiencek-Kurek, 2007). Although it appeared that the majority of the children did not understand the financial implications of their illness, one of the children though echoed his mother's concern about food.

This situation is exacerbated by the fact that any efforts by the parents/caregivers to acquire these special foods for their children from the community based government initiatives for food relief to the needy have proved fruitless because the needs of these children with heart disease are not catered for in the terms and references of such initiatives.

As a result of financial constraints the parents/caregivers admitted that they gave only those foods that were available at the household level, such as cow's milk, dry spinach served with mahangu pap, fish and chicken and perhaps a pumpkin, if the harvest had been good. Consequently, a typical meal for a child with heart disease from a poor low socio-economic background in Namibia would be made up from that short list of foods and the child would have to eat that for every meal.

It is obvious that the poor, nutritiously deficient diet, coupled with the low metabolism which is a physiologically inherited factor in heart disease, is likely to contribute to a failure to thrive among these children (Menon & Poskitt, 1985). As a result, all the child participants in this study were of a low weight for their ages.

In addition to the difficulties related to the acquisition of the special foods, the parents/caregivers indicated that they also required certain facilities that were necessary to care for their children at home, including mattresses and pillows to ease difficulty breathing. However, the evidence of a lack of those facilities that are necessary if the family is to provide care to a sick person at home is not unique to this study. The literature has proved that, despite the fact that organisations may exist to offer help to those who are in need, such organisations may have special terms of

reference and, as such, their help may be restricted to people in a certain circumstance (Forrester, 2008).

Indeed, in the Namibian context, there is no term of reference for the government to provide food and material assistance to children with heart disease in order to help their caregivers to cope with the demands of care. However and in line with the generic definition of "vulnerable children", which indicates that a child is vulnerable when facing worse odds and outcomes than the average child in a community (Heitzmann, Canagarajah & Siegel, 2001), the children with heart diseases from the rural areas in Namibia are vulnerable. They are also worse affected by the impact of heart disease in domains of health-increased morbidity and potential mortality, livelihood- food insecurity as regard provision of cardiac diet as well as a lack of materials that are necessary to facilitate care by their parents/caregivers at home, and as such, they need to be considered for the services of vulnerable children (Richter, Manegold & Pather, 2004).

In view of the problems that these parents and caregivers were experiencing, all of them made an appeal for the government to provide food supplements as an integral aspect of the health care approach adopted by the health services in respect of children with heart disease.

In conclusion, these assertions by the parents/caregivers and the children are supported by evidence from literature that, when not referred to any community based source of support, the caregivers may become vulnerable to the demands of care at home. Accordingly, the caregivers may be unprepared for their family member's discharge from hospital and, indeed, they may perceive it as upsetting and they may even feel abandoned at a critical time (Arnos, 2002). It is, therefore, important that, before the family member is discharged from hospital, these families be

referred to some form of social support at the community level to ensure continuity of care and, therefore, to ensure better coping on the part of the parents/caregivers (Miller, Townsend, Carpenter, Montgomery, Stull & Young, 2001). In view of the fact that these parents and caregivers experience financial burdens at a household level, it may be anticipated that the financial hardship also translates into difficulties as regards transport expenses to attend follow up treatment and also the cost of treatment.

4.4.2.2 Money required for the expenses related to travelling to hospital and the expenses involved in surgery for the child

Access to health care for children with heart disease in the Namibian context involves being able to access those locations where the required specialised health services are offered. As indicated by some of the parents and caregivers yet another issue which causes the parents and caregivers financial concern is the expenses related to travelling to hospital for follow up treatments and also the money that is needed for surgery for the children with financial concerns in this regard being alluded to by almost all of the parents/caregivers. Although these children are eligible for treatment as state patients, nevertheless their parents and caregivers have to find the money to cover the expenses for the transport for follow up treatments at the location where the specialised health services are offered.

In addition, the parents and caregivers indicated that, in some instances, none of their family members was working and earning a salary and, therefore, they are often forced to borrow money from their neighbours and as a result accumulate debts.

In view of the fact that these parents and caregivers are sometimes not able to afford the costs incurred when they have to pay for the transport to the locations where the specialised services are offered, these children are at risk of missing out on their medical consultations and, as a result, there may be high morbidity and even mortality among them. Indeed, and as the literature indicates, a lack of financial means may impede the access to health care services which is necessary to optimise the health, ability and general development of these children (Webb, 2009; Syme, Lefkowitz, & Kivimae Krimgold, 2002).

A lack of sufficient financial resources to afford to travel to and from the hospital was reported to translate into further disrupted social functioning as, in some cases, the parent or caregiver and the child had to find temporary accommodation in Windhoek so as to enable the child to attend at least two consecutive follow up treatments before returning to their home regions. In addition, in many instances, a lack of financial resources had delayed the treatment process, with the child being subjected to suffering over a longer period of time and more demands for care from the parents/caregivers, resulting, in turn, in disrupted social functioning and negative emotional experiences. There is no doubt that any repetition of this vicious cycle of negative experiences will, ultimately, result into poor coping on the part of the parents/caregivers.

The evidence from this study tends to support the documentation in previous studies on the financial constraints or financial burdens encountered by the families of children with special health care needs, including those children with congenital heart diseases with the parents and caregivers experiencing financial burdens related to their children's conditions (Arafa et al., 2008; Kuhlthsu, Hill, Yucel & Perrin 2005).

Furthermore, this evidence is congruent with the findings of both Beck and Wiencek-Kurek (2007)'s study on the Healthy Neighbourhood Heart Initiative and also Dekker et. al, (2009)'s study on incidences of depression among patients with heart failure. In line with the findings of this study, these authors all concede that, as a result of the extraordinary expenditure required to meet the health care needs of a family member with a heart disease, and the inability of the sick individual to work and sustain him/herself, some families may experience financial difficulties and become financially compromised to the extent that the family members with heart disease may be at risk of missing out on treatment (Beck & Wiencek-Kurek, 2007 & Dekker et al., 2009).

Although none of the children raised any concerns about financial difficulties related to accessing health care facilities for treatment this may simply be because they are minors and, therefore, they are less likely to understand the financial implications of their illness. However, it is not possible to ignore the moving accounts of their parents and caregivers.

Mounting evidence of the financial difficulties attached to the demands of caring for children with heart disease at the household level has been clearly indicated in this study and is supported by the literature. However, the extreme poverty, as characterised by a lack of access to the prescribed diet to support these children with heart disease and the lack of the basic facilities required to facilitate care at home are newly generated insights. This study has clearly revealed that financial problems constitute a major factor that may not be ignored as it would appear that all the other dimensions of poor coping are rooted in the lack of financial means to facilitate coping with the demands of care at home.

It, therefore, follows that it is incumbent on health care practitioners and social workers to be sensitive to the economic influences that exert disproportionate financial demands on the parents and caregivers as meeting the demands of caring for these children with heart disease requires more expenditure than is necessary for a child with a common, minor childhood illness. Health care practitioners should, therefore, assess the financial status of the families of children with heart disease and determine the children's eligibility for social welfare as a means of financial assistance to help their caregivers provide for the special needs which are implicit in caring for these children at home, enable them to access health care facilities and ultimately their parents/caregivers' coping with the demands of care at home (Webb, 2009).

In addition to the resources that are necessary to facilitate both the provision of care at home and access to health care facilities for treatment, the acquisition of relevant knowledge on the part of the parents and the caregivers would also contribute to counterbalancing the difficulties in caring for these children at home.

4.4.3 Sub-theme: The parents/caregivers experience a lack of knowledge about the children's diseases and the treatment outcomes

4.4.3.1 The parents/caregivers

It is suggested that those caregivers who possess information about the situation they are dealing with, are more likely to be in control of the situation and, as a result, they will cope better. Knowledge enables caregivers both to minimise and to negate the negative impact of the situation. In addition, knowledge means that the parents and caregivers will be better prepared to

accept their care giving role. As a result, they will be in control of the situation and cope better and realise positive health outcomes for their children (Ågren, 2008; Deyirmenjian et al., 2005).

Insight into aspects of care for the child would enable caregivers to detect any intensification of the symptoms and either provide appropriate palliative care promptly or seek the services of a health care provider. By so doing, they will be able to bring about an improvement in both the functional status and the quality of life of their children (Paul 2008). The implication is that the parents/caregivers should have knowledge of the children's condition and the care that is required. It is in the light of these arguments that Bugge, Helseth, and Darbyshire (2009) conclude that the quality and openness of the communication of the information about the patient's illnesses and the corresponding care may mitigate the likelihood of poor coping with the demands of care on the part of the caregivers.

However, according to the findings of this study, more than half of the parents/caregivers who participated in the study demonstrated a lack of knowledge of both their children's disease and potential treatment outcomes. This state implies that they had not been given sufficient information regarding the illness and necessary care for their children. In addition, a lack of knowledge about the illness and the treatment outcomes contributes to these parents'/caregivers' lack of confidence regarding providing the children with appropriate explanations about their conditions. In this regard, some of the parents and caregivers simply stated that they were not able to make their children understand the nature of their illness and, therefore, they needed the assistance of someone else to counsel the children so as to enable the children to understand the nature of the illness. It is obvious that insufficient and poor communication of health information

to the parents/caregivers by the professionals may exacerbate the parents'/caregivers' sense of inadequacy.

Moreover, it appeared that neither the parents/caregivers nor the children had been furnished with appropriate information about the course of treatment and the expected outcomes or the children's prognosis. This finding is in keeping with the vast body of literature to the effect that patients and caregivers who are not knowledgeable about the diseases and self-care regimens are less likely to adhere to the treatment programme and, they are therefore, disadvantaged. A lack of correct information inhibits parents/caregivers from responding to their children in appropriate ways and also interrupts the continuity of care that they – the parents/caregivers are expected to provide to their children (Paul, 2008; Helseth & Ulfsaet, 2005; Strömberg, 2005). It is clear that the parents/caregivers are in need of appropriate information to help them to talk to their children and to address what may be perceived as “the difficult questions” (Bugge et al., 2009, p. 3484).

In agreement with the findings from this study relating to a lack of knowledge on the part of the parents/caregivers, the data from previous studies also indicate substantial gaps in the knowledge pertaining to the patients' diagnosis and subsequent care and the prognosis of the disease, either on the part of the patients themselves or their caregivers. It would seem that this situation arises because of a lack of emphasis on health education – an essential component of the optimal care of patients with heart disease (Paul, 2008; Bugge et al., 2005).

Therefore, in line with the claims made in literature, it would appear that because of lack of appropriate knowledge about the child's prognosis, some of the parents/caregivers still harbour

high expectations in respect of their children even in cases in which it is not possible to surgically correct the child's condition but only symptomatic treatment is available.

Furthermore, in line with the findings of this study regarding the implications of a lack of knowledge about the children's condition and potential treatment outcomes on the part of the parents and caregivers, Dickstein, Cohen-Solal, Fillipatos et al. (2008) and Lainščak, Cleland and Lenzen (2007) also indicate that, in many cases, caregivers are simply not provided with information and counselling about care continuity at home (Dickstein et al., 2008; Lainščak et al., 2007). To that end, as the case with the findings from this study, in his report on "The psychosocial needs of family members of patients with terminal cancer", Forrester (2008) maintains that not only is the information which is provided to the patients and their family members in regard to the diagnosis of the disease and treatment outcomes inadequate, but there is also a lack of honest communication of these aspects to the patients and their families.

In conclusion, and in supporting of the relevant literature, it is evident that the communication of medical information and information about care continuity to the parents and caregivers of children with heart disease in Namibia is inadequate and, of course, this, in turn, affects the manner in which all facets of the illness, including diagnosis, symptomatic care and outcomes, are received and dealt with.

Accordingly, the literature advocates that sharing information with the patient's family is crucial as this helps to reduce the caregivers' uncertainty and anxiety about the unknown as well as helping to influence the nature and volume of support given to the patient (Forrester, 2008; Sittner et al., 2007).

In this regard, it is evident that it is essential that the caregivers be sufficiently knowledgeable about the patient's treatment regimen to ensure the efficient continuation of care at home (Dickstein et al., 2008; Strömberg, 2005). Furthermore, Hunt, Baker, Chin et al. (2005) as well as Colonna, Sorino, D'Agostino, Bovenzi, DeLuka and Arrigo (2003) add that caregivers ought to be provided with education that creates an understanding of the patient's illness and its causes, related clinical problems, symptomatic monitoring and prompt responses to changes in the clinical profile of the disease (Hunt et al., 2005; Colonna et al., 2003).

Similarly, in advocating the need for health care workers to share information about the patients with the families, Van Tilburg et al. (2009) and Walden, Dracup, Westlake, Erickson, Hamilton, and Fonarow (2001) concur with Glanz et al. (2008) in asserting that proper information may negate the negative emotional challenges and potential difficulties that the parents/caregivers may experience in explaining the illness and treatment to a sick child and, as a result, this enables them to help the child to adapt to the changes that are brought about by the illness. Hence, and inversely, the cognitive ability of the parents/caregivers is likely to facilitate their coping effectively with caregiving at home (Raina et al., 2005).

In conclusion, indeed, effective communication to the patients and their caregivers is an empowerment tool which hopefully minimises the difficulties and poor coping associated with providing care at home (Paul, 2008 & Wählin et al 2006). Therefore, the health care providers should provide honest explanations and offer information about the continuity of care at home to the caregivers for children with heart disease.

4.5 THEME 4: THE CHILDREN EXPERIENCE DECREASED VITALITY

The fourth theme that was identified and which is exclusive to the children, relates to the children's personal appraisal of their quality of life as a result of being sick with a heart disease. In this regard, and in agreement with Bennet, Cordes, Westmoreland, Castro, and Donnely (2000), the child participants in this study disclosed that they were experiencing low physical vitality. The children explained that their experiences of decreased vitality take the form of physical dysfunction. This, as is explained in the next section, is, of course, the result of the adverse effects of the heart disease on the children's physiology (Davidson, Cockburn, & Newton, 2008; Bennet, Cordes, Westmoreland, Castro & Donnely, 2000).

4.5.1 Sub-theme: The children experience physical dysfunction

The experience of physical dysfunction among patients with heart diseases relates to the objective inherent facts in heart disease and which are the results of hemodynamic instabilities which include, among other things, a decrease in cardiac output and the subsequent decrease in oxygen delivery to the body systems. This, in turn, is responsible for the decreased vitality experienced by these patients (Coovadia & Wittenberg, 2007; Mogotlane et al., 2005; Arafa et al., 2008).

Some of the children with heart disease who participated in this study indicated impairment of physical functions and the subsequent degree of limitation in terms of physical activities. The impaired physical functions were characterised by an array of physical symptoms. In this regard, the children referred to becoming tired after physical activities, experiencing chest pain and

difficulty in breathing, insomnia and feeling bloated and nauseous (Bennet et al., 2000; Heo, Lennie, Okoli, & Morser, 2009; Dekker et al., 2009).

In addition, it was also possible to infer that the children were experiencing physical dysfunction from the implicit remarks of some children who, at the time of interview, were not even attending school because of the limitations imposed on physical activities by their illness.

However, despite the fact that the physiological effects of the disease are confined to the children, the parents and caregivers, when explaining the burden of the demands of providing care, also supported the children's submissions and explained that the children experienced physical discomforts which manifested in exhaustion after physical activities and the inability to perform routine household chores or to walk to school. As a result, in some instances, the child had to be escorted to and from school.

These findings are consistent with the claims made in previous studies about the association between the severity of the disease, coping and the quality of life of patients with heart disease. These studies maintain that patients with heart disease often present a self-report of their physical dysfunctions, including difficulty in running, difficulty in breathing and bodily weakness (Luzark, Jones, Slusher, Limbers, Burwinkle & Varni, 2008; Ulvik et al., 2008; Dunbar-Jacob, 2005).

Likewise, the findings of prior studies on the symptom burden of patients with heart disease concluded that patients with heart diseases are destined to experience a wide range of physical

symptoms, including a lack of energy, chest pain, and shortness of breath, insomnia and anorexia. These symptoms, in turn, all signal a compromised quality of life and, therefore, imply a heavier burden of care on the parents/caregivers (Blinderman, Homel, Billings, Portenoy, & Tennstedt, 2008). However, unlike the claims in other studies, which place more emphasis on the experience of psychological dysfunctions, the children in this study placed more emphasis on the experience of physical dysfunctions rather than on the psychological experience.

Nevertheless, the different experiences of the participants, the central concept which can be deduced from the description of such experiences is more demands for care on the part of the parents/caregivers and poor coping, hence, the need for facilitation to cope with the demands of caring at home.

In concluding the discussion on the experiences of the parents /caregivers and the children were summarised as follows in accordance with the framework of the Transactional Model of Stress and Coping and Kubler-Ross's stages of grief as discussed by Webb (2009).

4.5 APPLICATION OF THE TRANSACTIONAL MODEL OF STRESS AND COPING TO THE STUDY FINDINGS

According to the Transactional Model of Stress and Coping, in response to a stressful situation, both primary and secondary appraisals are employed and coping methods are utilised. As a result, coping outcomes may emerge (Glanz et al., 2008).

4.6.1 Primary appraisal

During primary appraisal, a personal threat from challenges, namely, an individual is either vulnerable or the challenge is severe, is perceived. However, an appraisal bias may be employed in terms of which an individual perceives him/herself as being invulnerable. The motivational relevance appraisal may also be employed when the challenge is perceived as having a major impact on one's goal and concerns. In addition, a focal cause appraisal, in terms of which the individual perceives him/herself to be responsible for the challenge, may be employed. The outcome of the primary appraisal is either the motivation to employ coping strategies or feelings of inadequacy and hopelessness and escape avoidance behaviour (Glanz et al., 2008).

In accordance with the notion of primary appraisals, the parents and caregivers perceived the conditions of their children as being severe and/or life-threatening. They then perceived a heightened vulnerability in respect of their children and this, according to them, constituted an insurmountable challenge which may affect all their dimensions of life (Glanz et al., 2008). At this point, in accordance with Kübler-Ross's stages of grief approach (as cited in Webb, 2009, p. 28), the majority of the parents and caregivers were in the anger stage and were overwhelmed by depression as signified by a sense of hopelessness with not one of them being able to express a

constructive acceptance of their children's condition. The parents/caregivers also employed a causal focus appraisal as to who was responsible for the plight of their children. In addition, the parents and caregivers also perceived the demands of care as being intense and taxing and, therefore, they have made an appeal for assistance to enable them to cope with the demands of care at home. The children with heart disease, on the other hand, employed the motivational relevance appraisal in terms of which they regarded their illness as having a major negative impact on their personal goals. In both cases, a heightened perception of vulnerability generated a sense of inadequacy and poor coping.

4.6.2 Secondary appraisal

During secondary appraisal, the personal resources for coping, or what the individual is able to do about the situation, are assessed. This involves the ability to manage one's emotional reactions, perceptions of one's ability to change the situation, and the expectations about the effectiveness of one's coping resources. Research has proved that there is a positive association between the perceptions of control over the situation, the ability to engage in health promotion behaviours, the degree of coping and resultant wellbeing. On the other hand, if it is not possible to control the situation, a perceived control may increase stress and poor coping. Accordingly, a low level of perceived control is a strong predictor of poor coping (Glanz et al., 2008; Dracup et al, 2004).

Likewise, the parents/caregivers of children with heart disease from the rural areas in Namibia do not perceive their ability to manage their emotional reactions and they also did not have the ability to perform the health promotion activities necessary to improve the quality of life for their

children. As a result, they experienced feelings of inadequacy and, hence, they were coping poorly with the demands of care at home.

In accordance with the notion of secondary appraisals, these parents and caregivers in this study perceived themselves as not having the resources (social and material support) to facilitate the care required by their children. Moreover, the parents and caregivers were experiencing problems harmonising the responsibility of providing care to their children with their other social responsibilities and, as a result, they asserted that they are not able to cope with the demands of care.

4.6.3 Coping

Following the primary and secondary appraisal, coping methods are employed. These coping methods include emotional regulation and problem management/problem focused coping. Emotional focused coping efforts are directed at changing the way in which one thinks and feels about the challenges. The emotional focused coping approach is essential when it is not possible to change either the problem or the situation. Examples of emotional focused coping methods include denial, avoidance, venting of feelings, positive reinterpretation, acceptance and use of spirituality (Glanz et al., 2008). On the other hand, problem management is directed at changing an alterable challenging situation. Examples of problem management coping methods include, inter alia, active coping and the seeking of information and social support.

Likewise, the parents/caregivers of children with heart disease either engage in emotional focused coping efforts to moderate the effects of the situation on them or else they engage in problem management coping efforts to resolve the problem. However, in this study, the

parents/caregivers were not engaging in coping and this option had resulted in their experiencing inadequacy and poor coping.

4.6.4 Coping outcomes

Coping outcomes refer to the functions of the individual's adaptation to the challenges. Coping outcomes follow the primary appraisal of the situation, secondary appraisal of the ability to control one's emotional reactions or the resources available to manage the situation and the coping effort that was made. Coping outcomes are, therefore, influenced by the individual's coping effort. An individual may achieve the following three outcomes, namely, emotional wellbeing, health behaviours and functional status/physiological mode, with the potential interaction of the outcomes (Glanz et al., 2008; George, 2008). However, as the parents/caregivers of the children with heart disease were not able to engage in constructive coping methods, they developed negative self-concepts and experienced poor coping with the demands of care. This, in turn, may compromise the quality of care and the quality of life of the children concerned. In other words, as illustrated in figure 4.1 below, the results of the primary and secondary appraisals of the situation resulted in poor coping on the part of these parents and caregivers.

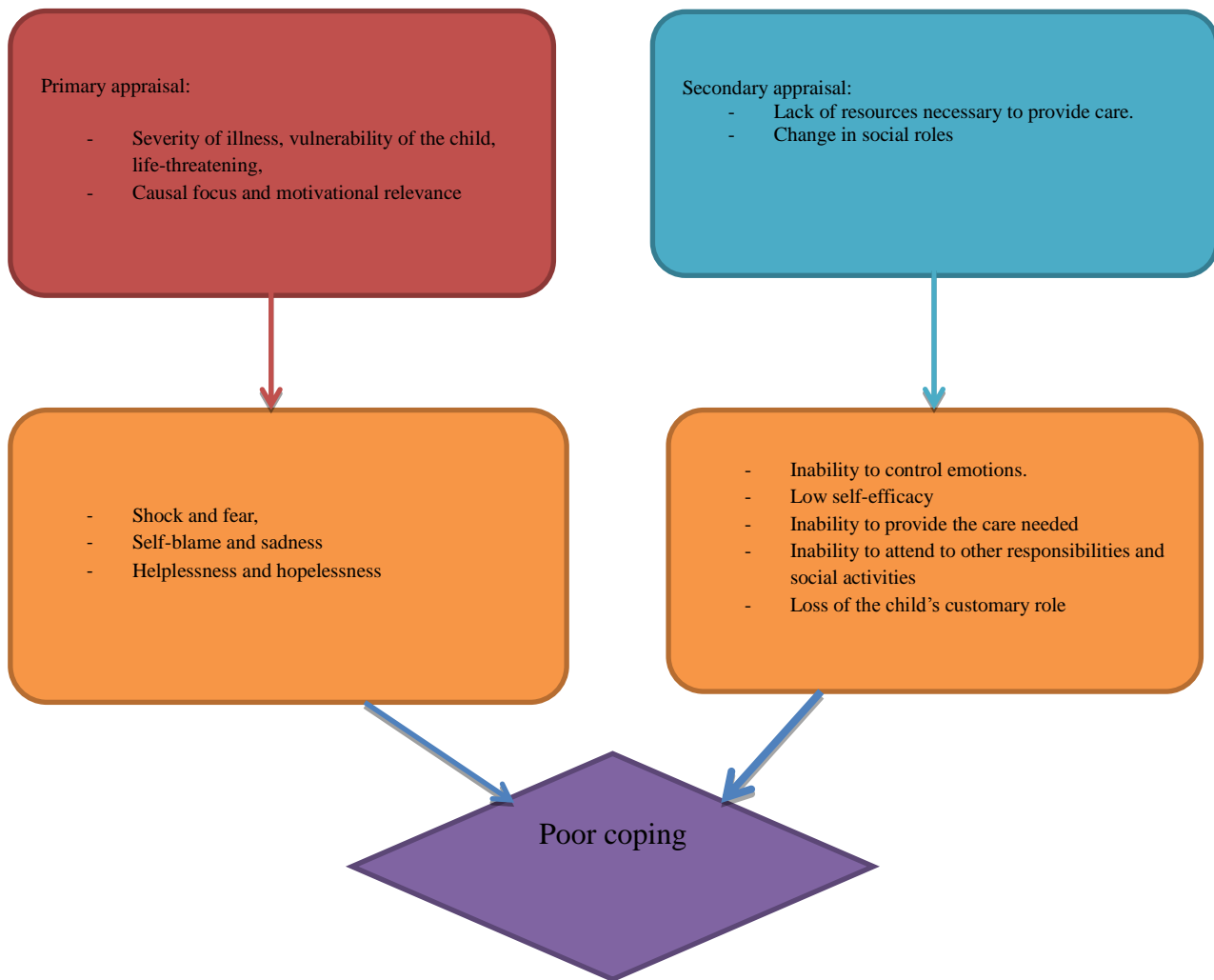


Figure 4.1: The parents'/caregivers' and the children's appraisals of their experiences

The experience of challenges depends on the way it is appraised by those affected. A given challenge may be perceived differently by different people. It is, therefore, the perceptions of the challenge which determine the behaviours aimed at coping and health outcomes (Glanz et al., 2008).

4.7 SUMMARY

This chapter presented the literature control in relation to the discussion on the experiences of the parents/caregivers as regards providing care to a child with a heart disease and the children's experiences of living with a heart disease. The discussion was based on all four themes, namely, the experiences of emotional challenges and disrupted social functioning and social relations on the part of both the parents/caregivers and the children, and the experiences of a lack of support and decreased vitality which were exclusive to the parents/caregivers and the children respectively. The findings were validated against the existing body of knowledge and current trends on the experiences of the caregivers as regards caring for a child or an adult with either a heart disease or any other life-threatening disease and specifically, the children's experiences of living with a heart disease. While experiences of challenging emotions and disrupted social functioning tend to support existing literature, the experience of extreme poverty which hinders the caregivers' effort to adapt to caregiving role at home emerged as new knowledge. In addition, the motivational appraisal of the effects of illness on the child participants in this student also emerged, to an extent as knew insight that contributes to the existing literature as regards caring for a child with heart disease, or else living with a heart disease.

The application of the Transactional Model of Stress and Coping to the findings was discussed. Thus far, some of the findings from this study have confirmed existing knowledge while others emerged as new knowledge. However, unlike in other studies where the negative experiences were mitigated by appropriate actions, much needs to be done to enable the parents/caregivers of children with heart diseases from the rural areas of Namibia to cope with the demands of care. The discussion of the findings concluded the first phase of the study. The next phase involves the

conceptualisation of the need to empower the parents/caregivers to cope with the demands of care at home. Chapter 5 describes the development of a conceptual framework of the study findings according to the three essential ingredients of a situation producing conceptual framework, as proposed by Dickoff et al. (1968).

CHAPTER 5

CONCEPTUALISATION

5.1 INTRODUCTION

In the previous chapter, the themes and sub-themes were discussed and a literature control conducted in order to place the findings from this study within the context of the existing literature. The discussions of the themes and sub-themes so far either confirmed the literature or else described the findings as new insights that may contribute to the existing literature. Accordingly, the need for support to the parents/caregivers in regard to coping with the demands of caring for their children as well as support for the children to adapt to living with a heart disease was identified. The conclusions drawn from the discussions of the findings are, therefore, used to guide the development of a conceptual framework for the study.

This chapter presents the inception of phase 2 of this study – the conceptualisation of or the researcher's abstraction regarding the research findings. A conceptual framework may be perceived as a guide for the development and the implementation of programme activities designed to address the challenging experiences of the parents/caregivers and the children in order to facilitate the parents'/caregivers' coping with the demands of care and the children's adaptation to the burden of living with heart disease (De Vos et al., 2007; Dickoff, James, & Wiedenbach, 1968).

Therefore, the conceptual framework for this study comprises the researcher's organised image of the agent (the one who is to perform the activities involved in the envisaged programme); the recipient (the one who is to receive the activities from the agent), the dynamics (the energy sources, purposes or motivation for the programme activities and which are, therefore, pivotal to

the agent-recipient interaction and facilitation process) and the context within which the experiences takes place and which is inclusive of the cultural and economic factors which are at play. Hence, there is a need to contextualise the agent-recipient interaction and the procedures in terms of which to address the dynamics and also whether they are both suitable to both the dynamics and the context. The discussion on the conceptual framework is concluded with a discussion on the terminus or the desired outcomes of the programme interventions.

Taking care of a child with a heart disease is a daunting task for both the parents and the caregivers. The parents or caregivers have to cope with specific problems and demands of palliative care to ensure optimal health for these children both before and after surgery.

However, it was suggested by the findings of this study that both the parents/caregivers and the children with heart diseases experience emotional challenges, disrupted social functioning and restrictive social relations as common negative experience of caring for a child with heart disease and of living with a heart disease respectively. Furthermore, it was also revealed that the parents/caregivers also experience financial burdens and financial difficulties related to providing care to their children with heart diseases while, from the children's perspective, once diagnosed with heart disease, they face specific challenges to their health, including impediments to their daily activities of living. This was referred to in the children's assertions that they experienced decreased vitality (chapter 4 – theme 4 and its sub-theme). In turn, these challenges often translate into demands for more care from the parents or caregivers.

The above mentioned conditions resulted into poor coping on the part of the parents/caregivers, as was manifested in a state of psychosocial turmoil, characterised by shock, disbelief, sadness,

self-blame, fear, feelings of helplessness and hopelessness and social dysfunction as well as depression on the part of the children.

The conceptual framework for this study is, therefore, aimed at guiding the development of the programme content and the procedures involved in the implementation of a home-based health care programme which is aimed at assisting the parents/caregivers of children with heart disease so as to enable their coping with the demands of care and, as a result to facilitate the desired outcome of quality of life for both the caregivers and the children.

5.2 IDENTIFICATION OF CENTRAL CONCEPTS AND ASSOCIATED CONCEPTS

In the context of this study a central concept refers to the definition of the caregivers' coping as described in the discussion of the findings, synthesis of possible solution to poor coping and the desired outcomes of the home-based health care programme interventions as the facilitation of parents and caregivers to cope with the demands of care for their children with heart disease at home (George, 2008).

Based on the findings of this study, it would appear that the parents or caregivers need to be vigilant in order to provide their children with the necessary care. However, vigilance and providing the required care presupposes that the parents or caregivers are in possession of the necessary knowledge and skills and that financial assistance and support systems are in place. It is, therefore, obvious that there is an urgent need for the empowerment of the parents and caregivers and even the children if the parents/caregivers are to cope with the demands of caring

for their children with heart diseases and the children are to cope with the burden of disease. However, this need will have to be met through counselling, motivation, the transfer of knowledge and skill training to enable the parents or caregivers to make use of the appropriate coping methods and social resources, all which may enhance coping, for the caregiver, provision of safer home-based care for the child and therefore facilitate positive outcomes for the children (Van Tilburg et al., 2009).

Accordingly, based on the empirical data of the first phase of the study, the following central concept was identified by the researcher: **“The parents and caregivers cope poorly with the demands of caring for their children who have heart disease and they need to be empowered to enable them to cope with providing a continuum of home-based care to their children with heart disease.”**

The associated concepts include those characteristics of the parents or caregivers which serve as antecedents of their own empowerment. These characteristics include the possession of knowledge and skills, a sense of responsibility, willingness and self-efficacy (George, 2008; Ågren, 2010). These characteristics are described in details in the section on the characteristics of the recipient. The aim of empowering the parents or caregivers is to provide them with the knowledge and impart the skills required to enable them to cope with the demands of the daily care activities and care expectations in respect of their children with heart diseases at home.

The concept of coping has different meanings in different contexts. For the purpose of this study, coping refers to the ability of parents and caregivers to deal with the changes imposed by the demands of caring for their children with heart disease. Coping may be regarded as a cognitive

and behavioural effort to manage specific internal (emotional experiences) and external (care activities) demands which are regarded as taxing or which exceed the resources or the ability of the individual concerned (Glanz et al., 2008; Kozier & Erb, 2008). In the context of this study coping is referred to as the parents'/caregivers' experiences of inner strength and self-determination to provide care for their children at home and within their socio-economic context. Imparting knowledge and skills to these parents and caregivers would, therefore, empower them to meet the demands of providing vigilant and complex care for their children with heart disease at home (George, 2008).

5.3 THE CONTENT OF A CONCEPTUAL FRAMEWORK

The conceptual framework for the programme in this study was constructed according to the three essential ingredients of a situation producing conceptual framework, as proposed by Dickoff et al. (1968). These three essential ingredients are:

- The goal-content, which is the aim of the conceptual framework or the articulation of the desired situation which is to be brought into existence (Dickoff et al., 1968). In the context of this study, the goal was to develop and implement a home-based health care programme aimed at assisting the parents and caregivers of children with heart disease in order to facilitate their coping with the demands of providing care at home.
- Prescription for activities, which is the specification of, or the directives for, the actions to be taken. These activities must be appropriate and, therefore, suited to leading to the realisation of the goal content (George, 2008; Dickoff et al., 1968). In the context of this

study, the activity prescription or directive refers to the identification of the following six points in respect of the prescription of activities aimed at realising the desired goal:

- Who is to perform the activity (Agent)
- Who is to be the recipient of the activity (Recipient)
- In what context is the activity to be performed (Context/framework)
- What is the end point of the activity (Terminus)
- What is the guiding procedure, technique or protocol of the activity (Procedure)
- What are the energy sources for the activity (Dynamic) (Dickoff et al., 1968)?

These six points in respect of activity prescription serve as an organising principle for the third essential ingredient of a situation-producing conceptual framework, namely, the survey list.

- The survey list comprises the identification of the major concepts of the activity prescription, namely, agent, recipient, framework or context, terminus, procedure and dynamic (Dickoff et al., 1968). In this study, the major concepts are placed in a relational order of casual connection of the agent, recipient, framework or context, procedure, dynamic and terminus, therefore ensuring a logical development and implementation of the recommended home-based health care programme according to which activities are prescribed, both now and in the future, in order to realise the goal or aim. This is in line with the suggestions of Dickoff et al. (1968).

5.4 THE RESEARCHER'S REASONING MAP

The survey list of Dickoff et al. (1968), which comprises the agent, recipient, framework or context, procedure, dynamics and terminus, was employed as a reference for the formulation of a conceptual framework for the purposes of this study. The purpose of the framework is to identify, categorise and describe the major and related concepts and describe their implications for the programme aimed at empowering the parents and caregivers so as to enable them to cope with providing home-based care to their children with heart disease or who may have to undergo heart surgery.

Based on the context of Dickoff et al.'s (1968) survey list, this chapter presents the characteristics of the agent for the facilitation of a home-based health care programme, the essential characteristics of the recipients (parents/caregivers) to enable them to be receptive to learning how to care for their children with heart disease, the context for the implementation of a home-based health care programme and the dynamics as the driving forces or the motivation behind the home-based health care programme.

The following chapters present the procedures and the terminus as discussed under the development, implementation and evaluation of the home-based health care programme. The researcher's reasoning map, which was developed for this study, is presented in figure 5.1 below.

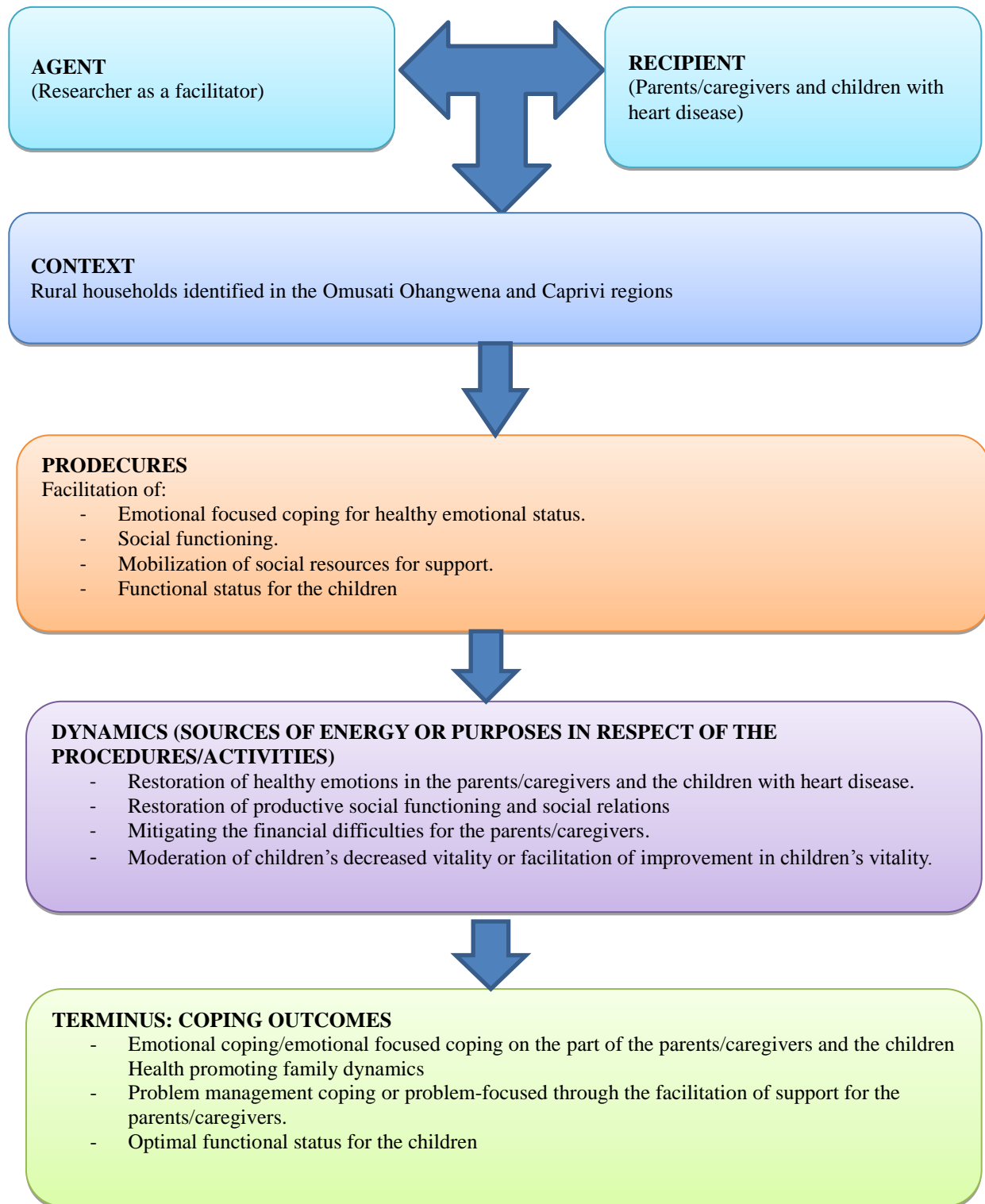


Figure 5.1: The researcher's reasoning map

The researcher's reasoning map represents the interaction and facilitation between the agent and the recipient, which is contextualised within a specific framework (the recipients' socio-economic and cultural background), whilst acknowledging or taking cognisance of the dynamics underpinning the interaction and the facilitation process. Both the context and the dynamics determine the procedures to be followed in order to attain the required outcomes. The terminus or the outcomes, namely, coping on the part of the parents or caregivers as well as the children are the functions of the effects of the procedures on the recipients and the context. In view of the fact that the six ingredients of Dickoff et al. (1968)'s survey list were adopted for the formulation of the researcher's thinking map, their individual applicability to this study is described in the next sections.

5.4.1 The Agent: The researcher as a facilitator

The concept "agent" refers to the person who performs the activities (Dickoff et al., 1968) and, in addition, who possess the skills and confidence required to render care and counselling with compassion and understanding of those in need of care in order to realise the desired situation (George, 2008; Meyer, 2004). For the purpose of this study, the agent is the researcher or else the agent may be any professional health worker who has to facilitate the activities for the development, implementation and evaluation of a home-based health care programme for the parents or caregivers of children with heart disease in order to facilitate the parents/caregivers coping with the demands of providing care at home.

5.4.1.1 The characteristics of an agent

In order to realise the desired situation, an agent ought to possess personal or internal strengths as well as the external strengths or resources as the prerequisites for a successful facilitation as regards the realisation of the desired situation. As was discerned from the literature, the two internal strengths or resources of the agent that are regarded as essential and which are applicable to the facilitation of a home-based health care programme for the parents and caregivers of children with heart disease for the purpose of facilitating coping are: value-including clarity of purposes, interest, knowledge and skills, competency and commitment and, the ability to establish and sustain a purposeful working relationship with the recipient characterized by dedication towards fulfilling the purpose (George, 2008; Dickoff et al., 1968).

Value: The concept of “value” refers to an accepted standard in respect of a person or a social group or else a quality that is desirable or highly regarded. Value refers to those desirable characteristics which serve as the measurement criteria for the agent’s actions (George, 2008). For the purpose of this study, value refers to the manifestation on the part of the researcher (and facilitator) of the standard which was expected of her as a professional health worker and includes, clarity of purpose, interest, mastery of requisite knowledge and skills, motivation, competency and commitment as explained below (George, 2008).

Clarity of purposes: Clarity of purposes refers to the delineation or the specification of the agent’s responsibility in the prescription in respect of the realisation of the desired situation (George, 2008). Clarity of purposes is explained in terms of the definition of the terminus or the desired situation that the agent wishes to bring into effect and sustain. In other words, clarity of purpose refers to the end result that the agent wishes to accomplish through his/her actions. For

the purposes of this study, the researcher's purpose is to develop and implement a home-based health care programme aimed at assisting the parents/caregivers to cope with the demands of caring for their children with heart disease.

Interest: Interest is an affective state, a specific person-objective or person-experience relationship of enjoyment which is derived from an individual's interaction/encounter with the phenomenon or environment in question (Krapp, 2005; Pecru, Goetz, Titz; Perry, 2002). It has been proved that interest may influence the level of both performances and endurance. In this study the researcher adopted the philosophical postulation made by the proponents of health promotion, who advocate for the engagement of health professionals in the processes of enabling people to increase their control over the determinants of their own health and, thereby, to improve their health status (WHO, 2010). Therefore, the researcher had an interest in prescribing procedures and appropriate actions to be implemented as enabling factors within the context of the parents/caregivers and the children with heart diseases as the recipients in order to facilitate the former's coping with the demands of providing care to these children.

Mastery of knowledge and skills: Knowledge refers to factual and interpretive information that leads to understanding and which is useful as regards taking informed action, while skills refer to the ability to enact the knowledge that has been acquired (Glanz et al., 2008). Mastery of knowledge refers to the state of being skilful in the execution of tasks or activities and, therefore mastery of knowledge is a prerequisite for success. The researcher, as an agent, is a 'health expert' who understands the demands of caring for patients with heart disease, the necessary resources which are required to facilitate the care that is needed and the health care interventions

that must be provided to meet such demands (Major, 2003). Accordingly, the researcher played the role of helping the parent/caregiver participants to secure knowledge and skills, coping methods and social support as the essential resources that are necessary for them to provide safe care for their children with heart disease at home and which, in turn, facilitate their coping with the demands of providing care and promote the subsequent positive health outcomes of their children.

Competency and commitment: Competency and commitment refer to the agent's state of being knowledgeable and skilful in what he/she is pursuing and providing the recipient with what the latter deserves (Egan, 1998). Accordingly, it is essential that the researcher was competent in the activities to be implemented to enable the parents or caregivers to learn and, as a result to cope with the demands for care at home.

Motivation: Motivation may be defined as the inner strength necessary for persistence in pursuing a specific action under particular circumstances and is influenced by the internal motive and external drive such as beliefs and environmental reinforcement (Wåhlin, 2009; Glanz et al., 2008; Barre & Schaine, 1996). Therefore, the researcher as an agent is motivated by the belief in assisting the patents and caregivers to cope with their situation at home.

- **Ability to establish and sustain a purposeful working relationship with the recipient:**

The agent–recipient relationship is of the utmost importance and, as such, it needs to be characterised by positive regard, accurate empathy and genuineness on the part of the agent towards the recipient in order to realise the goal of the helping process (Egan, 1998). Accordingly, it is incumbent on the researcher to maintain a positive regard for the recipient, by acknowledging that the recipients are human beings who have the ability to learn and use the knowledge acquired to make informed decisions necessary to improve their situations. It is essential, however to note that any excess of empathy be avoided to prevent reinforcing the recipient’s experience of helplessness and hopelessness. In addition, the researcher must display genuineness through listening to and observing (understanding) what is important to the recipients, according to the context of the individual recipient (keeping the client’s agenda in focus) and without judging the recipient’s limitations (Van Tilburg et al., 2009; Egan, 1998). Moreover, understanding and dedication on the part of the agent are characteristics that may enhance a purposeful working relationship with the clients and, as such, these qualities are to be maintained.

Understanding: With regard to the agent, the concept of understanding denotes a tolerance towards the recipient. Understanding is often influenced by the knowledge and skills possessed by the parties involved. For the purpose of this study, tolerance refers to the ability of the researcher to approach the parents or caregivers with respect, openness and sympathy (Gogineni, 1998). Webb (2009) maintains that the agent is expected to acknowledge the parents/caregivers as individuals who have strength, unlimited capacity and the aspiration to grow and change and, in collaboration with the agent, they will be enabled to attain success within their own contexts.

Dedication: Dedication is a pledge, a devotion or commitment to the fulfilment of the purpose (Wåhlin et al., 2009). For the purpose of this study, dedication refers to the researcher's resolve to improve the situation of the children with heart disease by empowering their parents or caregivers as a result of equipping them with methods of coping with the demands of care and with the knowledge and skills to enable them to provide safe home-based health care interventions (George, 2008; WHO, 2002; Dickoff et al., 1968;). Figure 5.2 summarises the essential characteristics that are expected of the agent.

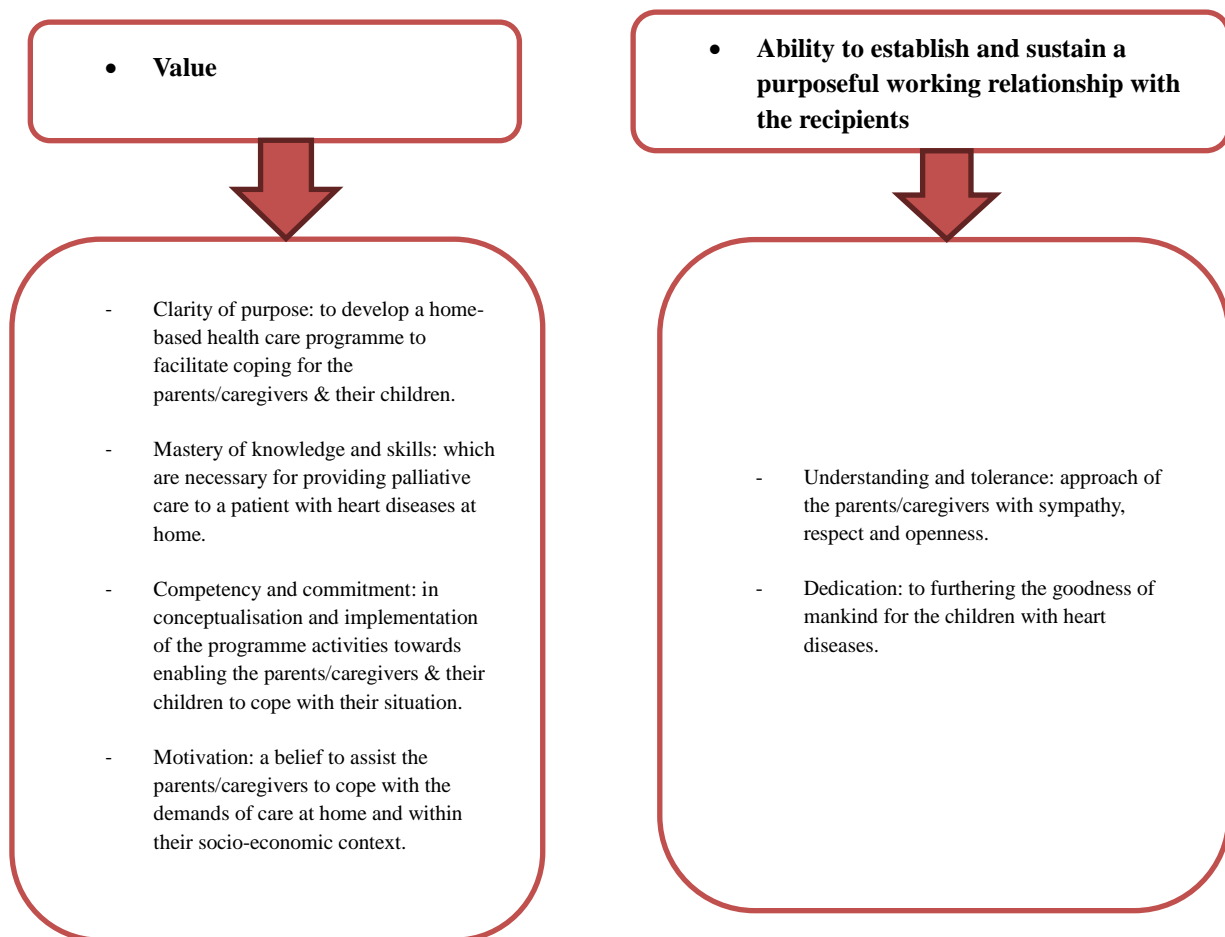


Figure 5.2: The essential characteristics of the agent

5.4.2 The recipient: The parents/caregivers of children with heart disease.

The recipient refers to any person who, for his/her benefit and in interaction with the agent, receives action from the agent in order to realise a goal or a desired situation (Dickoff et al., 1968). For the purpose of this study, the recipients are the parents and caregivers and, to an extent, the children with heart disease who, in an interaction with the researcher as an agent and through the procedures and activities, would be empowered with the characteristics which would enable them to cope with the demands of caring for their children with heart disease and who are living with the burden of heart disease respectively. Nevertheless, the discussion of the recipients' characteristics in this study is focused on the parents and caregivers as it is them who are playing a major role in realising coping with the demands of providing care at home.

The literature has proved that empowerment starts with the self. Based on that assumption, the parents or caregivers, as the individuals who are responsible for providing care for their dependent children, and, therefore, who are the recipients of the procedures and actions geared towards their empowerment, should, firstly, possess the required characteristics or qualities as described in the next section (George, 2008).

5.4.2.1 The characteristics of the recipients

As was discerned from the literature, the characteristics that are regarded as essential if the parents/caregivers are to be both responsive and receptive to learning how to provide care for their children with heart disease and how to cope with the demands of care as the desired outcomes include the following: sense of responsibility, understanding, knowledge, willingness, motivation, confidence or belief in what one does and self-efficacy or the belief in one's own

ability to change the situation (Wåhlin et al., 2009; George, 2008). These qualities could all assist in empowering the parents and caregivers and, therefore, enabling them to provide the necessary care to their children at home.

As a consequence of empowerment, the parents and caregivers would be both competent and confident and, as a result, they would be able to provide appropriate and safe care to their children. The following section contains a description of these qualities in order to illustrate their relevance and applicability to the parents or caregivers of children with heart disease as the recipients of the activities of the envisaged home-based health care programme to facilitate their coping with the demands of providing care at home.

Responsibility: Responsibility denotes the individual's availability and accountability towards those who are dependent on him/her (Stajduhar et al., 2008; George, 2008). In the same vein, the parents or caregivers of children with heart disease are responsible for providing care and meeting the demands of care for these children at home.

Understanding: Understanding refers to a state of being insightful and sympathetic towards another person (Gogineni, 1998). The parents/caregivers are expected to have an understanding of the nature and complexity of heart disease and its effects on their children as human beings and, therefore, to acknowledge their responsibility to provide care, alleviate suffering and promote the comfort of the children.

Knowledge: With regard to the recipients, knowledge refers to the possession of facts and the interpretation of information which leads to the information being useful as regards taking an

informed action (Glanz et al., 2008; Aljandro, Huberto, & Augustin, 2008). Parents and caregivers need to be assisted to understand the children's illness and the types of care demands and various care options that accompany the illness as these, in turn, affect the need for parental presence and the ability of the parents/caregivers to provide care. At the definitive level, and in addition to the knowledge of other tasks of caring, it is recommended that the parents/caregivers have adequate knowledge of how to perform specific caring activities to meet the demands of caring for their children at home inter alia the medications, dosages and their side effects in order to avoid lethal consequences from errors in administering medication as well as knowledge for the preparation of diet for the child (Strömberg, 2005; Ågren, 2010).

Understanding the illness and the expected course of the illness places the parents or caregivers in a better position to plan the appropriate care activities as well as to effect effective role negotiation by the family members (Deyirmenjian et al., 2005; Major, 2003). A degree of knowledge about the expected course of an illness also places parents in a better position to plan and carry out effective role negotiation.

Willingness: Willingness is defined as the power of mind to make decisions and act in accordance with these decisions (*Longmans Dictionary of English and Culture*, 1992, p. 501). Therefore, willingness is a desire which serves as a driving force to engage in action (George, 2008). By implication, a willing parent would, adopt positive attitude and be prepared to learn the required skills, and implement the behaviours which would facilitate their coping with the demands of providing care at home. The desire to perform and the actual performance of the activities would result in the next characteristic, namely, self-confidence or self-efficacy.

Self-efficacy: Self efficacy is a sum of personal judgment and beliefs about the personal capability to accomplish the task by one's own resources and action, even in the face of obstacles (Sniehotta, Scholtz, & Schiwarzer, 2005). Self-efficacy therefore refers to an intrinsic motivation which may influence cognitive ability and motivation and the possession of which is associated with success (Holstermann, Grube & Bogeholz, 2009; Hadley, Hair, & Anderson Moore, 2008).

With regard to this study, self-efficacy refers to the parents'/caregivers' personal judgment and belief in their ability to master the knowledge and skills which are necessary for them to provide appropriate instrumental and emotional care for their children, who have heart disease at home and the ability to meet the challenges as they arise (Deyirmenjian et al., 2005). The patents/caregivers are, therefore, expected to possess a strong sense of self efficacy, as may be demonstrated by a strong motivation to master the requisite knowledge and skills, being organised, confidence and the ability to take control of the situation at home. Figure 5.3 presents a summary of the ideal characteristics of the recipients.

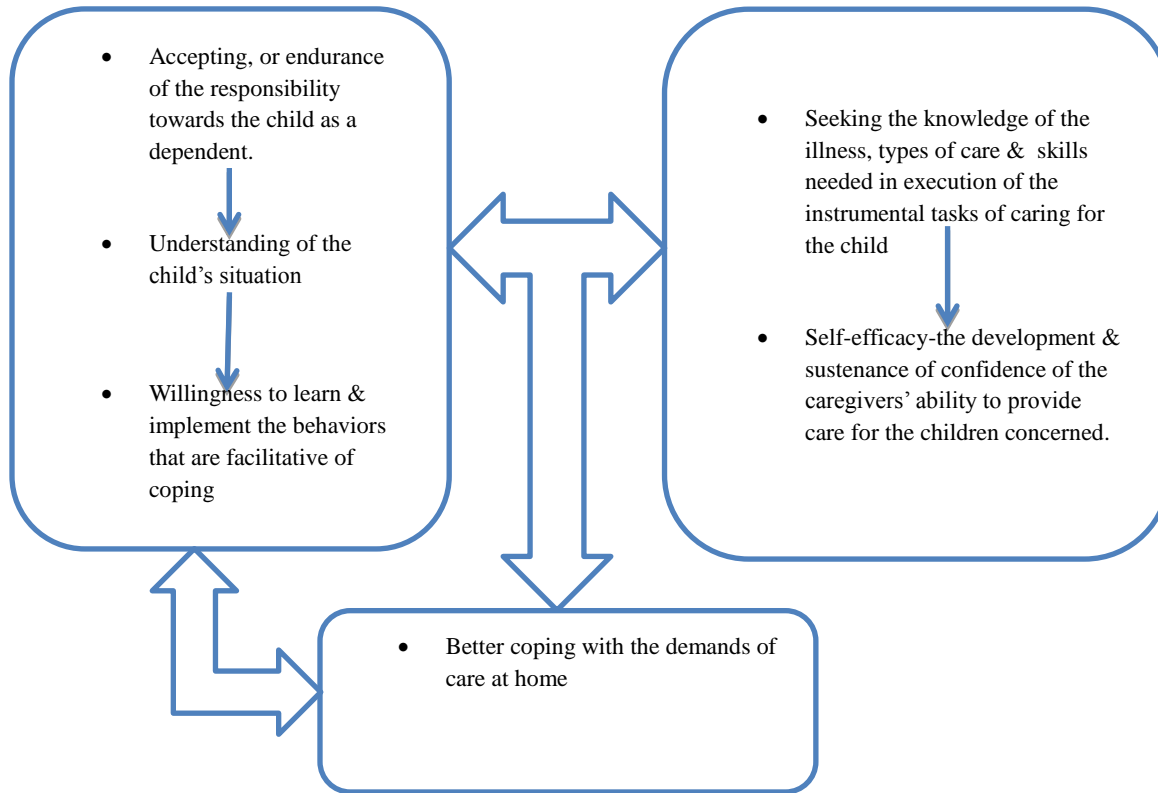


Figure 5.3: The characteristics of the recipients (parents/caregivers)

Figure 5.3 explains that, in a reductionist mode, a sense of responsibility on the part of the parents and caregivers is likely to reinforce their understanding and sympathy towards the child. As a result, the parents/caregivers perceive the need to learn to enact the behaviours that facilitate coping and they become efficacious in providing care to their children and therefore coping with the demands of caring. In addition, knowledge and self-efficacy reinforce a sense of responsibility, understanding and willingness to provide care to the child while, as regards their supportive relationship with the child, confidence and better coping enhances the parents'/caregivers' feeling of responsibility towards the child and their understanding of the child's plight.

5.4.3 Context/framework: Rural households from a low socio-economic background and headed by a subsistence agricultural farmer

According to Silverman (2010), a context is a situation, a framework, socio-economic background or a setting in which the activities are presented and its relation to the recipients, dynamics and the procedures or interventions aimed at realising the goal (Dickoff et al., 1968).

For the purpose of this study, the context refers to the situation – the two households in which the programme activities were implemented in the Omusati region. This context consisted of the parents or caregivers, aged between 29 and 49, and their children with heart disease who are between the ages of 12 and 17, living in rural households from a low socio-economic background and headed by an agricultural subsistence farmer. The cultural and economic factors which were at play had a bearing on both the agent-recipient interventions and the procedure aimed at facilitating empowerment (Dickoff et al., 1968). These characteristics were discussed in regard to the section on sampling in chapter 2 – the chapter on the research methodology.

5.4.4 Procedures

The concept of “procedure” refers to the guiding rules, protocols or the techniques according to which activities are to be performed. In the context of this study procedure refers to the pattern or steps to be taken in the implementation of the programme, while taking into consideration the context in which the programme is implemented (Dickoff et al., 1968).

For the purpose of this study, procedures imply the tasks or the responsibility of the researcher as an agent in empowering the parents/caregivers and the specific interventions to be performed during the researcher-parents interactions and which were aimed at empowering the parents/caregivers for the latter to cope with the demands of caring for their children with heart disease.

In this regard, procedures were necessary for the parents/caregivers to learn coping methods and through participation, to acquire knowledge and skills that they need for them to provide appropriate care for their children concerned. These procedures or interventions focused on emotional and problem solving coping, which is inclusive of supportive family dynamics and social support to the parents/caregivers and also on improving the physical functional status of the children. Chapter 6, which deals with the programme development, contains a detailed discussion of the procedures, while chapter 7 deals with the implementation of the programme activities.

Workshops on procedures that facilitated information sharing with the parents/caregivers (and to an extent the children) such as face-to-face counselling, information sharing, discussions and

demonstrations of interventions for home care are to be conducted at the households of the participants to teach them methods of coping and to create awareness of the community-based resources that they could access for social support. In addition, the interventions for the programme implementation serve as a reference for the evaluation of the programme outcomes. Therefore, the procedures or programme interventions also implied the evaluation of the outcomes for programme implementation on the recipients (See chapter 7 on programme evaluation.)

5.4.5 The dynamics

The concept of dynamic refers to the energy sources, purposes or the motivation behind the interventions (Dickoff et al., 1968). The dynamics which were arrived at in respect of facilitating the parents'/caregivers' coping with the demands of care are: restoration of healthy emotions for the parents/caregivers and the children, restoration of productive social functioning and social relations for the parents/caregivers and the children, mitigation of financial difficulties for the parents/caregivers and moderation of decreased vitality for the children. These dynamics are intended to mitigate the potential impacts of the negative experiences as were discussed under the themes in chapter 4. In other words, the dynamics are the energy sources or the motivations for the envisaged home care programme interventions. These dynamics are discussed in the following sections.

5.4.5.1 Dynamic 1: Restoration of healthy emotions in the parents/caregivers and the children with heart disease.

This dynamic is focused on the mitigation of

- **Shock, disbelief, sadness, fear and self-blame on the part of the parents/caregivers and depression on the part of the children with heart disease**

Shock, disbelief, sadness, fear, self-blame, depression and anxiety are all manifestations of disequilibrium and the maladaptation which have come about as a result of emotional responses to changes and demands and which, in turn, require counteractions in order to restore the balance (Higgison & Gao, 2008; Glanz et al., 2008).

In this regard, it is suggested that there is a need for the parents/caregivers to receive counselling. Counselling enable the parents/caregivers to strike a balance between acknowledging the child's symptoms and use emotion focused and problem focused coping adapts to the caring role of providing care and therefore coping with the demands of care.

In addition, and because the children's ability to cope with the symptoms is closely related to the emotional reactions of the parents/caregivers to the children's condition (Ulvik et al., 2008; Stajduhar et al., 2008), it is essential that the parents display healthy emotions in the course of providing care. Emotional control on the part of the parents/caregivers is likely to translate into the children assuming own control over the symptoms, perceiving positives in their situation and not always taking their situation seriously (Van Tilburg et al., 2009; Shu-Fan et al., 2007).

Furthermore, the literature has proved that it is of the utmost importance that those who are affected by a situation accept the situation and take things "one day at a time." In other words,

they should take a positive approach to the situation, cherish each day they have with the patient and not to become discouraged by the reality that lays ahead (Stajduhar et al., 2008). In this regard, studies indicate that there is a direct relation between the emotional wellbeing of the caregivers and better health outcomes for the recipients of care because the caregivers' emotional wellbeing facilitates adherence to the medication, diet and other instrumental tasks that need to be performed for the recipient of care (Sayers et al., 2008; DiMatteo, 2004). It is, therefore, important to ensure that the programme interventions include activities that facilitate the emotional coping effort of the parents/caregivers. A healthy relationship between the caregiver and the child is another aspect that is essential for the restoration of healthy emotions.

- **Reinforcement of a healthy parent/caregiver-child relationship to avoid the parents/caregivers overprotecting the children**

The literature has proved that illness may change the nature and quality of the relationship between the caregiver and the sick person. From the caregiver's perspective, this is more marked if the caregiver has a kinship relationship to the recipient, for example, parents may display resentment if their child becomes ill. The parents/caregivers may also deem it necessary to provide extra emotional care in a form of empathy and, perhaps, sympathy (Ågren, 2010; Stajduhar et al., 2008). However, it would appear that, if the caregivers are able to strike a balance between acknowledging the child's plight and hiding their emotions from the child, this is likely to mitigate the impact of the negative emotional experiences and facilitate coping (Van Tilburg et al., 2009; Stajduhar et al., 2008).

Therefore, there is a need for the parents and caregivers of these children with heart disease to learn to hide their emotions and develop inner strength in order to promote the wellbeing of the children. As indicated in the discussion on the mitigation of negative emotions in the previous section, healthy emotions on the part of the parents/caregivers may influence the recipients' health outcomes. However, the feelings of inadequacy, helplessness and hopelessness are still important emotional aspects which must be addressed in order to facilitate coping with regard to the parents/caregivers in this study.

- **Mitigation of feelings of inadequacy, helplessness and hopelessness which may result from caring for a child with a heart disease**

Feelings of inadequacy, helplessness and hopelessness have to do with the belief that there is nothing else one is able to do about a certain life situation with helplessness leading to hopelessness (Egan, 1998).

However, the literature has proved that if the parents and caregivers are able to exercise control over their situation, it may be possible for them to display positive expectations and they are then likely to engage in actions which would help them to realise positive expectations. This, in turn, results in improved coping. Accordingly, and as the literature proposes, it is essential that the parents and caregivers be challenged and encouraged to start engaging in actions and attitudes which enhance experience of empowerment and foster hope and facilitate coping (Wåhlin et al 2006).

Despite the fact that the parents/caregivers are not able to correct their children's physical disabilities/heart disease, it is, nevertheless, possible for the parents/caregivers to learn to

exercise some form of control over the way they perceive their children's situation and not to regard themselves as the victims of circumstance. In this regard, the researcher is of opinion that the parents/caregivers should be encouraged to perceive their children's situation as a challenge, maintain a brave front and build a positive vision of future for the children by interacting with their children in a constructive way and showing caring and warmth (Boyse, Boujaoude, & Laundry, 2011; Kettunen, Oskiparta, & Liimatainen, 2011).

- **Reinforcement of the hope for a cure for the child**

It is critical to note that no issue is more important for both the parents/caregivers and the children living with a heart disease than rejecting "defeat" and looking forward with hope. The uncertainty about the course of the illness and its outcomes raises the issue of hope. Hope is a feeling that things will, in fact, turn out for the best. In other words, hope is a belief that a desire will be fulfilled in spite of current adversities (Webb, 2009) and, to hope means to look forward with confidence. Therefore, in spite of all the adverse experiences which the parents/caregivers encounter, they should still be encouraged to hope for better health outcomes and a better life for their children. If the parents/caregivers are able to hope for the best, they are likely to be optimistic in terms of the care they provide to their children and, hence, they are more likely to cope with the demands of care. As a result, it is essential that the parents/caregivers are encouraged to cultivate a sense of hope, optimism and spirituality or faith-the catalysts and sources of strength which help an individual to adapt to changes (Cox et al., 2009; Brosig, Kupst, Pierucci, Kupst & Leuthner, 2007; Sittner et al., 2007).

In addition, the parents and caregivers should engage in actions which promote coping and positive health outcomes for their children, including being optimistic, seeking information and making use of the social support systems which are available to them (Ulvik et al., 2008; Glanz et al., 2008; Egan, 1998). All these initiatives may instil in the caregivers hope for positive health outcomes for their children.

5.4.5.2 Dynamic 2: Restoration of productive social functioning and social relations for the parents/caregivers and the children

This dynamic is focused on promoting supportive family dynamics, facilitating productive social relations and social functioning, facilitating support from social organisations and imparting knowledge about the children's disease and treatment outcomes to the parents/caregivers.

In this regard, it would appear that the following support systems ensure a sense of security for the parents and caregivers of children with heart diseases in the rural areas, namely, availability of family support, access to relevant, timely and clear information and the availability of health care systems and other social system which may provide the necessary support. Having a supportive network of family and friends, be it in person or via other forms of communication that provide either practical, hands on help or whom can offer a listening ear to parents and caregivers are crucial in helping the parents or caregivers to cope with their situations.

- **Promotion of supportive family dynamics.**

Luttik, Jaarsman, and Veeger (2007) are of the opinion that the negative experiences, compounded by the requirement to provide instrumental care such as assisting with providing for the basic needs of the family member who is not able to care for him/herself, may be a burden on the primary caregivers (Luttik et al., 2007). The experiences of the parents/caregivers in this study provide testimony to this statement. These study findings are in agreement with the existing theoretical assertions that providing care to a patient with a grave illness is often reported to be taxing to the primary caregiver. A primary caregiver who is absorbed by the illness of a family member may, ultimately, break down in ways that impact negatively on the health of the family member who is sick (Cox et al., 2009).

Accordingly, the literature suggest that, in order to ensure ‘balanced coping’ on the part of the caregiver, the functionality of a supportive family system is critical to manage the illness effectively and to ensure that the demands of care are met without sacrificing the individual need for self-care on the part of the primary caregiver. Supportive family dynamics include supportive relationships that support, protect and satisfy the needs of family members, especially during times of adversity and change. Supportive family dynamics are, therefore, essential to enable the family to deal with a crisis in a constructive manner and to emerge from the crisis and accompanying challenges. Such families are likely to adapt to challenges successfully and there are more likely to be significantly better outcomes for the family members (Anderson Moore, Whitney, & Kinukawa 2009; Sittner et al 2007; Walsh, 2006; Krysan, Moore, & Zill, 1990).

Furthermore, the literature emphasizes that cooperation among family members is vital as regards the attainment of optimal health outcomes for the relative who is not able to care for him/herself. As such, it is important to improve the quality of family relationship in the interests of the patient concerned. In this regard, shared care provides the opportunity for all members of the family to contribute to and be responsible for the care and treatment outcomes of the children with heart disease (Rook, Sorkin, & Zettel, 2004).

Although the central concept of this study focuses on the parents or the caregivers who are the primary caregivers and partners in the child's health management, there is also the recognition that the child's illness must not be allowed to dominate the primary caregiver's life. Supportive family dynamics are necessary to enable the primary caregiver to cope with the demands of care (Sittner et al, 2007; Major, 2003). Based on the suggestions above, it is deemed necessary to assist the families of children with heart disease to implement the required adjustments and adaptations to the need for providing care for the sick child. The parents and caregivers play a central role in providing care to these children at home and it is, therefore, important that a form of family support system is available to them as this will restore a sense of security. Figure 5.4 demonstrates the significance of family dynamics in restoration of productive social functioning and social relations.

In utilising the concept of a role theory, the parents/caregivers and other family members should first be guided to understand the child's current health care needs and to anticipate future needs for them so as to enable them to develop the caregiver's roles and to find ways in which to balance the need (for presence) to attend to the child and the ability to fulfil other roles. Based on

role demands for caregivers, it is essential that the role set be defined by defining the role of everyone who has a direct role in caring for the child to ensure that the child receives adequate care and without sacrificing the individual need for self-care on the part of the primary caregiver.

The definition of the role set requires that the child be included as, when appropriate, the child will play a major role in determining and meeting her/his own care needs. As a result, the role demands of the parents or caregivers and the role set for the child must be defined, the resources and barriers in respect of the existing roles be recognised, while the negotiation and integration of roles or contingency planning among reliable family members (depending on the competences and efficacy of each family member) should be ascertained in order to meet the care requirements of the child while ruling out the possibility of role ambiguity, role overload and the associated poor coping on the part of the primary caregiver (Major, 2003).



Figure 5.4: Supportive family dynamic

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A focal caregiver who taps into supportive family dynamics copes with the demands of care and provides adequate and safe care that enhances the quality of life of the child with a heart disease. In addition, siblings who are able to tolerate the sick child's limitations may help the sick child to build on his/her success and to develop pride in him/herself without the frustration of trying to force him/herself to perform strenuous physical activities which may compromise his/her health. The ultimate desired outcome is a healthy, supported child as a beneficiary of the caregiver's empowerment through supportive family dynamics.

In conclusion, role theory suggests the establishment of a system level partnership which, in this instance, should comprise both the family members and the community resources to form a synergy that would ensure effective coping on the part of the primary caregivers. This system level partnership would assist the parents/caregivers both to complete an assessment of their need for both instrumental and social resources in meeting the tangible and the emotionally focused caregiving demands and to build a supportive network with resourceful community members.

This type of system level partnership is likely to ensure that the parents/caregivers or the primary caregivers have access to the resources that will complement their efforts to provide the necessary care for the children with heart disease (Burkhauser & Metz, 2009 a). It is, therefore, important to promote social support in the form of a system level partnership between the parents/caregivers and resourceful members of the community and health care providers in order to facilitate parents'/caregivers' coping with the demands of providing care at home (Kroenke, Kubzansky, Schernhammer, Holmes & Kawachi 2006).

- **Facilitation of productive social relations, social support and social functioning**

The literature has indicated that meeting the caregiving responsibilities in respect of a family member with a chronic disease and who is often subjected to limitations in his/her age-appropriate functions and also has to undergo on-going medical treatment may impact on the daily activities of the caregivers negatively and create a change in routine and thereby necessitating a reassigning of the caregivers' roles (Jackson & Vessey, 2000). Therefore, the literature suggests that while the parents/caregivers need to have a self-conviction about their ability to cope, they also need to rely on support from other people, either within, or outside the medical profession (Bulsara, 2004).

In this regard Mitchell (2011) concurs with the proposition which is grounded in role theory to the effect that because of the demands on the parents/caregivers as regards providing care to a child with heart disease at home and, it is essential that the parents/caregivers receive support so as to enable them to restore their normal social functioning. The main purpose of restoring the productive social functioning of the parents/caregivers is to promote caregivers' own health by assisting them to balance the demands of caring for a child at home while maintaining their own health and meeting the demands of their other roles (Major, 2003).

The literature indicates that, despite the fact that they may need resources in order to cope, people who are isolated are at an increased risk of limited resources whilst those who maintain social relationship tend to experience a positive quality of life because social relationship may facilitate access to the resources that are needed to facilitate coping ` (Kroenke et al., 2006; Berkman, 1995).

Therefore, sound health promotion is possible only through a collective effort in the context of a supportive social relationship with members of the community and, thus, a strong integration in the community and a close personal relationship with others are the pathways to accessing those resources that will improve the quality of life for the individuals concerned. In addition to the role which a social network plays in modulating the negative effects of stress on the neuroendocrine system and mitigating potential poor health outcomes, a social network is also a means of improving the ability to cope with life experiences and maintaining quality of life by providing the individual with access to those resources which are necessary for coping (Richter et al., 2004; Berkman, 1995).

To that end, and within their cultural context, the parents/caregivers should be urged to make use of guidance from the health care providers as intellectual resources in respect of the knowledge and skills which are necessary for them be able to carry out the complex instrumental tasks of care in a safe way at home. However, despite the fact that health care professionals are able to provide the parents/caregivers with the specialist knowledge that is helpful to them, it is of the utmost importance that the parents/caregivers also make use of community based support groups or, in particular, spiritual leaders who may offer advice and reinforce spiritual strength. Establishing a relationship with someone outside of the family in who, they can confide and with whom they may talk and share their feelings is extremely important (Ware & Raval, 2007).

Other potential caregivers outside of the family circle on whose support the parents and caregivers of the children with heart disease in rural areas may rely may include friends, who may be relied upon for short-term, minor care needs, and social workers who could facilitate

social support. School personnel could also support the child during school hours as long as their involvement with the child's illness does not constitute any violation of either privacy or confidentiality nor lead to the isolation and/or even dehumanisation of the child at school (Webb, 2009; Major, 2003). This kind of support may help the parents/caregivers both to come to terms with the negative experiences they may go through as a result of their children's condition and to cope with the demands of providing care at home.

In addition to providing emotional support, this type of system level partnership may also enable the parents/caregivers to access the financial and material resources that are necessary to facilitate care. The caregivers in this study alluded to this need to access financial and material resources in order to alleviate the burden of care and, therefore, to facilitate their coping with the demands of care and ensuring improved health outcomes for the children (Stayers et al., 2008; Burkhauser & Metz, 2009 a).

Social support is therefore an essential and as such, should be incorporated in the programme geared to promote the well-being of the individuals, and the caregivers of children with heart diseases are no exemptions. Accordingly, and as the literatures postulates, it is important for the parents/caregivers to maintain social network with clinical health care workers, such as a district nurse and social worker, and spiritual counsellors in order to enhance coping with the demands of caring for their children (Webb, 2009).

It may, therefore, be concluded that in order to restore the caregivers' productive social functioning and enable them to promote their own wellbeing, role negotiation at the family level is essential, while a balanced coping may be brought about by the use of the resources which are available at the community level (Major, 2003). Figure 5.5 provide a representation of ranges of

resources at the community level whose support can enhance productive social functioning and social relations for the parents/caregivers of children with heart diseases from the rural areas in Namibia, and therefore to facilitate their coping with the demands of caring at home.

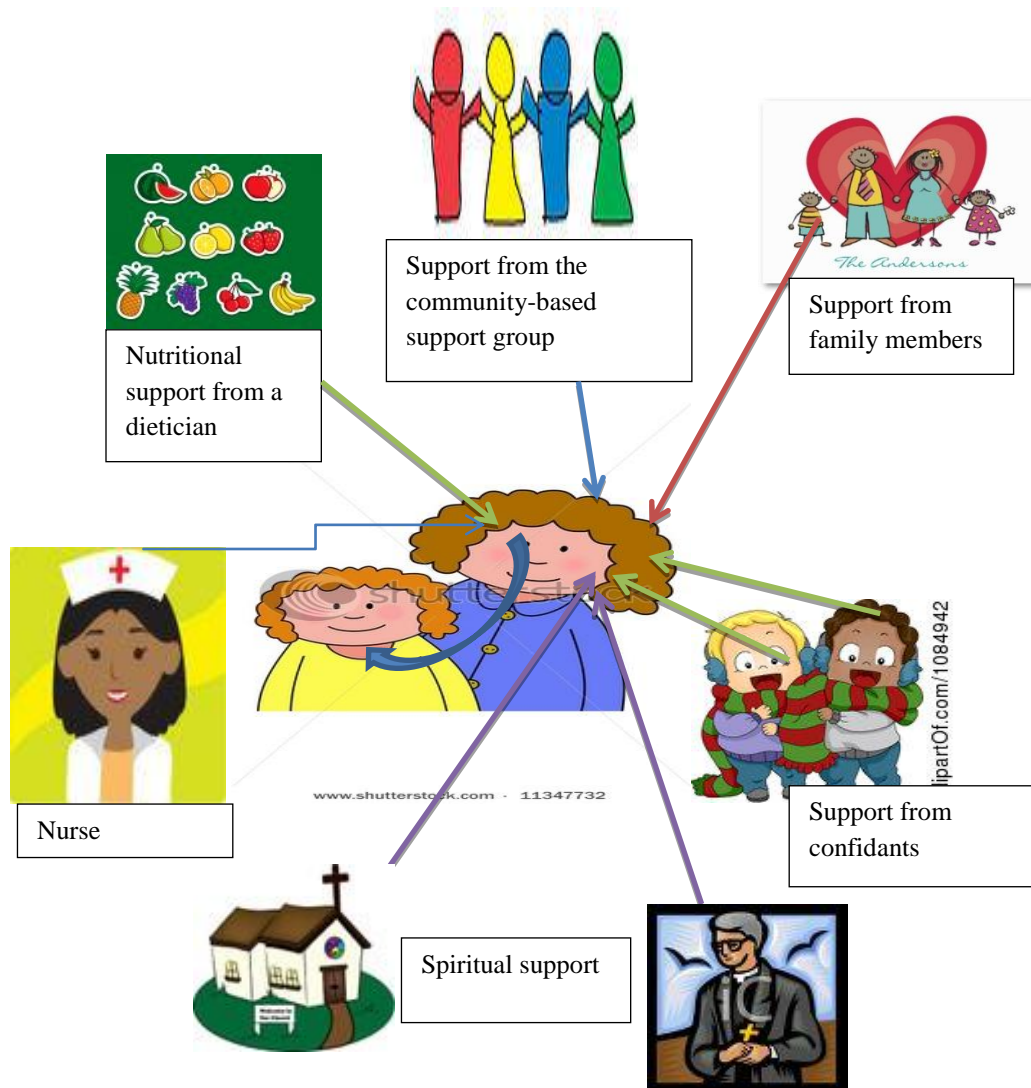


Figure 5.5 Mobilisation of social support to facilitate coping with the demands of providing care
Source: www.shutterstock.com

A health promotion approach which is characterised by social network which draw together all the determinant factors for coping, including supportive family dynamics, confidants, community support groups, health care providers, material resources and spiritual support, may

facilitate the caregiver's coping. Equally, the input from the different community-based resources facilitates coping with the demands of care at home on the part of the parents, and as a result, the children would benefit.

- **The parents/caregivers acquiring knowledge about the disease and treatment outcomes for the children.**

“Knowledge” refers to a body of facts or ideas that are acquired through learning from observation, experience and investigation (Stajduhar et al., 2008). Caregivers who are not knowledgeable about their patients' diseases and treatment regimens are at a disadvantage and are at risk of poor coping while executing their caring roles.

Patient education is a learning process directed at the patients and their caregivers to enable them to improve their knowledge and skills as a prerequisite for the realisation of self-care behaviours and adherence to the treatment regimen. Improved self-care behaviours and adherence to the treatment regimen reduce mortality and disabilities (Strömberg, 2005). In addition, access to relevant information clears misconceptions and anxiety and therefore influences the caregivers' ability to cope positively. If parents/caregivers were able to access information pertaining to their children's illness, the parents/caregivers in rural areas would be more prepared for what they may encounter while caring for their children (Stajduhar et al., 2008). Knowledge may ease the burden of caring as knowledge increases perceived control and facilitates the caregivers' adaptation to the demands of care (Strömberg, 2005).

The parents and caregivers of children with heart diseases from the rural areas are also expected to provide most of the physical and emotional care required by their children, provide instrumental care, manage complex symptoms at home and organise and coordinate health care activities on behalf of the children. If they do not possess adequate knowledge and skills, they would be unsure of their ability to provide the necessary care at home. Therefore, Paul (2008) and Strömberg (2005) further indicate that a lack of knowledge does not imply a lack of facts only. The authors argue that a lack of understanding the implications of noncompliance with the treatment and the inability to reflect or interpret the patient's responses to such compliance are also significant (Paul, 2008; Strömberg, 2005). Consequently, it is important that the parents/caregivers of children with heart diseases in rural areas not only receive information for the purposes of knowledge and training for skills, but that their empowerment also include information on how to access help from the professional or community-based resources or person(s) promptly if need be, to preserve the child's vitality and prevent morbidity and mortality (Stajduhar et al., 2008; Glanz et al., 2008; Brosig et al., 2007).

It has been proposed that advance preparation for the caring role is important if the parents and caregivers are to cope with the day to day caring activities and the demands of care. Gaining information from health care professionals and learning more about the aspects of care are some of the behaviours which would enhance the parents'/caregivers' knowledge and skills (Stajduhar et al., 2008). It is, thus, essential that the parents and caregivers from the rural areas be equipped with knowledge and skills as enabling factors so as to enable them to understand the complexity of the disease and its symptoms, to provide appropriate explanations about the facts of the diseases to their children and provide safe, symptomatic care for their children at home.

However, given the illness and the nature and volume of the information available, not all parents or caregivers are ready to learn about providing care at the time of diagnosis and their learning may be better once they are emotionally stable and have adopted their caring role. In addition, they may need the information to be repeated to them at some point in time. According to Paul (2008), if effective learning is to take place, the information on health education that is provided during hospitalisation should be complemented with significant outpatient health education at home for the reinforcement of the instructions (Paul 2008).

In that regard, it is important that all the instructions and advice which is communicated verbally to the patients and their caregivers also be provided in written format and at a reading level that is appropriate to that of the prospective users so that the caregivers may use this information as sources of reference in the future. In line with this argument, Strömberg (2005) suggests that the information on health education for the caregivers of patients with heart disease ought to be prioritised and, as such, should focus primarily on the psychological factors, social support, medication, diet and life-style modifications (Strömberg, 2005).

Based on the evidence from the literature, it was deemed necessary that health education for knowledge purposes should be included in the home-based health care programme which would provide support to both the parents/caregivers from the rural areas and their children with heart diseases to enable them to coping with the demands of care at home and to living with heart disease respectively. In this regard, the information on health education should include information on the effects and side effects of medication, dosages and adherences to treatment regimen, diet, life modifications with regard to activity tolerance and rest and the avoidance of

risk factors such as the exposure of the child to dust and to second-hand smoking (Paul, 2008). Figure 5.6 illustrate the types of information for health education to the parents acregivers of children with heart disease.

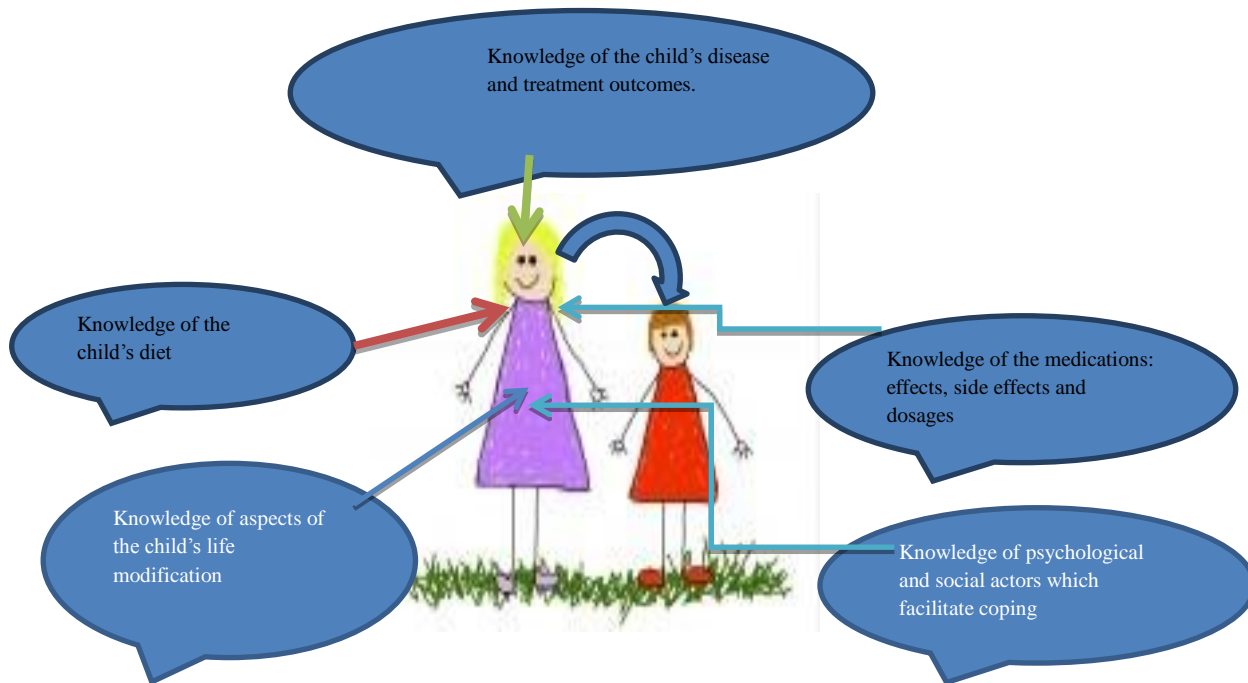


Figure 5.6: Knowledge and skills as enabling factors for the caregivers

(Sourced from the www.shutterstock.com)

A parents/caregiver who possesses the appropriate knowledge and skills provides safer care to the child.

5.4.5.3 Dynamic 3: Mitigating financial difficulties for the parents/caregivers

This dynamic focuses on addressing concern about money needed to cover the expenses related to travelling to hospital and for the child's surgery and money needed for the provision of a special diet for the child.

- **Money needed to cover the expenses related to travelling to hospital and for the child's surgery**

Financial resources may be regarded as the facilitative factors in the health care services. The families of children with special health care needs, including those with heart disease, experience financial difficulties related to their children's conditions (Arafa et al., 2008; Kuhlthsu, et al., 2005). In some families, the patients are at risk of missing out on treatment as a result of a lack of financial resources (Beck & Wiencek-Kurek, 2007). In this regard, Namibia is not an exemption. The findings of this study also indicated strong concerns about financial difficulties on the part of the parents and caregivers of children with heart disease from the rural areas. These parents/caregivers do not have the funds to cover the expenses of travelling to and from the health care facilities for the children's follow up treatments and to acquire supplementary food for their children who have heart diseases.

It is, therefore, of the utmost importance that these parents/caregivers obtain some form of assistance to alleviate their financial difficulties, for them to be able to cope with the demands of care at home. Despite the fact that facilitation for the provision of financial assistance to the parents/caregivers is not the individual health care provider's domain of decision making, a recommendations in this regard can be made (See chapter 8 on recommendations.)

- **Money needed for the provision of a special diet for the child**

Wandner and Hair (2009) are of the opinion that a fatty diet poses health risks for children and, of course, children with heart disease are no exception. In addition, the literature indicates that diet and nutrition are an important aspect of the lifestyle of cardiac patients. It is, therefore essential that cardiac patients or their caregivers make healthy food choices, specifically, reduced fat, cholesterol and sodium intake and sufficient fluid and fibres (Wandner & Hair, 2009). Accordingly, and for a growing child with heart disease his/her diet should include sufficient calories, protein and vitamins, while with carbohydrate salt, and fat in proportions that do not pose risks to the heart.

Despite the fact that the children with heart disease and their parents/caregivers in this study were from poor households, with a limited capacity to improve their food choices, in accordance with the views of Selektor and Weber (2008) and Charlton and Jooste (2001), nutritional education for these families should focus on food that is cultural sensitive, i.e. available, affordable and popular as long as the foods are consistent with the low salt, low fat and high fibre prescription (Selektor & Weber, 2008; Charlton & Jooste, 2001). Furthermore, it has been suggested that the meals for a cardiac patient should contain a balance of micronutrients, i.e. vitamins and minerals to compensate for the low metabolism that results from the slow circulation and as characterised by the failure to thrive of these children (Hurst, 2011; Menon & Poskitt, 1985). Accordingly, there is a need to develop a nutrition education programme to address the needs of the individual parents/caregivers of children with heart diseases as regards the knowledge and skills which are necessary to select and prepare a cardiac diet and to ensure that these parents/caregivers have control over the diet programme for their children.

5.4.5.4 Dynamic 4: Moderation of decreased vitality for the children with heart disease.

This dynamic is focused on the empowerment of the child and moderation of the experiences of physical dysfunction and the result of which would facilitate coping with the demands of care on the part of the parents. The next sessions described the interventions pertaining to this dynamic.

- **Counselling of the children**

Page and Czuba (1999) explains counselling as a social process that fosters power in people for them to act on the challenges that they experience for their own benefits, their communities and their society (Page & Czuba, 1999). Counselling is therefore a positive process that focuses the people's strength, involvement and participation in decision-making, thereby emphasising possibilities, solutions and the people's ability to control their lives (Wåhlin, et al., 2006). In the context of this study, counselling is a process aimed at enabling the children with heart disease both to demystify their negative assumptions about the course of their illness and potential treatment outcomes and to adjust to the symptoms of their illness and, thereby, gain control over their lives. The ultimate purpose is to stimulate the children's inherent joy of life and the will to strive towards coping with the experiences of the burden of the disease symptoms, or adjusting to living with the heart disease (Wåhlin et al, 2006)

As proposed by LeBlanc, Goldsmith, and Patel (2003), adjusting to a chronic illness may provide an excellent opportunity for a child to master crucial skills such as emotion regulation and problem solving, with mastery of these skills prompting strong self-esteem and confidence.

As a result, the children may then be in a position to minimise the negative perceptions and behavioural aspects related to their experience of the symptom burden of heart disease. In addition, the psychosocial adjustment of these children as patients will in turn engender better

adherence to the treatment regimens, therefore allowing the children to play a crucial role in the promotion of their vitality, early identification of illness related setbacks and early interventions for prevention. As a result of counselling, these children would be able to adjust to the course of their illness and this, in turn, would enable their parents and caregivers to cope better with the demands of care (LeBlanc, Goldsmith, & Patel, 2003).

- **Moderation of physical dysfunctions**

The experience of physical dysfunctions among heart patients is inherent in the nature of the disease. These physical dysfunctions arise as a result of hemodynamic instabilities, which include, inter alia, a decrease in cardiac output and the subsequent decrease in oxygen delivery to the body systems. These, in turn, are responsible for the decreased vitality (Ulvik et al., 2008; Coovadia & Wittenberg, 2007; Mogotlane et al., 2005; Arafa et al., 2008). These experiences of physical dysfunction require vigilance on the part of the parents and caregivers. However, vigilance and the ability to provide the required care implies that, because of the complex nature of a heart disease and its interrelatedness to the other body systems, the parents or caregivers should have the required knowledge and skills to enable them to provide safer care for their children. Therefore, it is essential that the envisaged health care programme providing the parents/caregivers with the information necessary to gain insights into the effects of heart disease on the body hence the children's physical dysfunctioning.

5.4.6 TERMINUS

The concept “terminus” which is included in the survey list refers to the goal, the end-point or what has been accomplished by the activities. Terminus refers to those doable objectives which are accomplished by the agent and which are acceptable to the recipients. The notion of terminus may also be used to indicate what may be pursued and implemented in terms of the completion of the activities in order to realise the desired situation (Dickoff et al., 1968).

As regard this study, “terminus” refers to the outcomes that the recipients would have derived from the programme interventions. In other words, terminus refers to the outcomes which are desired as a result of the learning experiences of the parents/caregivers as the beneficiaries of the programme interventions and the impact that such experiences may have on their coping as well as on the health status of their children with heart disease. The outcomes which are expected from the parents/caregivers as a result of the programme interventions include emotional regulation, knowledge of the available social support systems, behavioural capacity to carry out caring activities and skills required for the provision of safe care to the children. It is anticipated that these outcomes will enable the parents/caregivers to meet the demands of care for their children and promote emotional coping on the part of the parents/caregivers and the children alike. Specifically, as regards the children, the expected outcome is the achievement of optimum functional status for the children as a result of the appropriate care rendered by their parents/caregivers (George, 2008).

5.5 SUMMARY

This chapter discussed the conceptualisation of the study findings. The central and relevant concepts were identified as: parents/caregivers' poor coping and the need for the empowerment of the parents/caregivers through a home-based health care programme. Therefore Dickoff et al. (1968)'s survey list for the prescription of the activities of the home-based health care programme was applied as framework for the envisaged home based health care programme. Accordingly, researcher's reasoning map with regard to the application of the concepts of agent, recipients, procedures, dynamics and terminus to the study was described in accordance with the context of this study.

The characteristics which were deemed desirable in an agent as a facilitator for the empowerment of the recipients (the parents/caregivers) were discussed within the context of the study while the characteristics of the recipients (parents/caregivers) that were regarded as essential for both learning and compatibility in respect of the caring role were discussed in terms of their application to the study. The procedures to mitigate the challenges for the parents/caregivers and the children and the dynamics or the motives in respect of the procedures or the programme interventions were explained. Finally, the desired outcomes or the terminus from the procedures in relation to this study were indicated.

In conclusion, through the conceptualisation and in line with the guidelines proposed in the literature, it is proposed that the most important predictors of the parents'/caregivers' coping with the demands of providing care at home include the development of those characteristics within the parents/caregivers that will facilitate coping (as elaborated upon in the section on the

description of the recipient), the identification of procedures to mitigate the parents'/caregivers' negative experiences in respect of caregiving and the dynamics in respect of the procedures and which are aimed at realising the desired outcomes-the enhancement of the parents/caregivers coping with the demands of providing care at home (Raina et al., 2005). The next chapter presents the conception and description of the procedures or programme interventions as the content of a home-based health care programme in line with Dickoff et al.'s (1968) survey list.

CHAPTER 6

DEVELOPMENT OF A HOME-BASED HEALTH CARE PROGRAMME TO FACILITATE COPING ON THE PART OF THE PARENTS/CAREGIVERS

6.1 INTRODUCTION

In the previous chapter, a conceptual framework to the study was discussed. The dynamics to mitigate negative experiences for the parents/caregivers were identified and discussed. The conceptual framework forms the basis for the objectives and the contents for the home-based health care programme to facilitate coping with the demands of care on the part of the rural parents/caregivers of children with heart diseases. Part of phase two of the study involved developing a home-based health care programme within the conceptual framework. As the final part of phase two of the study, this chapter discusses the content for a home-based health care programme or the “procedures” designed to mitigate the negative experiences of the parents/caregivers in respect of the demands of providing care to children with heart disease.

Research has indicated that caregiving over the long term requires an intense focus and an involvement on the part of family members as family members play an important role in the treatment process of their significant other(s). It is, therefore, evident that a degree of readiness on the part of family members to be involved in the care of their significant other(s) may influence the quality of care rendered to the patient. However, the ability of the family members and the extent to which they are able to contribute is a cause for further concern. Therefore, in recognition of their role, it is essential that primary caregivers, as well as other family members, be empowered to enable them to cope with the challenges posed by the illness of a family member (Forrester, 2008).

The proponents of health promotion advocate a home-based care approach for people who are living with long-term illnesses and the empowerment of their family members for the latter to provide appropriate care to their significant ones at home (Forrester, 2008). Accordingly, it is incumbent on the part of health care providers to improvise and institute health care interventions in the form of a home-based health care programme to help the families to identify and use those resources which may mitigate both the factors and the circumstances which detract from coping as, in so doing, caregivers would be assisted to cope with the demands of providing care at home (Bugge et al., 2009; Egan, 1998).

Based on the argument above, the researcher resolved to institute an invention and to develop a home-based health care programme aimed at supporting the parents/caregivers of children with heart disease from the rural areas in Namibia so as to facilitate their coping with the demands of providing care at home.

6.2 RATIONAL FOR HOME-BASED HEALTH CARE PROGRAMME

The findings from the situational analysis revealed that there is a need for empowerment of the parents/caregivers of children with heart diseases from the rural areas of Namibia, to enable parents/caregivers to cope with the demands of care at home. As stated in the literature, the main principle underpinning a home-based health care programme is to facilitate the provision of a form of on-going care to the sick person by the caregivers, who often are relatives. In addition, a home-based health care programme should include access to the resources (psychosocial and material) which are needed to facilitate the caregivers' coping with the demands of care (WHO, 2002).

In line with the statement above, and as was indicated by the findings of this study, the central concept about the experiences of the participants was that the parents and caregivers cope poorly with the demands of caring for their children who have heart disease and they need to be empowered for them to enable to cope with providing a continuum of home-based care to their children with heart disease. In other words, there is a need for explicit activities that constitute the basis of a home-based care programme aimed at assisting the parents/caregivers of children with heart disease, and, in particular, those parents/caregivers and children who are from the rural areas in respect of providing on-going health care to their sick children at home. The fact that the parents/caregivers experience challenges which are related to the demands of providing care for their children with heart disease justifies formulating and instituting appropriate interventions.

The specific motives which are served by the home-based health care programme interventions include the facilitation of healthy emotions on the part of the parents/caregivers and the children, facilitation of self-fulfilling social functioning and socialisation for the parents/caregivers, facilitation of support from the family and society to the parents/caregivers and the facilitation of optimal physical functional status for the children.

The interventions incorporated in the home-based health care were designed to enable the caregivers to acquire the knowledge and skills required to carry out the tasks of care, make optimal use of resources at the family level and facilitate access to resources outside of both the family and the community in order to enable the parents/caregivers to cope with the demands of providing care at home.

6.3 THEORETICAL ASSUMPTIONS UNDERPINNING THE HOME-BASED HEALTH CARE PROGRAMME

Theoretical assumptions had helped to identify the central concept from the study findings.

6.3.1 Central concept

The central concept in respect of the experiences of the parents/caregivers and their children, as identified from the situational analysis, was a lack of coping with the demands of providing care at home. Accordingly, the corresponding need is the need to facilitate a mechanism for coping. It was, therefore, deemed necessary to incorporate theoretical assumptions about coping in order to guide the programme development, implementation and evaluation. The framework of the Transactional Model of Stress and Coping was adapted as the guiding instrument for this home-based health care programme (Glanz et al., 2008 & George, 2008).

6.3.2 Theory of coping

The theory of coping is regarded as applicable to this health care programme because, in the discussion of the findings arising from the situational analysis, its assumptions served as a framework for the description of the appraisals of the experiences of providing care and living with heart disease, respectively by study participants. Secondly, assumptions of the Transactional Model of Stress and Coping served as a reference for the identification of potential resources for coping which the parents/caregivers could utilise, including seeking both information and social support from existing community support groups. Finally, the assumption of the theory was applied as a reference for the evaluation of the outcomes of the programme interventions (Glanz

et al., 2008 & George, 2008). The application of the theoretical framework to this study is explained below.

6.3.3 The Transactional Model of Stress and Coping

Coping is essential for health promotion while practising coping helps an individual to experience adaptation and positive growth. Thus, in the context of this study, it is possible that coping may influence the psychological and physical health outcomes of the parents/caregivers in a positive way. Without coping, the parents/caregivers are at risk of experiencing psychological and, subsequently, physical deterioration (Glanz et al., 2008).

Three main coping outcomes, namely, the emotional wellbeing of both the parents/caregivers and the children, problem management by the parents/caregivers as the recipients of the programme interventions and the attainment of optimal functional status on the part of the children as the beneficiaries of their parents'/caregivers' coping efforts would be indicators of a degree of coping on the part of the recipients of the programme interventions (Glanz et al., 2008).

The participants' perceptions of the quality of learning resulting from the programme interventions would be indicators of an increased likelihood of coping and also predictors of emotional wellbeing, while the ability to identify and utilise the strengths within the family or to make use of resources within the community would signify the probability of problem management and, hence, the probability of coping. Coping, in turn, would enable the provision of quality care which would improve the children's health status. Finally, the children's perceptions of an ability to care for themselves may signify an empowerment that may, in turn,

lead to the promotion of optimal functional status and, therefore, an enhanced coping with the burden of the disease symptoms.

6.4 DEVELOPMENT OF A HOME-BASED HEALTH CARE PROGRAMME

The health care programme was conceptualized according to the elements of the survey list of Dickoff et al. (1968). The concept of “dynamic”, “terminus” and “procedure” were applied to represent the goal, objectives and interventions for the health care programme (see figure 6.1). As an educational programme, the contents of a home-based health care programme ought to be organised in accordance with the guidelines of a model for education. Accordingly, the aims and objectives of the home-based health care programme, as well as the content of the programme, are described in the following sections.

6.4.1 The aims of a home-based health care programme

The purpose of a home-based health care programme is to facilitate the parents/caregivers' coping with the challenges caused by the demands of caring for their children with heart disease. In this regard, the interventions of the programme are aimed at empowering the parents/caregivers to identify and use those resources that may help them to cope effectively with the demands of providing care to their ill children (Egan, 1998). As a result, the desired outcome is to realise effective coping on the part of the parents/caregivers as this will facilitate the provision of quality care and lead to an improvement in health status of the children. Providing a caring environment for all the parties involved would help the parents/caregivers to cope with the challenges posed by the demands of providing care to these children.

6.4.1 The objectives of the home-based health care programme

In a reductionist approach of this qualitative study, the objectives for a home-based health care programme are tools to realize the dynamics that were set to mitigate the negative experiences and, by so doing, to facilitate coping with the demands of care on the part of the parents/caregivers and coping with the burden of the disease by the children.

Following the formulation of the conceptual framework and the conceptualisation of the need to facilitate coping, as elaborated upon in the previous chapter, it was regarded as feasible that it would be possible to address the parents'/caregivers' experiences of disrupted social functioning as well as the lack of support from both families and society on the basis of one objective, that is, that of facilitating problem management or problem focused coping methods. On the other hand, the emotional challenges and the children's functional status needs would have to be addressed through coping methods exclusively to both the parents/caregivers and the children. Therefore, the specific objectives of this programme, which are designed to meet the needs as stated above, include the following:

- **Facilitate emotional coping methods for both the parents/caregivers and the children.** This objective is intended to cater for the common theme that both the parents/caregivers and the children experience emotional challenges.
- **Facilitate problem management or problem focused coping by the parents/caregivers and the children.** This objective is intended to cater for two themes, namely, the experience of disrupted social functioning on the part of both the parents/caregivers and the children and the lack of support for the parents/caregivers from both families and social systems.

- **Facilitate the optimal physical functional status of the children.** This objective is intended to cater for the theme relating to the children's experience of physical dysfunction. The following section provides a detailed description of the learning contents designed to meet each of the objectives.

6.4.3 The content/components of the home-based health care programme which are aimed at facilitating coping

The “dynamic” or motives, “terminus” or objectives and “procedure” or interventions for a home-based health care programme served as guidelines for the formulation of the programme content to facilitate coping with the demands of care and the burden of the disease respectively.

Coping effort refers to the methods that may be employed to facilitate coping (Glanz et al., 2008). Coping effort encompasses the following two dimensions, namely, coping efforts in the form of emotional regulation/emotional focused coping and coping efforts in a form of problem management/problem focused coping. Both these coping efforts are included in this home-based health care programme.

Emulating *the guidelines* on the organisation of *home-based health care programmes*, a home-based health care programme aimed at facilitating coping on the part of the parents and caregivers of children with heart disease contains different categories of components in respect the facilitation of emotional coping, the facilitation of problem focused coping and the facilitation of functional status for the children. Together all these components form a holistic home-based health care programme (WHO, 2002). The next section provides a detailed

description of the components for the home-based health care programme which are designed to meet each objective.

Objective 1: Facilitation of emotional coping effort on the part of the parents/caregivers and the children through:

- Bereavement counselling for the parents/caregivers and emotional regulation which includes the following coping techniques, namely, venting of feelings, seeking social support and meaning based coping which includes the coping techniques of positive appraisals/acceptance, revised goal/self-re-evaluation, spiritual beliefs, optimism and self-efficacy.

Objective 2: Facilitation of problem management coping or problem-focused coping for the parents/caregivers by facilitation of support for the parents/caregivers through:

- Supportive family dynamics, information seeking (“monitors” or keenness for information versus “bunters” or ignorance of information), seeking social support and socialisation or self-fulfilment social functioning.

Objective 3: Facilitation of the optimal physical functional status of the children through:

- Counselling of the children, compliance with prescribed medications, cardiac diet and nutrition, weight management, activity tolerance and palliative care or symptomatic care.

Figure 6.1 presents a summary of the components of the home-based health care programme.

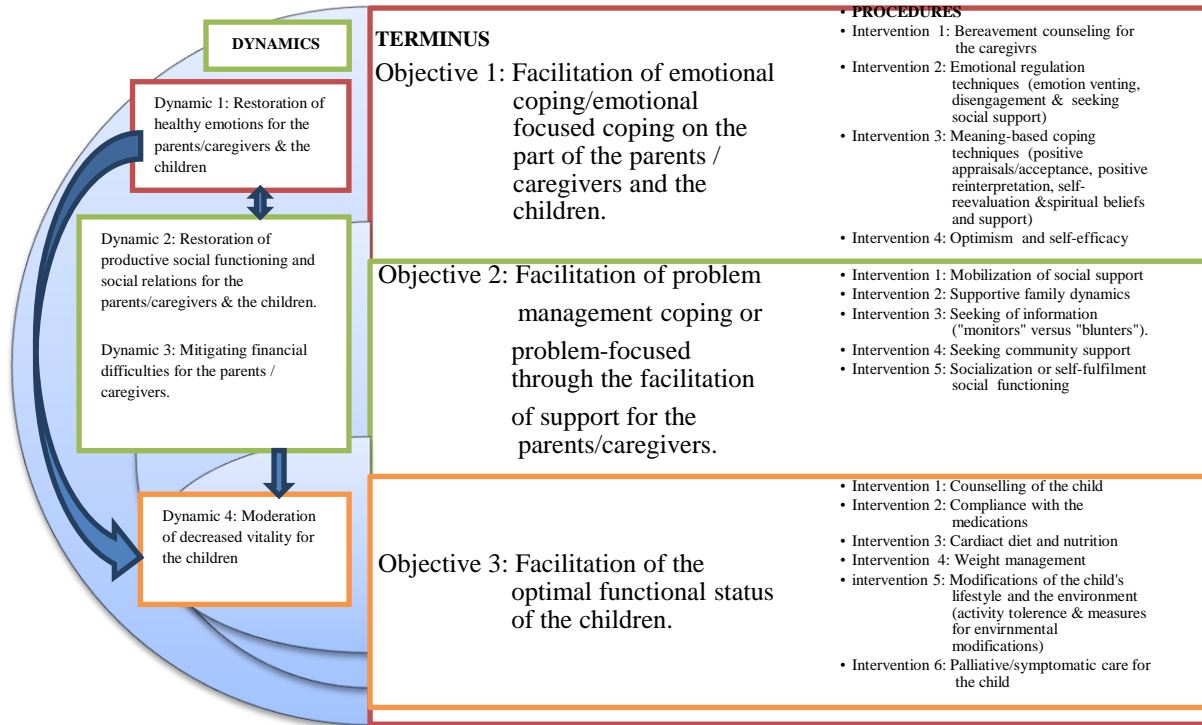


Figure 6.1: The contents/components of a home-based health care programme to facilitate coping

The concept about the content for a home-based health care programme explains a complimentary relationship of problem-management and emotional coping. In return, a healthy emotional status of a caregiver influences the child to cope with the burden of the disease. Furthermore, the ability to manage the problems enables the caregivers to provide quality care that in return facilitates optimal functional status for the children; hence the parents/caregivers would cope with the demands of care at home.

6.5 Description of the components of the home-based health care programme

In order to address the challenging experiences which the parents/caregivers encounter in caring for their children with heart disease, it is recommended that multi-component interventions, which draw together all the determinant factors for coping, be implemented so as to realise the set objectives. It is hoped that these interventions will reduce the parents'/caregivers' burden of caregiving and, in fact, enhance their coping with the demands of caring for their children with heart disease as well as helping the children to cope with the burden of heart disease (Acton & Kang, 2001; Gitlin, Burgio, Czja, Mahoney, Gallagher-Thompson, Burns, Hauck, Zhang, Schulz, & Oryn, 2003). In the following sessions, the components for the home-based health care programme to achieve the set objectives are described.

6.5.1 Objective 1: Facilitation of emotional coping/emotion focused coping on the part of the parents/caregivers and the children.

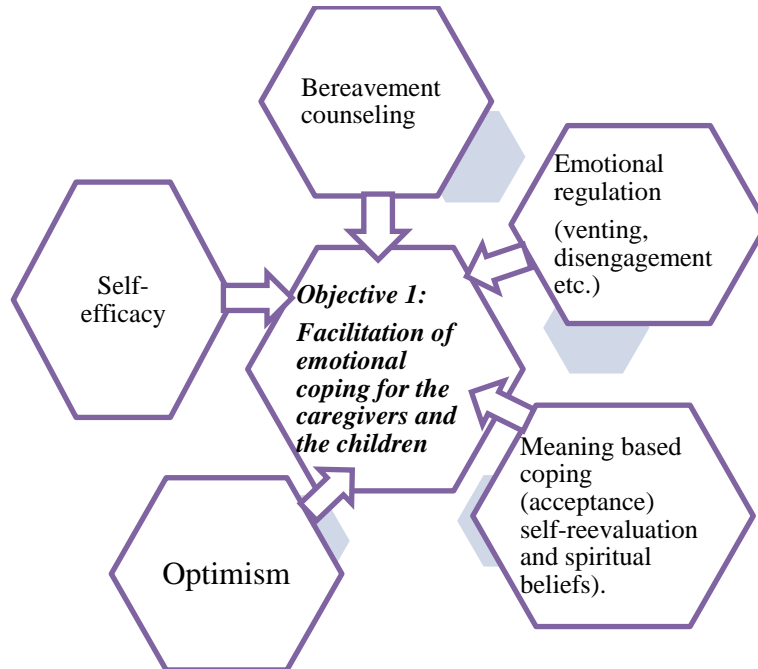


Figure 6.2: Content for Facilitation of emotional coping

Coping as a form of emotional regulation refers to the adoption of methods that are directed towards controlling the emotional reactions to challenges, or controlling the way in which one perceives challenges and as such, it include bereavement counselling, the venting of feelings and disengagement coping techniques as well as the use of the meaning-based coping methods which include the application of positive appraisals or acceptance, positive reinterpretation, spiritual beliefs, self-re-evaluation, optimism and self-efficacy as coping techniques (Glanz et al., 2008).

As regard the home-based health care programme for this study, the emotion focused coping was facilitated to enable the parents and caregivers to adapt to the challenges which they were facing

and which were, in fact, immutable in the hope that they would come to perceive the world as predictable and that things will work out well (Glanz et al., 2008). The specific interventions involved in the facilitation of emotion focused coping are described below.

6.5.1.1 Bereavement counselling for the parents/caregivers

Offering counselling and support is important for the parents and caregivers as they provide care to their children with a life threatening disease (WHO, 2002). The psychological health of these parents is vitally important in terms of their personal growth, in changing the way in which they perceive their children's situation and in helping them to cope with the demands of providing care at home. Bearing in mind that these parents and caregivers are from communities where the people fear any open discussion of illness and death or, as indicated in the literature, that people often find it difficult to discuss patients' prognosis, it is essential that these parents/caregivers receive bereavement counselling to enable them to come to terms with either a lifelong illness or a poor prognosis for the child concerned so they will be able to plan effectively for the future. Accordingly, emotional support through the medium of counselling the parents and caregivers is vitally important (Bugge et al., 2009; WHO, 2002).

6.5.1.2 Emotional regulation techniques (venting of feelings, disengagement and seeking social support).

Venting refers to self-expression, a letting out of emotions which may be done via a discussion of one's feeling with a family member or by expressing one's feeling to a confidant (WHO, 2002, Glanz et al., 2008). On the other hand, disengagement is an act of shifting the attention away from the challenge, either cognitively through the practice of positive techniques of disengagement, such as cognitive avoidance, for example, not thinking about the children's plight and the corresponding need for care. Alternatively, the parents/caregivers may choose to engage in practical activities to take their minds off thoughts about the children's condition (Glanz et al., 2008).

6.5.1.3 Meaning-based coping techniques (positive appraisal/acceptance, revised goal evaluation, self-re-evaluation, spiritual beliefs, optimism and self-efficacy).

Meaning based coping involves methods of coping that may induce positive emotions and, hence, increase the likelihood of coping. As such, meaning based coping includes coping techniques such as the positive reinterpretation of experiences in a personally meaningful way, self-re-evaluation, the use of religion and spirituality and, in the context of this study, an acceptance of the situation by the parents and caregivers. The use of spirituality or ascribing a religious meaning to the children's illness may be associated with the parents'/caregivers' capacity to derive a positive meaning from the adverse experiences and, as a result, they would be able to grow and adapt to the demands of care (Glanz et al., 2008).

6.5.1.4 Optimism

Optimism refers to the tendency to hold a positive rather than a negative, generalised expectation about outcomes – a feeling that what is desired will happen in spite of the current adverse situation. Accordingly, optimism would enable the parents/caregivers of the children with heart disease to look forward with courage, confidence and perseverance as regards the demands for care (Glanz et al., 2008). In addition, a feeling of optimism is a catalyst which may help these parents/caregivers to make positive appraisals of both the challenges and their ability to manage such challenges and, as a result, they should be able to cope (Cox et al., 2009 & Brosig et al., 2007). Therefore, optimism would be associated with controlled emotions, self-efficacy, more active coping and, ultimately, positive health outcomes for the children. Indeed optimism on the part of the parents/caregivers would make the difference between success and failure in regard the parents/caregivers' coping with the demands of care for their children with heart diseases at home (Giltay, Kamphuis, Kalmijn, Zietsman, & Kromhout, 2006).

The programme recipients, the parents/caregivers are to be encouraged to adopt optimistic attitudes and hope as regards positive treatment outcomes for their children. In spite of the plethora of adverse experiences which the parents/caregivers go through, it is essential that they be inspired, where possible, to hope for a cure, health and a better life for their children. If the parents/caregivers are optimistic and are able to hope for positive treatment outcomes for their children, they are more likely to display a positive attitude towards life and develop a sense of the meaningfulness in life and, and as a result, they will be more likely to cope with the demands for providing care at home (Glanz et al., 2008).

In addition, optimistic perceptions on the part of the parents/caregivers are more likely to reinforce healthy emotional reactions towards the experiences of the diseases burden on the part of the children, with subsequent fewer demands for caring for the parents/caregiver.

6.5.1.5 Self-efficacy

Self-efficacy refers to an individual's belief in his/her personal ability to engage and successfully accomplish the behaviours that are required to bring about the desired outcomes or to cope with difficulties. Self-efficacy or the individual's subjective appraisal of her/his ability or self-determination is important for the individual's empowerment. Self-efficacy therefore plays an important role in the concept of empowerment (Wåhlin 2009; Glanz et al., 2008 & Egan, 1998). The development of self-efficacy is enhanced by the possession of skills, learning from feedback and encouragement, success, modelling and a freedom from fear and anxieties. These characteristics enable the performance of desired tasks, an improvement of performance and reinforcement while, at the same time, overcoming the fear and anxieties that may keep one from initiating an action in order to realise a goal (Egan, 1998).

For the purposes of the health care programme in this study, the parents/caregivers are to be offered with demonstrations of the skills on how to practice empathic listening, feedback to improve their performance, reinforcement for success when the desired results have been attained and encouragement to overcome fears and anxieties, all which foster the cultivation and sustenance of self-efficacy.

6.5.2 Objective 2: Facilitation of problem-management coping or problem-focused coping for the parents/caregivers.



Figure 6.3: Content for the facilitation of problem-management coping

Coping in the form of problem-management refers to the utilisation of those coping styles/techniques which are directed at changing the situation in order to facilitate coping. Influencing the coping effort through problem management influences emotional regulation in a positive way. Hence the parents/caregivers are likely to cope psychologically, socially and with role demands (Glanz et al., 2008). The use of coping strategy of supportive family dynamics and coping styles such as, seeking information and socialisation in terms of self-fulfilling social functioning are some of the most important methods of problem management coping that may be employed to facilitate coping on the part of the parents and caregivers who are the beneficiaries of the home-based health care programme (Glanz et al., 2008). Possible techniques of coping are described below.

6.5.2.1 Mobilisation of social support

The mobilisation of social support is the key to the successful facilitation of the coping effort. The concept of mobilisation refers to the act of organising an endeavour or an engagement in assistance of those who are in need (*Longman Dictionary of English Language & Culture*, 1992, p. 853). In the context of this study, social mobilisation refers to advocacy as regards the parents and caregivers as the programme recipients to engage in those activities which are likely to facilitate their coping with the demands of providing care at home, while either awaiting the curative treatment for their children or coping with the end life stage of a child when the condition is not curable.

Social mobilisation also refers to lobbying for support from the society in regard to the parents/caregivers to make provisions that enable them cope with the demands of care. The mobilisation of resources for the support of the parents/caregivers may be facilitated through the mechanism of supportive family dynamics, seeking appropriate health information, using the expertise of health care workers, community-based support groups, socialisation and advocating material support from society at large in order to enhance coping. It has been proved that all forms of support significantly reduce caregivers' sense of inadequacy or their subsequent poor coping (Sorenses, Pinqart & Duberstein, 2003).

6.5.2.2 Supportive family dynamics

Raina et al. (2005) indicate that the responsibility for caregiving connotes a dynamic process that requires adaptation on the part of the primary caregiver as well as the restructuring of the caregiving responsibilities or the establishment of supportive family dynamics around the caring

roles of caregivers (Raina et al., 2005). Supportive family dynamics refer to the family characteristics which enable a family to deal with a crisis in a constructive manner and enable the family to adapt to challenges successfully. The literature has indicated that family system variables are stronger predictors of adaptation and adjustment than the disease factors or severity of the illness (Krysan et al., 1990).

Family support is realised through the inclusion of all those family members who are eligible to provide care to an ill member of the family, in order, inter alia, to, provide relief for the primary caregivers and, therefore to, enable the primary caregivers to have sufficient time to attend to their personal needs and, therefore, to enhance their own emotional wellbeing (Major, 2003).

The shared responsibilities that are accomplished through the involvement of all members of the family in order to meet the demands of caring for a child with a heart disease (and as implied by the experiences of the parents/caregivers in this study) include the communication of relevant information regarding the child's treatment and then making decisions and reaching consensus about the care to be provided as well as arranging for a substitute to care for the healthy children while the primary caregivers attend to the ill child. Support from the family is vitally important in mediating the demands of care (Forrester, 2008; Major, 2003).

6.5.2.3 Seeking of information (“monitors” versus “blunters”)

It has been argued that a lack of information may hinder the coping process. Without appropriate information, it is almost impossible to evaluate the degree of threat posed by challenges or to choose a coping response that is appropriate to the situation. Moreover, the possession of appropriate information may help to mitigate the emotional appraisal of the challenges being

faced and this, in turn, leads to better adaptation (Glanz et al., 2008). Accordingly, seeking appropriate health information is a highly recommended form of coping as it results in the clarification of misconceptions related to the children's conditions (Glanz et al., 2008, Chair; Pang, 2008).

For the purposes of this study, the parents/caregivers, as the recipients of the programme interventions, are to be encouraged to conduct themselves as "monitors" (information seekers) and discouraged from acting as "bunters" (avoiding information).

Furthermore, the parents and caregivers should be urged to choose "gain framing" (emphasising the benefits) of information seeking and the meaning of such information and to avoid "loss framing" (emphasising negativism) of the information and its meaning. The loss framing of the information that was sought would tend to exacerbate the emotional challenges experienced and lead to poor coping (Glanz et al., 2008). On the other hand, monitoring is associated with a high degree of adaptation and the minimisation of the emotional challenges experienced and, therefore, the enhancement of constructive participation in decision making as regards treatment. As a result, monitoring enhances coping.

6.5.2.4 Seeking health information from health care workers

The guidelines of the World Health Organization (WHO) with regard to providing palliative care at home indicate that caring for a person with a life threatening illness may place excessive strain on the caregivers (WHO, 2002). Furthermore, the literature postulates that health educators may play a vital role in helping the families of sick children to develop balanced coping methods, thereby enabling them to meet the medical and emotional needs of the ill child, while they still

meet the demands of their other roles and they remain socially health (Major, 2003). Against this background, health care providers should also be on the alert for the possibility that caregivers may have received horror or frightening information from inappropriate sources. It is, therefore, the task of the health care experts to encourage the caregivers to acquire appropriate information that will improve their knowledge and enhance their understanding of the children's condition and, which in return can improve their coping (Chair & Pang, 2008; Deelstra & Jacobson, 2005). It is, therefore, necessary that caregivers be encouraged to seek the support of health care experts and that this support be accessible and utilised as often as possible.

6.5.2.5 Seeking community support

The WHO (2002) asserts that through a mutual support of community based groups, members can provide emotional and social support to those who experience challenges, thereby helping them to cope with the challenges (WHO, 2002). It is essential that this type of support be offered to the parents/caregivers of children with heart disease as well, more so those who are from the rural areas as the recipients of the home-based health programme interventions.

Social support in this instance refers to both the availability and the dimensions of support network, including the number of friends, the availability of confidantes and downwards comparisons and community based support groups to facilitate the feeling of connectedness and an appreciation of the benefits that may be derived from those dimensions of support, and which can enhance the likelihood of coping. Hence, networking with friends may provide the parents/caregivers with psychosocial support as well as practical guidance about how they may meet the demands of caring for their children with heart disease (Sjöström-Strand & Fridlund, 2008).

In addition, social support includes the provision of the material facilities which are necessary to enable the parents/caregivers to provide adequate care to the children concerned (Glanz et al., 2008; Forrester, 2008). Furthermore, Pretorius et al. (2012) imply that heart disease is a health debilitating condition and, as such, it justifies the provision of a disability grant to such patients. Currently, in neighbouring South Africa, the provision of the recommended diet for a heart failure patient was estimated to cost approximately 30 to 40% of the disability grant made to South African nationals with heart diseases to enable them to supplement their staple foods with the fruit and vegetables which are essential components of the recommended diet for patients with heart disease (Pretorius et al., 2012). Hence, the same approach could be adopted and financial assistance provided to those children with heart diseases from the rural areas in Namibia, whose parents/caregivers are economically vulnerable to enable them to cope with the demands of providing care at home.

6.5.2.6 Socialisation or self-fulfilling social functioning

A lifelong illness and the treatment regimen for a member of the family is likely to cause strain and burnout, fatigue and poor motivation on the part of the caregivers as well as limiting the caregivers' time for socialisation. In view of the limited time available to them, caregivers are often not able to find time to attend to their personal needs and to socialise. The time devoted to the demands of care tends to take up the caregivers' personal time with the resultant negative impact on the caregivers' social functioning (Forrester, 2008 & WHO, 2002). This all, in turn, may result in poor coping. It is, therefore, recommended that access to community support be encouraged and that the help and support of friends and neighbours be enlisted as ways in which to facilitate problem management coping.

In addition, it is of the utmost importance that the caregivers be encouraged to ensure that they take recreational breaks and that they rotate the caring activities among family members who are able to help (WHO, 2002).

6.5.3 Objective 3: Facilitation of optimal physical functional status of the children.

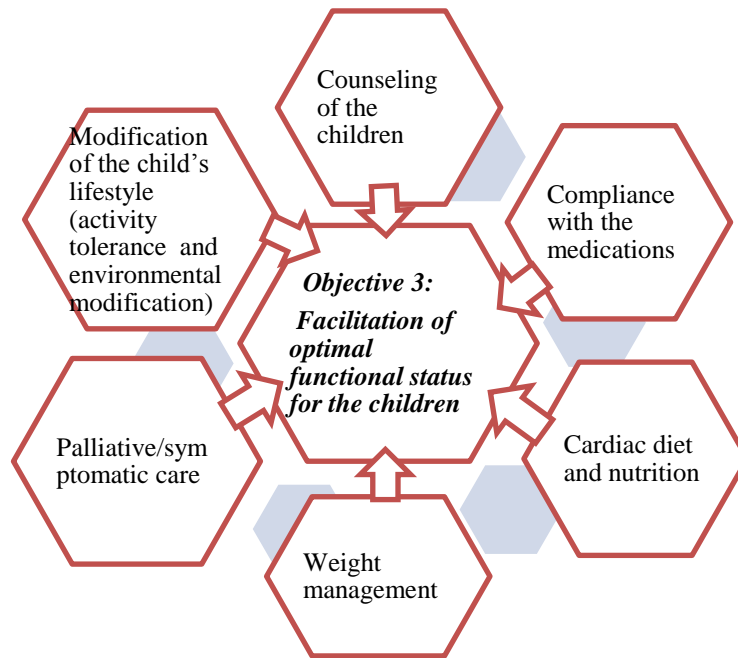


Figure 6.4: Content for the facilitation of optimal functional status for the children.

The facilitation of the optimal physical functional status of the children may be achieved through the empowerment of the children, adherence and compliance with the medication schedule, adherence to the cardiac diet and correct nutrition, weight management, the provision of appropriate palliative care/symptomatic care, modification of the children's lifestyle and measures taken to modify the environment. The detailed modalities for these interventions are described in the next sections.

6.5.3.1 Counselling of the children

Literature has indicated that a severe disease, including a child's heart disease, not only threatens family dynamics, but it also poses a challenge for the child as he/she confronts the loss of health, independence and, sometimes, a perception of eminent death. Although the children's responses as regards their personal appraisals of the disease burden obviously vary according to the age of the children and illness-specific factors, the experiences of stress, anxiety, depression, loss of optimal functional status and the need to adapt are common among these children (Webb, 2009). In this regard, it emerges from the literature that the sick children's behaviours as a result of their self-perception, influence both the caregiver's role and the family functions and, as such, are strong determinants in respect of the psychological and physical health of the caregivers.

It is, therefore essential that the children are also counselled to cope with the experiences they encounter in the course of their illness as this will also facilitate coping on the part of their caregivers (Mitchell, 2011; Raina et al., 2005).

Counselling serves the purpose of facilitating learning; developing the skills and positive perceptions of the recipients and enabling access to social support and is, therefore, an important agent for facilitating health promotion. Personal counselling would help the children with heart disease to develop life skills so they are able to identify challenges and construct self-directed solutions to the challenging experiences of living with heart disease. This, in turn, enhances their self-esteem and the subsequent coping with the burden of the disease. A positive self-concept in the times of trial is associated with positive emotional experiences and better coping (Kettunen, Oskiparta, Liimatainen, 2011; Hadley, Hair, Anderson Moore, 2008).

It was, therefore, important that the agent or the researcher ensured that the child was included as part of the role set for the facilitation of coping with both the demands for care and the experience of the disease burden as this acknowledges the active role that a child, especially an older child, may play in determining and meeting his/her own care needs. It is, therefore essential that a child be educated and empowered to self-manage his/her illness to the fullest extent possible.

6.5.3.2 Compliance with the medications

Patients with heart disease routinely take multiple medications several times a day. The administration of these medications to the patient is one of the complex instrumental tasks which the parents/caregivers have to cope with and some caregivers experience difficulty in dealing with so many prescriptions. A lack of skill as regards their administration of medicines and the supervision of the child may result in hazards for the child (Travis, Bethea, & Winn, 2000). In order to prevent emergencies from arising, it is therefore essential that the caregivers be equipped with the skills required to be able to observe any toxic effects, particularly in the case of those children who are not able to report such problems themselves (Reinhard et al., 2008). It is also vital that the caregivers understand the need to comply with the medication schedule. To comply with the medication schedule means taking the correct amount of the prescribed medication and at the proper time. It also implies never stopping medication unilaterally, even if one feels better, or missing the dosages because such a choice worsens the condition. Medications tend to be effective and have fewer less adverse effects if they are taken as prescribed by the physician who is concerned with the treatment of the child (Travis et al, 2000; WHO 2003; Reinhard et al., 2008)

6.5.3.3 Cardiac diet and nutrition

The literature indicates that a poor socio-economic status and a lack of awareness of the relationship between poor nutrition and heart disease are major contributory factors to morbidity among patients with heart disease (Pretorius et al., 2012) and this assumption applies to the situation of children with heart diseases and their caregivers who are from the rural areas in Namibia.

In order to assist the parents/caregivers and their children with heart disease to make informed choices of foods for the children, some of the views of Schroder and Schwarzer (2005), who indicate that the ideal diet for a patient with heart disease is a low salt, low cholesterol, high calorie and high fibre, diet, is recommended. Because of the structural nature of heart disease among these children, the parents/caregivers ought to be advised to offer foods with high energy and protein to enhance vitality, promote growth and to maintain effective oncotic pressure within vascular system to reduce oedema. Therefore, low fat is not necessarily a recommendation for these children. Equally important, the literature indicates that a cardiac patient should be provided with a diet which is rich in vitamins and with adjusted fluid intake as indicated in order to enhance the body's immunity and to prevent an excess volume of fluid in the already compromised state of the heart, while at the same time, providing nutrition and extra calories to the child (Pretorius et al., 2012).

It is, therefore, important that the parents/caregivers of children with heart disease receive instructions from the health care providers about the specific foods that they must provide for their children at home.

However, the choice of a correct diet requires knowledge. In addition to their poor socio-economic status, it appeared that the parents/caregivers concerned did not possess the knowledge necessary to make appropriate choices for a diet that would promote a healthy heart, while at the same time met the needs for growth. It is therefore necessary that the parents/caregivers be provided with detailed information on safer choices as regards their children's diet – see following paragraphs.

Fish products are extremely healthy for patients with heart disease. Fish has unsaturated fat, which reduces the risk for coronary diseases while providing the omega-3 fatty acids as a source of energy to the heart muscles. In addition, the child should eat beans and bran or whole grain such and brown bread. The legumes in these foodstuffs provide fibres that prevent constipation and the risk of a load on the heart. Three scrambled eggs per week are sufficient to meet nutritional goals while guarding against both the risk of hyper cholesterol and the risk of coronary heart disease.

Excess consumption of red meat, sources of trans fat such as fried foods, fast foods, biscuits and sweetened beverages such as soda/cola, sweetened juices, sport drinks and alcohol should be avoided at all costs as they increase the risk of coronary heart diseases and cardiomyopathy in an already weakened heart (Pretorius et al., 2012).

However, in view of the fact that the recipients of the programme interventions in this study were from the rural areas of Namibia and not able to afford many of these nutritious foods which, in the main, have to be purchased from the market (as stated in the research findings), they are to be encouraged to make use of the locally available foods which are sources of essential nutrients but, at the same time, do not cause problems for the heart. Examples of such locally affordable food

include mahangu porridge, butternut, poultry meat, spinach and brown bread when affordable (MoHSS, 2007). The use of locally available and nutritious fruits such as the wild berries are also to be encouraged, as long as they are consumed with sufficient fluids and no seeds to avoid constipation.

6.5.3.4 Weight management

Maintaining proper body weight is important to overall health including the heart. Eating significant amounts of food, eating fatty foods and leading a sedentary lifestyle all contribute to weight gain. This clearly also applies to patients with heart disease. A person is considered to be overweight when that person's weight is ten or more percentage of his/her expected body weight. Overweight contributes to a poor health status on the part of any patient with the concomitant implication of poor coping on the part of the caregivers. However, children with heart disease are at risk of failing to thrive or are often a low weight for their age as a result of a poor metabolism and low energy (approximately half the ideal energy only available for growth in children with heart disease) because of the slow circulation caused by the compromised functional status of the heart (Menon & Poskitt, 1985).

In their research into nutrition for children, Wandner and Hair (2009) and Hair, Thompson and Wandner (2008) found, in line with a researcher from the Services of Mercy Heart Centre, that controlling weight with diet management is the best option for cardiac patients to maintain an appropriate body weight. It is, therefore, proposed that patients with heart disease or their caregivers should make sensible dietary choices of diet, as was discussed in the previous section on cardiac diet and nutrition (Wandner & Hair, 2009; Hair, Thompson & Wandner, 2008).

In this regard, the diet should include high calories/kilojoules to supply the extra energy required to catch up with growth. In addition, while the diet should be soft to prevent the loss of calories through strenuous digestion and to aid easy absorption, salt should be avoided in order to prevent fluid overload and potential load on the heart (Paul, 2008; Menon & Poskitt, 1985).

The second method of weight control available to patients with heart disease is physical exercise. Physical exercises refer to those activities that involve body movement such as walking and jogging. Physical activities help burn fats, maintain ideal body weight and, in patients with heart disease, help prevent complications such as atheroma and subsequent coronary heart diseases – a situation that worsens the delicate heart status of children with heart diseases. However, it is important to inform that parents/caregivers that the child, as a cardiac patient, must perform physical exercises according to the recommendations of the physician (Jolliffe, Rees, Taylor, Thompson, Oldridge & Abraham, 2001).

6.5.3.5 Palliative care/symptomatic care

Palliative care refers to a combination of active symptomatic and compassionate care to meet the physical, psychological, social and spiritual needs of an individual living with a lifelong illness, thereby helping him/her to make the most of each day and maintain a sense of hope as a result of the emphasis of living and personal choice for both the patient and the caregivers. Palliative care therefore aims to improve the end of life quality of a sick person by relieving the symptoms and enabling the person to die in peace and with dignity (WHO, 2002).

Palliative care at home for a patient with heart disease involves making provision for both the basic needs and for comfort measures and include bathing, ventilation, positioning the patient so as to relieve chest pain, recognising the intensification of the disease symptoms, deciding to seek the services of a health care provider and managing follow up treatments. Furthermore, issues related to the prevention of the common illnesses that are associated with heart diseases, such as the common cold and the subsequent upper respiratory infections, oral hygiene and immune boosting diet are included in palliative care. Therefore, the parents/caregivers must be skilled, inter alia, in teaching the children deep breathing techniques to ease the symptomatic burden of difficult breathing (Boyse et al., 2011; WHO, 2002).

For those children who, as a result of “causal appraisal”, may believe that they may have caused the illness themselves, it is essential that the parents/caregivers let the children know that it is acceptable to feel angry, scared or lonely. However, the parents/caregivers should help these children to differentiate between reality and fantasy and reassure the children that the illness is not their fault (Bush, 2011).

In addition to the specific aspects of the treatment regimen and the palliative care that were discussed in the previous sections, it is important to introduce some measures aimed at modifying the child’s lifestyle and the environment in which the child is living to enhance the child’s well-being.

6.5.3.6 Modification of the child's lifestyle and of the environment

According to Paul (2008) and Schroder and Schwarzer (2005), successful management of heart diseases requires a voluntary control of unhealthy behaviours as well as long-term adaptations of the patient's lifestyles to reduce the strain on the heart. The adjustment of activity levels and control of the exposure to smoking and pollution are some of the necessary modifications that need to be effected (Paul, 2008 & Schroder; Schwarzer, 2005).

Activity tolerance

It is recommended that patients with heart disease should perform moderate physical activities for approximately 60 minutes on a daily basis in accordance their activity tolerance and guidance from the physician while, at the same time, being alert to any indications of activity intolerance(Jolliffe et al., 2001). It was, therefore, necessary to include a session on the adjustment of activity tolerance for the children in the study as part of the programme interventions.

Despite the fact that the child may try to counter the control over his/her world by challenging the limits imposed by the illness, the parents/caregivers must endeavour to be firm in respect of those things over which the child does not have a choice and offering choices in respect of flexible aspects of the treatment only, and without being overly rigid and striking a balance between their role as primary caregivers and the child's need for independence. For example, the parents/caregivers must enforce any restriction of activities as prescribed by the physician. In addition, despite the fact that it may interfere with the child's independence and sense of mastery, it is necessary that the parents/caregivers restrict these children in their activities with other

children, in accordance the treatment regimen. However, to the extent allowed by the child's physician, the parents/caregivers should help the child to participate in school or other activities.

The child should also be offered with ways in which he/she may contribute to the family in a meaningful way as this will help the child to develop confidence and a sense of mastery. By allowing the children to help in the management of their illness (with close adult supervision), the parents/caregivers will help these children to develop a sense of mastery as they realise their own ability to cope with their illnesses (Boyse et al., 2011; Kettunen et al., 2001). The modification of the environment is also important, particularly as regards preventing the child from being exposed to environmental pollutions.

Measures for environment modification

Environmental factors such as smoking, dust and pollutants adversely affect the health outcomes of a patient with heart disease. Nicotine from cigarettes replaces the oxygen at the hemoglobin level, thereby lowering oxygen consumption in the body. Therefore, exposure to smoking compromises the blood's oxygen saturation and this is followed by low metabolism and the resultant cachexia (Paul, 2008; Menon & Poskitt, 1985). Polluted air, on the other hand, increases the risk to airways infection with these complications tending to exacerbate heart diseases, and negatively affecting the child's health outcomes and enhancing morbidity.

It is therefore, of importance that a child with a heart disease should be protected from environmental pollutants such as dust and second hand smoking. In other words, the parents/caregivers ought to be well informed about the need to maintain environmental hygiene in their houses and to prevent the child from being exposed to second hand smoking.

It is recommended that family members who smoke should smoke outdoors. Furthermore, as the families of the study participants made use of open fires to cook and provide warmth in winter, it is important that the parents/caregivers be advised to ensure that the child is not exposed to smoke from open fires.

In conclusion, and in accordance with the concept of the Dying Person's Bill of Rights, it is hoped that the programme interventions result in the emotional, social and physical needs of the programme beneficiaries being met. Implicitly, the programme interventions should help the parents and caregivers to cope with the demands of care and, as a result, the children should receive quality home-based quality care and be enabled to retain a sense of hope. This, in turn, should mean that their health status will improve or they would be able to live their last days with dignity and die in peace (Forrester, 2008).

6.6 SUMMARY

This chapter explained the theoretical assumptions in respect of coping and which underpinned the home-based health care programme. The aims, objectives and the components of the home-based health care programme were presented while the modalities for the implementation of the home-based health care programme were also discussed. This chapter concluded the second phase of the study. The next chapter introduces the inception of phase three of the study with chapter 7 describing both the implementation of the programme interventions to facilitate coping among the parents/caregivers and their children and the evaluation of the outcomes of the programme implementation.

CHAPTER 7

PROGRAMME IMPLEMENTATION & PROGRAMME EVALUATION

7.1 INTRODUCTION

In the previous chapter, the development of a home based health care programme was discussed. The programme content was described. As the last phase of the study, phase 3 involves the implementation of the interventions of the home-based health care programme and the evaluation of the outcomes of the programme implementation. The summary, study limitations, the recommendations and the conclusions, conclude this phase of the study.

This chapter describes the implementation and evaluation of the programme interventions and is therefore, divided into two sections. The first section describes the implementation of the programme interventions and the second section deals with the evaluation of the outcomes of the programme interventions.

7.2. PROGRAMME IMPLEMENTATION

This section describes the procedures involved in the implementation of the interventions of the programme for home care. The context and the methods used as well as the theories that were applied in the implementation of the programme interventions are discussed.

7.2.1 Context for the implementation of a home-based health care programme

As discussed in the previous chapter, the context for the programme is the situation or environment in which the activities of the programme are to take place (Dickoff et al., 1968). In this study, the context for the programme implementation comprised the two (2) rural households headed by subsistence agricultural farmers in the Omusati region where the programme interventions were implemented (see figure 7.1). These two households were included in the households which featured in the data which were collected during situational analysis for the description of the parents/caregivers' experiences of caring for a child with a heart disease and that of the children's living with a heart disease. The findings of the situational analysis guided the conception of the themes, programme objectives and programme content.

The programme interventions were implemented at the participants' households by the researcher, as an agent, to the parents/caregivers and the children, as the recipients, while taking into account the socio-economic and cultural aspects that could have influenced the outcomes of the programme implementation. The purpose of the individualised household programme interventions was to maximise the individualised benefits for each participant as the interventions were aimed at the individual rather than the group. It was believed that the individualised programme interventions would be more effective for the recipients, so as to enable them to benefit from the proposition that the clients of health services tend to learn better in their home environment than in health care facilities (Sorenses et al., 2003; Lepscyzyk, Laleigh, & Rowley, 1990).



Figure 7.1: The households of the children with heart diseases and their parents/caregivers –the context for the programme implementation

Indeed the structures of the households and the quality of agricultural subsistence farming are testimony to the impoverished life of these families. This impoverishment, in turn, means that they experience financial difficulties as regards providing special care for their children with heart disease.

7.2.2 The art/method of facilitating the implementation of a home-based health care programme

The programme was implemented through workshops that were conducted at the households of the participants. If the objectives for a home based health care programme are to be realised, it is important to apply those skills that are suitable for the participants' context. Accordingly, the principles of adult learning and experiential learning were employed to facilitate effective learning by the participants.

7.2.2.1 Principle of adult learning

Based on the assertions above, the principle of adult learning was applied to facilitate self-directed and active learning on the part of the parents/caregivers as adult learners. The assumptions listed above are in line with the suggestion of Knowles (n.d.) and Atherton (2002), to the effect that, unlike children, adults desire to be self-directed and to take responsibility for their decisions, with the adult approaching learning as a problem solving tool. Knowles concludes that adults learn best when they believe that what they are learning is of immediate value and, therefore, adults approach learning as a problem solving tool. In that regards, the parents/caregivers were requested to confirm the set objectives for the programme as their priorities for learning with regard caring for their children at home. The application of adult learning principles facilitated the realisation of the programme objectives as expected outcomes.

7.2.2.2 Experiential learning approach

Experiential learning emphasises a holistic learning approach in terms of which learning is realised through an interaction of concrete experiences, reflective observations, abstract conceptualisation and active experimentation (Kolb, 1984). This concept of experiential learning was applied in the implementation of the programme interventions of this study. The participants were given information for knowledge about the disease of the children and the aspects of caring. Demonstrations were given on practical aspects of caring and the participants were given feedback on skill performance and where necessary, they were encouraged to improve.

Through concrete experiences, the participants learnt or acquainted themselves with new knowledge and values provided by the researcher and through self-exploration, they discovered existing potentials at family levels and in the community and they identified options. Abstract conceptualisation enabled the participants to systematically comprehend what was being learnt, for example, practice of emotional coping methods and to apply new knowledge and skills in providing care for their children with heart diseases at home. Active experimentation allowed the participants practically to test the concrete learning and abstract conceptualisation of some of the programme interventions that involved complex instrumental tasks such as food preparation and the measuring out of medications. Practical engagement with the activities related to concrete learning and conceptual abstraction helps to clarify and personalise concrete learning and, in the end, the learning becomes part of the personal knowledge base (Kirby, 2000). According to Gentry (1990), if one hears, one may forget, if one sees, one may remember, but doing creates an understanding.

Finally, and through reflective observation, the participants were given opportunity to reflect back on their learning experiences consciously and also on how they could apply the insights gained to coping with the demands of providing care for their children at home. Figure 7.2 explains the application of experiential learning to the learning process of the parents/caregivers.

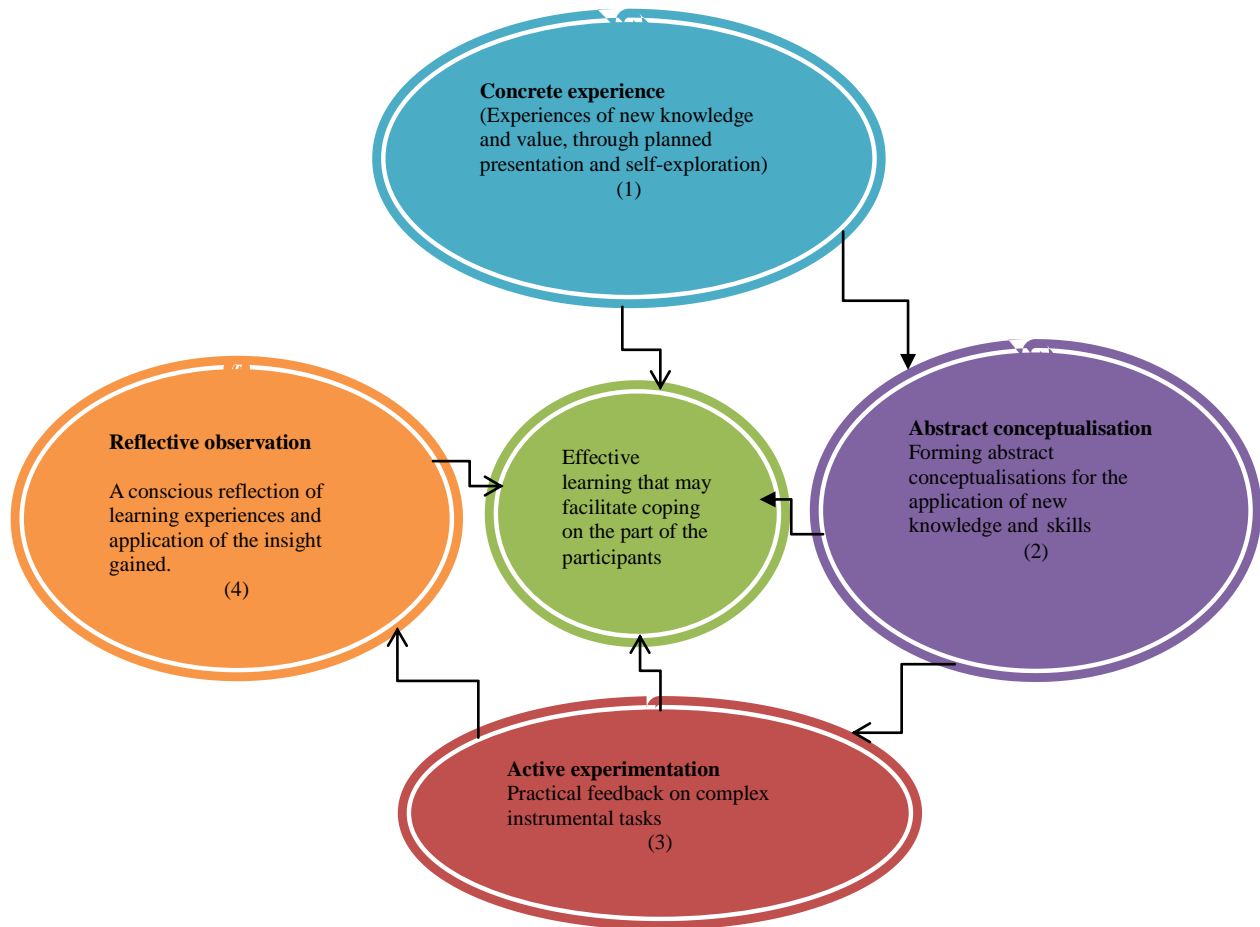


Figure 7.2: Application of experiential learning cycle

7.2.2.3 Facilitation

Facilitation is an interactive goal oriented process of learning which places emphasis on self-discovery rather than on the didactic (Pretorius, 2008). Accordingly, during the programme implementation, the parents/caregivers were guided to explore and discover their existing potentials, identify options, further their personal learning and realise their full potential that would enable them to cope with the demands to care for their children who have heart disease at home (Meyer, 2004).

In addition, the participants were guided as individuals to learn from new information. By so doing, they broaden their knowledge base, the application of which can facilitate coping with the demands to care. The role of the researcher involved keeping the participants on track and helping them to stay focused (Williams & Walker, 2003). The methods of teaching were adjusted according to the educational level of the parents/caregivers to allow them to understand both the information and practical experiences (Paul, 2008).

Counselling and methods of learning such as discussion, information sharing, demonstrations, feedback and self-evaluation were employed to ensure the effective facilitation of the programme activities (Kobus, 2007).

7.2.2.4 Participants' active participation

In addition to the facilitation, the active participation of the participants was required in order to realise the objectives of the programme interventions. The parents/caregivers, as adult learners, were engaged in the discussion in order to identify and address their learning needs, an exercise

that is likely to reinforce the perception that the information is relevant to their situations; hence they could apply the new knowledge to facilitate their coping (Paul, 2008). The active engagement of the participants with both the facilitator and the learning content, as characterised by the interchange of ideas and attempt at problem solving, all culminated in the increased retention of what had been learnt following the implementation of programme interventions (Cowley, 2004; Stein, 1998).

7.2.3 The process of programme implementation

The implementation of the programme interventions was conducted in four sessions over two days per household. Two sessions were held per day to allow the participant to learn at the pace convenient to them, given their socio-economic context. As a result, the programme interventions were implemented over a total of four days for the parents/caregivers and their children with heart disease at the two households.

Participation was voluntary and informed, verbal consent was obtained from each of the participants before the commencement of the programme activities. Each participant either received a programme schedule with a list of the activities to be covered or was informed of the programme schedule beforehand. Those who can read and write were given a note book and a pen to record the information which he/she may have deemed worth noting for future reference.

In the interests of a supportive family relationship, three to four adult participants from each household participated in the programme interventions (Taylor-Powell, Steele, & Douglass, 1996).

Multi-component interventions addressing the challenges which had been identified and which the parents/caregivers faced in their caregiving roles were implemented in the sessions of various coping methods which would facilitate coping with the demands of caring (Acton & Kang, 2001; Gitlin et al., 2003).

Session one focused on facilitating emotional coping to realise healthy emotions, and was designed to address the theme relating to the participants' experiences of emotional challenges while session two dealt with facilitating the mobilisation of social support to realize the restoration of productive social functioning and mitigation of financial difficulties, and was designed to address the two themes of the participants' experiences of disrupted social functioning and the lack of support respectively. Session three focused on facilitating the promotion of the children's functional status to moderate the children's experiences of decreased vitality.

7.2.4 The implementation of the programme interventions

Multi-component interventions of a home-based health care programme to facilitate coping with the burden of the demands of caring were implemented as described on the next sessions.

7.2.4.1 Session 1: Facilitation of emotion focused coping

Intervention 1: Bereavement counselling

In the initial stage of this session, a brief bereavement counselling session was conducted for the parents/caregivers to help them to come to terms with either their children's lifelong illness or with a poor prognosis. This activity involved a discussion on:

- Understanding the potential treatment outcomes of the children's diagnosis.

- In line with the children's medical records when the treatment options offered opportunities to alleviate the symptoms only and not necessarily a complete cure, this was reinforced to the parents and caregivers (Nicolini & Gherli, 2009; Gibson, 2007).
- Encouragement to the parents/caregivers or the participants to accept the children's condition.
- A demonstration on listening with sympathy and providing care with respect, dignity and a non-judgmental attitude toward the child. The parents/caregivers were encouraged to listen with empathy to the children's concern and to provide care with respect, dignity and non-judgmental attitudes towards the children (WHO, 2002).

Intervention 2: Emotional regulation coping

A discussion on the following techniques of emotional regulation was held with the parents/caregivers:

- ***Emotional venting:*** Emotional venting refers to self-expression, a letting out of emotions. The parents/caregivers were encouraged to practise venting by discussing their feelings and concerns with a family member or a confidant (WHO, 2002 & Glanz et al., 2008).
- ***Disengagement:*** Disengagement is an act of shifting the attention from the challenge, either cognitively or by engaging practically in alternative activities. The parents/caregivers were taught to employ disengagement as a method of coping and to disengage from their thoughts about the plight of their children. Instead, they were encouraged to practise positive techniques of disengagement, including cognitive

avoidance – not to think about their children’s plight; distraction – by engaging with something else to shift the attention away from their thought about their children’s plight and the corresponding demands for care, while at the same time being aware of the necessity to avoid any negative disengagement, such as denial and avoidance (Glanz et al., 2008).

- **Optimism:** In order to facilitate practising optimism, the participants were taught to learn how to break their maladaptive thought patterns about the negative experiences of caring for their children with heart disease. Seligman and Csikszentmihalyi (2000)’s model for challenging negative beliefs through the practice of adversity, beliefs, consequence, disputing/decatastrophising and energisation (ABCDE) was used to teach the participants to learn how to practise optimism and its steps were applied as follows:

Adversity: During this step, the parents/caregivers were asked to describe and create a complete picture of their negative experiences as regards caring for their ill children.

Belief: During this step, the parents/caregivers were asked to explain whether their negative thoughts are internal or external, stable or temporary.

Consequence: During this step, the participants were asked to state the feelings which they had experienced after the adversity step or to indicate anything they could do in reaction to the adversity.

Disputing/decatastrophising: During this step, the participants were asked to dispute their negative interpretations, as regard the condition of their children and the demands of caring, to generate alternatives and to formulate a plan to realise the alternative outcomes.

Energisation: During this step, the participants described the emotional and behavioural consequences/results following the disputation.

Finally, the participants were informed that turning negative thoughts over and over can only lead to poor coping. Instead, the parents/caregivers were encouraged to continue practicing optimism on their own to ensure that their thoughts continued to remain grounded in positive expectations because practicing optimism allows them to cope with the demands of caring (Seligman & Csikszentmihalyi, 2000).

Intervention 3: Meaning-based coping

In order to facilitate learning the art of meaning-based coping, the parents/caregivers were introduced to the exercise of positive appraisal/acceptance, positive reinterpretation and self-re-evaluation and also spiritual beliefs as methods of coping. In this regard, the participants were requested to explain in ways that were personally meaningful to them how they should respond to their children's condition and to the demands of providing care to respective children. This exercise was followed by an introduction to and explanation of the following techniques of meaning based coping, namely:

- Acceptance – for the parents/caregivers to accept their children's condition.
- Self-re-evaluation – to assess and try to change their feelings about the challenges of caring for their children.
- Using religion and spirituality for growth and capacity to derive positive meanings from the challenges of caring for their children with heart disease (Glanz et al., 2008).

Intervention 4: Self-efficacy

The parents/caregivers were taught to learn how to employ self-efficacy in terms of practising empathic listening and responding to their ill children by being sensitive and listening attentively, for them to understand their children's emotional status and their point of view correctly and without necessarily feeling with or experiencing the world of their children in order for the children to experience and appreciate that they are being attended (Egan, 1998).

A demonstration was given which integrated the skills of listening and modelling, feelings and encouragement. The participants were requested to demonstrate, in turn, how to use the techniques for filtering listening to identify and focus, without judgment, on concerns that were important to the children while understanding the children and encouraging them to live optimistically. The participants' successes were acknowledged and they were encouraged to reduce their fears and anxieties as key elements to facilitating their learning of self-efficacy (Egan, 1998). Furthermore, participants were encouraged to acknowledge their successful performances and to improve where necessary and as to be persistent and avoid the fear and anxiety that prevent them from initiating action (Egan, 1998).

In addition to challenging negativism through the utilisation of emotional coping styles, the parents/caregivers were encouraged to enhance their coping through the use of the social support that was available to them – see next section.

7.2.4.2 Session 2: Mobilisation of social support for the parents/caregivers

The participants were engaged in exercises to explore the resources that were available at the family level as well as at the community level and which they could use to help them to cope. The social resources that were discussed with the participants included supportive family dynamics, seeking appropriate health information, seeking social support and socialisation.

Intervention 1: Supportive family dynamics

In order to facilitate the practice of supportive dynamics within the family and proposed by the literature, the parents/caregivers were guided through an exercise designed to help them to realise the potentials within their families and to make use of those strengths in order to help them to cope with the demands of providing care for their children with heart disease at home (Krysan et al., 1991).

As a result, the participants were guided to identify the conditions and behaviour patterns within the family that they believe may help them to endure and become more cohesive as well mutually supportive and appreciative as regards meeting the demands of caring for their children (Helseth & Ulfsaet, 2005; Raina et al., 2005). During the exercise which formed part of this activity, the negotiation of the responsibilities or the sharing of the care interventions within the family and the degree and quality of communication between the family members who were able to provide care to the sick child were explained to the participants. At the same time, the structure and behavioural indicators of supportive dynamics within the family and the probability of the family being able to cope were reinforced. This exercise included the following information that was provided to the participants.

- Clear role definition for the family members so as to enable the various members of the family to establish patterns of clear and equitable negotiation as regards carrying out the required interventions of care for the ill child e.g. who is responsible for the hygiene, who prepare food and who administers the medication.
- Communication of decisions on the nature of the care to be provided to the child.
- Encouragement, recognition and appreciation of the contributions of the primary caregiver to the child's wellbeing.
- Commitment to the family, by acting as a team and providing mutual support in terms of the wellbeing of the child.
- The role of religion or a spiritual orientation as spirituality may induce positive emotions and is, therefore, a predictor of the increased likelihood of coping (Krysan et al., 1990).

Intervention 2: Seeking of information

As indicated in the description of the programme content, the parents/caregivers were urged to act as monitors and to seek health related information pertaining to their children's condition to help them to make informed decisions. A discussion was held about the relevant information about symptomatic care, diet, level of activities, follow up treatments, likely treatment outcomes and modification of the children's lifestyles and the home environment that the participants needed to obtain from health care providers, so as to reduce any uncertainties they may have had and to foster more realistic thoughts (Chair & Pang, 2008).

As suggested by the World Health Organization's guidelines on the practice of home-based health care interventions, the participants were encouraged to make use of information from

the health care workers at the health care facilities and also the written information in pamphlets as knowledge base which helps them to cope. In addition, pamphlets on cardiac diet were provided to the participants for future reference should they be able to afford the required foods (Glanz et al., 2008; WHO, 2002).

Intervention 3: Seeking of social support

As regards utilising social support, the participants were engaged in a group discussion to explore and identify the resources that were available in the community and which they could utilise to help them cope with the demands of providing care at home. In order to realise this objective, the participants carried out the exercise and identified supportive environment that was available to them, such as:

- Confidants in the community who could offer a listening ear when they felt burdened by the demands of care.
- Individuals whom they knew were in a similar situation or who was even worse off, as the downward comparison could bolster their self-esteem.

As a result of the exercises, the participants were able to identify family members and local spiritual leaders as their confidants. This, in turn, enhanced their self-esteem and self-efficacy, therefore increasing the likelihood of their coping (Glanz et al., 2008).

The participants were encouraged to make use of those dimensions of a support network which were available to them as social support offers them the opportunity to adjust to their challenges, thereby contributing to their coping and more positive health outcomes for their children.

Intervention 4: Socialisation

The participants were asked to explore the availability and adequacy of the support network offered by their friends, confidants and neighbours as external resources which would help them find the strength needed to cope with their situation. In view of the rural context of their lives, the participants were also encouraged to identify any local community organisations, including community development initiatives and religious organised activities, and to participate in the relevant activities of such community resources, both as a way of socialising and as sources of the inspiration that they needed to cope with the challenges posed by the demands of providing care to their children (Glanz et al., 2008; Sayers et al., 2008; Krysan et al., 1990). In addition, and as discussed in the activities related to supportive family dynamics, the participants/caregivers were encouraged to ensure that they took recreational breaks and to rotate the caring activities amongst the available family members (WHO, 2002).

7.2.4.3 Session 3: Facilitation of optimal physical functional status for the children

Facilitation of a physical functional status for children with heart diseases is possible through a rehabilitation programme which includes a set of non-pharmacological activities such as the empowerment of the child, compliance with the medication schedule and cardiac nutrition, weight management, activity tolerance and the provision of palliative care interventions to relieve the symptoms that were explained to the parents/caregivers – See below. In addition, changes in lifestyle, including avoiding both stress and passive smoking on the part of the children, were also explained (Duffy, Hoskins, & Chen, 2004; Joliffe et al., 2001).

Intervention 1: Counselling of the children

In addition to counselling the parents/caregivers, the children were also counselled to enable them to develop coping skills and to construct self-directed solutions in respect of the challenging experiences of living with heart disease (Mitchell, 2011).

Accordingly, the child participants participated in a discussion on their disease, to enable them to develop some concept of their illness therefore, providing learning experience for the children about their illness (Sternberg & Zhang, 2000). Appropriate remedial actions which included the clarification of misconceptions, the development of resilience and the encouragement of purpose and future were formulated (Mitchell, 2011; Bush, 2011).

In addition, a discussion was held on the loneliness which the children were experiencing and which was depicted by the children's pictorial naïve drawings about their personal experiences of their illness (see annexure 7). In this regard, the children were encouraged to make a self-discovery and identify actual and potential successful practices that they could engage with in order to mitigate the challenges imposed by their illness (Kettunen et al., 2001). Finally, the child participants were encouraged to comply with all aspects of their treatment regimen including taking the medication as prescribed, following the correct diet and adjusting physical exercises as indicated by the physician (Boyse et al., 2011; Kettunen et al., 2001).

Intervention 2: Compliance with the medication schedule

One of the critical aspects of providing home care for a family member with heart disease is carrying out the necessary complex instrumental tasks, including administering medication. It is essential that the caregiver be aware of any potential side effects of the prescribed medication as these side effects may be life threatening (Travis et al., 2000; WHO 2003). It is, therefore, vital that the caregivers be knowledgeable and skilful as regards the instrumental care they are to provide in order to protect the recipients of the care from any danger (Reinhard et al., 2008; Scherbring, 2002; Bucher, Loscalzo, Zabora, Houts, Hooker & BrintzenhofeSzoc, 2001; Schumacher, Stewart, Archbold et al., 2000).

Accordingly, the importance of observing any side effects of the various medicines that are prescribed for children with heart disease, including aspirin and digitalis, was explained to the parents/caregivers. These side effects include the risk of bleeding from Aspirin or any anticoagulant. Other side effects that were explained included those related to digoxine and other digitalis toxic such as the slowing of the heart rate, irregular pulse patterns, polar of the skin and sweating and the subsequent risk of shock (Chummun, Gospaul, & Lutchman, 2009). In this regard, the parents/caregivers were encouraged to seek the immediate assistance of a health care provider should the child experience any side effects from the medications (Higgins, Thoebald, & Peters, 2008; Grubb & Newby, 2006; Deelstra & Jacobson, 2005).

To conclude this activity, practices on how to administer the medications to the children, including understanding the prescriptions in respect of the dosages, time intervals between administering the medication and the measurement of the dosages were reinforced to the

parents/caregivers. The participants then had to carry out these activities themselves, thus reinforcing active experimentation (Sternberg & Zhang, 2000).

Intervention 3: Cardiac diet and nutrition

Another important instrumental caregiving activity for a child with structural heart disease involves a cardiac diet which enhance vitality and promote growth, while at the same time minimises the risk of further heart disease. In this regard, the participants were informed about the cardiac diet which is high in protein and calorie, such as red meat and poultry, mahangu and maize porridge, as sources of protein and to maximize the energy that is necessary for the child's growth. Parents/caregivers were also advised to offer the children foods that are low in salt to prevent fluid retention and the risk of overload to the heart.

A standard therapy in the management of patients with heart failure, namely, a salt intake of 2 to 3mg of salt, which equals less than $\frac{1}{4}$ of a teaspoon, per day was explained to the participants (Pretorius et al., 2012; Charlton & Jooste, 2001). In addition, the locally available foods which contain the essential nutrients and vitamins e.g. wild berries and spinach, to strengthen the child's immune system and to promote thriving were explained (Chummun et al., 2009; MoHSS, 2007; Ford-Martin, 2006).

Furthermore, the parents and caregivers were encouraged not to abandon the traditional millet porridge in favour of Western food which are low in fibre, for example, rice and white bread. Instead and according to the guidelines for a diet for patients with heart diseases, the parents/caregivers were advised to prepare the children's meals from the locally cultural sensitive, yet unrefined starchy and which are sources of essential nutrients foods such as red meat and poultry, mahangu, maize porridge, sorghum, beans and cat fishes, as well as brown

bread and oats, when affordable, as these foods are all sources of protein, energy fibre, certain vitamins and minerals (Pretorius et al., 2012; MOHSS, 2007).

It was explained to the participants that the children should be given small portions at a time, sufficient fluid and food rich in fibre, while avoiding seeds from wild berries in order to prevent constipation and the subsequent load on the heart and difficulty in breathing (Eshah & Bond, 2009).

Based on the suggestions above, the patents/caregivers then demonstrated how to prepare meals from the locally available sources of nutrients to meet the dietary requirement of the children.

In conclusion, unless indicated otherwise by the physician, the safe daily food intake for the children was explained to the participants. As proposed by Scholtz, Vorster Jr., Matshego, and Vorster (2001), this diet, which these parents should be able to afford, comprises 400 to 500 ml milk daily, two to three servings of fish per week and four eggs per week or one egg on every alternative day as the sources of the protein, energy, minerals and vitamins that are essential for the child's growth and a healthy heart (Scholtz et al., 2001).

Intervention 4: Weight management

Weight management for patients with heart diseases has been shown to improve significantly the patients' blood lipid profiles, vital signs performances (blood pressure and pulse patterns) and the overall survival of the patients (Eshah & Bond, 2009). The parents/caregivers were provided with the following important information as regards controlling the children's weight.

Maintaining a proper body weight is essential to overall good health, particularly in the case of a patient with a heart disease. Eating large portions of food, especially fatty foods, and leading a sedentary lifestyle all contribute to weight gain, also for patients with heart disease. In addition, being overweight for a heart patient compounds the risks for heart disease and contributes to poor overall health. This, in turn, has implications for poor coping on the part of the caregivers.

However, it was explained to the parents/caregivers that the failure to thrive or “low weight for age” on the part of their children is a function of a low metabolism which is caused by a compromised cardiac output and poor distribution of the oxygen (Menon & Poskitt, 1985). This, in turn, could be resolved only once the heart defect has been cured, should a cure be possible.

In addition, the parents/caregivers were advised to assess the child for oedema which may result from the fluid retention that accompanies the consumption of salt or a compromised venous return. It was stressed to the parents that it is essential to be alert to signs of both visible oedema, such as pedal oedema, and invisible oedema, such as difficulties in breathing as signifying oedema of the lungs. If they should detect any of these signs they were to seek the attention of a health care provider immediately (Sayers et al., 2008).

Activity 5: Activity tolerance

In accordance the recommendation on physical activities and activity tolerance for a patient with heart disease, the parents/caregivers were advised to identify those activities that the child was able to tolerate. However, should the child experiences any signs of activity

intolerance, such as tiredness and respiratory distress, the child should resume bed rest in order to reduce the heart's workload and the demand for oxygen (Sue, 2011; Chummun et al., 2009; Eshah & Bond, 2009).

In conclusion, it was emphasised to the parents/caregivers that, despite the benefits of performing physical activity, the child should only perform those physical activities that were recommended by the medical personnel (Sayers et al., 2008; Jolliffe et al., 2001).

Activity 6: Palliative care/symptomatic care for the children

Palliative care to relieve the symptoms of the deranged cardiovascular system is one of the instrumental tasks that the parents/caregivers of children with heart diseases are required to perform at home. The aspects of providing palliative care at home for a patient with heart disease, including providing basic comfort measures such as bathing, ventilation, positioning the patient and relieving chest pain as well as recognising any intensification of the symptoms, deciding to seek the services of a health care provider and the management of follow up, were explained to the participants. In addition, issues related to the prevention of the illnesses that are associated with heart diseases, such as respiratory infections, through protection of the child from cold, pollution, second hand smoking and practice of oral hygiene for the child were clarified (Coovadia & Wittenberg, 2007; WHO, 2002).

In accordance with the concept of the “dying person's Bill of Rights”, the programme interventions would ensure that the emotional, social and functional challenges of the beneficiaries would be met. In particular, the parents and caregivers would be better able to cope and, thus, the children would receive quality care and be allowed to retain a sense of hope. As a result, their health status would improve (Forster, 2008).

7.3. PROGRAMME EVALUATION

7.3.1 Introduction

In this section, the evaluation of the programme implementation and programme outcomes are discussed. Bugge et al. (2009) suggest that it is not sufficient merely to develop and implement programme interventions, but it is equally important to incorporate the programme evaluation into the process if the researcher is to understand how the programme works and to assess the outcomes from the programme interventions. Programme evaluation therefore, involves the assessment of whether the programme activities are congruent with the programme objectives which have been formulated (Pretorius, 2008). For the purpose of this study, both the process and the outcomes evaluations were conducted.

7.3.2 Purposes of programme evaluation

According to Metz (2007) and Taylor-Powell et al. (1996), the purpose of conducting an evaluation is to assess both the process of the programme implementation and the effects or outcomes of the programme interventions. For the purpose of this study, process evaluation focused on the logistic aspect for the implementation such as: contentment of the programme with the context of implementation as regard the information given to the participants, the use of learning styles and skills practices and time allotment to each intervention. Outcomes evaluation on the other hand assessed the effectiveness of the programme interventions in meeting the parents'/caregivers' need to cope with the demands of providing care for their children with heart diseases at home.

The expected outcomes of the programme evaluation include indicators of how satisfied the participants were with the programme activities or their perceptions as to whether the programme was likely to make a difference to their coping, thereby indicating whether the programme had been worth the effort. In addition, it was felt that the outcomes of the programme evaluation would be useful both in establishing the trust of the recipients and in attracting stakeholders to promote the implementation of the programme interventions by the parents/caregivers and other health care providers to ensure the long-term duration of the programme (Taylor-Powell et al., 1996; Metz, 2007).

7.3.2.1 Process evaluation of programme implementation

As proposed by Metz (2007) and Taylor-Powell et al. (1996), a process evaluation was conducted at the end of each day's workshop to assess the feasibility of the programme implementation in order to ensure that the programme was operating efficiently (Metz, 2007; Taylor-Powell et al., 1996). Knowledge of "what works" is of assistance in ensuring that the programme implementation focus on those programme activities that would be of the greatest benefit to the participants and that the programme interventions match the participants' context. On the other hand, knowing "what does not work" allows the mode of delivery of the programme interventions to be modified or improved (Metz, 2007). In this regard, the contentment of the programme with the context of implementation as regard the information given to the participants, the use of learning styles and skills practices, time allotment to each intervention were evaluated and the result which indicated that it is feasible to implement the

programme. Then the programme interventions were adjusted according to the context of the participants.

7.3.2.2 Outcomes evaluation of the programme interventions

The evaluation of the programme outcomes is also extremely important and, therefore, a qualitative outcomes evaluation was conducted three months after the programme implementation to assess the long-term effects of the programme interventions on the participants.

In line with the propositions of the WHO (2002), Metz (2007) and Taylor-Powell et al. (1996), regarding the aim of an outcomes evaluation, an outcomes evaluation for the programme implementation served the purpose of determining whether there had been changes in the participants' patterns of copings as a result of the programme interventions. To that end, the parents'/caregivers' empowerment as regard coping with the demands of providing care for their children with heart diseases at home was evaluated. The results of the evaluation reflected the positive impact on the participants. As a result, it is possible to anticipate the potential long term, desired effects for the participants in term of coping with the demand of care at home. In addition, it was felt that the outcomes of the programme evaluation would be useful in attracting stakeholders to promote the implementation of the programme interventions by the parents/caregivers and other health care providers to ensure sustenance of the programme (Taylor-Powell et al., 1996; Metz, 2007).

The outcomes from the evaluation of the interventions of the home-based health care programme were aligned to the three (3) main objectives of the programme implementation (refer to page 208-211). The specific objectives for the programme outcomes evaluation are as follows:

7.3.3. The objectives for the programme outcomes evaluation

The threefold objectives of the programme outcomes evaluation are described below:

7.3.3.1 Objective 1: Evaluation of the participants' (parents/caregivers and the children) knowledge of aspects of emotional coping:

As regards this objective, the evaluation focused on assessing whether interventions had succeeded in equipping the participants with the ability to develop the positive self-concept which is necessary for positive emotional outcomes. The aim was to assess whether the participants' attitudes, perceptions and opinions has changed as result of the programme interventions (George, 2008; Silverman, 2004). As proposed by Carver, Scheier and Weintraub (1989), the parents/caregivers were evaluated on the use of venting, religion, acceptance, disengagement and self-re-evaluation and seeking social support to facilitate their coping and, ultimately, enhance their emotional wellbeing (Glanz et al., 2008), and the outcomes of which indicated caregivers' acquaintance with and practice of these methods of emotional coping following the their participation in the programme interventions (see annexure 10).

7.3.3.2 Objective 2: Evaluation of the participants' (parents/caregivers and the children) knowledge and skills that is required to identify and utilise the social network.

As regards this objective, the evaluation focused on assessing whether the participants had acquired the knowledge and skills necessary to identify and utilise the existing social network for the purposes of coping. Accordingly, the appreciation of supportive dynamics at the family level, the scale of social support available, information seeking and socialisation on the part of the parents/caregivers were evaluated. The findings indicated that the parents/caregivers were making use of the family strengths, such as sharing the responsibility for the care of the child among the eligible members of the family, as well as use of the resources available at the community level resources to cope (see annexure 10).

7.3.3.3 Objective 3: Evaluation of the children's knowledge about their disease and of self-care.

As regards this objective, the evaluation focused on assessing the children's ability to construct self-directed solutions to help them cope with the experiences they encountered in living with heart diseases (Mitchell, 2011). In addition, the parents'/caregivers' ability to recall the important aspects of safe, symptomatic care in order to enhance the children's functional status were also evaluated (Glanz et al., 2008). The responses indicated that the participants benefited from the programme interventions as they demonstrated possession of knowledge of the child's disease and skills to execute care interventions. The parents/caregivers also implied that as a result of the programme interventions, they were

able to teach the child to perform the behaviours which enhance their (children)' coping with the burden of the disease, such as rest and wearing warm clothes (see annexure 10).

7.3.4 Process of programme outcomes evaluation

In a qualitative study, asking for an informed consent is a process and not a one-off- event (Parahoo, 2006). All the participants from the two households where the programme was implemented were asked to participate voluntarily in the outcomes programme evaluation. The data for the programme outcomes evaluation were collected through the medium of interviews, field notes and the testimonials of the participants' experiences of the programme interventions. It was felt that, taking into account the capabilities and the understanding of the participants, these methods would be the most likely to secure the required information (Taylor-Powell et al., 1996). The following open-ended questions were posed to give the participants the opportunity to describe their experiences of the programme interventions as regard the quality and the degree of learning gained from participating in the programme activities.

Question 1: What did you learn from the programme?

It was felt that the information derived from the responses to this question would probably justify the degree of learning which the participants have derived from the programme interventions. Therefore, in addition to the evidence of active experimentation and mastery in certain of the instrumental tasks of care, the participants stated that they had found the programme essential and that the programme interventions had enabled them to provide appropriate care to their children. It emerged that the programme interventions have provided them with knowledge and skills that they needed for them to cope with the demands of

providing care to their children with heart diseases at home (see annexure 10, about the data on the participants' experiences of the programme interventions).

Question 2: What was difficult for you in the programme?

It was felt that the information derived from the responses to this question could serve as a yardstick as regards the quality of learning that the participants had derived from the programme. In this regard, the limitations of the programme were indicated by the participants asserting that, they needed repetition of the programme interventions, for them to be thoroughly knowledgeable about all the aspects that they learnt. These outcomes serve as justification for the improvement on the facilitation of the implementation of the programme interventions, such as time allotment to each intervention, to ensure effective learning on the part of the participants.

7.3.5 Discussion on the outcomes of programme evaluation

The purpose of the programme evaluation was to assess the feasibility of implementing the programme, as well as the long-term outcomes of the programme interventions. Accordingly, the discussion of the findings from the programme evaluation also focused on the indicators of the feasibility of implementing the programme and the programme outcomes (Taylor-Powel et al., 1996). The following paragraphs summarises the conclusions about the findings of the programme evaluation.

The feasibility of implementing the programme could possibly be inferred from the successful implementation of the programme activities through the medium of the methods that were discussed in the previous sections on the process evaluation of the programme implementations.

Likewise, positive programme outcomes, which are likely to contribute to the caregivers' coping and the children's empowerment, could possibly be ascertained from the participants' testimonials and their active experimentation in respect of some of the programme interventions. The participants indicated that they had felt empowered by being provided with much needed information. Moreover, the parents/caregivers regarded the innovation of a supportive relationship with family members to enable the sharing of feelings towards the child and the tasks of caring as extremely important.

In accordance the findings from other studies, which stipulated that programmes interventions that are focused on the family context enable a better understanding and coping with the situation, the interventions from this programme also enhanced cohesion within the families of the participants (Thastrum, Munch-Hansen, Wiell, & Romer, 2006). As a result, the parents/caregivers reported positive changes in their ability to make use of the strengths at the family level carry out the instrumental tasks of care and seek appropriate social support to help to cope with the demands of providing care at home.

The interaction with the researcher, with the participants being regarded as individuals with potential and whose views were considered as worthwhile, also added another dimension to the participants' appreciation of the programme interventions.

Furthermore, and in line with the findings from other studies, the programme evaluation also indicated that, as a result of counselling interventions, the children were also demonstrating the ability to practice self-care management in response to their symptoms (Riegel, Vaughan Dickson, Goldberg, & Deatrlick, 2007).

In conclusion, despite the fact that the parents/caregivers had indicated that the insights that they had gained from the programme had enhanced their understanding of their children's conditions and changed their perceptions of their children's condition, nevertheless they did indicate they need continuous professional support within their own unique context as well as in the context of the family dynamics. The latter is supported by the arguments of Barnes, Kroll, Burke, Jones, and Stein (2002).

Table 6.1 below, which is based on a modification of Bennett's framework of the hierarchy of evidence for programme evaluation, presents the outcomes of the programme evaluation (Bennett & Rockwell, 1995).

Table 7.1: Outcomes of the programme implementation

Focus Area	Outcomes	Indicators
<ul style="list-style-type: none"> Programme implementation 	<ul style="list-style-type: none"> Successful implementation of the programme activities. Facilitator and participants' satisfaction with the programme interventions. Facilitation of supportive agent and advocates of the programme activities. 	<ul style="list-style-type: none"> Focal caregivers and other family members participated in programme implementation. Active participation on the part of the participants. Feedback on practical skills included in the programme interventions from the participants. Supportive group are available.
<ul style="list-style-type: none"> Programme context 	<ul style="list-style-type: none"> Adjustment of the programme activities to suit the participants' socio-economic status. 	<ul style="list-style-type: none"> Satisfaction with the programme activities within the context of the programme implementation. The use of participants' vernacular enabled a better understanding on the part of the participants. Modification of the programme activities according to the material resources available to the family.
<ul style="list-style-type: none"> Programme outcomes 	<ul style="list-style-type: none"> Narrative of the knowledge and skills gained from the programme interventions. The programme activities were carried out successfully. 	<ul style="list-style-type: none"> Identification of resources to for problem focused coping (resources at the family level for role sharing, use of substitutes to allow the parents/caregivers to socialize) Identification of resources at local level for the emotional focused coping and at the community level for the spiritual support that may enable coping. Correct performance of aspects of palliative care (assessment of the children for cyanosis, correct positioning of the children to ease breathing , correct measurement of dosages of medicines and correct preparation of diet for the child) Children's empowerment (ability to adjust to activity tolerance and remembering the type of food they are allowed to eat).
<ul style="list-style-type: none"> Programme limitations 	<ul style="list-style-type: none"> Need for regular visits by health care providers were alluded to by the parent/caregiver participants 	<ul style="list-style-type: none"> Need for assessment of the children's condition. Need for provision of emotional and material support

The outcomes of the programme evaluation were summarised according to the objectives of the programme evaluation as displayed in the figure 7.3 below:

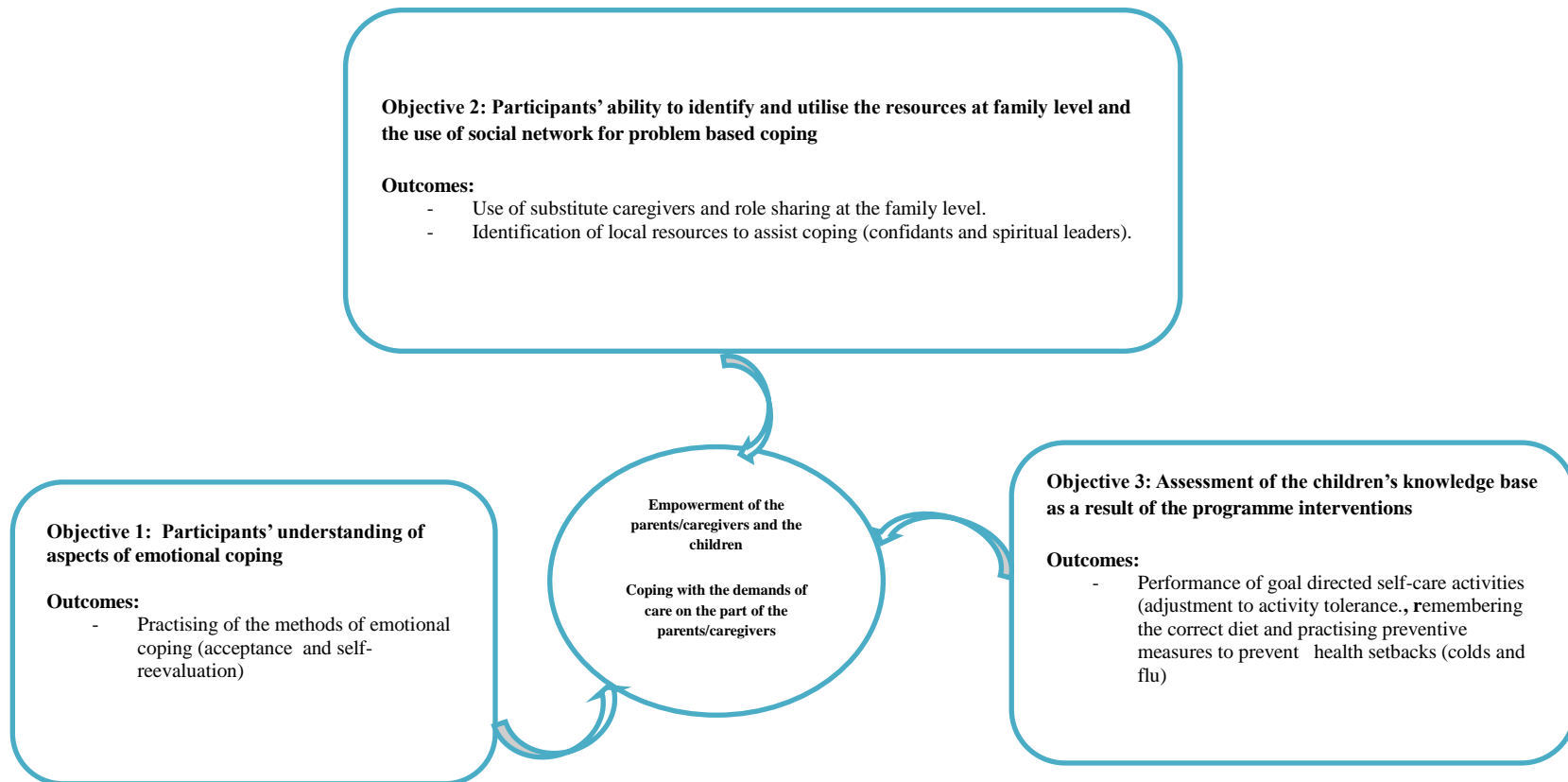


Figure 7.3: Outcomes of the programme evaluation

7.4 SUMMARY

Section one of this chapter discussed the implementation and evaluation of the programme interventions aimed at empowering the parents/caregivers, to enable them to cope with the demands of care for their children who are diagnosed with heart disease. Firstly, the implementation of the programme was described with the context and purposes of the implementation being elaborated upon. The facilitation of the programme implementation was based on the principles of adult learning and experiential learning so as to allow the participants the opportunity for self-directed learning as they actively assumed the responsibility for their own learning through the medium of concrete experiences, reflective observation, conceptualisation and active experiences.

The workshop sessions and the specific interventions conducted during each session of the programme implementation were discussed. Three sessions of empowerment interventions were held to meet the following objectives – the facilitation of emotional focused coping on the part of both the parents/caregivers and the children, the mobilisation of social support for the parents and caregivers and the facilitation of the optimal functional status for the children (see discussion on the process of the programme implementation).

Section two of this chapter contained a brief discussion the process evaluation as regard the feasibility of implementing the programme interventions and the outcomes evaluation about changes in the participants' patterns of copings as a result of the programme interventions. In this regard, the results of the process evaluation indicated a strong feasibility as regards the implementation of the programme. This may be inferred from the successful implementation of

the programme activities and interventions as planned for the purposes of the study and by the evident congruence of the programme content with the context where the programme was implemented.

The outcomes evaluation indicated the trust of the participants in the programme as they were satisfied with the programme interventions and therefore indicated that the programme is likely to make a difference to their coping with the demands of caregiving at home. The parents/caregivers regarded the programme as having been worth the effort. Finally, the participants demonstrated gain in knowledge base as regard the child's condition, the skills and community-based resources that are necessary for them to cope with providing home care for their children with heart disease. In view of the fact that the outcomes of the programme evaluation were in line with the objectives of the programme interventions, the study will now be concluded. The limitations of the study and recommendations for future research will also be discussed.

CHAPTER 8

SUMMARY, LIMITATIONS, RECOMMENDATIONS AND CONCLUSIONS

8.1 INTRODUCTION

This chapter presents the summary the limitations, recommendations and conclusions of the study regarding the implementation of home-based health care interventions for the empowerment of parents/caregivers so as to enable them to provide care at home for their children with heart disease.

8.2 SUMMARY

In this chapter, the goal and objectives of the research are revisited to ensure that they have been realised. If the goal and objectives of the study have, indeed, being realised then the study will have contributed to the existing body of knowledge in respect of providing care for a patient with heart disease within the family context.

The objectives of the study were to explore and describe both the parents'/caregivers' experiences of providing care to their children with heart disease at home as well as the children's experiences of living with heart disease, within their socio-cultural context that may influence the way in which both the parents/caregivers and the children cope with either the demands of care or the burden of the disease. The findings of a phenomenological situational analysis revealed poor coping with the demand of caring on the part of the parents/caregivers.

This study comprised three sequential research phases. **Phase one** involved the description of the parents'/caregivers' experiences of providing care to children with heart disease at home and the experiences of the children as regards living with the heart diseases. The participants were purposefully selected at the health care facility (cardiac clinic) in Windhoek at the time of follow up treatment and were all from the rural areas of Namibia.

Description of the participants' experiences as regard the phenomenon under study was implemented by conducting in-depth interviews and field notes of the parents/caregivers and the children and through the pictorial, naïve drawings by the child participants. Following their transcription, the interviews provided a rich text of data. As women, the parent/caregiver participants expressed their intimate thoughts and share the emotional aspects of their lives more readily. The fact that the parents/caregivers displayed their vulnerabilities as regards providing care at home assisted the researcher in arriving at her findings.

Four main themes were identified after the data arising from the interview and field notes had been analysed, based on the Tesch open-coding method of qualitative data analysis and the description of pictorial naïve drawings (Creswell, 2008).

The first theme involved the emotional challenges that both the parents/caregivers and the children with heart diseases experience and was related to either the emotional reaction as a result of the child's diagnosis and the perceptions of the possible adverse consequences of the illness. Several corresponding sub-themes were identified. These included the emotional turmoil of shock, sadness and hopelessness. The second theme involved the challenges that signified disrupted social functioning as a result of the limitations that were imposed by either the demand

for the parents/caregivers to provide on-going care or by the limitations that the illness imposed on the child. Again, several sub-themes were derived at from this main theme. These sub-themes included a lack of support and knowledge as an important means of facilitating the primary caregivers coping with the demands of care. The third theme arose from the moving revelations about the need for financial assistance to enable the parents/caregivers to provide the special cardiac diet, facilities required to care for the children and to be able to afford to travel to health care facilities for follow up treatments. The fourth main theme was exclusive to the children and involved their adverse experiences related to the symptoms of the heart disease, a consequence of the impact of heart disease on the physiology of the body. As the final step in the first phase, within the context of the themes and sub-themes, the data were contextualised and cross validated to position the findings within the context of the existing body of knowledge about the phenomenon under investigation. Based on these findings, parents/caregivers' poor coping with the demands of caring was conceptualised.

Phase two involved the formulation of a conceptual framework. The central and related concepts about the need for the empowerment of the parents/caregivers to assist them to cope with the demands of care at home were formulated. The conceptual framework led to the development of a home-based health care programme aimed at assisting rural parents/caregivers of children with heart diseases to cope with the demands of providing care at home. The nature and extent of the home-based health care programme was based on the "situation producing" concept or causal-connectedness as proposed by Dickoff et al., (1968, p.433) with regard to the agent as a facilitator, the recipients of the interventions, the dynamics to mitigate the challenges, the procedure to address these challenges and the terminus as the outcomes from the procedures

(Dickoff et al., 1968). Accordingly, home-based health care programme interventions for the empowerment of the parents/caregivers and their children were developed and described.

Phase three involved the implementation and evaluation of the programme interventions aimed at empowering the parents/caregivers so as to enable them to cope with the demands of providing care at home. The implementation of the programme interventions were based on the concept of adult learning and experiential learning to enable the parents/caregivers to facilitate self-directed, active, concrete observation and experimentation learning (Atherton, 2002; Kolb, 1984). Eventually home-based health care programme interventions were implemented and evaluated in the Omusati region in Namibia.

The programme implementation was executed during two days workshops which were held at each of the two households which had been purposefully selected for the implementation of the programme interventions. The implementation was structured in four sessions with relevant interventions taking place during each session.

Session one focused on the facilitation of emotional coping and included the interventions pertaining to bereavement counselling and the use of the coping styles that are essential for the regulation of the emotions. Session two sought to create awareness in the parents/caregivers about the essential components of social support and focused on the encouragement of supportive family dynamics, seeking appropriate health information, seeking social support and socialisation as significant resources at the family-community level that the parents/caregivers could harness to help them to cope with the demands of care.

Session three involved the promotion of the optimal functional status of the children and involved counselling about coping skills and for them to construct self-directed solutions in respect of the challenging experiences of living with heart disease as the option that enables them to cope with their experiences of the disease as well as other interventions of palliative care, including compliance with the medication, the diet and nutrition and modification of the child's life style and environment.

Session four focused on the evaluation of the process of programme implementation. At the end of each day's workshop, a process evaluation on the feasibility of the programme implementation was conducted in order to identify the success and challenges of early implementation and, therefore to ensure that the programme could operate efficiently and as a result, remedial actions were taken during the implementation of the programme.

The evaluation of the programme outcomes was conducted three months after the implementation of the programme interventions to assess the long-term effects of the programme interventions as are signified by changes in the participants' patterns of coping. These positive outcomes may be conceptually replicated into the desired long-term effects or the impacts of the programme interventions on the envisaged recipients (WHO, 2002; Metz, 2007; Taylor-Powell Steele & Douglass 1996). The participants offered recommendations on the successful implementation of the programme and the gains from the programme interventions.

8.3 LIMITATIONS OF THE STUDY

As inherent to research activities, several limitations may be associated with this study. As a common research problem, the respondents may have expressed only what they felt that the researcher should hear or which was socially acceptable rather than their genuine experience, and not expressing the feelings and behaviours that they may have believed would be negatively judged. In addition, in view of the fact that the data were filtered through the perceptions of the interviewer and the co-coder, the interpretation of the data may have been limited to these perceptions, therefore imposing limitations on the data.

Furthermore, as is the nature of findings from qualitative research, it may not be easy to generalise the conclusions that were drawn from this study, the result of which is based on non-probability sampling method and a small size sample that was used in the study.

In addition, two day training sessions is not necessarily enough to allow the participants sufficient learning about the interventions of the programme and the practising of new knowledge and skills as it transpired from the outcomes evaluation that the participants need repetition of information for thorough knowledge. Accordingly, it is not possible for the researcher to conclude that the implementation of the programme interventions would have long term impacts on all the respective participants. It is, therefore, important to ensure on-going support for the participants.

8.4 RECOMMENDATIONS

The findings from the study revealed poor coping of the parents/caregivers from various perspectives, including the role played by the personal characteristics of the caregivers. Therefore the recommendations on this study encompassed aspects of the various perspectives which influence the provision for care and, therefore, the level of coping with the demands of care. Webb (2009) indicates that it is possible to ensure the facilitation of quality care for children with special health care needs, including those with heart diseases, only through access to coordinated, complementary services to ensure comprehensive health care (Webb, 2009). Therefore, in this regard, four types of recommendations are made as regard to the clinical health care setting, health care and social services, future research and with regard to training of health care workers.

As concerned with confirmation of the diagnosis and the prescriptions of the treatment regimen, the clinical health care setting is a primary focal point for the initiation of health care interventions aimed at the empowerment of the parents and caregivers to facilitate their coping with the demands of providing care at home.

Furthermore, and in line with the existing literature, members of the frontline staff at the district level of the health care services play an important role in the effective implementation of a health care programme within the community. The literature also advocates that, as the implementation drivers, frontline staff should be trained to acquire the relevant knowledge and skills to enable them to enrich both the programme activities and expected outcomes by providing technical support to the intended beneficiaries of the programme (Metz, Burkhauser, & Bowie, 2009; Collins & Metz, 2009).

In addition, not all the resources that are necessary for the empowerment of the parents/caregivers are to be found within the limit of the clinical health care setting and health care services. The financial implications to which the participants alluded presuppose support from the social welfare. In conclusion, no study is a complete endeavour in itself and future research is also needed to extend the research findings concerned.

The following recommendations are suggested with regard to the four perspectives to enable the Namibian rural parents/caregivers to cope with the demands of providing care to their children with heart diseases at home.

8.4.1 Recommendation for the clinical practice setting

The emotional experiences pertaining to the perception of the nature of heart diseases, the expectation of care and living with the burden of the disease symptoms all impact negatively on the emotional wellbeing of both the parents/caregivers and the children. The emotional, social and economic challenges that the caregivers experiences can influence the quality of care provided to these children at home (Deyirmenjian et al., 2005, Raina et al., 2005; Rotter, 2000; Murray, Manktelow, & Clifford, 2000). Therefore, the need for health education to enable the parents/caregivers to maintain a sound level of care for their children at home has been undeniably demonstrated in this study and warrants the following recommendations.

- In view of the potentially negative impacts on the parents/caregivers and the children, it is recommended that health care professionals should assess and identify the existence of actual or potential emotional and socio-economic challenges confronting the parents/caregivers in meeting the demands of care at home.

- Have identified the need for coping on the part of both the parents/caregivers and the children, health care professionals should teach the parents/caregivers and the child the knowledge and skills specifically to facilitate both emotional coping and problem focused coping to enhance the possibility of coping before the children are discharged from the hospital.
- In order to ensure the reinforcement of the much needed information provided to the parents/caregivers, health education should include information and instructions for palliative care that address discharge medications, follow up appointments, diet, and weight monitoring and the steps to take should the disease symptoms intensify as well as health education about lifestyle modification with regard to activity tolerance and controlling the exposure of the child to environmental pollution (Sutherland, Hearn, Boum, & Elston, 1994).
- If the clinical settings are to be able to measure and audit the assessment of actual or potential emotional and socio-economic challenges confronting the parents/caregivers and their children with heart diseases in meeting the demands of care at home, as proposed by the American Heart Association (referred to by Paul, 2008), it is recommended that the clinical setting use a checklist with multi-component indicators regarding the health education for patients with heart diseases and their caregivers as recommended in this study (Paul 2008; Phillips, Wright, Kern, Singa, Shepperd, & Rubin, 2003). See table 8.1 below.

Table 8.1: Checklist for health education for the parents/caregivers and the children with heart diseases (adopted from the American Heart Association and adjusted to the local situation)

PART 1: HEALTH INFORMATION FOR EMOTIONAL COPING	
<ul style="list-style-type: none"> Information given to the parents/caregivers on the nature of the children's heart disease and potential outcomes? If yes, by Dr..... 	<p>Yes/No</p>
<ul style="list-style-type: none"> Information given to the parents/caregivers on waiting time for surgery: If yes, by Dr..... 	<p>Yes/No</p>
<ul style="list-style-type: none"> Counselling provided to the parents/caregivers on the techniques of emotional coping methods as appropriate to the parents'/caregivers' context? <input type="checkbox"/> Venting of feelings, <input type="checkbox"/> Self-re-evaluation, <input type="checkbox"/> Acceptance <input type="checkbox"/> Seeking social support, <input type="checkbox"/> Spiritual beliefs, <input type="checkbox"/> Optimism and <input type="checkbox"/> Self-efficacy. 	
<ul style="list-style-type: none"> Counselling provided to the parents/caregivers on the techniques of problem management coping as appropriate to the parents'/caregivers' context: <input type="checkbox"/> Supportive family dynamics, <input type="checkbox"/> Seeking of appropriate health information relevant to the care of the children, <input type="checkbox"/> Participation in community based support groups, <input type="checkbox"/> Cooperation with confidants and downwards comparisons, <input type="checkbox"/> Recreation and socialisation. 	
<ul style="list-style-type: none"> Counselling provided to the child about coping with the burden of the disease symptoms (Based on the age of the child)? 	<p>Yes/No.</p>

PART 2: INFORMATION REGARDING ADHERENCE TO THE TREATMENT REGIMEN				
Section 1: Information on medications				
Discharge medications (List)	Dosages of each medication	Frequency	Side-effects	Start date/time
<ul style="list-style-type: none"> Medication/food interaction information given? 			Yes / No	
<ul style="list-style-type: none"> Information to avoid over the administration of over the counter medications? 				
Yes/No				
Section 2: Diet information				
Information given on: <input type="checkbox"/> Low-sodium, <input type="checkbox"/> Fat-free, <input type="checkbox"/> Low cholesterol, <input type="checkbox"/> High fibre, <input type="checkbox"/> Soft/digestible diet, <input type="checkbox"/> Limited quantities at a time, and <input type="checkbox"/> Adjusted daily fluid intake.				
Section 3: Weight monitoring information				
<ul style="list-style-type: none"> Information given to the parents/caregivers on monitoring the child's weight? Yes/No 				
Section 4: Lifestyle and environment modification information				
<ul style="list-style-type: none"> Information given on the type of activities allowed? 			Yes/No	
<ul style="list-style-type: none"> Information given on monitoring activity tolerance of the child? 			Yes/No	
<ul style="list-style-type: none"> Information given to the prents/caregivers about the hygiene of the households? 				
Yes/No				
<ul style="list-style-type: none"> Information given to the parents/acregivers and the children on preventing the 				

children's exposure to second hand smoking ? Yes/No

PART 3: INFORMATION ON OTHER ASPECTS OF REHABILITATION

- Information given about: Bedrest for 1 to 2 hours daily
Yes/No
- Information given on what to do if the the symptoms worsen Yes/No
- Information given on follow up treatments Yes/No
- Health care facility for follow up.....
- Follow up date.....

PART 4: INFORMATION ABOUT THE NEED FOR FINANCIAL ASSISTANCE

- Assessment conducted about the need for financial and material assistance to facilitate coping with the demands of care at home
Yes/No.
- Referrals for financial and/or material assistance Yes/No
- If referred, state the services or the facility to which referred.....

PART 5: AGREEMENT OF THE PARTIES AS REGARDS THE INFORMATION PROVIDED

The information as stipulated herein was provided to and understood by the parents/caregivers and the children, where applicable

Signature of the health care provider.....Date:.....Time.....

The information as stipulated herein was explained to me, I understood the information and have received a copy of this form.

Signature of the parent/caregiver.....Date:.....Time.....

- It is, however, important that health care providers in the clinical setting note that the majority of caregivers are not emotionally ready for learning at the time of diagnosis and that learning would improve once they have adapted to the situation (Paul, 2008,). It is, therefore, necessary that all the instructions and advice which have been verbally communicated to the parents/caregivers and the children, also be provided in a written format so that the caregivers may refer to them as sources of information at a later date and at their convenience (Price & Leaver, 2002).

8.4.2 Recommendations for Health Services and Social Welfare

- The sustaining of the home-based health care programme requires on-going support to these parents and caregivers. It is, therefore, recommended that the implementation of the interventions of this study be mainstreamed in the health care programmes at the district level of health care delivery. The mainstreaming of the programme interventions at the district level would ensure regular home visits by a health care professional to provide support within the household context, to reinforce the health information which was provided at the time of hospitalisation, therefore to assist with the adaptation of knowledge and skills. This, in turn, would help the caregivers to overcome feelings of hopelessness and deal with setbacks (Paul, 2008; Burkhauser & Metz, 2009 b).

It is also important that health care providers who are specifically trained (training would enhance their interest in the programme) to oversee the implementation of the programme

interventions aimed at enhancing coping on the part of the parents/caregivers be appointed at the district level of health care services.

- The extent to which coping has been facilitated should not exclusively be measured against the efforts from the health services. The determinants for coping on the part of the parents/caregivers are not all within the exclusive remit of the health services. Welfare policies that facilitate the accessing of financial assistance influence the ability of vulnerable families to achieve and maintain a degree of empowerment (Berkman, 1995). It is, therefore, recommended that the services of social grant be extended to the children with heart disease whose parents/caregivers are economically vulnerable in order to facilitate their coping with the demands of providing care at home, until the child's condition is resolved.

The literature recommends that, once the programme interventions have proved to be effective, it is worth transferring them and adapting them to suit situations within similar contexts (Metz, Bowie, & Blasé, 2007).

- In conclusion, in view of the evidence of poor coping of same nature that emerged on the part of the rural parents and caregivers of children with heart diseases and the children, and who are from different regions with various cultural contexts and practices, the intervention components and the implementation of the programme have the potential to be transferred to other beneficiaries from the contexts similar to those of the participants of this study in all the regions of Namibia.

8.4.3 Recommendations for future research

Future research is recommended to:

- Assess the participants' increased ability to cope and their quality of life as a result of the programme implementation to validate the correlation between the programme interventions and the caregivers' coping.
- Validate if the recommendations for clinical setting & Health Services and Social welfare are implemented in order to ensure the continuation of the programme interventions.
- Investigate the health care professionals' perception of the parents'/caregivers' and their children's situation.

8.4.4 Recommendations for training of health care workers

As responsible for training the prospective clinical nurse practitioners, it is important to acknowledge that training institutions plays a role as regard producing nurse who are skilled in providing individualized care to the clients including the children with heart disease and their caregivers. In that regard, it is also important that a concept of “home care to facilitate demands of care for the caregivers of children with heart disease” be included in the curriculum for basic training of registered nurses at the local training institution.

8.3 CONCLUSIONS

The conclusions of the study were drawn from the summary on the objectives of the study, as regard the experiences of caring for a child with a heart disease by the parents/caregivers and that of living with a heart disease by the children, as well as on the outcomes of interventions of a health care programme.

In concluding this study, the researcher is of opinion that the objectives of the study were achieved. Objective one and two were to describe the caregivers' experiences of caring for a child with heart disease and of living with heart disease by the children. In this regard, diverse experiences of caring for a child with a heart disease by the parents/caregivers and of living with a heart disease by the children were explored and described. The parents/caregivers and children alike experienced emotional turmoil as characterized by denial anger, a perception of the child's vulnerability, uncertainty and a lack of resources to facilitate care at home. Therefore, the need for support to the parents/caregivers to cope with the demands of care was expressed.

The third objective was to develop a home based health care programme to facilitate coping with the demands of care on the part of the parents/caregivers. Therefore a conceptualization was made of the need to facilitate collective support to the primary caregivers from the family members, community, health care services and other organizations to facilitate coping with the demands of care on the part of the caregivers. The parents/caregivers need to move out of the limbo of emotional- and care vulnerability, and construct self-directed solutions to mediate the effects of the negative appraisals of the caring role in order for them to cope with the demands of care for the child.

Equally important the availability of materials support, knowledge and skills and the substitutes for the primary caregivers in providing care for the child with a heart disease at home was valuable to the caregivers.

The implementation of a contextualized home-based health care programme of multi-component interventions facilitated a positive caring environment in which next of kin and social support are regarded as invaluable resources as regards providing on-going care at home.

The parents/caregivers indicated that the implementation of the programme had rendered bearable the management of their children with heart diseases at home. Programme interventions had enabled the family members to adopt a new perception of the children's condition and the care demands. They were able to reorganise roles and set priorities to manage the demands of caring for the child. It is, therefore, expected that these families will achieve the new "life" as a result of their new capability to coping with the demands of care. Therefore, if the programme were extended to more of families from a similar context, their situation may also improve. The challenge now involves ensuring the sustainability of this programme.

In conclusion, knowledge about the experiences of the parents/caregivers of children with heart diseases as well as the experiences of living with the heart diseases by the children, conceptualization of a home based health care programme the development, implementation and evaluation of the interventions for the home based health care programme to facilitate caregivers' coping with the demands of caring at home are distinct contributions to the body of existing knowledge from this study.

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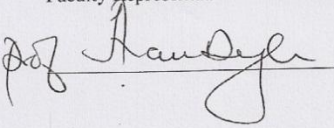
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ANNEXES


PHASE 1: DESCRIPTION OF THE PARTICIPANTS' EXPERIENCES

Annexure 1: Approval of the study proposal by the University of Namibia

			
<p>UNIVERSITY OF NAMIBIA Private Bag 13301, 340 Mandume Ndemufayo Avenue, Pionierspark, Windhoek, Namibia</p>			
<p>FACULTY OF MEDICAL AND HEALTH SCIENCES</p>			
<p>Letter of permission: Post graduate students</p>			
<p>Date: 17 NOV 2009.</p> <p>Dear Student: Ms K. Amakali</p> <p>The post graduate studies committee has approved your research proposal.</p>			
<table border="1"> <tr> <td>An investigation into the need of a health care programme for parents and care takers of children diagnosed with heart diseases in Namibia</td> </tr> <tr> <td> </td> </tr> <tr> <td> </td> </tr> </table>	An investigation into the need of a health care programme for parents and care takers of children diagnosed with heart diseases in Namibia		
An investigation into the need of a health care programme for parents and care takers of children diagnosed with heart diseases in Namibia			
<p>You may now proceed with your study and data collection and formal registration for the degree.</p> <p>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.</p> <p>Please contact your supervisors on a regular basis.</p>			
<p style="text-align: center;">Faculty Representative Post Graduate Studies Committee</p> <p style="text-align: center;"></p>			

Annexure 2: Permission by the Ethics and Research Unit of the Ministry of Health and Social Services to conduct the study among the clients of the health services

9 - 0/0001



REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Private Bag 13198 Windhoek Namibia	Ministerial Building Harvey Street Windhoek	Tel: (061) 2032562 Fax: (061) 272286 E-mail: hilmanangombe@yahoo.com
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Enquiries: Ms. H. Nangombe Ref.: 17/3/3/AP Date: 17 March 2010

OFFICE OF THE PERMANENT SECRETARY

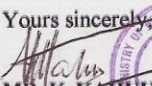

Ms. K. Amakali
Faculty of Health Sciences
University of Namibia
Windhoek
Namibia

Dear. Ms Amakali

RE: Investigating the needs of the parents/caretakers of children diagnosed with heart disease in Namibia for home based health care program to facilitate coping.

1. Reference is made to your application to conduct the above-mentioned study.
2. The proposal has been evaluated and found to have merit.
3. Kindly be informed that approval has been granted under the following conditions:
 - 3.1 The data collected is only to be used for academic purpose;
 - 3.2 A quarterly progress report is to be submitted to the Ministry's Research Unit;
 - 3.3 Preliminary findings are to be submitted to the Ministry before the final report;
 - 3.4 Final report to be submitted upon completion of the study;
 - 3.5 Separate permission to be sought from the Ministry for the publication of the findings.

Yours sincerely,



MR. K. KATIURE
PERMANENT SECRETARY

"Health for All"

Annexure 3: An informed consent from the parent/caregiver participants to participate in the interview.

Introduction to the parents/caregiver (an interviewee)

To the parent (s)/caregiver(s)

My name is Kristofina Amakali

I am a student at the University of Namibia. Your name was obtained from the paediatric cardiac clinic at the Windhoek Central hospital for you to participate in the study. I am going to ask you a few questions about your experience of caring for your child who is sick of a heart disease. The aim of the interview is for me to obtain information that may help me to understand the experiences that the parents and caregivers of children with heart disease go through.

You are free to respond to each question as you feel you should. There are no right or wrong answers. You have the freedom to speak what is on your mind.

You are also free not to answer any question if you so wish. You are free to withdraw from the interview at any time should you so wish.

The interview is confidential. Your name will not be attached to the information which you will provide and all the information that you will provide during the interview will not be revealed to another person.

The following open-ended question was then posed to the parent or a caregiver(s):

How is it (for you) to have a child with a heart disease?

At the end

Is there anything you want to add or any concern that was not addressed or you wish to tell me about?

Thank you for your time and the information you gave me

An informed consent from the parent/caregiver participant

Name of the parent/caregiver:

Parents/caregiver (circle the correct choice)

Age:years

I....., hereby give my consent to participate in an interview without coercion.

Signature of the participant:Date:Time:

Witness.....Date:.....Time:.....

Researcher:Date:Time:

Annexure 4: An informed assent for the child participants to participate in the interview**Introduction to the child participant (an interviewee)***To the child with heart disease*

My name is Kristofina Amakali. I am a student at the University of Namibia. Your name was obtained from the paediatric cardiac clinic at the Windhoek Central hospital for you to participate in the study. I am going to ask you a few questions with regard to your suffering from a heart disease. The aim of the interview is for me to obtain information that may help me to understand children's experience of being ill with a heart disease.

You are free to respond to each question as you feel you should. There are no right or wrong answers. You have the freedom to speak what is on your mind.

You are also free not to answer any question if you so wish. You are free to withdraw from the interview at any time should you so wish.

The interview is confidential. Your name will not be attached to the information which you will provide and all the information that you will provide during the interview will not be revealed to another person.

The following open-ended question was then posed to the child with a heart disease:

How is it for you to have a heart disease? Draw a picture and tell the story about the picture!

At the end of the interview

Is there anything you want to add or any concern that was not addressed, or you wish to tell me about?

Thank you for your time and the information you gave me.

An informed assent for the child participant

Name:

Age:

Parent's consenting statement:

I..... (parent/guardian) declare that I gave an informed consent for my child
..... to participate in the interview.

Signature of the parent/caregiver:Date: Time:

I..... (child) hereby give my assent to participate in an interview
without coercion.

Signature of the child participant:Date:Time:

Witness:Date:.....Time:

Researcher:.....Date:.....Time:.....

Annexure 5: Transcribed data from the parent/caregiver participants

Case 1 (From Omusati)

Age: 38 years old

Gender: Female

Question: How do you experience caring for a child with a heart disease?

(Lombwela ndje nkene wu uvite mokusila oshimpwiyu okanona koye nhono ta ke ehama uuvu womutima).

Response

“Otashi ehameke unene. Onduuvite nayi kutya omolwashike okanona kandje ke na uuvu itau vulu okupangwa. Tashi ti osho ndi na okukala tandi sile okanona hano oshimpwiyu onkalamwenyo yak ayihe ta ka ehama? Ihe kandi na nkee, ondi na oku shi taamba ko. Onde shi taamba ko kutya Kalunga osho a pa ndje. Otandi tal okanonoa kandje nomutima ta gu ehama oshoka ota dhiladhila kutya esiku limwe otaka ka sa omoluuvu mbuno. Onda li ngaa ndi na einekelo kutya, esiku limwe ota k aka mona epango. Ihe ngashiingey onda kanitha omukumo, shaashi oka yile koKapa, ihe oka galuka ko inaa ka pangwa.

“Uupwakadhi omukwawo, iimaliwa mbyoka twa pumbwa opo to w ape okuyakula okanona megumbo. Otashi pula oshimaliwa okufala okanona koshipangelo. Ihe ngame itandi longo. Omathimbo gamwe ohandi lomwelwa ndi fale okanona koshipangelo methimbo ehupi, po pwaana oshimaliwa. Omolwaashoka, nge tweya koshipangelo koVenduka, oha tu kala ko ethimbo, opo okanona ka mone epango iikando iyali, nopo ihe tatu shuna kegumbo, konooli-Omusati. Nege okanonoa otandi ka thigi nokamwayinakadhona yak kale paashiikilwe yetu mOvenduka, sigo ka mono epango lwaali, yo ta yeya ihe kegumbo.”

“Oshinima oshikwawo iikulya. Omathimbo gamwe okanona iha ka hala iikulya mbi tayi liwa kaanegumbo. Ngame ita ndi vulu okulanda mbyono ke hole ngaashi olwishi nomakaloni. Nomahini gogene pomathimbo gamwe itandi vulu okuga landa. Koshopangelo aapangi noodohotola ota ye tu lombwele kutya, okanona natu kape iikulya yoina iipalutha noovitamine., ngaashi iiyimati. Ihe ngame itandi vulu oku yi alnda shaashi kandi na iimaliwa. Ando okwali uunona mbuno una uuvu womutima and tau pewa iikulya ngaashi aavu you HIV no AIDS nenge ngaashi aantu haa pewa iikulya youshikukuta. Yo (aapangi noondohotola) otaye tu lombwele owala tu okanona iikulya yoovitanime, ihe tse ka tuna mpo ta tu yi kutha”.

“Oshinima oshikwawo oshina sha nosikola yokanona, neilongo lyako. Okanona oha ka faula oskola olwindji omolwoshipangelo, okuya koshipangelo, nenge omathimbo keli moshipangelo. Ngashiingey onduuvite nayi, oshoka eilongo lyokanona ita li uka we komeho. Molwaashika, ondu uvite nayi noonkondo. Ando opwali poshipangelo puna oskola opo okanona ka ye koskola, shaashi onda hala ando ki ilonga ka pite oskola. Onda li neinekelo kutya okanona hano ka mone elongo ngaashi uunona uukwao.

Follow up question

Is there any other thing you wish to tell me? (Opena ishewe oshinima shime wa hala u shi lombwele ndje)?

Response

“Aawe, ka pena we sha. Ihe ondu uvite nayi kutya uuvu mbuno itau ka manitha okanona oskola. No handi kala nde ka etela ohenda sho taka ti: “onda hala oku ya koskola”. Ohandi kala nda hala okulila nokuli, shaashi epulo ndjono oha li dhimbulukitha ndje kutya uuvu itau yeluka”.

Translation

“It is painful. I am afraid that my child may die because the illness is incurable. So I have to care for this child with the illness like that for the rest of the child’s life. I have no other option, but to accept the situation. I have accepted that this is what God has given me. I am really looking at my child with pain in my heart, because I imagine that he one day he will die from this disease. I hope that one day he will get a surgery that renders him a complete cure; but now I lost hope because he one went to Cape Town and but he came back untreated”.

“Another problem is money that we need to provide the requirement of care for the child. It needs money to take the child to hospital for follow up, but I do not work. Sometimes one gets a short notice to bring the child to the hospital. That is why sometimes we have to stay in Windhoek temporary for a child to attend two consecutive follow up treatments before we go back to the north (Omusati region). Alternatively, I may leave him with his sister for them to say with the acquaintance here in Windhoek in order for the child to attend follow up treatment”.

“Another thing is food. Sometimes the child does not want to eat the food which the rest of the family eats. I cannot afford the foods that the child prefers such as rice and macaroni. Even milk, sometimes I cannot afford it. At the hospital, the nurse and doctors tell us that we should provide the child with foods that are nutritious and with vitamins, like fruits, but I cannot afford it. I just think if there could be a provision for the patients with heart disease to receive food supplements, like the case with patient who has HIV and AIDS (PLWA) and those who receive drought relief. If only the hospital can refer us to the appropriate authority for food supply! The only thing they (hospital personnel) tell us is to provide the child with foods that are nutritious and vitamins- something we cannot afford”.

“The other thing is about school attendance and performance of the child. The child is often out of school, because of hospitalization. I am concerned because this affects his opportunity for education negatively. I wish he could attend school to be successful. Now I am concern and I wish that there could be a school near the hospital for him to attend school because I have a dream for him. I have always hoped to see him succeeding at school like other children”.

Follow up question

Is there any other thing you wish to tell me? (Opena ishewe oshinima shime wa hala u shi lombwele ndje)?

Response: “No, no more. I am really worried about the negative effects on the child’s school performance. I always sympathize with him as he always says”: “I want to go to school”. “I mean, I sometimes feel like crying when such questions remind me about the degree of the illness-that it is incurable.

Case 2 (from Oshana)**Age: 44 years old****Gender: Female****Question: How do you experience caring for a child with a heart disease?****(Lombwela ndje nkene wu uvite mokusila oshimpwiyu okanona koye nhono ta ke ehama uuvu womutima).****Response**

“Ondi uvite nay, shaashi otandi dhiladhila kutya okanona kandje ota ka si omolwuuvu mbuno. Omathimbo gamwe otandi itula moompadhi dhoakanona kandje, ndi humbate ko kuuvu. Unene tuu sho it aka vulu okudhana nuunona uukwawo, nege okuyola mokule. Aluhe okena okukala ka mwena. Otandi dhiladhila nkene kena uudhigu omolwokukal nuuvu womutima, shaashi onkalamwenyo yako inayi manguluka. Omafimbo gamwe ohandi ipula omapulo teti: Onda yona shike kuKalunga, opo okanona kandje ka kale nuuvu ita pangwa. Naasho itandi vulu okulandela okanona kandje iikulya mbi taka vulu okulya, ohandi kala nda kanitha omukumo, shaashi itandi vulu okw kwatha okanona kandje”.

“Petameko lyuuvu onda li nokuli nda lombwelwa kutya okanona ita ka vulu okupangwa koshipangelo, nonda kanitha einekelo moshipangelo. Onda fal okanona komundohotola gwopaumwene, sigo tandi kala needjo dhiimaliwa. Ayihe mbino onde yi ningi shaashi nda hala okuhupitha omwenyo wokanona kandje! Inadi hala okukanitha okanona kandje. He yokanona omathimbo gamwe oha kala ashike ewete to mu ningile nayi, ngele to mulombwele uupwakadhi wokanona. Ke na ko nando nasha nokanona. Shino natango ohashi kanithitha ndje omukumo’.

“Ndele nando ongawo, ondi inekela kutya pamwe esiku limwe okanona kandje ota k aka mona epango, ee ta ka yeluka, ka kale ngaashi aanonoa ooyakwawo. Ando ka mone epango, ando otandi kala nda manguluka’.

“Oshinima oshiwawo shon shi uvitithe uudhigu, oshimaliwas. Oshapumbwa oshimaliwas opo ndi sile okanona hano oshimpwiyu, ndi lande iikulya mbyoka taka vulu okulya. Shaashi itaka li iikulya iitoye, mbika otayi ka kungitha. Okehole ike oshikulya shomahangu, olwishi nomahini gojougard. Ishewe, koshipangelo onda lombwelwa iikulya mboka ndi na oku pa okanona, ihe ngame itandi vuly oku yi landa, shaashi kandi na iimaliwa”

“Oshimaliwa shoku fala okanona koshipangelo ka pena. Omolu ofutu okufala okanona koshipangelo, onda mana po uumaliwa auhe mbono nda li ndina. Olwindji ohandi lombwelwa ndi fala okanona koshipangelo meni lyootundi 24. Onkee ohandi ka hehel iimaliwa kaantu. Ngashiingeyi ondi na oondjo dhoshimaliwa shaantu. Nomolwaashoka itandi vulu nokufuta oskola yokanona. Molwaashoka oskola inayi futwa, okanona itaka pewa onzapu. Ko ta ka zi ko ta ka lili. Ondi uvite nayi.”

“Oshinima oshikwawo iikulya. Molwaashoka kandi na mpo he mono oshimaliwa opo ndi landele okanona iikulya, onda ya kuKansela woshokandjo shetu, opo okanonona kandje ka kale kaka pewa iikulya. Kansela okwa pula ndje kutya nandi ete ombapila yandohotola ndjo tayi ulike kutya okanona naka ka lye iikulya mbyono tandi indile. Sho nda yi kundohotola, ndohotola okwa ti okanona ka ke na uulema washa. Okuza mpono, ondii gandja kuKalunga mwene a ninge sho ta ningi. He yokanonona malwa manene, ita kwathele nando oshimaliwa. Nge we mu lombwele sha shina sha nokanonona, omayamukulo nga to mono, ogo nga inoo tegelela. Aakwanezimo yandjo wo, itaa kwathele ndje wo”.

“Oshikwao, oskola yokanonoa. Okanona okena omagano, ihaka ndopa koskola. Ihe uuvu itau pitika eilongo lyokanona li ye komeho. Opwa tya ngaa, omathimbo gamwe ohaka loloka ngele take ende oku ya koskola. Ohandi ka humbata/kuminine ndi ka fala koskola. Paige okwa ning oomvula mbali (2) keeli moskola, noku li konima moskola. Ompito ye yo ku mana oskola, op a mone elongo, opo a kwafe ndje numwayina otayi shonopekwa. Onkee, ondi uvite nayi, shaashi oye (okanona) nda li ndi inekela ta ka kwatha ndje monakuyiwa’.

Follow up question

Is there any other thing you wish to tell me? (Opena ishewe oshinima shime wa hala u shi lombwele ndje)?

Response

Aawe, oondhoka wala nde ku lombwele.

Translation

Response

“I feel frightened, because I feel my child may die because of this illness. Sometimes I put myself in the shoes of my child, for example when she has to live a restricted life style. She ought not laugh, play or shout. She has to remain silent. I imagine the pain she goes through because of this restricted lifestyle. I ask myself as to what I have done before God that my child is sick of a disease that is incurable. Even when I cannot afford the food that the child can tolerate because of the illness, I feel helpless, because I cannot provide the necessity for my child.”

“At the beginning, I understood that my child’s illness cannot be cured. So I lost hope in the hospital treatment and I even took my child to a private doctor for treatment, until I accumulate debt. All these I tried to do because of my child. I do not want to lose my child. The father sometimes feels disturbed by the child’s illness or does not care about the child at all. This makes me feel helpless. Despite that, I keep on hoping for the cure of my child. If she get treated successfully, it will be a relief for me. I hope if she is cured, she will be healthy like other children”.

“Another thing that I am worried about is finance. To look after this child, I need money to buy the foods that the child tolerates. The child cannot eat food with sugar, as these make her nauseous. There are foods that she prefers such as rice, mahangu porridge and yougards. There are also those foods that I was told by the hospital personnel to provide for the child. Most of the time I cannot afford these foods”.

“I cannot also afford money to take the child to hospital. Because of travelling to hospital and hospitalization, I spent all the money that I had. Often I am notified to take the child for follow up treatment within 24 hours. So I have to borrow money from other people. Now I am indebted to other people. As a result, there is no money to pay for the school fee. Then the child does not get a report from school because I did not pay the school fee. Then she comes home crying. I feel bad”.

“One other thing is food. Because I do not have sources of finance to buy foods for my child, I consulted our counselor for my child to get food allowance. The counselor requested me to provide the doctor’s certificate that the child needs special food. But the doctor said the child is not disabled. Having gone through all that, I surrender myself in the hands of God, for Him to do

what He can do. To make things worse, the farther does not assist financial at all. When you tell him something about the child), his response would be something one does not expect. Other family members do not help also”.

“About schooling: She is a gifted child. She usually does not fail. However, the illness has affected the child’s schooling negatively. Sometimes she gets tired when going to school. So I have to carry her to school. Right now, the child was out of school for 2 years. She is now behind with schooling. She is now deprived of a chance to progress and complete education, for her to be able to help me and her siblings. I feel bad because I count on her as someone to help me in the future”.

Follow up question

Is there any other thing you wish to tell me? (Opena ishewe oshinima shime wa hala u shi lombwele ndje)?

Response: “No, it is all those that I told you

Case 3 (from Caprivi)**Age: 44 years old****Gender: Female****Question: How do you experience caring for a child with a heart disease?**

(The parent/caregiver from this case was interviewed in English only as English was the only medium the researcher and the caregiver can communicate. There was no transcription of the data)

Response

“It is not easy, because as a mother, you need to take care of the child all the time. You cannot go anywhere, because the child is sick all the time, many days sick and few days healthy. He cannot stay alone. I cannot go away from home. As a mother all your heart is at home with him. I always feel afraid that may be the child is seriously sick while I am away from home. As a cashier, I cannot even stay restful at work, because I keep thinking of him at home. When at work, I am only the body, but all my mind is with the child. But I cannot stay away from work, because then I will not have money to care for him. One does not also have time for other things. All the time you are on the road, every second month to Windhoek for a checkup”.

“When family and friends heard that my child’s illness is for life, they became tired and stay away from us. It is like they condemned us because the child’s illness continues”.

“Money is another problem. One cannot do without money because I spend more to take him to the hospital in Windhoek for follow up or when all of a sudden he is sick. I also have to repeat paying school fees as he has to repeat grade”.

“We also have problem of food. The food he eats differs from what the rest of the family eats. There are foods prescribed by the doctors, like bananas and fruits juices and sometimes I cannot afford because I do not have all the money to buy the necessary food as I have to put money aside to travel to hospital”.

“The child also has problem with schooling. These days the child cannot work up to school, he cannot work a distance or carry his school bag. He becomes tired and gets difficulty in breathing. As a result, he stays out of school too often for too long. I am worried because I wish him to complete school. Like now, he will repeat grade seven (70, when he could pass, because he is a brilliant child”.

Follow up question: Is there any other thing you wish to tell me?

Response: “There are so many things, but all of them cannot come up now”.

Case 4 (from Oshana)**Age: 49 years old****Gender: female****Question: How do you experience caring for a child with a heart disease?****(Lombwela ndje nkene wu uvite mokusila oshimpwiyu okanona koye nhono ta ke ehama uuvu womutima?)****Response**

“Omaupwakadhi ogendji gena sha nesiloshimpwiyu lyokanona hano, omolwuuvu wakao. Uupwakadhi iikulya. Okanona okena okulya iikulya yi ili. Yimwe yomwaambyoka, out na oku yi landa kostola, ihe ka tu na oshimaliwa. Niikulya ngaa mbyon aapangi, noondohotola ye tu lombwela tu lande tse tu pe okanona, ita tu vulu oku yi land shaashi kape na oshimaliwa. Onkee okanona ohatu ka owala iikulya mbyo hatu li megumbo, ngaashi omahini, enyangwa nokahi, nge tw mona. Oyo owala oakanona ka kali mbyo, kehe esiku, kape na eyooloko. Onda kanitha omukumo shaasho kape na ekwatho lyiikulya. Poathimbo gamwe ohatu pewa tuu okandjuhwa kaashiinda, tu dhipage, tse tu pe okanona onjame.”

“Oshinima oshikwawo, oshinasha nokufala okanona koshipangelo, twa pumwa oshimaliwa. Shaashi oakanona ohaka fudha nuudhigu, nge tatu yi koshipangelo, ohatu indile ashiinda ye tu fale nehauto lyawu, shaashi okanona itaka vulu okweenda miihauto yilwe ngaashi okataxi. Ohatu futu nee oshimaliwa oshindji shaa shi twa indila oshihauto shaantu”. Uupwakadhi uukwawo ishewe, oakanona ohaka kala taka ehama. Ohaka kala ka taka fudha nuudhigu. Onkke itaka vulu

noku dhana nuunona uukwawo. Okanonoa oka pumbwa ishewe iigwilo oyindji, opo ka vule okufudha nawa. Ihe omolwoshimaliwa kasha lipo, itatu vulu okulanda iigwilo iyali”.

“Oshinima oshikwawo, okanona okapumbwa okusilwa oshimpwiyu, ethimbo alihe, shaashi oka ninga ike oshilema omoluuvu. Ita ka vulu we okulonga sha megumbo, ngaashi oku ka tyaya iikuni, nege ngaa okusila uumwayina oshimpwiyu. It aka vulu we okwiiyoga. Onkee skehe esiku okena okuyogwa. Onduuvite nay, shaashi manga uuvu ina wu yap o, okanona okali ike kena uukolele ngaashi aanona oyakwawo, no ka li ha ka yakulandje megumbo”.

“Upwakadhi uukwawo, omolwonkalo yokanona, ito vulu oku zapo pegumbo. Unene tuu aakuluntu ngaashi ngame yina. Itandi vulu okuza po pegumbo. Itandi vulu okuya ngaashi kiiigongi yongerki. Ondina okukala pegumbo aluhe opo ndi tonatele okanonoa, nongele onkalo tayi lunduluka, ngame tii ka fala koshipangelo.

Follow up question

Is there any other thing you wish to tell me? (Opena ishewe oshinima shime wa hala u shi lombwele ndje)?

Response

“Aawe, okombinga yaambyono nda popi”

Translation

“There are many problems we experience regarding caring the child. The problem is food. The child has to eat special food and sometimes these foods are not available at home. One needs to buy them, but there is no money. Even those foods that the nurses and doctors told us to buy, we simple do not buy them because we have got no money. We only give foods that are available at the home such as cow milk, pumpkin and cat fish. So the child has to eat that all the time. There is no variation of at home. I feel helpless and hopeless because there is no help to solve the food problem. Rarely, you get some foods like a chicken to slaughter from the neighbors”.

“Another problem is attending follow up treatment which needs money. Because the child experiences difficulty in breathing, we have to arrange special transport from the neighbors / request neighbors to take us to hospital with their cars. For this we pay extra fees”.

“The other problem is the experiences of the symptoms by the child. The child experiences difficulty in breathing with every activity. So he cannot play with other children. He also needs extra pillows to easy breathing. Because of financial constraints, we cannot afford two pillows”.

“Another issue is extra care that the child needs. The child is disabled by the illness. He can no longer participate in household chores, such as looking after his siblings and fetching woods. Because he gets tired easily, he cannot meet some of his basic needs. For example, the child has to be bathed every day. I feel bad because my child was normal and healthy. Sometime I use to rely on him to do some household chores”.

“Another problem is the restriction on social life of the family. The child cannot stay alone at home. So for the parents, especially me as a mother, I cannot go away from home. For example I

cannot go to church activities that take days. I have to stay at home to observe any change in the child's condition and take him to the hospital".

Follow up question

Is there any other thing you wish to tell me?

Response

"It is all about what I told you".

Case 5 (from Omusati)**Age: 29 years old****Gender: Female****Question: How do you experience caring for a child with a heart disease?****(Lombwela ndje nkene wu uvite mokusila oshimpwiyu okanona koye nhono ta ke ehama uuvu womutima?)****Response**

“Petameko tse otwa li twa tila noonkondo shaashika olwo lwotango mezimo lyetu ta u monika omuntu ena uuvu womutima. Omutima ndishi ogwo hagu kalitha omuntu nomwenyo. Onkee ondi uvite kutya okanona kandje oke na uuvu uunene. Onkee ondi uvite kutya okanaona kandje otaka vulu okusa ethimbo kehe, omoluuvu mbuno. Ihe otandi kambadhala okushitambula ko, shhasi muuyuni mbuno olye e na sha nangoye. Omuntu ou na owala okushi tambula ko. Owte shi tambula ko kutya kalunga osho e tu pa”.

“Okusila okanona hano oshimpwiyu, otashi pula oshimaliwa. Otwa pumbwa oshimaliwa, shokufalitha okanona koshipangelo. Megumbo lyetu ka mu na omuntu ha longo ena ondjambe yoshimaliwa, opo tu ikwathele. Onkee pomathimbo gokufala okanona koshipangelo, ohatu yi noontu dhaantu tatu indile iimaliwa yokufuta iihauto (yokuya koshipangelo) kaashiinda. Ishewe epango lyokanonona olya pumbwa oshimaliwa. Onkee itatu vulu okupangitha okanona hano, (ngele otu na okufuta)”.

“Shi na sha niikulya, omathimbo gamwe ohatu pewa iikulya kaashiinda. Otwa pubwa oshimaliwa opo tu landele okanona iikulya, mbi ke na okulya, sigo ka pangwa. Ano miimaliwa

mbi hatu hehela kaashiinda, ohatu landele mo wo okanona iikulya. Onkee otandi indile omakwatho giikulya nogiimaliwa kukehe omusamaria e tu kwathe”. “Ishewe, tse oothigwa. Itashi vulika tu monenwe ekwatho opo okanona ketu ka mone epango?”.

Itashi vulika and uunona mbuno u kale and moshipangelo shawo moka tau silwa oshimpwiyu kaapangi nenge aayakuli”?

Ishewe, koshipangelo otwa lombwelwa kuty, okanona natu kape iikulya yoovitamine ihe pomathimbo gamwe tse ka tu shi naanaa kutya iikulya yoludhi luni yi na oovitamine mbyoka tu na okupalutha nayo okanona. Molwaashoka okanona iha ka li omagadhi nomongwa, otashi pula ethimbo niilonga oyindji, oshoka iikulya yokanona ota yi itelekelwa”.

“Okanona ohaka loloka mbala, nohaka kala taka fudha nuudhigu. Ngele taka dhana nuunona uukwawo, okena okutonatelwa. Ano ethimbo kehe opena okukala omutonateli opo e na okukala, shaashi pamwe okanona ota ka si”. Then the caregivers broke in tears and the interview was terminated.

Translation

“The family was shocked because this is the first time someone is diagnosed with a heart disease in the family. The heart is the one that keeps people alive. I perceive my child’s illness as of a higher degree. Therefore I feel that the child can die anytime. But I try to accept it, because in this world, who else care with you? One just has to accept it. We take it that this is what God has given us”.

“Taking care of this child is financially demanding. One needs money to take the child to the hospital. Nobody in the family earns a salary to rely on. So, when it comes to taking the child to

the hospital for the follow up treatment, we actually go around borrowing money from the neighbour to pay for the transport so we can take the child to the hospital.”

“Also for him to get treatment, it needs money, but we do not have money. Therefore, we cannot afford the money that is needed for his (surgery) treatment.”

“Another problem is about food. We need money to give her the correct and enough foods and vitamins and all the care she needs to be healthy until she gets the treatment for cure. As far as food concern, sometimes we receive foods that the child tolerates from the neighbors. From the money we borrow from the neighbours (to take the child to the hospital), we also buy some foods for the child.” We are also orphans. Can we not get assistance for our child to get treatment?”.

“I am appealing for the assistance in the form of money and foods that we cannot afford. If only the government or a good Samaritan can help us in this regard! We were also told at the hospital that we should provide the child with foods which have vitamins, but sometimes we do not even now the foods which have those vitamins. We were also told that the child should not eat fat and salt and this gives extra work as one has to prepare the child’s food separately.” Can the government not provide hospice for the these children to be cared for by trained health care workers”

“The child also gets tired easily and experiences difficulty with breathing. When she plays with other children, she needs to be supervised. One ought to be available every time to assist her, otherwise she may die. Then the caregivers broke in tears and the interview was terminated.

Annexure 6: Transcribed interview data from the interview and description of the pictorial naïve drawings by child participants

Case 1 (From Omusati region)

Age: 17 years old

Gender: Male

Diagnosis: Ventricular Septal Defect (VSD)

Question 1: How do you experience living with a heart disease?

(Lombwela ndje nkene wu uvite sho to ehama uuvu womutima).

Response

“Ondi uvute nayi. Onda hala ndi yeluke opo ndi ye koskola. Onda hala ando okwa li egumbo lyetu lili moVenduka, opo ndi pangwe, ndi yeluke ngaye ndi koskola. Tala, ngaashi nena, ondi uvite ndi li hwepo, ndele ondi li ike pegumbo. Itandi vulu okuya koskola”.

“Na ishewe, kandi hole omaiyuvo gamwe nga handi kala ndi na ngaashi, ela tali fulu, okuloloka mbala unene tuu nge nda matuka”.

Draw a picture and tell how the picture tells how you feel!

(Thaneka efano ee to fatulula kutya otali ti shike kombinga yoye)

Response

“Aawe, kandi shi ku faneka”

Follow up question: Is there any other thing you want to tell me?

Opena ishewe sha wa kala u shi lombwelendje?

Response: “Aawe, kape na we sha shilwe”

Translation

How do you experience living with a heart disease?

Response

“I feel bad. I wish I could get a cure. I wish to get a cure so I can continue with schooling. I also wish to live next to the hospital here in Windhoek, so I can be treated to heal. Like now, I feel better, but I am just at home. I cannot go to school. I also do not like some experiences because of my illness such as the distension of the stomach and discomfort, getting tired easily, especially after running”

Draw a picture and tell how the picture tells how you feel!

Response

“No, I do not know”.

Follow up question: Is there anything else that you want to tell me?

Response

“No, nothing”

Case 2 (From Ohangwena region)**Age: 12 years old****Gender: Female****Diagnosis: Rheumatic Heart Disease (RHD)****Question 1: How do you experience living with a heart disease?****(Lombwela ndje nkene wu uvite sho to ehama uuvu womutima).****Response**

“Ondi uvite nayi, shaashi otandi ehama. Onkalamwenyo yandje kayi liwe nawa. Molwaashoka otandi ehama, ondi indikwa okulya iikulya iitoye, yo yi na osuuka, nuuleke wochocolate, nununamunate. Ohandi kala nda hala okulila, sho handi kala nda tala yakwtu taa li iikulya iiwanawa. Itandi vulu okudhana, nokumatuka naanona ooyakwetu. Koskola aanona ngle taya dhana, ngame ondina okukal nda mwena, nda kuutumba. Otashi hala okulilitha ndje, nodi uvite nayi shaashi itandi vulu okudhana”.

Draw a picture and tell how the picture tells how you feel!**(Thaneka efano ee to fatulula kutya otali ti shike kombinga yoye)****Response**

“Eewa”

Follow up question: Is there any other thing you want to tell me?**(Opena ishewe sha wa hala u shi lombwele ndje)?****Response: “None”**

Translation**How do you experience living with a heart disease**

“I feel bad because I am sick. I feel that my life is not normal. Because of the illness, I am not allowed to eat sugar, salt, chocolates and soft drinks. I feel like crying when others eat attractive food. I cannot also play, like run and jump with other children. At school when other children play, I have to be sited, quiet and I use to feel like crying when I see the other children playing. I am hurt because I cannot play”.

Draw a picture and tell how the picture tells how you feel!**Response**

“Ok”. Then the child drew a picture which is displayed in annexure 7

Follow up question: Any other things that you wish to tell me?**Response**

“No”

Case 3 (From Caprivi region)**Age: 11 years old****Gender: Male****Diagnosis: Rheumatic Heart Disease (RHD)**

(The child participant from this case was interviewed in English only as English was the only medium the researcher and the caregiver can communicate. There was no transcription of the data)

Question: How do you experience living with a heart disease?**Response**

“I do not feel Ok, because others are at school and I am sick, I cannot go to school. Also other children do things at school like soccer and I cannot do it”.

Draw a picture and tell the story about the picture**Response**

No, I cannot”

Case 4 (From Oshana)

Age: 12 years old

Gender: Male

Diagnosis: Rheumatic Heart Disease (RHD)

Question: How do you experience living with a heart disease?

(Lombwela ndje nkene wu uvite sho to ehama uuvu womutima).

Response

“Ondi uvite nay shaashi otandi ehama”

Translation

How do you experience living with a heart disease

“I feel bad because I am sick”. Then the child kept quiet and he looked tired. Therefore the interview was terminated.

Case 5 (From Omusati region)**Age: 12 years old****Gender: Female****Diagnosis: Tetralogy of Fallot****Question: How do you experience living with a heart disease?****(Lombwela ndje nkene wu uvite sho to ehama uuvu womutima).Thaneka efano ee to fatulula kutya otali tis hike kombinga yoye.****Response**

“Aantu otaa ti otandi ehama, ndele ngame ondi wete ike ndi li nawa. Hapo, ohandi kala ngaa ndi uvite nayi, sho handi loloka. Sho tandi yi koskola nenge tandi zi koskola, ohandi uve omutima wandje tagu dhenge, taguti “duku, duku, duku”. Kuza mpono, otandi loloka. Ohandi kuutumba manga ndi vululukwe. Uunona umwe otau pitilile ndje po ike, tau ka thika komagumbo, manga nda kuutuma. Oha ndi ka thika kegumbo kwa toka. Itandi vulu wo okudhana naanona koskola, shaashi ohandi loloka mbala”.

Draw a picture and tell how the picture tells how you feel! (Thaneka efano ee to fatulula kutya otali ti shike kombinga yoye)

“Ok”

Translation

Question: How do you experience living with a heart disease?

Response

How do you experience living with a heart disease

“The people say I am sick, but I am just OK. Well, I am often disturbed by the symptoms. When walking from school, the heart start beating so hard, like “duk, duk, duk” and I get tired. So I have to sit down to rest. Others pass by and get home and I will get home late. I cannot also run and play with other children at school, because I get tired easily”.

Draw a picture and tell how the picture tells how you feel!

Response

“Yes”. Then she drew which is displayed in annexure 7.

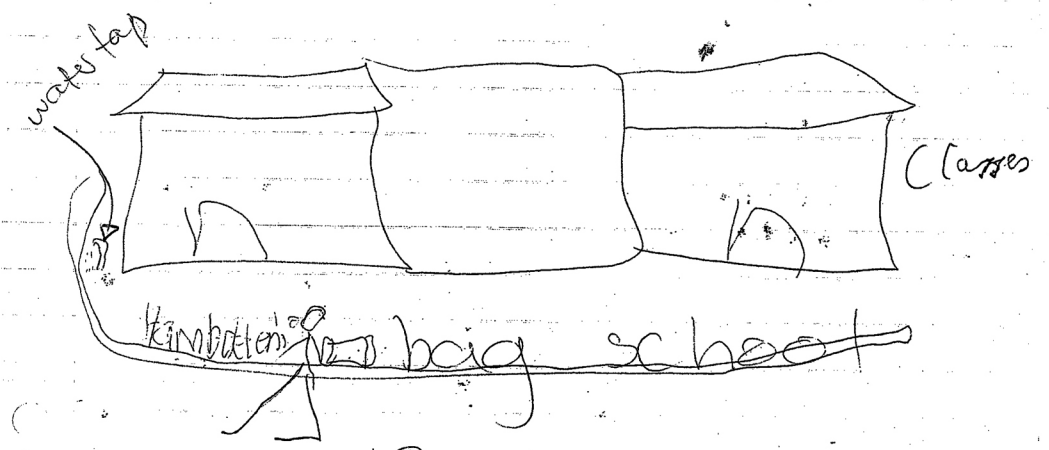
Follow up question: Is there any other thing that you wish to tell me?

Response

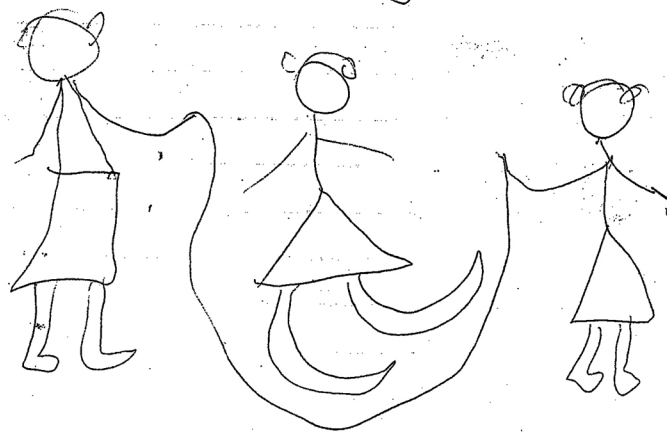
“No”. The participant was almost repeating herself.

Annexure 7: Pictorial naïve drawing by the child participants





These are my friend playing



PHASE 3: PROGRAMME IMPLEMENTATION AND EVALUATION**Annexure 8: An informed consent from the parent/caregiver participants to participate in the interventions for the programme implementation****Introduction to the parents/caregiver (an interviewee)***To the parent (s)/caregiver(s)*

My name is Kristofina Amakali

I am a student at the University of Namibia. This activity is a follow up to the investigation that was done in the previous phase of situational analysis. I am here to teach you about several aspects of providing care at home to your child with a heart disease. The aim of the programme interventions is to help empower you with knowledge about your child's condition and with skills to help you to provide care for your child at home. In addition, you will also be introduced to various resources which are available at the family and community level and which you may utilise to help you to cope with the demands of providing care at home.

You are free to participate as much as you are able and ask questions for greater clarity when needed. At the end of each session and at the end of the entire teaching session, I will ask you few questions to assess what you have learnt.

At the end

Is there anything you want to add or any concern that was not addressed, or you wish to tell me about?

Thank you for your time and for participating in the programme activities.

An informed consent from the parent/caregiver participant

Name of the parent/caregiver:

Parents/care giver (circle the correct choice)

Age:years

I....., hereby give my consent to participate in the activities of the programme implementation without coercion.

Signature of the participant:Date:Time:

Witness:.....Date:Time:

Researcher:Date:Time:

Annexure 9: An informed assent for the child participants to participate in the interventions for the programme implementation

Introduction to the child participant (as a participant)

To the child with heart disease

My name is Kristofina Amakali

I am a student at the University of Namibia. This activity is a follow up to the investigation that was done in the previous phase of situational analysis. I am here to talk to you about your heart disease. The aim of the programme interventions is to help empower you with the knowledge about your condition and to teach you skills that you need in order to cope with the symptoms of the disease.

You are free to voluntarily participant as much as you can and ask questions for clarity when needed. At the end of each session and at the end of the entire teaching session, I will ask you few questions to assess what you have learnt.

At the end

Is there anything you want to add or any concern that was not addressed, or you wish to tell me about?

Thank you for your time and for participating in the programme activities

An informed assent for the child participant to participate in the activities for the programme implementation

Name:

Age:

Parent's consenting statement:

I..... (parent/guardian) declare that I gave an informed consent for my child
.....to participate in the activities of the programme implementation.

Signature of the parent/caregiver:Date: Time:

I..... (child) hereby give my assent to participate in the activities of the
programme implementation without coercion.

Signature of the child participant:Date:.....Time:.....

Witness:Date:Time:

Researcher:.....Date:.....Time:.....

Annexure 10: Outcomes for the programme evaluation

What did you learn from the programme?

It was felt that the information derived from the responses to this question would probably justify the degree of learning which the participants would have derived from the programme. In addition to the active experimentation and mastery involved in certain of the instrumental tasks of care, the participants stated that they had found the programme essential and that the programme activities had enabled them to provide appropriate care to their children. Thus, it emerged that they were satisfied with the programme activities. The following statements provide evidence of reactions to the programme activities:

“I have learnt a lot from the explanation about the child’s illness and treatment.”

“I have also learnt about those aspects of care for the child to prevent the child from getting sick, like how to protect the child from cold not to get sick.”

“I now know how to position the child to easy breathing.”

“Sharing information with a health care provider also encourages one to have faith and wait for the child’s treatment with confidence.”

“Your explanation about the waiting time for treatment also put me at ease.”

“We started using substitute care at the family level to allow the focal caregiver to socialise.”

As is demonstrated by the following response the parents/caregivers were also able to recall the correct formula of diet:

“The child (with heart disease) should eat less or no oil/fat and more of brown bread.”

Finally, as is evidenced by the following responses from the caregivers, even the children had demonstrated empowerment:

“By now he knows that if he gets tired, he has to rest. He knows the he does not have to get cold. He always puts on his jersey every morning. He knows he has to wash with warm water. Therefore he puts his water in the sun to warm before bathing.”

What was difficult for you in the programme?

It was felt that the information derived from the responses to this question could serve as a yardstick as regards the quality of learning that the participants had derived from the programme.

The participants offered the following responses:

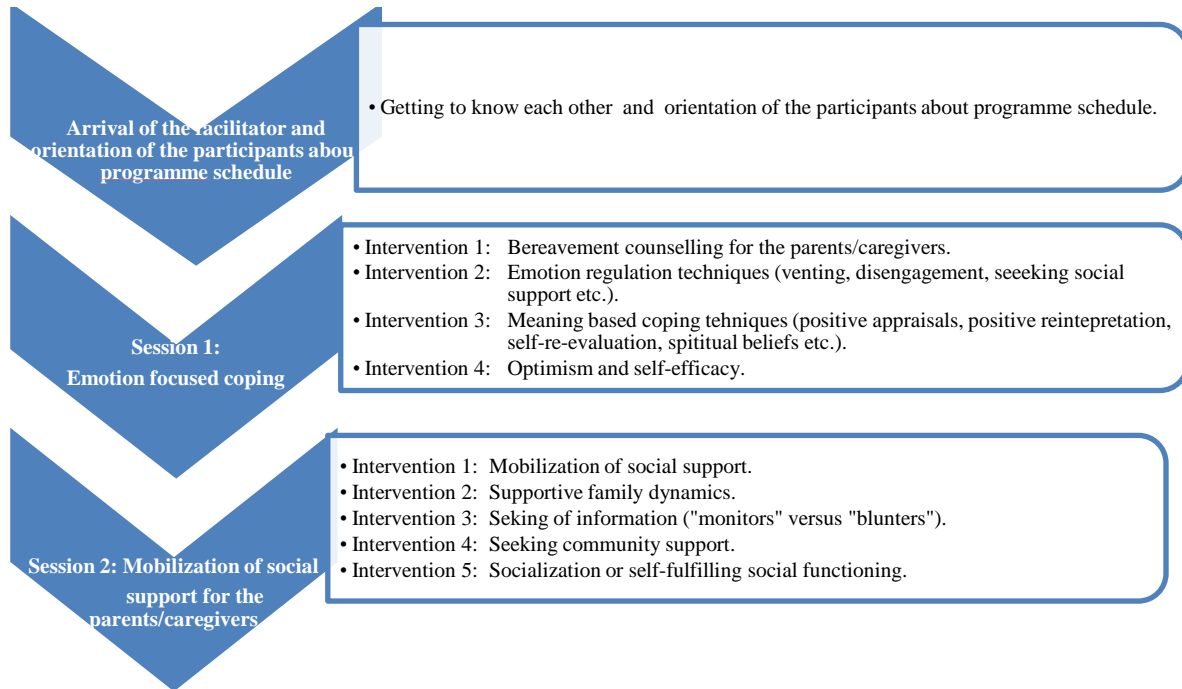
“The information is good. However, it needs repetition, until one is thoroughly knowledgeable about all the aspects that you taught us.”

“The other problem is that there is no continuous support by health care providers, in a form of a visit you paid to us.”

“There is a need for a visit by a health care provider on a regular base to assess the child’s condition, at least two times a year.”

Annexure 11: Agenda for the programme implementation

Day 1



Day 2

