

## **A Support Programme for care Givers of Children with Heart Disease in Rural Namibia**

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### **Abstract**

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The majority of children with heart diseases in Namibia receive treatment as outpatients, with their caregivers responsible for their continuing care. To provide the required care for these children, require vigilance on the part of the caregivers. Many of these children reside in rural areas with their caregivers who might only have a limited educational background, and with limited financial resources as they depend on subsistence agriculture for a living. The development of this support programme originated from the results of a study to answer the question on how caregivers of children with heart diseases from the rural areas in Namibia manage this responsibility. As a result, a programme of interventions for home-based health care to facilitate the caregiver's coping with the demands of care was developed, implemented and evaluated. The findings of outcomes evaluation indicated that the caregivers gained knowledge about the child's condition, skills for providing care at home and the information about community-based resources that can provide them with support to cope. If extended to many families of similar context, the programme interventions can render caring for a child with a heart disease at home bearable. This paper describes the implementation of interventions for a home-based health care programme, and the subsequent outcomes of the programme evaluation.

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**Keywords:** Heart diseases, home-based health care, coping, interventions, implementation, evaluation, outcomes

### **1. Background**

Heart diseases contribute to about ten percent of all paediatric admissions to healthcare facilities in Namibia.

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Congenital heart defects and rheumatic heart disease account for 60% and 40%, respectively of these diseases. Moreover, congenital heart defects account for nine percent of neonatal death in Health facilities in Namibia. At the time of this study, there were about 500 children under the age of 18 who were in need of heart surgery (WHO, 2009).

The majority of these children receive treatment as outpatients and their caregivers are to provide care for these children at home. To provide the required care for a child with a heart disease requires vigilance on the part of the caregivers. This presupposes that caregivers have the necessary knowledge, skills and access to the support systems for them to cope with the demands of care for these children (Coovadia & Wittenberg, 2007; Beck & Wiencek-Kurek, 2007).

Nevertheless, this assumption is not true for the majority of cases in Namibia. Many of these children live in rural areas and their parents/caregivers have low levels of education and they depend on subsistence agriculture for living. Therefore a qualitative, descriptive naturalistic study was conducted to assess rural caregivers' experiences of caring for a child with a heart disease at home. The findings revealed that caregivers experience challenged emotions related to the children's diagnosis. They also experience disruptive social functioning and social relations because of the demands to provide care for the child with a heart disease at home. Lack of support from the family and the societal organisations also hinders their coping with the demands of care for the child concerned (Amakali, 2012). Thus the findings revealed poor coping with the demands of caring, while the children's poor coping with the burden of the disease compounds the demands of caring on the part of the caregivers (Amakali, 2012). Following the first phase of the situational analysis and the findings of the study, a home-based health care programme of multi-component interventions was developed. The programme interventions were invented as interface to mitigate the negative experiences and to enable caregivers to provide appropriate home care that facilitates positive health outcomes for the children. The implementation of the programme interventions and the outcome evaluation of the programme interventions were completed in phase three of the study (Amakali, 2012).

## **2. Purpose of the Study**

The purpose of this article is to describe the implementation and evaluation of a support programme that was developed to facilitate coping with the demands of care, based on the experiences of care givers of children with heart diseases in rural Namibia.

### **3. Conceptual Framework**

A naturalistic constructivism, interpretive paradigmatic approach was adopted in the development and implementation of the support programme (Polit & Beck, 2012). The conclusions on the findings of the outcome evaluation were based on what the participants regarded as their experiences of the programme interventions and their perceptions that the programme interventions rendered the care of a child with a heart disease bearable to them (Amakali 2012). The context in which their experiences occurred and which can influence their experiences was also considered (Polit & Beck, 2012; Sandelowsky, 2000). In addition, the framework of the *"transactional model of stress and coping"* were applied in prediction of the way the caregivers and the children appraise the challenges associated with providing care or living with a heart disease and the benefits derived from the programme interventions toward the care for the child at home (Polit & Beck, 2012; Glanz, Rimer, & Viswanath, 2008).

### **4. Study Design and Methods**

The development and implementation of the support programme was the final phase of an original study by the author (Amakali, 2012). In the first phase of the original study, the researcher utilized a qualitative, descriptive, contextual and naturalistic study to describe the caregivers' experiences of caring for a child with a heart disease, as well as the experiences of living with a heart disease by the children (Streubert-Speziale & Carpenter 2007; Sandelowsky, 2000). The target population for the study were all the caregivers of children with heart diseases from the rural areas in Namibia. From the findings, a subsequent multi-component home-based health care programme in support of caregivers was conceptualized, according to the survey list of Dickoff, et al (1968).

### **5. The Support Programme**

The interventions for this proposed home-based health care programme were developed by the researcher as an agent for the caregivers, who were to be regarded as the recipients. The programme interventions were derived from the findings of the original study of the author (Amakali, 2012).

These interventions focussed on the facilitation of emotional coping, mobilization of social support for the caregivers, appreciation of supportive family dynamics and facilitation of optimal functional status for the children with heart diseases (Pretorius, Sliwa, Ruf, Walker & Stewart, 2012; Wählin, 2009; Boyse et al., 2011; Paul, 2008 & Glanz et al 2008). The interventions of the programme were grouped and organised as three objectives. These three objectives were formulated in the original study with the aim to address the main findings that had been categorized as three themes, thus an objective for each theme. An outline of the programme content is provided for in table 1.

**Table 1: The Components of a Home-Based Health Care Programme**

<b>Original study finding ,</b>	<b>Objectives</b>	<b>Interventions</b>
The caregivers and the children experiences challenging emotions	Facilitation of emotion focused coping for the caregivers and the children	Bereavement counseling venting, disengagement, optimism, acceptance, self-re-evaluation, use of religion self-efficacy.
The caregivers experience disruptive social functioning, social isolation, lack of support from the family ad social systems	Facilitation of mobilization of social support for the caregivers	Supportive family dynamics. Seeking of appropriate information about the child's illness & social support. Socialization.
the children experience decreased vitality	Facilitation of optimal functional status for the children	Counseling of the children. Cardiac diet and nutrition Management of the child's weight. Activity tolerance. Symptomatic care for the child Compliance with the medication schedules.

The programme implementation, which will be discussed next, occurred during 2011.

## 6. Ethical Considerations

Ethical measures were adhered to in all phases of the study to ensure protection of the participants.

Formal ethical clearance for the main original study, of which this support programme was one phase, was obtained from the University of Namibia. Informed consent for this phase was verbally obtained from the caregivers before the commencement of the implementation and evaluation of the programme activities. Equally, verbal, informed assent for the children's participation was obtained from their caregivers (Streubert-Speziale & Carpenter 2007; Parahoo, 2006). Participation was voluntarily. The purposes of the interventions, expectations from the participants and of the evaluation were explained to them. The researcher explained the possible beneficence in participation in the programme implementation. The programme interventions and outcome evaluation were presumed to pave the way for a solution for their need to cope with the demands of care at home.

## **7. Programme Implementation**

The programme was implemented by the researcher in two (2) rural households of children with heart diseases. The two households were purposefully selected from the five households which featured in the original study done by the researcher.

Each participant either received a programme schedule with a list of activities to be covered or was verbally informed of the programme activities. They were also given a note book and a pen to record the information which they may have deemed worth noting for future reference. The concept of experiential learning which includes among others, active participation, and concrete experience were applied in order to maximize learning by the participants (Knowles (n.d.); Pretorius, 2008; Meyer, 2004). A full day was allocated for the implementation of the interventions at each of the two households. The programme interventions were implemented in three sessions at each household. Each session lasted longer than an hour. To that end, the participants were provided with information about simplified pathophysiology and caring principles.

### Session one

This session focused on the interventions for facilitation of emotion focused coping. Bereavement counselling, among others was conducted to the caregivers for them to come to terms with either the child's lifelong illness or with a poor prognosis.

This activity involved a discussion on understanding the potential treatment outcomes of the children's diagnosis. The discussion provided a sympathetic clarification of what is meant by symptomatic treatment, and palliative concepts were introduced (Nicolini & Gherli, 2009; Gibson, 2007).

Mastering of self-efficacy was demonstrated about listening with sympathy and providing care with respect, dignity and a non-judgmental attitude toward the child (WHO, 2002).

The use of religion was also discussed with the participants. In this regards, the participants were encouraged to use their religion as a foundation to derive positive meanings from the challenges of caring for their children (Glanz, Rimer, & Viswanath, 2008).

### Session Two

Session two focused on the discussion of supportive family dynamics and the mobilization of social support for the caregivers. In that regards, the inclusion of all family members who are eligible of providing care to the child concerned in order to provide relief for the primary caregivers was encouraged. Seeking of appropriate information about the child's care from health care workers was explained. The importance of social support and socialization of caregivers was also stressed (Chair & Pang, 2008; Raina, 2005).

### Session Three

Session three focused on the interventions which facilitate the optimal functional status for the children with heart diseases. Counselling of the children for them to construct self-directed solutions in respect of experiences of the symptoms of a heart disease was discussed (Mitchell, 2011). In addition, the diet for a child with a heart disease was discussed.

Therefore the preparation of the child's diet from the food stuffs that were available at the household was demonstrated to the caregivers. Nutrition, weight management and activity tolerance were discussed.

Symptomatic care for the child and compliance with the medication schedule were also addressed under this section (Pretorius, Sliwa, Ruf, Walker, & Stewart, 2012). The participants were given feedback on skill performance and when necessary, they were encouraged to improve (Cowley 2004). The participants reflected on how they could apply the insights gained from the learning experiences for them to cope with the demands of providing care for their children at home (Kobus, 2007).

## **8. Programme Evaluation**

The programme was evaluated four (4) months after its implementation. As the literature proposes, the purposes of an outcomes evaluation was to determine whether the programme interventions has empowered the caregivers with the knowledge and skills which they needed in order to cope with the demands of providing appropriate home care for their children concerned (Bugge, Helseth and Darbyshire, 2009; Metz (2007& WHO, 2002 ). The specific objectives for the programme evaluation were of three folds. Objective one was about evaluating the participants' (caregivers and the children) knowledge of aspects of emotional coping. Objective two was about evaluating the caregivers' knowledge and skills of symptomatic care for the child and their ability to identify and utilise the social network. Objective three focused on evaluating the children's knowledge about their disease and of self-care.

### **8.1 Methods of Programme Outcomes Evaluation**

A qualitative outcomes evaluation was conducted after four months following the implementation of programme interventions. The data were collected through the interviews, and the testimonials of the participants' experiences of the programme interventions. These methods were the most likely to secure the required information from the participants taking into account the capabilities and the understanding of the participants. Open-ended questions, as displayed below were posed to give the participants the opportunity to describe their experiences from the programme interventions.

What did you learn from the programme interventions?

What was difficulty for you in the programme interventions?

What can be improved in the programme interventions?

The data analyses were analysed according to the Tech's method of qualitative data analysis (Creswell, 2008). Codes were allocated to the main ideas and the findings were organised as themes.

## 8.2 The results from the Programme Evaluation: Presented as Themes

Four themes emerged from the evaluation of the programme.

Theme one: Positive feedback on acquiring knowledge and skills

Theme two: Feelings of acquiring an inner strength

Theme three: The realization of the family being a source of strength.

Theme four: The realization of the community as source of support.

### Theme one: Positive feedback on acquiring knowledge and skills

The caregivers and children alike learnt the knowledge about the child's illness and the care required by the child. In this regard, the caregivers' asserted that they and the children alike gained knowledge about the child's condition. Caregivers indicated that they were able to carry out the instrumental tasks of care for their children concerned. The following quotes from the participants are testimonies to that.

"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."

"The child (with heart disease) should eat less or no oil/fat and more of brown bread."

Furthermore, and in concurrence with the findings from other studies (Riegel, Voughan Dickson, Goldberg, & Deatrick, 2007), the caregivers 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. This claim is evidenced from the following quotes by the caregivers:

"By now he knows that if he gets tired, he has to rest. He knows that 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." Theme two: Feelings of Acquiring an Inner Strength



Theme two denoted that the caregivers have developed inner strength and determination to provide home-care for the child with a heart disease as evidenced by the testimony from one of the caregiver participants: *"Your explanation about the waiting time for treatment also put me at ease."* The interaction with the researcher was considered as worthwhile, and as such it added to the feelings of inner strengths for the caregivers.

"Sharing information with a health care provider also encourages one to have faith and wait for the child's treatment with confidence".

### **Theme Three: The Realization of the Family Being a Source of Strength**

Theme three maintained that the family, due to the concept of family dynamics, could significantly contribute to the caring for a child with a heart disease at home. Additionally, and in accordance the findings from other studies (Thastrum, Munch-Hansen, Wiell, & Romer, 2006), the caregivers reported that the programme interventions enhanced cohesion of the family members as regard the care for a child with a heart disease. Therefore, the caregivers reported that they were then able to share the responsibilities of caring for the child with a heart disease as can be verified from some of the quotes by one of the participants in this regard:

"We help each other at the family level to allow the focal caregiver to socialise".

### **Theme Four: The Realization of the Community as Source of Support**

In addition, the family could utilize community resources to assist in their cope strategies with the demands of care at home. Furthermore, the caregivers reported that they were better informed about seeking appropriate social support. In that regard, the caregivers indicated that they make use of local religious support and they participated in local community development initiatives as sources of emotional coping. The interaction with the researcher, who could be regarded as a community member was considered as worthwhile.

As a result, caregivers **implied** the need for more of such opportunity. The following quotes, among many, bear testimonies to that:

“The information is good. However it needs repetition, until one is thoroughly knowledgeable about all the aspects that you touch 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 (2 times) a year”.

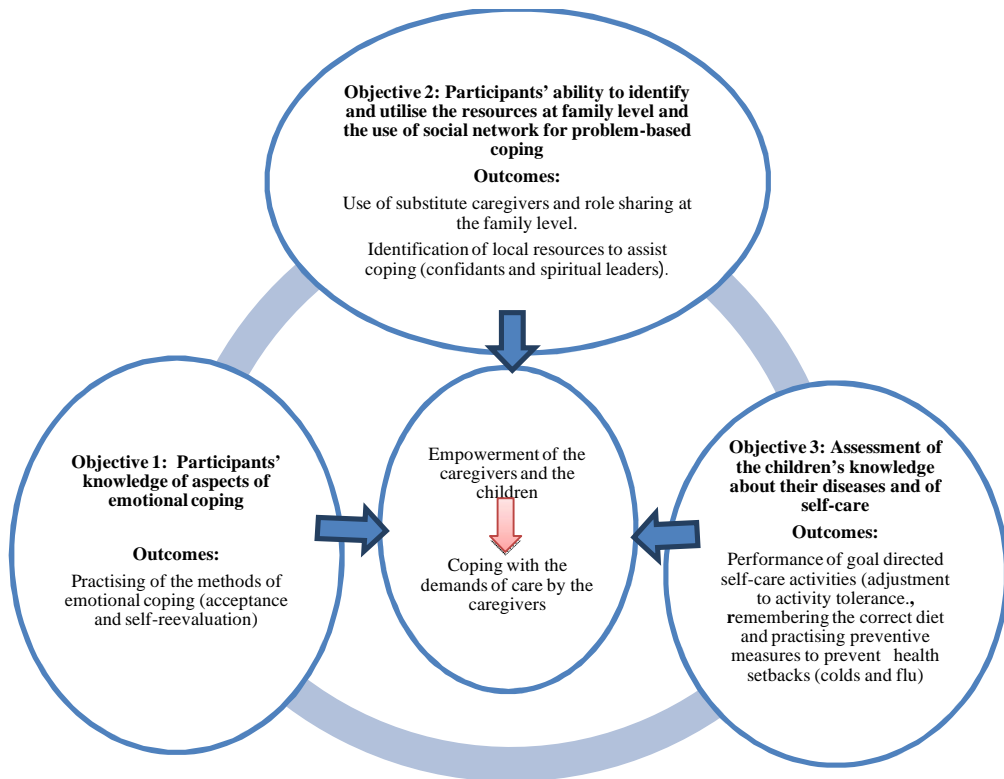
## 9. Discussion

The caregivers indicated that the implementation of the programme interventions had rendered bearable the management of their children with heart diseases at home. The caregivers demonstrated a gain in knowledge and skills necessary to carry out instrumental tasks. They gained inner strength and discovered the possible resources available in families and communities.

Through the discussions, the interchange of ideas and concrete experiences, the caregivers acknowledged that they had learnt new knowledge and values. These included successful attempts at problem solving and active experimentation with instrumental tasks such as practicing empathy towards the children. It also included successful preparation of the child’s diet from the locally available food stuffs and the measuring out of medications. These learning experiences all culminated in the increased retention of knowledge and skills necessary to provide home care for the child concerned (Cowley, 2004). Thereby, caregivers demonstrated knowledge, understanding and self-efficacy, thus the essential qualities which are required of a competent caregiver who can provide safe home-care for a child with a heart disease (Ågren 2010; George, 2008; Glanz et al., 2008; Aljandro, Huberto & Augustin 2008; Sniehotta, Scholtz & Schiwarzer, 2005).

Equally important is that the programme interventions had enabled the family members to adopt a new perception of the children’s condition and the demands of care. Following the programme interventions, the caregivers were able to move out of a limbo of emotional- and care vulnerability. They were then able to construct self-directed solutions to mediate the effects of negative appraisals of the caring role.

They were able to reorganise roles and set priorities to manage the demands of caring for the child at home, therefore demonstrating a collective responsibility for the provision of home care to the sick child (George, 2008; Stadjuhar, Legh Martin, Barwich & Fyles 2008). If the programme were extended to more of families from a similar context, their situation may also improve. Indeed as Beck and Wiencek-Kurek (2007) implied that: instead of passing judgement on people because of their socio-economic situation, it is more important to acknowledge that caregivers of children with heart diseases from the rural areas in Namibia are individuals with potentials, who are trying to cope with a difficult situation and they therefore needed to be assisted for them to do the best they can do. Caregivers were empowered and were therefore able to redefine the challenges, conceptualize them as manageable and could develop inner strength and self-determination. They were able to identify and utilize the strengths within the family and at the community level in order for them to cope with the demands of caring, hence, overcoming a sense of powerlessness (Mitchell, 2011; Raina, O'Donnel, Rosenbom, Brehaut, Walter, Russel, Swinton & Wood, 2005). The challenge now involves ensuring the sustainability of this programme. Figure 2 below displays the outcomes for the programme evaluation.



**Figure 1: Outcomes of the Programme Evaluation**

## 10. Limitations

The key limitation of the findings from the outcome evaluation of this support programme is inherent in the small sample size of the participants. It would therefore be the responsibility of interested organizations to determine independently the transferability of this study.

## 11. Recommendations

The positive findings from the implementation and evaluation of the support programme assisted the researcher to recommend that this programme be implemented at district level.

This programme could also be considered as an example to be included in the palliative curriculum content of the School of Nursing and Public Health at the University of Namibia

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