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Implementing a Home-Based Health Care Programme for the Children with Heart Diseases from the Rural Areas in Namibia: Making a Difference in Coping with the Demands of Care at Home

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Abstract - The purposes for the implementation of a homebased health care programme interventions was to empower the caregivers of children with heart diseases from the rural areas in Namibia, and the children alike for them to employ constructive coping methods, access community-based resources and implement care interventions which enhance positive health outcomes for their children concerned and therefore, to facilitate caregivers' coping with the demands of care at home. Therefore, a qualitative outcomes evaluation was conducted three months after the implementation of the programme interventions to assess the long-term effects of the programme interventions on the participants. The findings indicated that the caregivers and the children with heart diseases gained knowledge about the child's condition, skills for providing care at home as well as information about community-based resources that can provide them with support to cope. In conclusion, if sustained for a long-term, the programme interventions can make a difference in coping with the demands of home care for the caregivers of children with heart diseases from the rural context. This paper describes the processof implementation of a home-based health care programme intervention, and the subsequent outcomes of the programme evaluation.

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Implementing a Home-Based Health Care Programme for the Children with Heart Diseases from the Rural Areas in Namibia: Making a Difference in Coping with the Demands of Care at Home

Kristofina Amakali [α] & Louis F. Small [σ]

Abstract - The purposes for the implementation of a home-based health care programme interventions was to empower the caregivers of children with heart diseases from the rural areas in Namibia, and the children alike for them to employ constructive coping methods, access community-based resources and implement care interventions which enhance positive health outcomes for their children concerned and therefore, to facilitate caregivers' coping with the demands of care at home. Therefore, a qualitative outcomes evaluation was conducted three months after the implementation of the programme interventions to assess the long-term effects of the programme interventions on the participants. The findings indicated that the caregivers and the children with heart diseases gained knowledge about the child's condition, skills for providing care at home as well as information about community-based resources that can provide them with support to cope. In conclusion, if sustained for a long-term, the programme interventions can make a difference in coping with the demands of home care for the caregivers of children with heart diseases from the rural context. This paper describes the processof implementation of a home-based health care programme intervention, and the subsequent outcomes of the programme evaluation.

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I. Introduction

Providing care for a child with heart disease could be a daunting task for any caregiver, particularly for those living in poor conditions in rural Namibia. Likewise, the data from a qualitative, exploratory, descriptive and contextual study that describes the experiences of providing home care for a child with a heart disease by the Namibian rural caregivers has revealed poor coping with the demands of caring on the part of the caregivers, 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). As a result, a home-based health care programme with multi-components interventions was developed for implementation to mitigate the negative experiences, and to provide caregivers with the knowledge and skills for them to provide appropriate home care that facilitates positive health outcomes for the children concerned (Amakali, 2012).

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II. Purpose of the Study

This paper describes part of the study on assessing the need for a home-based health care programme in support of the caregivers of children with heart diseases from the rural area in Namibia (Amakali, 2012).For the context of this paper, the study purposes are of two folds. The first purpose was to implement the interventions of a home-based health care programme to facilitate caregivers from the rural areas in Namibia to learn knowledge and skills necessary for them to provide appropriate home care for their children with heart diseases. In addition, the study aimed at validating the potential long-term effects as outcomes of the programme interventions on the recipients.

a) Study Design and Methods

A qualitative, descriptive study was conducted to implement the interventions and evaluate the outcomes of the interventions respectivelyin the same subjects (Burns & Grove, 2001). The study was conducted in two phases. Phase one entails the implementation of home-based health care programme interventions to empower the caregivers in order for them to cope with the demands of providing home care for their children with heart diseases. Phase two entails the outcome evaluation of the programme interventions and the recommendations.

III. Phaseone: Implementation of the Programme Interventions

a) Study Population

The study population on whom the study findings can be generalized were all the Namibian rural

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caregivers of children with heart diseases who were receiving treatment at the public health care facilities in Namibia.

b) Sample and Sampling

A sample of two households, each with a child with a heart disease and the caregiver(s) and headed by the subsistence agricultural farmersin the rural Omusati region of Namibia were purposefully selected to participate as the recipients of the programme interventions which aim at empowering caregivers to cope with the demands of home care to a child with a heart disease. The two households were purposefully selected from the total sample of those households which participated in the situational analysis and the identification of the need for facilitation of coping with the demands of home care for the caregivers.In observation of ethical codes, informed consent for voluntarily participation on the part of the participants was observed (Parahoo 2006).

c) Process of Programme Implementation

The interventions for the aforesaid home-based health care programme were implemented through workshops at two of the rural householdswhich participated in the situational analysisthat identified poor coping with the demands of home care and as such, the need for the home-based health care interventions to facilitate coping with home care on the part of the caregivers. The programme interventions were therefore implemented at the participants' households while taking into account the socio-economic and cultural aspects that could have influenced the outcomes of the programme interventions and was therefore adjusted to the educational level of the caregivers to allow them to understand both the information and practical experiences from the programme interventions (Paul, 2008)(see figure 1). The purpose of the individualised household programme interventions was to maximise the benefits for each participant or the family unit, therefore for 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, Pinquart & Duberstein, 2003; Lepscyzyk, Laleigh, & Rowley, 1990).

In this regard, sessions of different interventions were implemented. Session one focused on interventions for facilitation of emotion focused coping and addressed aspects such as bereavement counselling, techniques of emotional regulation coping such as venting, disengagement and optimism, meaning-based coping such as acceptance, self-re-evaluation, the use of religion and spirituality and self-efficacy (Glanz, Rimer, & Viswanath, 2008). Session two focused on interventions that can facilitate the mobilization of social support for the caregivers such as enhancement of supportive family dynamics, seeking of appropriate information and social support including socialization (Chair& Pang, 2008; Raina 2005, Berkman, 1995). Session three focused on interventions which facilitate the optimal functional status for the children with heart diseases and includes counselling for the children to develop skills and be able to construct self-directed solution in respect of the challenging experiences of symptoms of a heart disease (Mitchell, 2011). Additionally, essential aspects of caring for a patient with heart diseases, inter alia the cardiac diet and nutrition, weight management, activity tolerance, palliative care for the child and compliance with the medication schedule were also addressed under this section (Pretorius, Sliwa, Ruf, Walker, & Stewart, 2012). Table 1 displays the components of a home-based health care programme that was implemented.

Table 1 : The components of a home-based health care programme

Sessions	Objectives	Interventions
Session one	Facilitation of emotion focused coping for the caregivers and the children	Bereavement counseling, venting, sengagement, optimism, acceptance, self-re-evaluation, use of religion and self-efficacy.
Session two	Facilitation of mobilization of social support for the caregivers	Supportive family dynamics, seeking of appropriate information & social support, and socialization.
Session 3	Facilitation of optimal functional status for the children	Counseling of the children, cardiac diet and nutrition, management of the child's weight, activity tolerance, palliative care for the child and compliance with the medication schedules

Learning by the caregivers as the primary focus necessitated the application of the principle of adult learning and experiential learning approach. These approachesare presupposed to facilitate self-directed and active learning on the part of the caregivers whereby the latter approach learning as a problem solving tool or the believe that what they are learning is of immediate value, and learning through the medium of concrete experiences, reflective observations, abstract conceptualisation and active experimentation (Knowles (n.d.),Pretorius; 2008, Meyer; 2004; Williams & Walker, 2003;Atherton 2002& Kolb, 1984).

To that end, the participants were given information for knowledge about the disease of the children and the aspects of caring. Demonstrations on practical aspects of caring were given and the

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participants were given feedback on skill performance and where necessary, they were encouraged toimprove.As Cowley (2004) and Stein (1998) propose, the interchange of ideas and attempt at problem solving, inter alia the practice of empathy towards the child and the preparation of food from the locally available food stuffs were encouraged to reinforce learning on the part of the participants.

Finally, and through reflective observation, the participants were given the 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(Kobus, 2007). Figure 1 below presents the context for the implementation of programme interventions.

Figure 1 : The households and crop field for caregiver(s) of a child with a heart disease in the rural Namibia –the context for the implementation of programme interventions

Indeed the structures of the households and the quality of agricultural subsistence farming are testimonies to the impoverished life of these families. This impoverishment, in turn, means that they cannotcope with providing special care for their children with heart disease.

IV. Phasetwo: Programme Evaluation

The literature advocates for the evaluation of the programme interventions, to assess whether the programme outcomes are congruent with the set programme objectives (Bugge,Helseth and Darbyshire, 2009; Metz (2007; WHO 2002 & Tailor-Powell, Steele, S. & Douglah). Therefore for the purposes of this study, an outcomes evaluation was conducted to determine whether the programme interventionshas empowered caregivers with the knowledge and skills which they need in order to cope with the demands of providing appropriate home care for their children with heart diseases.

The 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 that is required to identify and utilise the social network, while objective three focused on evaluating the children's knowledge about their disease and of self-care.

a) Methods of Programme Outcomes Evaluation

A qualitative outcomes evaluation was conducted. All the participants from the two households where the programme was implemented were asked to participate voluntarily in the outcomes programme evaluation. The data were collected through the interviews, field notes and the testimonials of the participants' experiences of the programme interventions. Taking into account the capabilities and the understanding of the participants, these methods was the most likely to secure the required information from the participants (Parahoo, 2006 &Taylor-Powell et al., 1996).

V. The Findings

The findings of the programme outcomes evaluation indicated that the programme interventions had has a positive impacts on the recipients. As a result, the caregivers reported that they gained knowledge about the child's condition, and they were able to carry out the instrumental tasks of care as verified by the following testimonies.

"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."

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"Your explanation about the waiting time for treatment also put me at ease."

Additionally, and in accordance the findings from other studies, caregivers reported that the programmes interventions enhanced cohesion within the families of the participants (Thastrum, Munch-Hansen, Wiell, & Romer, 2006). As a result, the caregivers reported positive changes in their ability to make use of the strengths at the family level, as they were then able to share the responsibilities of caring for the child with a heart disease as can be verified from the 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".

Caregivers also reported that they were better of informed about seeking appropriate social support for them 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.

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

Furthermore, and in line with the findings from other studies, 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 (Riegel, Voughan Dickson, Goldberg, & Deatrick,2007). This claim is evidenced in quotes from the caregiver participants.

"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."

VI. Discussion

The caregivers indicated that the implementation of the programme had rendered bearable the management of their children with heart diseases at home. The participants demonstrated gain in knowledge base as regard the child's condition, the skills necessary to carry out instrumental tasks of care at home and the knowledge of community-based resources that are necessary for them to cope with providing home care for their children with heart diseases.

Through the discussions, interchange of ideas andconcrete experiences the participants learnt new knowledge and values.Attempts at problem solving andactive experimentation with instrumental tasks such as practicing empathy towards the child concerned, preparation of the child's diet from the locally available food stuffs and the measuring out of medications allowed the participants to practically clarify and personalise concrete learning and, whichall culminated in the increased retention of knowledge and skills necessary to provide home care for the child concerned (Cowley, 2004; Kirby, 2000; Stein, 1998).Thereby caregivers displayed knowledge, understanding and self-efficacy as 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 limbo of emotional- and care vulnerability, and were able to construct self-directed solution 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 willingness and a sense of responsibility for provision of home care for the children concerned as their dependents (George, 2008; Stadjuhar, Legh Martin, Barwich & Fyles 2008). Therefore, if the programme interventions were to beextended to more of families from a similar context, their situation may also improve. The challenge now involves ensuring the sustainability of this programme.Figure 2 below displays the outcomes for the programme evaluation.

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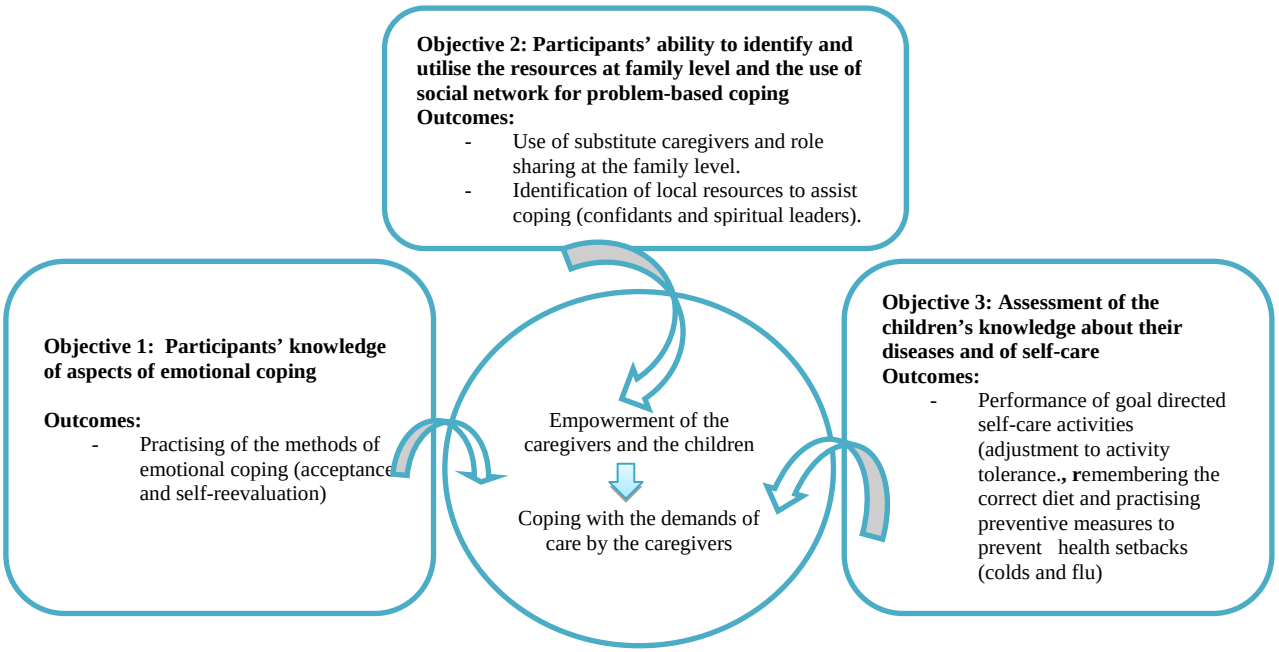

Figure 2 : Outcomes of the programme evaluation

Indeed as Beck and Wiencek-Kurek (2007) states that in instead of passing judgement on people because of their socio-economic situation, it is rather important to acknowledge that caregivers of children with heart diseases from the rural areas in Namibia are individuals with potentials, trying to cope with a difficulty situation and they therefore need to be assisted for them to do the best they can do.

VII. Conclusions

The outcomes evaluation indicated the trust of the participants in the programme interventions. The caregivers regarded the programme as having been worth the effort and indicated that the multi-component interventions facilitated a positive caring environment with the next of kin and social support as invaluable resources for the provision of on-going care at home. If sustained, the programme is therefore likely to make a difference to their coping with the demands of caregiving at home. Hence the recommendation for mainstreaming of the programme interventions in the health care programme at the district level of health care delivery, for a sustainable support to these caregivers and their children concerned.

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