

ORIGINAL RESEARCH

Beyond routine care for children with heart diseases from the vulnerable context: A clinical practice perspective

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Abstract

The statistics of children with heart diseases are notable in Namibia many of whom are from the rural area. While waiting for surgical corrections or when the child is a case for palliative care, these children have to be cared for at home, a task that can be doubtful for a rural caregiver. A qualitative, exploratory, phenomenological and contextual study was conducted to describe the experiences of rural caregivers regarding provision of home care for children with heart disease. The children's experiences of living with the disease at home were also assessed because the burden of the diseases intensifies the demands for care. The findings revealed that both the caregivers and the children experience challenged emotions, disruptive social functioning, lacking of support from the family, lack of support from societal organisations as well as experiences of low vitality among the children. These experiences together, signify the overall poor coping by the caregivers and the children. Therefore, caring for a child with a heart disease at home requires a plan of individualized care which considers the context and the socio-economic status of the caregivers as the determinants for coping with providing care at home. Based on the findings, key recommendations were made among others to the clinical practice setting as an entry point to the care provided to these children. This paper provides a detailed description of the proposed health care intervention in the clinical setting to facilitate effective home care to children with heart diseases from the rural context.

Key words

Children, Heart diseases, Clinical, Care, Parents, Caregivers coping, Socio-economic

1 Introduction

The literature has proven that congenital heart disease (CHD) and rheumatic heart disease (RHD) are on the increase in children on the African continent^[1]. Namibia is not an exemption to the statistics, as close to ten percent of all paediatric admissions to its health care facilities were cases of heart diseases by the year 2009^[2].

Given the intensity of the heart diseases, many of the pediatric heart patients in Namibia receive treatment as outpatients. Thus going home means coping with the child's symptomatic care, performance of complex instrumental tasks, trying to meet the demands of care with limited resources, fear and uncertainties about the treatment outcomes by the caregivers in an environment away from the health care experts^[3,4].

Additionally, the family's socio-economic context dictates the care that is provided for the child at home. To provide the required care at home suggests that caregivers have necessary support systems in place and are knowledgeable in order to provide quality care to these children ^[5, 6].

However, it transpired from the study ^[7] and in concurrence with the existing literature ^[8] that providing care at home for these children, becomes problematic for some families who are from the rural areas in Namibia. The families are unable to provide effective care at home because they have no secure sources of income. Their livelihood depends on subsistence agriculture owing to their low level of education. It is also with no doubt that the complexity of a heart disease places challenges to care ^[9] and especially on the caregivers with low level of education. Hence, there is a need for a proactive care approach at the clinical setting to enable quality care to these children at home.

Purpose of the study

The aim of the original study ^[7] was to determine the challenges that face caregivers in providing care to their children with heart diseases. The findings provided the ground to suggest solutions for the mitigation of the challenges related to care at home. Whereas the detailed description of the moving stories of the caregivers' emotional responses to their children's illnesses and challenges related to providing home care were dealt with in the previous paper ^[7], this paper provides a detailed description of the intervention for these children which is exclusive to the clinical setting in order to assist their caregivers to manage the challenges related to providing care at home.

2 Study design and methods

The original study comprised three sequential research phases. Phase one involved the description of the challenges that the caregivers face in providing home care and the challenges that the children face because of 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. They were from three different regions (Caprivi, Omusati and Oshana) of the country in order to verify if the challenge regarding home care for a child with a heart disease is similar to families from different cultural contexts in Namibia ^[10], yet the findings reveal that the experience is similar among the caregivers from different cultures and who are of similar economic context across Namibia.

The study sample consisted of five multiple cases of a rural caregiver and the child with heart disease. The interviews were conducted in the mother tongue of the participants or in English. The interviews were terminated when saturation point was reached ^[11-13]. Field notes and naïve drawings made by the child participants complimented the data from the interviews ^[14]. Findings were formulated according to Tesch's method of data analysis ^[15].

Phase two was about the conceptualization of the findings. The central concept of "poor coping with the demands of care and of living with the disease burden" was identified. Programme interventions to facilitate coping with the demands of home care was conceptualized according to Dicoff *et al.*'s ^[16] survey list of a situation-producing framework. These include the interventions for: emotional focused coping to restore healthy emotions in the caregivers and the children; social functioning to restore productive social relations of the recipients; mobilization of social resources for support to mitigate the financial difficulties and activities that enhance functional status of the children to moderate the children's decreased vitality ^[17]. Phase three dealt with the development of a health care programme and the implementation of the programme interventions as solutions to the challenges of the participants. This paper focuses on the description of the proposed clinical-based intervention of the health programme.

2.1 Conceptual framework

The framework of the "transactional model of stress and coping" was applied to predict the way the caregivers and the children appraise the challenges associated with either providing care or living with the disease during the situational analysis phase of the study. Similarly, the framework was applied to predict the way in that the caregivers and the children appraise and predict the benefits that can be derived from the programme intervention toward the care for the child at

home^[18, 19]. Therefore caregivers' appraisals for the programme interventions were that the programme interventions rendered the tasks of home care bearable to them. They demonstrated a positive self-concept regarding the children's condition and they were able to tap into the strengths from the programme interventions to cope with the situation in their own contexts.

2.2 Ethical consideration

Formal ethical clearance for the main study, of which this paper is part of, was obtained from the Ethical and Research Committee of the Namibian Ministry of Health and Social Services. Written, informed consent was obtained from the caregivers to participate in the study. Equally, written, informed assent for the children's participation was obtained from their caregivers. Participation was voluntarily and the participants could withhold their consent to participation^[20]. The purposes of the study, expectations from the participants were explained to them. Possible beneficence that can be accrued from the study was explained to the participants, as the study was presumed to pave the way for a solution for their need to cope with the challenges associated with home care. However, the researcher's boundary was also clarified in order to minimize expectations and potential for stress to the participants^[20]. Participants were protected from harm which could be occasioned by the study by avoiding sensitive, intrusive questions which could elicit adverse emotional reactions from the participants. Immediate renegotiation of the consent was considered when necessary during the interview^[14, 20].

3 Results and discussion

As a background to the proposed care intervention for children with heart diseases in this study, a brief description of the findings from the main study is provided. During the situational analysis, the participants were able to express themselves effectively and discussed the challenges relating to their economic and cultural context when caring for their children concerned at home. The first category of the findings involved experiences of the emotional challenges related to emotional reaction as a result of the child's diagnosis and the perceptions of the possible adverse consequences of the illness. These include among others, the experience of shock as a result of the child's illness; sadness and self-blame for the child's condition and feelings of inadequacy to care for a child with a heart disease.

The second category of the findings involved the challenges that signified restriction of socialization on the caregiver because of the demand to provide on-going care for the child concerned. The third category of the findings arose from the moving revelations about the need for financial assistance to enable the caregivers to provide the special cardiac diet, facilities required to care for the children and for the expenses related to travelling to health care facilities for follow up treatments.

The fourth main category of the findings was exclusive to the children and involved their adverse experiences related to the symptoms of the heart disease.

Lack of support and knowledge that are necessary to facilitate the primary caregivers' threshold to the challenges of caring were identified in the original study. Based on these findings, caregivers' poor coping with the demands of caring was conceptualised^[7]. The central and related concepts about the need to assist the caregivers to keep a brave front in spite of the demands to care were formulated according to Dickoff *et al.s'*^[16] concept of "situation producing". To that end, the assessment of risk factors that influence continuous care for these children was identified as an important care intervention to be initiated at the induction of care for these children at the clinical setting and the logic of which is discussed below.

The emotional experiences pertaining to the perception of the nature of heart diseases, the expectation of care, economic challenges and living with the burden of the disease symptoms all impact negatively on the psychological wellbeing of both the caregivers and the children. The negative impact on the psychological wellbeing of the caregivers can influence the quality of care provided to these children at home^[21, 22]. Therefore, the findings from the original study on the exploration of caregivers' experience of caring for a child with a heart disease^[7] has undeniably demonstrated the need for

health education and support to the caregivers at the induction of clinical care of the child with a heart disease, to enable caregivers to maintain a sound level of care for these children at home.

The researcher is of the opinion that the clinical setting is the entry point to health care of children with heart diseases. As concerned with confirmation of the diagnosis and the prescriptions of the treatment regimen, clinical health care setting is a primary focal point for the initiation of health care interventions. As such if need be, clinical setting should refer the child for support in order for the caregiver to be able to withstand stress associated with providing care at home. In view of potentially negative impacts on the caregivers and the children, it is of most importance that clinical professionals assess and identify the existence of actual or potential emotional and socio-economic challenges confronting the caregivers in meeting the demands of care at home^[23].

Have identified the need for coping on the part of both the caregivers and the children and in concurrence with the trend of the existing literature^[3], clinical health care professionals should teach the caregivers and the child the knowledge and skills specifically to facilitate both emotional coping and problem-focused coping before the children are discharged from the hospital. This will enhance the possibility of coping with the challenges of care at home. Understanding the illness and the expected course places the parents in a better position for planning of care activities that are appropriate as well as for effective role negotiation by the family members^[21, 24].

In order to ensure the reinforcement of the much needed information provided to the caregivers, health education should include among others, information and instructions for palliative care that address discharge medications, follow up appointments, diet, and lifestyle modification with regard to activity tolerance and controlling the exposure of the child to environmental pollution^[25].

It is, however, important that health care providers in the clinical settings 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. Therefore, it is, necessary that all the instructions and advice which have been verbally communicated to the caregivers and the children-when possible, 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^[26].

However, the extent to which coping can be facilitated should not be measured against the efforts from the health services only. The determinants for coping on the part of the caregivers are not all within the exclusive remit of the health services. Welfare policies that facilitate the accessing of financial and material assistance also influence the ability of vulnerable families to achieve and maintain a degree of empowerment^[26]. It is, therefore, implicit that the socio-economic context of the child be assessed about the need for financial assistance and for the possibility of being eligible for social grant if his/her family is economically vulnerable until the child's condition is resolved.

The literature proposes that the clinical settings should use a checklist of multi-component indicators regarding health education that is provided and for assessment of the need for support to patients with heart diseases^[26, 28]. Likewise, if the local clinical settings are to be able to measure and audit the assessment of actual or potential challenges confronting the caregivers and their children with heart diseases (in meeting the demands of care) at home, it is commendable that the clinical settings should use a checklist of multi-component indicators regarding providing health education and assessment of the need for support to caregivers of children with heart diseases.

Based on the assumption above, the researcher improvised and developed a checklist for health education to the caregivers and the child concerned and for assessment of the needs for support to caregivers to enable continuous care at home. The checklist was adapted from the American Heart Association's checklist for health education to patients with heart diseases^[26] and was adjusted to the context of this study. It is discernable that a thorough assessment and identification of the solution to the socio-economic factors that can influence care at home may ease the task of providing home care to children with heart diseases who are from economically vulnerable background. Table 1 presents the proposed checklist for health education and for the assessment of the caregivers and the children with heart diseases.

Table 1. Checklist (proposed) for health education to the caregivers and the children with heart diseases (adopted from the American Heart Association and adjusted to the study context)

| PATIENT'S PARTICULARS | | | | |
|---|----------------------------|-----------|--------------|-----------------|
| Name..... Surname..... | | | | |
| Registration Number..... Ward..... Hospital..... | | | | |
| Diagnosis (optional)..... Date:..... | | | | |
| PART 1: HEALTH INFORMATION FOR EMOTIONAL COPING | | | | |
| • Information given to the caregivers on the nature of the child's disease and potential outcomes ? | | | | Yes/No |
| If yes, by: Dr..... | | | | |
| • Information given to the parents/caregivers on waiting time for surgery? | | | | Yes/No |
| If yes, by: Dr..... | | | | |
| • Counselling provided to the caregivers on the techniques of emotional coping methods as appropriate to the caregivers' context? <input type="checkbox"/> Self-re-evaluation, <input type="checkbox"/> Acceptance <input type="checkbox"/> Seeking social support, <input type="checkbox"/> Spiritual beliefs, <input type="checkbox"/> Self-efficacy <input type="checkbox"/> Optimism <input type="checkbox"/> Venting of feelings | | | | |
| • Counselling provided to the caregivers on the techniques of problem management coping as appropriate to the caregivers' context: <input type="checkbox"/> Use of resources in the family <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"/> Networking with confidants and downwards comparisons, <input type="checkbox"/> Recreation and socialisation. | | | | |
| • Counselling provided to the child about coping with the burden of the disease symptoms (Based on the age of the child)? | | | | Yes/No |
| 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 |
| | | | | |
| | | | | |
| | | | | |
| Medication/food interaction information given? | | | | Yes/No |
| Information given on avoidance of 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, <input type="checkbox"/> Adjusted daily fluid intake. | | | | |
| Section 3: Weight monitoring information | | | | |
| • Information given to the caregivers on monitoring the child's weight? | | | | Yes/No |
| Section 4: Lifestyle and environment modification information | | | | |
| • Information given on the type of activities allowed? Yes/No | | | | |
| • Information given on monitoring activity tolerance of the child? | | | | Yes/No |
| • Information given on avoidance of emotional upset for the child, including crying)? | | | | Yes/No |
| • Information given to the caregivers about the hygiene of the households? | | | | Yes/No |
| • Information given to the caregivers 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 symptoms worsen? | | | | Yes/No |
| • Information given on follow up treatments? | | | | Yes/No |
| • Name of 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 |
| • Need(s) identified ? | | | | 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 caregiver and the child-where applicable | | | | |
| Signature of: | | | | |
| 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: Caregiver.....Date:.....Time..... | | | | |

4 Conclusions

Health care facilities are the entry point for the confirmation of the diagnoses of heart diseases for children in Namibia. While waiting for surgical corrections or when the child is a case for palliative care, these children have to be cared for at home. Poor coping with providing home care calls for a professional intervening to enable caregivers to provide effective care at home. By implication, induction of clinical care for these children should include assessment of the socio-economic context that influence the continuous care at home and when necessary, refer the child to appropriate services. Reference to appropriate services would facilitate caregivers' coping with the demands of care and as a result, the positive health outcomes for the children concerned.

4.1 Limitations of the study

The data from the situational analysis which forms the basis for the programme intervention may have only the information that the participants prefer to share. As a result, the proposed intervention for solutions may be limited because it is based on the interpretation of the limited perspectives that were provided by the participants. It would therefore be to the discretion of interested organizations to determine independently the transferability of the conclusions of the study.

4.2 Recommendations

It is recommended that clinical health care providers should assess the socio-economic contexts which determine the quality of care provided to children with heart disease at home. When necessary, referral should be made to appropriate services. Health care should provide continuous professional support to concerned families. In conclusion, a concept of "home care" should be included in the curriculum for basic training of professional nurses at the local training institutions.

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