ORIGINAL ARTICLE

A Study to Assess Problems Encountered by Immediate Family Members in Caring for Children Affected With Sickle Cell Disease at University Teaching Hospital, Lusaka, Zambia

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ABSTRACT

Objective: The objective of the study was to assess the problems experienced by immediate families in caring for children affected with Sickle Cell Disease (SCD) seen at University Teaching Hospital (UTH) Lusaka, Zambia.

Design: The study was a cross sectional descriptive study conducted at the SCD outpatient clinic paediatrics department, UTH Lusaka. The study population was parents and guardians of children affected with SCD seen at the clinic. The respondents were selected using convenient non probability sampling method. A total number of 145 parents and guardians of children with SCD seen at UTH were enrolled into the study.

Data was collected using a semi structured interview schedule consisting of both closed and open ended questions to enable the investigator collect both quantitative and qualitative data. SPSS version 16 was used to analyze data. Chi square test was used to measure association between variables. The cut off point for statistical significance was 0.05.

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Results: This study revealed that majority of respondents (83%) had low levels of knowledge on the disease. This influenced their understanding of the disease and negatively affected the way they cared for the affected child and increased the burden of care. This was attributed to the fact that majority of respondents (70%) had only attained low primary education. There was a significant association between educational levels of respondents and knowledge of the disease (p value 0.01). The other reason for low levels of knowledge was that majority of respondents had not received any educational materials on SCD.

The study revealed that most of the families (76%) had low monthly income and the cost of caring for the child caused a huge financial strain to the families. This was a major source of anxieties to the families. There was a significant association between monthly income and experiencing financial problems by the families to take care of family needs (p value 0.01).

This study revealed that majority of respondents (77%) experienced depression, guilt feelings, anxiety and blue moods due to living with a child affected with SCD. There was a significant association between the number of times the child had been hospitalized and depression in the parent (p value 0.001).The study also revealed an association between feelings of guilt and levels of knowledge on SCD by the respondents (p value 0.002).

The study findings revealed that Majority of the

respondents (98%) indicated that living with a child affected with SCD affected the interrelationship within the home environment as well as with other people outside the home mainly attributed to Stigma, frequent illness episodes and hospitalizations of the affected child.

Conclusion: From this study, the families of children affected with SCD face a wide range of problems in caring fro the children ranging from lack of adequate knowledge on how to manage the disease at home due to lack of knowledge on the disease. Psychological problems experienced include depression, guilty feelings, blue moods, which adversely influence the way they care for the children.

The families also experience financial burdens in taking care and meeting the needs of the children. A common manifestation of SCD in children is unpredictable episodic pain crisis which leads to frequent hospitalizations and families have to spend money in such circumstances.

Families also face challenges in interpersonal relationships both within the home environment as well as with other people outside the home.

As revealed from this study, it is evident that these problems are interrelated. It has also been revealed that management of SCD patient does not just involve treating the crisis and other medical complications, but also alleviating the problems experienced by families of affected children so as to enable them have an improved quality of life.

INTRODUCTION

Sickle Cell Disease (SCD) affects millions of people throughout the World and is one of the most prevalent and costly genetic disorder[1]. It is known to be wide spread reaching its highest prevalence in people of African heritage. However, it is also found in people of Mediterranean, Caribbean, south and Central America, Arabian and Indian ancestry[1]. Being a chronic and an incurable disorder, the family of affected children experiences a wide range of problems which have an impact on the rest of the family and are associated with lower levels of family cohesion[2]. Patient with SCD endure frequent and prolonged bouts of pain and may require multiple hospitalizations to address pain and other SCD complications. This causes a burden of misery .Acute painful events known as crisis, is an important part of the care burden of the caregivers and families of children with SCD. It is difficult to provide support for crises that may occur at any time of the day or night and that are unpredictable .[3] The morbidity of a painful crisis event and other complications that brings a child to medical attention, does not end once the child is discharged from hospital. Children experience persistent pain even at home after discharge from medical treatment.[4]

In view of the burdens and the impact SCD has on patients and families of affected children, the World Health Organization (WHO) at its 59 assembly in January 2006 recommended that SCD be acknowledged as a public health issue and emphasized that there is urgent need to establish simple cost effective high strategies to reduce the morbidity and mortality associated with SCD in countries most affected with SCD[1]

The study therefore investigated some the problems and burdens influencing the care of children affected with SCD by families. Investigating these problems has great potential of alleviating some of the problems and for improving support and management for children with SCD. Along with the necessary curative and preventive care, one also has to assist these patients and their families in different fields of life. Improved support for these families can make a difference not just in their mental health but also possibly in the physical health of the child and help them enjoy a fruitful and productive life as possible.

METHODOLOGY

Study design and sampling

The study was a descriptive cross sectional study conducted at SCD outpatient department UTH. The study population were parents and guardians of children affected with SCD seen at UTH. 145

respondents were selected using convenience non probability sampling method. The inclusion criteria for this study was all the parents or guardians of children affected with SCD seen at UTH paediatrics department SCD outpatient clinic as long as they were willing to participate in the study.

Questionnaire

A semi structured interview schedule which consisted of both close and open ended questions was used to collect data from respondents. The interview schedule had some questions constructed with reference made to some validated tools such as Flanagan's Quality of Life 16 Item scale[6] and the WHO Quality of Life BREF scale.[7] During data collection, the researcher and assistants interviewed 145 respondents face to face using the questions on the semi structured interview schedule. Confidentiality was assured to the respondents and their consent obtained before commencing the interview.

Data Analysis

Data Analysis was done using SPSS Version 16 package. Chi square was used to compute associations among variables. Only a p value of 0.05 or less was considered statistically significant. Variables that were subjected to chi- square associations computations included families economic status, frequency of hospitalizations, knowledge on SCD, educational level of parents, social support, availability of informational materials

RESULTS AND DISCUSSIONS

Knowledge on Sickle Cell Disease

The findings revealed that knowledge level on SCD among the majority of respondents (83%) was low. The low level of knowledge was attributed to the fact that majority of the respondents (71%) had low educational level. This study revealed a significant association between educational level and knowledge of the disease (p value 0.03). The other explanation for the low levels of knowledge was that majority of respondents had not been counselled on SCD and had not received any educational materials regarding SCD.

The other reason for the low level of knowledge among respondents, was attributed to the fact that majority of the respondents (82%) had not received any additional informational materials regarding SCD such as books, pamphlets or videos on SCD. The main source of information they had was from the health workers.

The above findings are contrary to those revealed in a study that was conducted by Oluwole [8] in Nigeria. His study revealed that the majority of respondents (97.4%) were aware of SCD and had multiple sources of information on SCD such as seminars, health workers, media, peer, books, family friends and internet. All these avenues are important resources of dissemination of information.

Economical problems

The study revealed that the families experienced financial burdens in caring for children affected with SCD and this was a major source of anxieties to the families. Most of the families (76%) had a monthly income of less than k500.000 which was graded as low in this study. Therefore the cost of caring for the child caused a huge financial strain to the families. The respondents spent considerable sums of money on buying medicines, medical investigations and transportation costs when their child was admitted in hospital. It is worth mentioning that in Zambia 73% of the population is poor and live below poverty datum level since many earn little or no regular income to sustain their livelihood[9]. This kind of situation puts families with children with chronic illness such as SCD in more financial burdens. There was a strong association between monthly income and families borrowing money to take care of family needs (p value 0.01)

This study revealed that majority of main caregivers (69%) who were mothers of the affected children, were unable to work because of the responsibilities of caring for the affected child. This inability of the mothers to work negatively impacted on the economical status of the families which were already impoverished.

The study revealed an association between family income and families experiencing financial problems (p value 0.01).

Psychological problems

The researcher used the Flanagans[6] and WHO quality of life scales to construct questions in the schedule in order to assess psychological factors.

This study revealed that majority of respondents 77%) experienced depression there was an association between the number of times the child had been hospitalized and depression in the parent (p value 0.01).

These findings are similar with those of Tweel et al [10] whose study entitled "Quality of life of caregivers of children with SCD "found that caregivers of children with SCD had depressive moods and that the risk of having another child with SCD had a negative effect on mood.

This study revealed that the respondent experienced feelings of guilt living with a child affected with SCD. There was an association between feelings of guilt and levels of knowledge on SCD by respondents (p value 0.002). Some mothers reported that their guilt stemmed from the fact that other people assumed that the mothers knew about SCD gene and their pregnancy and they still chose to conceive an ill child. The mothers described that this blame contributed to their feeling of guilt about genetically transmitting the SCD trait to their children.

The findings revealed that respondents experienced anxiety and blue moods reason being that even though their child had reached school going age they had not started school due to the illness and frequent hospitalizations. This was a major stressor to the parents.

Social problems

Although providing care for a child with SCD is inherently stressful, other factors such as social support mediate the impact

The study revealed that majority of the respondents (76%) experienced strained interpersonal relationship within the home environment among the parents ,siblings and other immediate family members due to living with a child affected with SCD. The reasons given were that family members did not interact well because the child was often sick and the other siblings cold not even play normally with the affected child due to all health restrictions such as avoiding exhaustion, keeping warm, taking a lot of fluids and many more.

The research suggested that the child's illness had an impact upon the interaction within the family, alters the parent-child interaction, increased the amount of emotional strain upon the primary caregiver, and threatens social stability of the family.

The findings of this study revealed that having a child with SCD affected their relationship with other people outside the home. Majority of them (85%) stated that their relationship was affected because other people stigmatized them and said they were cursed. It is therefore not surprising that some of the respondents (45%) felt ashamed of other people knowing that they had a child with SCD. The study also revealed that lack of adequate time for socialization due to care giving responsibilities also contributed to social isolation.

These finding are similar with those of a study that sought to explore the psychological impact of SCD in Nigerian population.[11] The study showed that among the Igbo communities SCD is believed to be the result of malevolent 'Ogbanje'(reincarnation) that is repeated cycle of birth, death and reincarnation in cursed families.

Interestingly this study has revealed that majority of respondents (64%) reported that their relationship with their spouses was affected. The respondents reported that their husbands felt neglected because the wives (mothers of affected children) spent most of the time caring for the child. Some of the respondents (5%) actually reported that they had been divorced by their husbands because of having a child with SCD. The wives were blamed to be the ones who caused the disease on the child. This could be attributed to the fact that as shown from this

study, majority of the respondents (87%) had never been jointly counseled. Husbands or spouses may lack Knowledge, awareness and understanding of SCD which leads to them blaming their wives.

This study revealed an association between joint spousal counselling regarding SCD and relation between spouses being affected due to living with a child with SCD (p value 0.01).

This study revealed that most of the respondents (63%) indicated that they received support towards they care of the child in form of spiritual material financial from families. friends and the church. However, such support was received once in a while and this resulted in the families fending for themselves most of the time. Hence it was not sufficient and effective enough to help relieve the care burden.

Managing a child with SCD maybe a source of distress therefore a good source of regular and sustained support system for family members helps relieve the burden of care. This is supported by Burlew et al [12] whose research suggested that families who had social support available appeared to cope more favorably with their Childs illness. In addition the more social support available to the patient and the family from significant others the more likely the patient is to comply with the treatment regime.

Recommendations

Based on the findings , the researcher recommended that the Ministry of Health to introduce National programmes of SCD which will be directed towards management and support of SCD patients and their families in order to alleviate some of the burdens experienced by the families. SCD is widely distributed in every province in Zambia , therefore there is need fore the establishment of SCD clinics in every major clinics and District Hospitals to enable proper follow up of patients with SCD.The services offered at these centers should incorporate into its protocols of management of SCD aspects such as mandatory counselling on SCD to affected families and easily understandable literature be provided for parents to take home for them to have better understanding of the disease. The investigator recommended the need for the health workers together with the affected families and other interested stakeholders to advocate for the formation of the Zambia SCD Association which will bring into focus the public health importance of providing strategies for psychological, social as well as avenues for income generating activities for financial support to the patients and their immediate families.

There is need to introduce effective and efficient Information. Education and Communication (IEC) programmes to make the communities in our country aware of SCD. The health workers through the Ministry of Health and other stake holders should develop several avenues of disseminating information such as dramas, posters, media , programmes both audio and visual ,educational videos on SCD and many more. This is important to increase public awareness and understanding of the disease in the general population and help reduce stigma associated with the disease.

Health professionals especially doctors and nurses working with children and families affected with SCD should spear head to advocate for the formation of Zambia SCD Association which will bring into focus the public health importance of developing liaison services to meet the health needs and support of the patient and the families of affected children. Through the Association, important events such as the World SCD disease day (19thJune) can be observed in Zambia every year to as it is in other countries. SCD is a major public health concern in Zambia and it is high time such an association came into being.

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