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Assess Mother's Knowledge Regarding Their Children With Sickle Cell Disease

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Abstract: **sickle cell anemia is the most common genetic disease; it is an inherited disorder that the red blood cells become crescent-shaped because of a genetic defect. It is affecting the quality of life and associated with a high level of mortality.**
Objective: the aim of this study was to assess the mother knowledge of sickle cell anemia.
Method: cross-sectional study involving 50 mothers' of children with sickle cell anemia who living in Riyadh, Saudi Arabia. Data was collected via a questionnaire filled in by trained Arabic speaking research assistants who interviewed mothers about the sickle cell anemia aspects of their Children, assessed their knowledge and behavior concerning sickle cell anemia in their children as well as collecting the necessary sociodemographic characteristics of the mothers, and children themselves.
Result: it was found that 40%, and 34% of the mothers were in their thirties and illiterate, respectively. 52% of the their children were female, and 42% current age between 8-13years , 66% were under 2 years when they first diagnosed with Sickle cell anemia. The results showed that 34 out of 50 of mothers were unaware about etiology and symptoms of disease and the crisis. 70% of their children were admitted to emergency department yearly. The least known information among mothers was the complications of sickle cell anima (20%).
Conclusion: the results showed that mothers were significant inferior knowledge about etiology and symptoms of disease and the crisis. More education is needed to help the mothers of Sickle cell anemia to attain the necessary knowledge and practices to care for their children.

Keywords: **Sickle cell disease, sickle cell anaemia, crisis.**

I. INTRODUCTION

Sickle cell disease (SCD) is a heritable disorder characterized by mutation on the β-globin gene as result produce of abnormal hemoglobin S and is associated with high morbidity and mortality.

SCD is present throughout Saudi Arabia, mostly in the eastern and southern provinces. Information about the prevalence of SCD in Saudi Arabia is not well established, however, the prevalence for sickle-cell trait ranges from 2% to 27%, and up to 2.6% will have SCD in some areas. (1)

In sickle cell disease, the inter- and intra-individual variability has a major influence in disease manifestations. Disease manifestation may start as early as 6 months of life, which coincides with the switch of fetal haemoglobin to adult Haemoglobins. (2)

Sickle cell disease patients receive healthcare by routinely visiting primary care doctors for general check-ups, managing pain, and routine laboratory tests. Many of these patients do not have an assigned hematologist to provide counselling or advice on pain management. (3)

Many researches indicated i that patients with SCD experienced a lower quality of life compared to the general adult's population. Found that children with SCD as well as their parents scored significantly lower on several quality of life domains including; general physical, motor and independent daily functioning. Others identified deteriorations in social and school competence for children with SCD, compared to healthy peers, but they did not find an association with disease severity as measured by sickle cell genotype. (4)

There is a persistent need to focus on primary prevention of SCD through public health education and other control measures. Decent knowledge about SCD is needed for individuals especially carriers to make informed decisions about their reproductive life and other health related choices. [5]

OBJECTIVES:

The aim of this study is to assess the mother knowledge of sickle cell anemia and its effect on the quality of life.

II. METHODOLOGY

A cross-sectional study involving 50 mothers' of children with sickle cell anaemia who living in Riyadh, Saudi Arabia. Data was collected via a questionnaire filled in by Arabic speaking research assistants who interviewed mothers about the sickle cell anaemia aspect of their Children, assessed their knowledge and behaviour regarding sickle cell anaemia in their children as well as collecting the necessary sociodemographic characteristics of the mothers, and children themselves. Pre-tested and interview administered questioner adopted from literatures were employed to record mother's knowledge about SCD. The data analyses were conducted using Microsoft Excel 2013.

III. RESULTS

A. Demographics data:

The mothers were found to be in their thirties (20/50) and illiterate, 40%, and 34%, respectively and 58% were housewives. The demographic details of the participating mothers and their children are tabulated in Table 1.

The results showed that 34 out of 50 of mothers were unaware about etiology and symptoms of disease and the crisis. 70% of their children were admitted to emergency department yearly. The least known information among mothers was the complications of sickle cell anima (20%). Table II shows the mothers' answer.

TABLE 1: DEMOGRAPHIC DETAILS OF THE PARTICIPATING WOMEN AND THEIR CHILDREN.

Variable	Frequency (n=50)	Percentage
Mothers' Age (Years)		
Under 20 years	0	0%
20-29	10	20%
30-39	20	40%
40-49	12	24%
50-59	8	16%
Education level		
High school	11	22%
Diploma	2	4%
Bachelor	15	30%
Master	4	8%
PhD	1	2%
Illiterate	17	34%
Mother's occupation		
Working	21	42%
Not working	29	58%
Your child's gender		
Male	24	48%
Female	26	52%
Child age when he/she first diagnosed with SCA		
At birth	1	2%
2 years or under	33	66%
3-5 years	15	30%
6-8 years	1	2%
Your child's current age		
2 years or under	4	8%
3-7 years	14	28%
8-13 years	21	42%
13-18 years	11	22%

TABLE II: THE MOTHERS' ANSWERS OF OUR QUESTIONER

Variable	Frequency (n=50)	Percentage %
Where you can get information about SCA		
Your child doctor	30	60%
Website	14	29%
Family and friends	6	12%
Supportive group	0	0
How frequently does your child see his/her doctor		
Daily	0	0%
Weekly	1	2%
Monthly	31	62%
Annually	18	36%
How frequently does your child go to the emergency room		
Never	2	4%
Daily	0	0%
Weekly	1	2%
Monthly	12	24%
Yearly	35	70%
The most symptom of SCA interferes with your child's at daily life		
Chest Pain	6	12%
Unspecific pain	8	16%
Fever	1	2%
Shortness of breath/ breathing problem/ cough	3	6%
Paleness	10	20%
Fatigue	22	44%
How can you help your child deal with the disease		
Follow a healthy diet	6	12%
Drink a lot of water	1	2%
Stay physically active	7	14%
Taking his/her medications	36	72%
How your child feels living with Sickle Cell Anemia		
His feeling alone	6	12%
Family and friends wont understand his/her suffering	10	20%
Social life restricted	14	28%
Has difficulty to preform normal activity	13	26%
Treated different by other	7	14%
Are you aware of your child crisis symptoms		
Yes	11	22%
No	34	68%
Little information	5	10%

IV. DISCUSSION

The results of the present study in central region highlight some main points on mothers' knowledge about sickle cell disease. The mother sources of information about SCD had an impact on their extent of knowledge. Participants who were aware of their child symptoms were exposed to education about SCD through medical sciences had higher knowledge.

In cross-sectional study of patients with sickle cell disease, it was estimated that 6 of 10 sickle cell disease patients had at least three emergency department visits within a 6-month period. Well education and poor general health resulted in an increase in the rate of sickle cell disease -related emergency department visits. These findings can contribute to medical practitioners' ability to manage and educate patients with SCD.[3]

In study done in 2010 in Nigeria regarding Mother's knowledge of sickle-cell anemia, 59% of the mothers did not know the reason for the disease. [5]

Despite how well the parent prepared a child with Sickle Cell Disease is often a surprise for them. Families that have children with sickle cell disease (SCD) endure numerous potentially stressful experiences and daily hassles related to the biological complications of SCD. More counseling and present of a medical educator are highly needed for the mother with newly diagnose child. [5] A recent study found that participants recommended more public about sickle cell by using such as media, social media, internet, schools, churches, outreaches, and seminars. Findings from this study also identified educational level (tertiary education) and gender as predictors for higher knowledge of sickle cell. Where educators/healthcare givers were able to sit down with the Mother's and provide a detailed explanation of SCA. This importance of education and genetic counseling in improving knowledge of SCA. Lacking an understanding of what to expect and of the importance of attempting to prevent or alleviate crises, the mother is not prepared to help the child. [6]

In recent study conducted in Nigeria regarding the mothers knowledge of SCD 34% of mothers informed about hereditary basis of anaemia while 49% no one explained to them the disease, Physicians, nurses, and literature were the primary sources of information of the mothers regarding SCD, as well as its medical care. The considerable gaps in appropriate knowledge on sickle-cell anaemia in Nigeria observed indicates that adequate and appropriately presented information to parents or guardians of patients should be an essential part of a comprehensive care plan. [7]

Our study has limitations the main limitations of the study were study type and adequate time and place. The study did not include mothers of other different locations; hence, we cannot applied the results to general population since this study conducted in one city only, and by this we would have required more resources as well as time. More studies needed to find the correlation between the mother knowledge and quality of life of their children.

V. CONCLUSION

The results showed that mothers were significant inferior knowledge about etiology and symptoms of disease and the crisis. More education is needed to help the mothers of Sickle cell anemia to attain the necessary knowledge and practices to care for their children.

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