BIO-ECONOMICS, KNOWLEDGE AND AWARENESS OF SOCIAL SUPPORT MECHANISMS AVAILABLE FOR CHILDREN LIVING WITH SICKLE CELL DISEASE AMONG PARENTS IN NSUKKA URBAN, ENUGU STATE, NIGERIA

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Abstract

Social support is an important component of health care for people with chronic health conditions such as cancer, heart disease, diabetes, arthritis, sickle cell disease, stroke and so on. This study investigated bio-economics, knowledge and awareness of social support mechanisms available for children living with sickle cell disease among parents of children living with sickle cell in Nsukka urban. Data were collected using in-depth interview (IDI). Sample size of seventeen (17) participants was used in the study. The data was analyzed and coded using the NVivo software. The findings from the study revealed that parents were not knowledgeable of social support mechanisms but had literal knowledge of the term. The findings also show that the respondents acknowledged the benefits of social support to their children as well as to themselves. It also shows that there is a relationship between the bioeconomic status of parents; education, social class, family income level, place of residence, level of education of; parents of children living with sickle cell and their; ability to access social support services. The study concluded that bioeconomic status of parents affects their attitude and relationship with sickle cell patients. Hence, it was recommended that constant education and sensitization should be provided to those living in rural areas on issues of stigma and discrimination chronic illnesses like sickle cell anaemia.

Keywords: Social support; Awareness; Sickle cell disease; Economics

INTRODUCTION

Sickle Cell Disease (SCD) is a global public health issue affecting red blood cells, with 20 to 25 million SCD patients worldwide (Wen et al., 2017). It is associated with severe anemia, poor oxygen transport, and organ failure, with approximately 300,000 infants born with SCD annually, with 75% of them living in Africa. SCD is most prevalent in malaria-endemic regions, with Nigeria having the highest prevalence of SCD patients at 2% to 3%. The disease requires comprehensive and lifelong management, involving participation from healthcare providers and parents (Osunkwo, 2021). Early identification of signs of risk for complications is crucial to prevent its aggravation. Parental education about SCD has been shown to reduce mortality and pain.

Pediatric SCD causes physical and mental health challenges, including fever, anemia, pain, stroke, acute chest syndrome, and restrictive lung disease. Common musculoskeletal complications include acute osteomyelitis, chronic osteomyelitis, avascular necrosis, septic arthritis, chronic leg ulcers, pathological fractures, and

vertebral collapse (Ojewunmi et al, 2019). Psychological counseling, social support, and proper pain management can minimize the risk of developing health-related and behavioral problems (Nasiri et al., 2020). This study aims to improve the quality of care for SCD children by examining the knowledge and awareness of social support mechanisms available for children living with SCD among parents in Nsukka urban.

Experiences of parents of children living with SCD

Parents and caregivers of children with Sickle Cell Disease (SCD) face numerous challenges, including emotional difficulties, financial burdens, and disruptions in their lives (Karadağ et al., 2018). Studies have shown that parents experience frustration when their children experience pain and worry about their child's future. Inability to develop tailored programs contributes to these emotional difficulties. A study by Nwanonyiri et al. (2018) found that parents experience frustration when their child experiences pain and the lack of social aid and support can lead to emotional distress. Karadağ et al. (2018) found that 70.4% of families struggle to make time for their children, and the disease disrupts family activities and relationships. Van (2015) found that many parents are concerned about their child's future and the expectation of pain crises, which contributes to emotional distress. The lack of support and other factors contribute to the emotional distress faced by parents.

Sickle cell disease (SCD) costs an average patient nearly $1 million in lifetime healthcare costs, with annual costs exceeding $30,000 for adult patients. Studies in Ekiti, Southwest Nigeria, and by Havugarurema (2020) have shown that parents of SCD patients often lose working days and lose their jobs due to their commitment to their children's illnesses. Lack of public awareness about SCD contributes to its negative impact on families' socioeconomic status. Asamoah (2021) also explored pain management options for SCD patients and their parents/caretakers, finding that during crises, parents may miss or lose work days, leading to financial distress for patients and their families. Poor management of SCD contributes to the socioeconomic status of many families with SCD.

Besides these studies that highlight the financial burden of SCD on families and the need for better health sector investments, others (Guedes, 2012) posit that, stress of SCD disease management can lead to depression in parents and financial strain, as well as burnout and exhaustion. Studies have shown that 33.8% of caregivers of children with sickle cell disease (SCD) in Nigeria struggle with managing, their children's care and 84.4% feel sorrowful or depressed. This distressing situation can lead to mental illness in the caregiver and lower health-related quality of life (Guedes, 2012).

Madani et al. (2018) found that over half of caregivers struggled with time management, with low participation rates in daily activities due to assisting patients with medication, recurrent disease complications, and transportation. The lack of support from organizations, public institutions, and networks contributes to the poor quality of life for SCD patients.

Kuerten et al. (2020) found that 70% of caregivers struggled with family activities, finding time to complete household responsibilities, and feeling too tired to complete chores. Financial hardship was found to be a significant predictor for feeling of burnout.

Asamoah (2021) explored pain management options for SCD patients and their parents/caretakers, finding that during a crisis, parents may miss or lose work days and may even lose their jobs, putting patients and their families in financial distress. Poor

management of SCD contributes to the socioeconomic status of many families with SCD.

Social work services for children with SCD

Social work is an emerging profession in Nigeria that plays a crucial role in providing social welfare services to sickle cell patients. Despite not yet gaining professional status, social workers play a significant role in hospital emergency services, assisting in patient diagnosis and reducing hospital costs. They provide counseling, crisis intervention, and referrals to community services and support groups (Onalu et al., 2020). Hematology social workers are experts in recognizing the impact of sickle cell disease on patients and their families (Tsai & Kesselheim, 2020). They provide emotional and psychosocial support to pediatric patients, addressing any concerns patients and their families may have. Social workers work with the entire family, including patients, parents, and children, aiming to reduce the emotional burden of illness on the family. They assist families in making decisions about whether to stop working to care for a sick child, handling the needs of healthy siblings, dealing with growing financial demands, and finding emergency financial relief (Hassan, 2016). Social workers also coordinate services, investigate new resources and services, provide guidance, and conduct ongoing assessments of patient and family needs. They assist families in balancing the requirements of their healthy siblings with those of their sick child (Cartwright, 2021). Overall, social workers serve as a counselor, therapist, liaison, and advocate to assist families in meeting various new and complex requirements for their children and families.

Theoretical framework

Health Belief Model (HBM)

The Health Belief Model (HBM) was developed in the 1950s by Hochbaum, Rosenstock and Kegels (Hochbaum, 1958; Resource Center for Adolescent Pregnancy Prevention (ReCAPP), 2015). The premise of the HBM is that people will take action to prevent, screen for and manage disease conditions if they believe that the illness can be avoided and that adopting a recommended action will help them prevent it or, reduce susceptibility or severity or lead to other positive outcomes (ReCAPP, 2015). The HBM is a framework for motivating people to take positive health actions by using the desire to avoid a negative health consequence as the prime motivation (Tarkang & Zotor, 2015).

This model suggests that a person will take a health-related action such as the use of social support mechanisms if that person feels that a negative related condition or side-effects can be avoided, or has a positive expectation of taking a recommended action, or perceives that the benefits of partaking in a new behavior or new action will reduce the chances of developing a medical condition or illness and its related symptoms. The HBM is used as a theoretical orientation in this study to provide an understanding of the influence of parental health beliefs on the different social support mechanisms, parental beliefs about the severity of SCD, parental perceptions of the benefits of social support, as well as the factors influencing their beliefs, and what effect it has on the health and wellbeing of the child. Tarkang and Zotor (2015) observed that parents' attitude towards Complementary and Alternative Medicine (CAM) and use can be explained by the HBM, as parents take action relative to prescribed treatment and/or use support mechanisms to prevent or minimize the harmful side-effects of cancer symptoms or treatment side-effects for their children, SCD inclusive.

METHODOLOGY

The study adopted cross sectional survey using convenience sampling technique. The area of the study is Nsukka Urban of Enugu state, Nigeria. The study population comprised of parents whose children have sickle cell disease in Nsukka Urban. Participants were determined by snowball sampling method. Being a qualitative study, 17 participants were selected for an indepth interview using an indepth interview schedule (Appendix A). This study made use of thematic content analysis to explore the data and identify underlying themes (Creswell, 2014). This method of data analysis was selected as it focuses on the extraction of "content areas" or "coding" so as to categorize and analyze themes to create a comprehensive picture of an individual's experience. In order to prepare the data for analysis, all interviews were transcribed by the researchers. NVivo software was used to assist in the analysis and coding of transcripts. This helped the researcher to create links and relationships between various concepts and references and look at how the data interacts and influences one another, in order to try to find the larger meaning of the data.

Result

Seventeen participants took part in the study and they consisted of seventeen mothers. The table below show the socio-demographic distribution of participants.

Table 1: Demographic characteristics of participants for the indepth interview

Name	Age	Gender	Marital status	Religion	Education	Age of child with SCD
Parent 1	48	Female	Married	Christian	University	12
Parent 2	42	Female	Married	Christian	University	9
Parent 3	48	Female	Married	Christian	University	13
Parent 4	40	Female	Married	Christian	University	5
Parent 5	38	Female	Married	Christian	University	7
Parent 6	43	Female	Married	Christian	University	11
Parent 7	45	Female	Married	Christian	University	10
Parent 8	41	Female	Married	Christian	University	9
Parent 9	46	Female	Married	Christian	University	13
Parent 10	39	Female	Married	Christian	University	8
Parent 11	48	Female	Married	Christian	University	12
Parent 12	40	Female	Married	Christian	University	6
Parent 13	43	Female	Married	Christian	University	9
Parent 14	36	Female	Married	Christian	University	8
Parent 15	47	Female	Married	Christian	University	9
Parent 16	43	Female	Married	Christian	University	11
Parent 17	47	Female	Married	Christian	University	13

Table 1 shows the demographic characteristics of all the participants interviewed for this study. The table reveals that the ages of the participants ranged from 36 to 48 with a mean age of 45 years, which indicates that majority of the participants were relatively in the middle-aged population. Out of the 17 interviewed participants, all were female; indicating that only females participated in the study. With regards to the marital status of the participants, all participants were married. All the participants were Christians. From table 1, all participants have completed university degree education, although at different points in time. Additionally, the

data in the table show the ages of their children with SCD to range from 6 to 13.

Respondents' awareness of social support mechanisms available to their Sickle Cell Disease-child in Nsukka urban

The findings reveal that respondents are aware of social support in the sense that they understood it to be 'the way one can care for a child who is sick'. Accordingly, respondents literally understood what social support is, but do not know how it is applied in relation to helping their children with SCD. They expressed an understanding of the term but they did not have sound information and skills about management regimen that can be used to prevent complications of SCD. There were expressions of surprise and confusion at the sound of the term, as they were just hearing it relatively for the first time. One respondent (parent 12) said:

> "I have never heard of the term before. To my understanding, support is the way others can help you and you can help someone, particularly during a difficult time or situation. If we are to relate it to having a child with sickle cell, I would say it has to do with how you can provide aid to your child as they go through this tough illness" **(Parent 12).**

Another respondent also said;

> "Before today I haven't heard of social support but after hearing the explanation of the topic, I am able to understand it small" **(Parent 14)**.

Another respondent added;

> "I understand social support to be the ways that you can show care for a child or someone who is sick by caring for them and showing support to them" (**Parent 3**).

Among all seventeen indepth interview participants, only one of them gave a clear definition of social support without much guidance while the others required several minutes to understand the subject post-study interview.

The respondents revealed that their main source of information was on social support were from health practitioners. One respondent said;

> "It's today I'm hearing of it. I've never heard anything like social support before. I'm just doing what I can to answer your questions. Let's just say I heard it from the doctors in the hospital, they will tell you what you should do and what you shouldn't do" (**Parent 9**).

Also, another respondent said;

> "I initially was not aware of the name "social support" prior to this interview. I am just hearing the name for the first time. I just know that after my child was first diagnosed in the hospital, the doctor told me certain things. They said these are the things you need to do to help your child live a normal life" (**Parent 11**).

Although the parents credited the little knowledge they had to health practitioners, many said that they still had to go in search of information elsewhere because the information received from health practitioners could not sustain them for so long. Parent 12 stated;

> "Maybe if I knew more on the subject, it would have resulted in better results in how I handled different situations because the doctors can't tell you everything. Sometimes you are on your own." Other credited knowledge-sources on social support to include friends and family members alike.

Another respondent, parent 3 also said;

> There are some things that require someone to tell you if not you can never know. I remember someone, a friend, telling me that you need to

> give your child enough water. I did not know this before I had been told and I don't think I could have guessed. I think because I am a friend to (have befriended) many women in similar situations, I have also learnt (learned) different things from them that have helped me provide better care & support to my child.

Many parents also said that they had gained most of their knowledge via trial and error and due to experience. That is, trying different methods of care and discarding the one that does not produce positive results. A parent said; "In the beginning I was very confused but, as you try different methods you learn what works and what does not work from it." (**Parent 7**).

Another respondent, parent 11 also said;

> During the early stages of his (the SCD-patient child of the respondent) life there, was a lot of confusion and I just didn't know what to do. As I got older and gained more knowledge it became easier and, I got more confident in my ability to provide the best care for my child.

Another respondent, parent 1 also said; "Yes. I believe that my managing SCD (experience), as I got older, improved greatly. You learn from experience and when you are in this situation every day for, many years then, you gain more knowledge".

Another respondent, parent 10 also said; "I asked for help from nurses and doctors and even though the name was not specified it, helped me to gain some knowledge and the rest I was able to figure out on my own".

Usage of social support to reduce the impact of Sickle Cell Disease and Social Confusion Disorder on the health status of the SCD-child by parents of SCD-patients

The study reveals that parents of SCD-patients are often unaware of the different types of social support available to help manage the impact of Sickle Cell Disease and Social Confusion Disorder on their Sickle Cell Disease-child. Some parents provide care support, provisional support, and encouragement support, while others are unaware of the specific types. Most respondents reported to have found that providing proper healthcare, a healthy diet, and teaching their child how to take their medications can help reduce the impact of SCD.

Other respondents emphasized the importance of arming their Sickle Cell Disease-child with information on how to take their medications and provide care independently. They taught their Sickle Cell Disease-child to take their medications and not to joke with them, as it is essential for their health. Additionally, eight respondent's identified prayer as another type of support to reduce the psychological impact of SCD.

Following, some respondents pray daily for their child living with Sickle Cell Disease, encouraging them by talking to them, praying with them, and providing daring for them to live a normal life. These respondents believe in God's ability to see their Sickle Cell Disease-child through in lieu make prayer a part of their family's routine.

Perceived benefits of using social support in improving the health status of the child

From the indepth interview, respondents had greatly benefited from using social support information to improve their Sickle Cell Disease-child's health status. Many respondents emphasized the importance of taking action to prevent sickle cell crises and boosting their overall well-being of their Sickle Cell Disease-child. In addition, most respondents learnt from, social support engagement the, importance of sickle cell children drinking plenty of water, avoiding treating pain at home, and seeking medical care if sickle cell crisis persists. They also learnt from, social support engagement other

effective strategies to prevent their Sickle Cell Disease-child from falling sick, such as using mosquito nets.

Thus, from the indepth interviews, respondents' knowledge of social support, and information gained by participating in social support improved their own lives, making them more efficient in addressing difficult sickle-cell crisis situations and fostering a closer relationship with their children suffering sickle cell disease. Particularly since respondents were mothers of children suffering sickle-cell, knowing that their child has the support he/she needs makes them happier and more confident in their ability to care for them. They also revealed that this helped manage the health of any child of their suffering sickle-cell wisely, ensuring they are always by their side. Additionally, the study respondents also emphasized highlights their use of; and importance of; communication between parents and their children suffering sickle-cell, making the job of supporting these children easier.

The factors that influence the knowledge and awareness of social support mechanisms for parents of children living with SCD in Nsukka urban

From the indepth interviews, several factors that influence parents' knowledge and awareness of social support mechanisms for children living with sickle cell disease (SCD) are factors such as age, social class, education level, public awareness, income level, place of residency, religion, and lack of trained professionals. Emphasizing education as a major challenge, most respondents revealed that being aware of social support mechanisms helps in, providing effective support for their children living with sickle cell whilst protecting these children of effects in false beliefs or stigmas associated with the notion that sickle cell was caused as a result of callousness and carelessness of their parents who were ill informed to marry despite their genetic-make-up.

On financial status, respondents asserted finance aids them to live a stress-free life, provide basic necessities, and access quality healthcare. However, from the indepth interview, poor public awareness can limit knowledge of parents of children living with sickle cell, especially in rural areas where people may not be fully conversant with the meaning of sickle cell and may not be aware of social support mechanisms and how to use them.

Respondents asserted social class also to aid accessing knowledge, since 'having money puts individuals in contact with many people and provides access to more information than the average person'. However, 'many people of lower classes may not know more effective alternatives to reduce pain', which may be detrimental.

Whilst respondents overall revealed these factors of, education, income, and social class in shaping knowledge, preparedness and awareness of SCD-mechanisms to; prevent sickle cell crisis by parents and/or patients living with sickle cell; some respondent asserted that these factors were not all handy. Hence, they were challenged handling sickle-cell crisis. Following, creating awareness on social support and social support mechanisms would aid parents of children living with sickle cell better understand and provide effective support for their children, ultimately improving their overall well-being.

Role of social workers/services in aiding and improving access to support services for sickle-cell patients in Nsukka urban

The study found through indepth interview that, social workers need to be greatly involved in assisting patients and parents of children living with sickle cell access information pertaining social support and;

social support mechanisms and services. Further, respondents also stated that 'collaboration' between social workers and other health practitioners can serve to address the challenge relative to gaining information on support mechanisms. In lieu, respondents identified several roles that social workers can play to assist parents of sickle-cell patients improve/gain access to these. These roles include; enabler-role, counseling, case management, educator-role, broker, referrals-role, creator of awareness, research and; advocacy roles.

For instance, one of the respondents said; "Social workers should work in collaboration with doctors in the hospital. Because usually the first time you find out your child is sick, it's in the hospital. At least if there's an office (for social workers) you could go to after finding out; the social worker could explain to you and you could ask your questions and they will offer advice so that that parent can know how to handle the situation properly" **(Parent 11)**.

Another added that;

> "Now that I know that it is possible for a collaboration, I think it would be beneficial to the parents to have a smoother access to information. It will make it less stressful for us and we will not be surprised every time something new happens. I remember very well the first time my child experienced a crisis attack. If I had known beforehand, I would have acted faster. Doctors only tell you about medication and not what you will face down the road" **(Parent 14)**.

In buttressing this point, another respondent added;

> "They should work with doctors so that when parents are made aware of their child's illness, the doctors can direct them to the offices of the social workers. I believe social workers can serve as bridges that can help parents get the needed assistance and information required to help their children" **(Parent 15)**.

Respondents further highlighted the need for social workers to organize group sessions which can also help parents learn through the experiences of others;

> "I believe there's need to also organize meetings with other parents so that we can form a support group. It helps to know other people who are also going through something similar to you; it will also help us help ourselves" **(Parent 9)**.

Affirming another, respondent added;

> "I would prefer to be in a group session because it will help you know about other people's experiences and opinions. It is better to have people going through a shared experience with you than to be alone especially in a situation like this" **(Parent 7)**.

Discussion of findings

This research examined the knowledge and awareness of social support mechanisms available for children living with sickle cell disease among parents in Nsukka LGA. Although respondents (parents of sickle cell patients) were not knowledgeable about social support mechanisms, they revealed providing suitable care for their children on the basis of the information they had. The study found that respondents use various types of social support mechanisms to reduce the impact of sickle cell disease (SCD) and improve their child's health status. This is evidenced in an earlier study (Gansari, 2019) conducted using quantitative research-design in the United States on self-management support for chronic disease in primary care. The study posited that there is need for education to be provided to people with chronic health conditions like sickle cell disease.

The most common types of support known to respondents include; providing care, medication, encouragement, prayer, and provisions like food. Respondents also recognized the benefits of using social support mechanisms in improving their child's health, such as; improved health standards, improved relationships towards; better performance in school and home duties, fewer hospital visits, reduced stress, and increased will to manage pain. These findings were in agreement with Salvador et al. (2015) who indicated that because young children have limited coping skills and limited ability to communicate their pain properly, it is up to the primary caregiver to correctly interpret and treat the pain that the child may be experiencing.

Given the result of factors influencing the knowledge and awareness of social support mechanisms of parents of children living with SCD in Nsukka LGA to include; education, age, social class, poor public awareness, income level, place of residency, and lack of trained professionals; social workers should embark on mass literacy. The mass literacy should educate the populace and caregivers on the importance of social support on the well-being of the people in need of it, in this case, the sickle cell patients. Corroborating, Onalu et al. (2020) in their study of perceived factors that predict the availability of social support when it is needed by older adults in Nnewi, South-East Nigeria, posit factors such as; financial status and social domain impacted on the extent social support was accessed.

Subsequent on the study, social workers can assist parents in accessing these services in Nsukka urban by playing roles such as; enabler, case management, educator, counselor, broker, referrals-role, awareness creator, keeping up with research and trends on new methods towards providing more social support mechanisms, and advocating for the right professionals to be there. In so doing, social workers can help parents gain knowledge on support mechanisms and access social support services towards improving overall well-being of sickle-cell patients.

Relationship between findings and theoretical framework

Social support is characterized by having people, both friends and family, offer emotional, instrumental, informational and appraisal support during times of stress and illness towards coping with certain issues. Thus, the study was anchored on the Health Belief Model (HBM) developed in the 1950s by Hochbaum, Rosenstock, and Kegels because of its contribution to the understanding that individuals can approach an illness given their perception, knowledge and understanding of the illness. The model posits that a person's belief vis-à-vis an illness or disease coupled with a person's belief or otherwise in the effectiveness of prescribed/recommended health behavior or action(s) may predict the likelihood such person would adopt the prescribed health behavior.

Conclusion and recommendation

This study investigated the knowledge and awareness of social support mechanisms available for children living with sickle cell disease among parents in Nsukka LGA. The study found that parents showed some level awareness of social support mechanisms but did not display adequate knowledge of these mechanisms, and how to use these mechanisms. Hence, this study recommends that government, social workers and social support stakeholders, create more awareness, put in place more social support service and improve funding for social support service in order to facilitate knowledge of social support mechanisms. Following, impede the dissemination of wrong information that contravenes appropriate mechanisms for

managing sickle-cell and/or several other diseases inherent upon grave health conditions for children living with SCD. Finally, social workers should lead the advocacy on improved funding by government towards more support service-projects hence, ensure more people gain access to information on support mechanisms.

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