Original Article

Health Services Access for Young Children with Sickle Cell Anaemia in the Chilubi District of Zambia

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ABSTRACT

Background: Young children with sickle cell anaemia (SCA) require frequent medical interventions to prevent fatal complications and improve quality of life.

Methods: The care givers of 40 randomly-sampled children <5 years old with SCA who lived in rural Chilubi district in northern Zambia were interviewed in 2016.

Results: Most of the parents had poor knowledge of SCA, treated most SCA symptoms at home, and were unaware of the SCA complications requiring emergency clinical care. Distance and cost were frequent barriers to accessing medical services. The local clinic was perceived to lack the human and material resources necessary to offer high-quality care.

Conclusions: Community-based family health education programs may increase parental knowledge of SCA and reduce some of the barriers to seeking care for their children. Additional SCA training for nurses and clinical officers will enable them to provider higher-quality preventive and therapeutic care.

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INTRODUCTION

Each year more than 300,000 babies are born with sickle cell anaemia (SCA), also known as sickle cell disease, a genetic condition that misshapes the red blood cells, reducing their ability to deliver oxygen throughout the body.[1] About 75% of babies with SCA live in sub-Saharan Africa.[1] Sickle cell crises can cause organ damage and extreme pain[2] as well as cognitive impairment.[3,4] SCA can also cause serious and potentially fatal complications such as splenic sequestration, acute chest syndrome, pulmonary hypertension, aplastic crises, strokes, and heart and kidney disease.[5,6]

Children with SCA may have significant impairment of their quality of life due to disease complications and frequent hospitalizations.[7] Although improvements in the rate of early diagnosis and management of SCA have helped decrease the mortality rate associated with SCA,[8] more than half of all children born with SCA in sub-Saharan Africa do not survive to their fifth birthdays.[1,9] Reliable access to affordable healthcare services are important for improving survival likelihoods and quality of life for young children with SCA.

This study examined access to health service for young children with sickle cell anaemia in Chilubi district in the Northern Province of Zambia. Chilubi district is home to Lake Bangweulu, one of Zambia's largest bodies of water. The swampy environment

Key Words: *sickle cell anaemia; sickle cell disease; access to health care; health attitudes; sub-Saharan Africa*

around the lake enabled the local population to remain relatively homogeneous. This isolation and the resulting consanguinity (family marriages) have meant that some types of genetic disorders affecting the Bisa tribe have a relatively high prevalence in the district, including SCA. The district also has high rates of under-nutrition and malaria that exacerbate the complications of SCA. The goal of this study was to identify associations between factors related to accessing healthcare services and quality of life among children under-5 living with sickle cell disease in Chilubi district in Zambia.

METHODS

At the time of the study in 2016, total of 200 children younger than 5 years old with an SCA diagnosis lived in the catchment area for the Santa Maria Mission Zonal Rural Health Centre (ZRHC). To generate a random sample of 40 participants for this study, a list of the children in the clinic's registry was printed and the families of every fifth patient were invited to participate in the study. The sampled participants represented all three of the geographic zones within the district, with 20 children sampled from Santa Maria on Chilubi Island (technically a peninsula), 15 children from Matipa on the mainland, and 5 children sampled from Mayuka in the swamps. Outreach to the families of sampled patients was done with the support of Santa Maria Mission ZRHC as well as local Growth Monitoring Promoters (GMPs) and Community Malaria Agents.

The study protocol was approved prior to initiation by the University of Lusaka and by the Chilubi District Medical Office. Permission to access patient medical records and the HMIS were granted by the Provincial Medical Office and the District Medical Office. Interviewers received training on research methods and cultural communication skills prior to reaching out to families of SCA patients, and a fieldwork manual guided all of their work. All parents or guardians of participating children signed informed consent statements prior to being interviewed for the study. The confidentiality of all information was carefully maintained.

Mothers of under-5 children with SCA were interviewed about their knowledge of SCA signs and symptoms, their understanding of sickle cell crises, their knowledge of treatment options, their use of the Santa Maria Mission ZRHC and other healthcare facilities (if any), and their perceptions of how the presence of hospital services at the ZRHC impacts the quality of life for children with SCA. The distances from patient homes to the ZRHC were quantified, and the socioeconomic status of each household was ascertained based on questions about the employment status of adults in the household and the stability of that employment. These data were analysed using quantitative and qualitative methods. All data were collected between September and December 2016.

To understand the health profile of the region in which the study participants live, health system records for Chilubi district were examined. These included Zambia's Health Management Information System (HMIS), the inpatient and outpatient registers of the local healthcare facility, and records from GMPs and other community health workers. The facilities, personnel, equipment, and supplies available for SCA management at the Santa Maria Mission ZRHC were examined, and healthcare providers were interviewed about their knowledge, attitudes, and practices. Information was also gathered about community-level conditions. Santa Maria residents live an average of 6 km from the ZRHC, and the community was home to about 6300 residents in 2010. Matipa residents live on average about 70 km from ZRCH, and the area was home to about 8100 residents in 2010. Mayuka residents live up to 500 km by road from the ZRCH, because there are so few roads in the area due to it being located by a protected national park. The Mayuka area was home to about 7200 residents in 2010.

RESULTS

Most of the participating parents had poor knowledge about sickle cell anaemia. Of the 40 interviewed mothers of under-5 children with SCA, only 24 could name an example of the type of sickle cell crisis that could lead to death in young children. Only 13 considered SCA crises to be paediatric emergencies requiring clinical care. Mothers who lived far from the clinic had significantly lower levels of SCA knowledge than mothers who lived within walking distance of the clinic. Additionally, mothers who did not participate in labor outside the home had significantly lower levels of SCA knowledge than mothers who reported being employed or engaging in other income-generating activities. Most mothers advocated for the use of traditional remedies at home when their children have SCA crises.

Accessing professional medical care for SCA was reported to be difficult for most of the participating families. Only 8 of the 40 mothers reported that their under-5 child with SCA was able to access quality healthcare services from Santa Maria Mission ZRCH whenever needed. Only 5 of the 40 mothers reported that they would be able to quickly access medical care. For many families, the key barrier to care was the long distance to the clinic from their homes, including 100% of the homes in Matipa and Mayuka and some in Santa Maria. Canoes were reported to be the main mode of transportation to the clinic. In the rainy season, roads are often impassable by motor vehicles. In addition to physical barriers to access, rural residents have few financial resources to use on transportation. The average monthly income in Zambian kwacha among participating households was K237 (equivalent to about US$25) in Santa Maria, K108 in Matipa, and only K87 in Mayuka, placing nearly all households below the national poverty line (which was K214 per adult equivalent per month in 2015)[10]. Another perceived barrier was the limited services available at the health facility, which is a rural health centre and not a fully-equipped hospital.

The evaluation of Santa Maria Mission ZRHC revealed several challenges with resources, facilities, supplies, and equipment that impeded the capacity of its clinical staff to provide high-quality care for young patients who have SCA. While the clinical laboratory was able to conduct a sickling test, no protocols for management of SCA in children were available to clinical care providers. There were no SCA specialists on staff. The children's ward, sanitary facilities, and kitchen were in poor condition, and inpatients did not reliably receive adequate nutrition. Hydroxyurea, which reduces the frequency of painful sickle cell attacks, was not stocked in the pharmacy. Intramuscular diclofenac, an analgesic used for pain management in sickle cell patients, was not reliably available. The health centre also had an inconsistent supply of whole blood, which is a life-saving therapy for SCA. It was not able to perform splenectomies or other surgical procedures. No physiotherapy or other rehabilitative services were offered for stroke patients and other causes of disability in children with SCA. Because of these resource limitations, the clinic staff were not able to provide health education about SCA, conduct routine check-ups on SCA patients in their catchment area, or provide genetic counselling to couples who might be carriers of the sickle cell gene. The focus was on providing clinical care during patient crises rather than on preventing crises and managing the condition prospectively. The participating mothers of under-5 children with SCA had a high awareness of many of these limitations. Most reported that they would be more willing to travel long distances to the clinic if the quality of services available at the clinic were improved.

DISCUSSION

The key barriers to accessing medical care for under-5 children experiencing sickle cell crises in rural

northern Zambia include low socioeconomic status, limited knowledge about SCA, and the distance to the nearest healthcare facility. Children with SCA who live in households with low socioeconomic status often have parents who have relatively few years of schooling and limited knowledge about health and disease.[11] Parents with little formal education might not understand when their children need medical care, and they might fear being mistreated or made fun of by clinic staff.[12,13] The cost of transportation and health care, or the perception that care might be expensive, can also be a barrier to accessing routine and emergency SCA care.[14]

Health education programs for all parents of children with SCA, no matter what their socioeconomic status or educational backgrounds, may be critical for mitigating the complications of SCA in their children.[15] Educational sessions increase parental knowledge, and they may also increase trust and improve communication between parents and medical staff. Improved communication may reduce some of the perceived barriers to accessing SCA care.[16] Family health education sessions may also reduce the psychological stress that SCA imposes on caregivers.[17]

However, improved health literacy among families of low-income SCA patients will not be sufficient to improve quality of life for SCA patients unless their local healthcare facility is a well-staffed and well-equipped one that can reliably manage mild and moderate complications and is able provide rapid referrals to affordable higher-level facilities when severe SCA complications arise. A well-resourced health facility in places with a higher-than-typical prevalence of SCA should be prepared to prevent serious complications in paediatric SCA patients by providing testing for the disease, offering comprehensive healthcare services, treating infections early, and implementing high-quality pain management strategies.[18,19]

Resource constraints such as inadequate supplies and personnel are perceived to limit the ability of healthcare facilities to provide high-quality services, conduct health education programs, and enhance the quality of life of local children with SCA. It is a fact that additional resources for clinics like Santa Maria Mission ZRHC would enable clinic staff to provide higher-quality care to patients and to equip family caregivers with the health information, education, and communication they need to enhance their children's quality of life. Additional resources for sickle cell disease care are urgently needed in places like Chilubi that have an especially high prevalence of SCA.

However, even rural clinics that do not have the resources to offer advanced clinical services can implement cost-efficient interventions that will reduce the rate of complications in SCA patients. First, community-based family health education may help enable a model of patient care that focuses on crisis prevention rather than crisis management. This may be especially valuable in communities that are far from health facilities. Second, although a rural health centre is unlikely to be able to support an SCA specialist on staff, the quality of care at clinics can be increased if the nurses already on staff are provided with additional training in SCA care practices.

Although this paper must be interpreted conservatively because it reports on a small study from just one part of Zambia, the results are congruent with other studies of challenges for families of children with SCA in sub-Saharan Africa. Together, these studies support the need for healthcare facilities in places with high SCA prevalence to implement low-cost, effective strategies for improving caregiver knowledge about SCA, reducing barriers to seeking care before severe complications develop, and increasing the ability of nurses and other clinical care providers to offer excellent health education, clinical care, and case management of young children with sickle cell disease.

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