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Use of complementary and alternative medicine in the management of sickle cell disease

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Original Article

Abstract

BACKGROUND: Sickle cell disease (SCD) is the most prevalent genetic hemoglobinopathy with an estimated 300,000 babies born with the disease globally every year. Due to the chronic nature of the disease, there is a pressing need for safe, effective, and affordable therapeutic agents for SCD. In many settings, use of complementary and alternative medicine (CAM) has been reported in the management of the disease. However, there is limited documentation about the use of CAM among patients with SCD in Uganda. Thus, this study was conducted with the aim to determine the prevalence of CAM use and the most commonly used CAM among patients with SCD at Mulago Sickle Cell Clinic (MSCC).

METHODS: This cross-sectional study was conducted for a period of 3 months using an interviewer-administered questionnaire to collect data from 293 participants who were recruited into the study using simple random sampling method at Mulago National Referral Hospital Sickle Cell Clinic, Uganda. The collected data were analyzed using SPSS software to express univariate data as median, mean, mode, percentage, and frequency tables and graphs.

RESULTS: CAM use was reported among 76.7% of the participants with the majority using more than on type of CAM. Biological products were the most commonly used form of CAM followed by spiritual healing; 74.6% of the CAM users used biological products, 25.2% used spiritual healing and prayer, while 0.6% used energy therapies. The most commonly used CAM include avocado leaves (50.9%), herbal concoctions (28.3%), beetroot (19.8%), prayer (18.8%), garlic (13.7%), and anointed water (12.6%).

CONCLUSION: This study found a high prevalence of CAM use among patients with SCD.

KEYWORDS: Complementary Medicine, Alternative Medicine; Sickle Cell Disease

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Introduction

Sickle cell disease (SCD) refers to a group of hemoglobinopathies caused by mutations in the β-globin gene leading to the production of abnormal forms of the β-subunit of hemoglobin, and thus, a predominance of abnormal sickle hemoglobin in erythrocytes.[1-3] These disorders include thalassemia and sickle cell anemia which is the most common and severe form of SCD resulting from the homozygous inheritance of sickle hemoglobin from both parents.[4] This disease is characterized by polymerization of the abnormal hemoglobin, sickling of erythrocytes, hemolysis, microvascular obstruction, and organ damage.[5] Persons living with SCD experience fevers, leg ulcers, jaundice,

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pulmonary symptoms, fatigue, dizziness, headaches, acute severe pain, stroke, and priapism especially during a sickle cell crisis.[6,7] These devastating symptoms continue to affect school attendance, physical activity, and socialization of the patients and contribute to 30–50% incidence of disability and unemployment.[8-10]

Globally, an estimated 300000 babies are born with SCD annually[4,11] and 75% of this global burden is based in Sub-Saharan Africa,[5] where scarce health resources and inadequate awareness among health care providers and the general public contribute to shocking rates of early mortality.[11] The incidence of the Sickle cell trait in countries like Cameroon, Democratic Republic of Congo, Gabon, Ghana, and Nigeria reportedly ranges from 20% to 30%, and it is as high as 45% in some parts of Uganda.[12] In Uganda, it is estimated that 25,000 babies are born with the disease annually and 50% to 90% of these babies die before their 5th birthday, often without an established diagnosis.[13,14]

SCD is a chronic disease; therefore, the goal of treatment is to manage and control symptoms, and to limit the number of crises, and thus, there is a need for continuous treatment, even when the patient is not experiencing any painful crisis.[7] Conventionally, the routine treatment includes disease modifying agents like hydroxyurea, analgesics, anti-malarials, nutritional supplements, fluids for hydration, blood transfusion to replace the sickled cells, multiple vaccines, and antibiotics.[4,10,14] However, as has been reported in most chronic diseases, there is a pressing need for safe, effective, and inexpensive therapeutic agents.[15] In many low and middle income countries like Uganda, there is limited utilization of these conventional treatment modalities due to limited access and the high associated costs.[16] Therefore, many patients with chronic diseases resort to the use of various complementary and alternative medicine (CAM), as these are considered cheaper and locally available, to alleviate the symptoms and devastating experiences associated with diseases like SCD.[17,18]

The World Health Organization (WHO) reports that over 80% of the world's population relies on CAM either as the mainstay of treatment or as a complement to the conventional therapies.[19] CAM refers to the wide range of healing practices, briefs, products, and therapies that are not generally considered a part of conventional medicine and largely do not exist in the institutions where conventional health care is taught and provided, but are used by patients in the treatment of various conditions.[20,23] CAM has broadly been divided into mind–body medicine, alternative medical systems, lifestyle and disease prevention, biologically-based therapies, manipulative and body-based systems, and bio-electromagnetics.[19,20] Over the years, therapies like acupuncture, homeopathy, naturopathy, herbal medicine, and dietary supplements have gained a widespread adoption in the general population; however, their use varies from region to region.[24,25] Although studies conducted in Africa have revealed that herbal medicine is the most used form of CAM among patients with chronic diseases including SCD,[20,26,28] there is no documented study on the matter in Uganda despite the high prevalence of the disease in the country since many users do not ever disclose their CAM use to their doctors or nurses.[27] Thus, this study was conducted to determine the prevalence of CAM use among patients with SCD seeking health care services at Mulago sickle cell clinic, Uganda. The study was also aimed at finding the commonly used forms of CAM.

Methods

This cross-sectional study was conducted at Mulago Hospital sickle cell clinic (MSCC) for a period of one month in July 2019. MSCC is located at Mulago National Referral Hospital which is the largest center for specialized diagnosis, research and comprehensive treatment of SCD patients in Uganda. It receives a large number of SCD patients referred from around Uganda and East Africa. It is also the only national specialized referral SCD clinic in Uganda offering outpatient care for children and adults from Monday to Friday between 8:00 am to 5:00 pm. Patients receive routine medications and some interventions such as blood transfusions, intravenous antibiotics, and parenteral analgesics. The clinic is staffed by pediatricians, nurses, a medical record officer, a counselor, and volunteers, visiting professors, and rotating medical students. It handles over 1000 patients a month, with 50-70 patients reported per day.

The target population in this study included all adult SCD patients and caretakers of children with SCD seeking health care services at MSCC.

The desired sample size was determined using Slovene's formula:

$$n = \frac{N}{(1 + Ne2)}$$

Where n is the number of samples needed, N is the study population (The average number of patients attended to in the last 6 months; 1025), and e is the margin of error of 0.05.

$$n = \frac{1000}{(1 + 1000x0.05x0.05)}$$
$$n = \frac{1025}{(3.5)}$$
$$n = 292.85$$

Therefore, a total of 293 participants were enrolled in the study.

Systematic probability sampling method was used to ensure that all eligible respondents had equal opportunities by picking every second patient or caretaker of a child with SCD that referred to the clinic during the study period until the required sample size was achieved.

The study included adult patients with SCD and caretakers of children with SCD seeking care at Mulago sickle cell clinic. Those that consented were enrolled into the study.

Caretakers of critically ill patients were excluded so as not to delay care. Adult patients who were critically sick or could not speak English or Luganda were also excluded. Moreover, a child who did not have a parent or guardian during the time of the study to consent for them was excluded.

Data was collected using a semi-structured interviewer administered questionnaire that was developed by modifying an already existing questionnaire used in a similar study conducted in Nigeria.[26] The original questionnaire was used to assess CAM use among children with 3 chronic diseases, epilepsy, asthma, and SCD. On modification, only questions focused on SCD where maintained. The questionnaire was pre-tested on a group of 10 patients at the same clinic before this study was started in order to determine the time it takes to fill it. The phrasing and sequencing of questions was also assessed during the pretest. Then, 2 research assistants were recruited and trained on how to administer the questionnaires. The study was explained to caretakers and only those that agreed to participate were recruited. The questionnaire was administered in person and in the waiting room where the vital signs of their children are taken to ensure privacy.

The questionnaires were pretested on a set of caregivers other than those in the target population to ensure reliability and validity. The questionnaires were administered through face-to-face interviews to ensure the

completeness of the questionnaires. Questionnaires were examined at the end of each day to ensure that they are correct and complete, and stored safely under lock and key. The questionnaires were inspected for completeness and consistency. Any questionnaires with less than 90% response were eliminated. Data was categorized, coded, and entered into SPSS software (version 23, IBM Corp., Armonk, NY, USA). Univariate data was descriptively analyzed using median, mean, mode, percentage, and frequency tables and graphs.

Ethical Considerations

Ethical approval was sought from the research and ethics committee of Mulago Hospital.

Participants were adequately informed in a language that they understood about the nature, potential benefits, and risks of the study. Written informed consent was obtained from all eligible guardians or patients' next-of kin. All the patients' records were handled with confidentiality; the data was kept under lock and key. Participants were free to withdraw from the study at any time and they were assured that this would not affect their routine management.

Results

Socio-demographic characteristics of the study participants

A total of 293 participants were recruited into the study. The majority of them were women [227 (77.5%)]. The mean age of the participants was 34.1 years and their age ranged from 18 years to 73 years. The majority (71.3%) had attained secondary education and higher, and only 16.2% were unemployed. The majority of the participants (56.2%) earn 300,000 shillings and less (Table 1).

Use of Complementary and Alternative medicine (CAM): In terms of CAM use, 77.1% and 76.7% of the respondents reported having ever used CAM and were currently using CAM, respectively (Figure 1).

Table 1. Distribution of respondents by their socio-demographic characteristics

Variables	Subgroups	n (%) (n= 293)
Age (years)	18-34	149 (50.9)
	35-73	144 (49.1)
	Male	66 (22.5)
Gender	Female	227 (77.5)
Education level	Primary and below	84 (28.7)
	Secondary and higher	209 (71.3)
Occupation	Unemployed	57 (19.5)
	Trading business	26 (8.9)
	Peasants	97 (33.1)
	Civil servant	37 (12.6)
	Professional job	55 (18.8)
	Small scale business	21 (7.2)
Earning (Ug. shs)	300000 and less	114 (56.2)
	Above 300000	89 (43.8)

Moreover, 45.7% of the caretakers used CAM on a daily basis for various reasons. The majority (48.8%) used CAM to increase blood levels for the patients, and 13.7% used CAM to treat yellowing of eyes, while 8.2% used it to boost the patient's immunity. However, the majority (55.1%) have never disclosed CAM use to their health care providers.

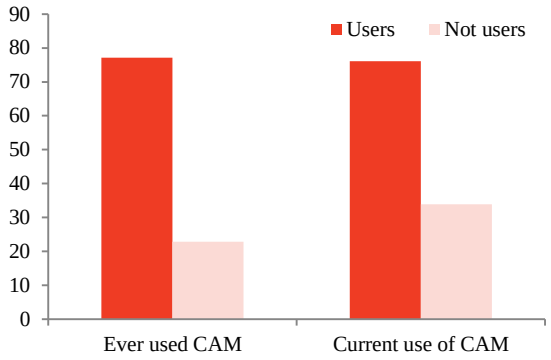

Figure 1. The prevalence of complementary and alternative medicine use

Complementary and alternative medicine modalities used in the management of sickle cell disease: Although most participants used more than one type of CAM, biological products were the most commonly used form of CAM followed

by spiritual healing/prayer (Figure 2). Moreover, 74.6% of the CAM users used biological products, 25.2% used spiritual healing and prayer, while 0.6% used energy therapies.

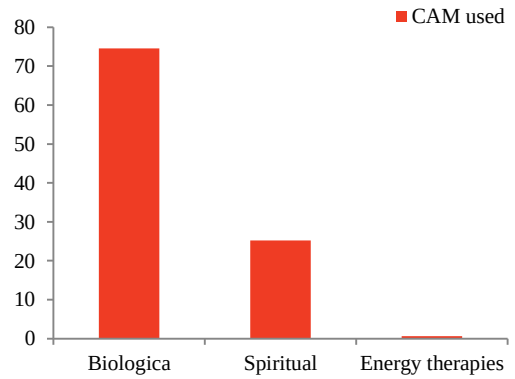

Figure 2. The type of complementary and alternative medicine used by the participants in the management of sickle cell disease

The most commonly used CAM includes avocado leaves, which were used by 50.9% of the caretakers. This was followed by herbal concoctions (28.3%), beetroot (19.8%), prayer (18.8%), garlic (13.7%), and anointed water (12.6%), as shown in table 2.

Table 2. The various complementary and alternative medicine modalities used for sickle cell disease

CAM modality	Frequency (n = 293)	Percentage (%)
Avocado	149	50.9
Mixed herbs	83	28.3
Beetroot	58	19.3
Prayer	55	18.8
Garlic	40	13.7
Anointed water/oil	37	12.6
Pawpaw leaves	28	9.6
Supplements	19	6.5
Hibiscus	12	4.1
Massage	6	2.0
Aloe vera	5	1.7
coffee	5	1.7
Ginger	4	1.4
Black jack	3	1.0
Concoction	3	1.0
Vitamins	3	1.0
Fruit juice	3	1.0
Tianshi	2	0.7

Source of information about complementary and alternative medicine use for patients with sickle cell disease: The majority of the caretakers reported that they learnt about CAM use through their relatives and friends. The influence of mass media like television and radio programs was also observed in this study (Table 3).

Table 3. The source of information about complementary and alternative medicine use in sickle cell disease

Source of information	n (%)
Relatives/friends	84 (28.7)
Television	66 (22.5)
Radio	37 (12.6)
Newspaper	29 (9.9)
Churches	22 (7.5)
Newspaper	19 (6.4)
Churches	11 (3.7)
Open market	16 (5.4)
Medical staff	9 (3.1)

Discussion

In the present study, a high prevalence of CAM use was observed in the management of SCD in Uganda, a finding that is in line with the recent review conducted by Alsabri et al.[20] This implies that CAM is used by the majority of the patients in managing symptoms like pain associated with the disease.[29,30] The 76.7% prevalence reported in this study is slightly lower than the 91.6% and 88.5% reported recently in Mississippi state by Thompson and Eriator,[25] and in Nigeria by Busari and Mufutau, respectively.[27] However, it is higher than the 63% reported by Sanchez et al. in the United States of America.[29] Indeed, several studies have documented the increase in use of CAM in chronic conditions.[26,31,32]

In the setting of this study, the high prevalence is associated with limited access to health care services and inability to afford the various treatment modalities, like hydroxyurea.[3,4] Given that SCD is a chronic condition, associated with various devastating symptoms, yet many of the participants were laborers that could not easily afford the

conventional modalities of treatment, the probability that a patient was using CAM for managing SCD was high.

One interesting finding in this study is that only 44.9% of all the CAM users had ever disclosed the practice to their health care providers. The lack of disclosure may be associated with the negative remarks health care providers give patients about some CAM like herbal medicine, yet, in this survey, they were reported as the most commonly used.

In the present study, biological products were the most common form of CAM used among patients with SCD. The 74.6% prevalence of biological CAM use reported in this study is in line with the other findings across Africa where biological products have been reported as the most common form of CAM used in chronic diseases like SCD.[9,27,33,34] For example, in Nigeria, Busari and Mufutau found that the prevalence of biological CAM use was 62.9%, and an earlier study by Oshikoya et al. revealed a 58% prevalence for CAM use among patients with SCD.[26,27] These trends are slightly different from those reported in the western world where other forms of CAM like bioenergetic therapies like prayer, and spiritual and energy healing are the most common forms of CAM. The most recent review by Alsabri et al. in the USA revealed that prayer was the most commonly used form of CAM (45%) followed by other forms of spiritual healing (34%), and 31% of patients relied on massage therapy.[20] In an earlier study in the United States, Thompson and Eriator had reported a 27%, 18%, and 14% prevalence for prayer, the use of relaxation techniques, and reliance on massage, respectively.[25] The striking difference between the trends in the use of biological products like herbs reported in studies conducted in Africa and those in developed countries in the west has been attributed to the fact that these therapies have been integral parts of the African healthcare system since time immemorial.[9] A recent study by Lubega et al. on the prevalence of herbal medicine use in the management of CAM revealed that 77.6% of the caretakers used herbal medicine for their children with SCD.[9] This may also be attributed to the fact that Africans have a strong patronage in the African traditional medicine, in which herbal medicine is an integral component of CAM. More than half of the caretakers used avocado leaves for the patients and 28.3% use other form of herbal medicines. This is a finding that has never been reported in previous studies. This is probably due to the fact that there is a geographical variation in the plant cover across Africa. Avocado trees are very common fruit trees in Uganda and many of the caretakers had access to the leaves free of charge from their gardens or the neighborhood. Prayer is a widely reported form of CAM among patients with chronic diseases.[27,31,35] In this study, prayer was reportedly the most commonly used form of mind and body interventions by the caretakers (18.8%). This is slightly similar to findings from Nigeria where it was used by 12% of the caretakers.[27] However, dependency on prayer in this study is much lower than the findings from the developed world, where it is reportedly the most common form of CAM. For example, the patronage of prayer was at 60% among sickle cell patients in USA.[31] Beet root, anointed water, and garlic were also other commonly used forms of CAM.

The study population was from an urban area, so the findings may somehow differ if the same study was conducted in a rural setting. This may affect the generalizability of the study findings.

The present study did not receive any research grant or funding from any local or international funding agencies. It was mainly funded by the authors.

Conclusion

This study reports a high use of complementary

and alternative medicine in the management of sickle cell disease among patients at Mulago Sickle Cell Clinic.

Conflict of Interests

Authors have no conflict of interests.

Acknowledgments

We acknowledge the tremendous support by the research assistants and nurses at Mulago Sickle Cell clinic during data collection. We appreciate the cooperation of the patients and caretakers who accepted to take part in this study.

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