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RESEARCH

Sickle cell disease-related knowledge and perceptions of traditional healers in tribal communities in India: implications on sickle cell disease programme

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Abstract

Sickle cell disease (SCD) is a progressively debilitating genetic disease, and India is the second most affected nation in the prevalence of births with SCD. This SCD prevalence is high among Indian indigenous tribal communities, whose healthcare is pluralistic. Traditional healers are an essential part of tribal pluralistic care. This study aimed to understand the extent of SCD-related knowledge and practices of traditional healers and their willingness to participate in the SCD programme, which is primarily meant to screen and treat SCD. Following the grounded theory approach, data were collected by in-depth interviews with 40 traditional healers selected from five SCD endemic districts. Text data were coded through a deductive approach, and thematic content analysis was carried out. A few healers knew about SCD. However, almost all are aware of anaemia and its symptoms. Most healers were unaware of the cause of SCD and mentioned that malnutrition and anaemia are reasons for the recurrence of SCD-related symptoms. Most of the traditional healers did not give any treatment. Some gave symptomatic treatment and provided herbal medicines along with some rituals. Though some healers treated some of the typical symptoms of SCD like spleen enlargement, jaundice, swelling and pains in joints, they did not link them with SCD. All traditional healers expressed concern and said they support the government-run SCD programme. The programme should recognise the role and importance of traditional healers. Necessary education on SCD may be given to the healers. Such involvement and education empower the healers in appropriately guiding the people concerning SCD care.

Keywords Sickle cell disease · Knowledge · Perceptions · Traditional healers · Indigenous people

Introduction

Sickle cell disease (SCD), a progressively debilitating genetic disease, impacts the world's poorest and most vulnerable populations. Globally, more than 300,000 births with SCD occur yearly (Piel et al. 2013a). India is the second most affected nation in the prevalence of births with SCD

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(Piel et al. 2013b). India makes up half of the world's SCD burden, along with Nigeria and the Democratic Republic of the Congo (Aygun & Odame 2012). In India, births with SCD and the prevalence of SCD are high among indigenous (tribal) communities compared to the rest of the population (Rao 1984). About 104 million are from tribal communities in India. Because of the poor socioeconomic status and remote habitation of the tribal population, healthcare-seeking is poor (Government of India 2018). Pluralistic health care-seeking is common among these communities, and people depend on traditional healers considerably, in addition to utilising the modern healthcare system (Bhasin 2005).

Despite the huge burden of SCD in the country, particularly among vulnerable communities like tribes, the SCD programme is still in draft format, and no health systems approach exists to deal with the burden (Government of India 2021; Raman et al. 2021). The primary healthcare system, which primarily caters to the preventive and curative services to the tribal populations, totally ignored SCD, and there are no treatment or referral systems in most tribal areas (Geethakumari et al. 2021). However, there is growing attention that leads to the development of an SCD programme (Government of India 2016; Anonymous 2022). Recently, the Indian government has elaborated the strategic roadmap for screening around 70 million people under the age of 40 years for SCD patients in 200 districts of 17 states in three years. And this screening is to eliminate the disease in the next 25 years (Anonymous 2022). The draft document of the programme proposed to include (i) awareness, education and screening programmes in community and schools, (ii) laboratories for newborn screening at the district level, (iii) screening of pregnant women and their husbands to prevent the birth of children affected with SCD, and (iv) prenatal diagnostic centres in medical college hospitals in selected states (Government of India 2016). However, these documents have no clarity on the implementation plan and timeline. In this context, a study to develop models of screening and treatment was undertaken in six tribal-dominated districts of India (Babu et al. 2020, 2022). These models have been developed and tested to make them suitable to implement at the primary healthcare level and to integrate with the primary healthcare system. These models and the lessons learnt are being communicated with India's SCD programme.

In the SCD programme, the involvement of traditional healers is essential. The acceptance of traditional healers is high in tribal communities. The practices of these healers are indigenous and usually beyond the modern system of medicine. As part of the tribal culture, the traditional healers constitute an essential part of the pluralistic healthcare system. These healers are easily accessible to the community and have high credibility. For accessing modern healthcare, people seek advice from their traditional healers. Thus, traditional healers are essential in generating people's awareness and acceptance of healthcare services (Geethakumari et al. 2021).

Hence, the traditional healers' knowledge of SCD and their willingness to participate in the government SCD programme are crucial to making the SCD programme successful. There should be provision to integrate traditional healers' services and educate the healers on SCD-related knowledge and the programme. Hence, this study aimed to understand the extent of SCD-related knowledge of traditional healers, their practices and their willingness to participate in the SCD programme in five SCD-endemic tribal districts of India.

Methodology

This study was conducted before implementing a model of SCD care among the tribal population (Babu et al. 2020). Though this intervention is conducted in six sites, the data for this paper were available from five sites only. It is because of a workforce shortage in one site during the formative phase. Institutional ethics committees of the institutes from these five institutes approved the study protocol. Consent was obtained from all the healers involved in the study by informing the purpose of the study. After explaining the purpose of the study, all of the healers involved gave their consent.

Study area and design

This is a qualitative study with a grounded theory approach, and data were collected through in-depth interviews with traditional healers. The study was carried out in five districts predominantly having tribal populations and are endemic to SCD. These districts represent different geographical zones of India. These districts are Anuppur (Madhya Pradesh state), Chhoteudepur (Gujarat state), Mysuru (Karnataka state), Udalguri (Assam state) and Visakhapatnam (Andhra Pradesh state). The details concerning SCD and public health facilities are available elsewhere (Babu et al. 2020).

Study participants and selection

This study is based on a sample of 40 traditional healers living in the tribal communities of these districts. From each district, eight traditional healers were selected. During other community-based surveys, traditional healers and their locations were identified by the research staff who conducted the community-based surveys in consultation with the principal investigator of the study district. Out of the healers identified, eight healers were selected to cover different geographical areas of the study district. These eight healers in a district

were sampled from four primary health centre (PHC) areas, predominantly inhabited by tribal communities. Initially, it was decided that eight healers per district were the minimum, and planned to increase the number of healers based on the data saturation. Data collection was stopped after these interviews, as data saturation was noted after completing these interviews.

Data collection

The study has adhered to all qualitative research principles (Patton 2014). The interview guide was developed by consulting the previous studies (Gomes et al. 2015; Hsu et al. 2016; Muoghalu et al. 2017; Adegoke et al. 2018) during a brainstorming session of the study researchers, who are the authors of this paper. The semi-structured interview guide was written in English, and subsequently, it was translated to the native languages of the study areas. The English version of the interview guide is available as supplementary information. Interviews were conducted in the native language of the healer at the time of their convenience. Selected healers were contacted, and the research staff took a prior appointment wherever required. As the prior appointment was made and interviews were conducted according to the convenience of the healers, none of the healers refused to participate in the study. Interviews were conducted by post-graduate research staff who were trained in qualitative research. This training provided exposure to the theoretical aspects of qualitative research and field experience in conducting various qualitative methods and data management. Face-to-face classroom teaching and followed by field training were conducted. The interviews with traditional healers lasted for 40–60 min, and all standard guidelines were followed during conducting these qualitative interviews (Hudelson 1994; Spradley 2016). With the consent of the study participants, all interviews were audio-recorded. The content of the interviews was regularly reviewed by the principal investigator and the research staff of each study district for newer information and redundancy.

Data management and analysis

All qualitative interviews were transcribed to the native language by listening to the audio. Adjunct notes were used to cross-check. These transcripts were translated into English. The transcription and translation were done by the research staff who conducted the interviews. Guidelines for transcription and translation were followed (Mergenthaler & Stinson 1992; Mclellan et al. 2003). The interview transcripts were read thoroughly and coded by adopting a deductive approach by the principal investigators of the study districts. Thematic content analysis was carried out by identifying the themes (Kyngäs et al. 2019). By thorough reading, the text data were organised by themes. Several issues were explored under each theme, and related text quotes were identified and segregated. These quotes were read thoroughly by all authors and discussed. Later, inferences were made through cross-checking and consensus. These activities were guided by the first author, the national coordinator of this research. These discussions helped refine the themes, and a review was done to ascertain dual criteria of internal homogeneity and external heterogeneity (Patton 2014). Reporting guidelines of "Consolidated Criteria for Reporting Qualitative Research (COREQ)" were used to ensure transparency in reporting the methodology (Tong et al. 2007). Appropriate verbatim was provided to support the inferences with anonymous identifiers.

Results

The results are based on the qualitative data collected from 40 traditional healers in five districts. The majority (36 out of 40) of the healers are men, and two from Mysuru, one each from Udalguri and Visakhapatnam, are women. Most healers are 50 to 70 years old, with a median age of 55 years.

Heard of SCD

A few traditional healers heard of and knew about SCD. However, almost all were aware of anaemia and its symptoms. Those, who knew the SCD, mentioned various symptoms of SCD like splenomegaly, jaundice, anaemia, joint pains, etc. They said that SCD is an illness of blood. All sampled traditional healers from Gujarat, and none from Assam knew of SCD.

> A traditional healer from Gujarat said, "This disease causes severe pain in hands and legs, loss of blood, recurring jaundice and blood turning into water."

Knowledge of the cause of SCD

Most traditional healers were unaware of the cause of SCD and mentioned that malnutrition and anaemia are reasons for the recurrence of SCD-related symptoms. A few traditional healers from Andhra Pradesh explained that SCD passes from one generation to the next. Some traditional healers from Gujarat had misconceptions. They perceived the overconsumption of corn as the reason. Also, the food grown using chemical fertilisers has emerged as one of the causes in Gujarat.

> Typical verbatim, as told by a traditional healer from Gujarat, is, "I don't know where this sickle cell disease comes from. But when people come, I treat them based on the symptoms."

A traditional healer from Gujarat said, "People here eat food grown with chemical fertilisers. They also eat more corn…, and these cause sickle cell disease."
Another traditional healer from Andhra Pradesh said, "If the previous generation has the gene, sickle cell disease transfers to the next generation, which means it is hereditary".

Treatment of SCD

Most traditional healers did not give treatment for SCD. A few from Madhya Pradesh, Gujarat and Karnataka gave symptomatic treatment, and herbal medicines were provided, along with conducting some rituals. But the traditional healers were hesitant to disclose the treatment details. However, some mentioned the names of the herbs they used during treatment. Some healers prescribed herbal medicines that were used for anaemia. The healers acknowledged that the people received treatment from them and got relieved from the illness. The healers further informed that the patients who got relieved brought other patients suffering from a similar illness. The traditional healers from Assam and Andhra Pradesh reported that they never treated SCD.

A typical quote from Gujarat traditional healer is, "I don't prescribe any medicine for this illness. But I give medicine for pain, jaundice, abdominal pain".
Another traditional healer from Karnataka mentioned in response to the question on how people responded to treatment of SCD, "Yes, people are satisfied with my treatment, and they brought their friends and relatives to seek the cure".

In addition to enquiring about SCD treatment-related practices, traditional healers were probed to know how they treat typical symptoms of SCD. However, these healers could not link these symptoms with SCD. Most of the healers (33 of 40) revealed that they treat spleen enlargement, which manifests as swelling of the stomach. Mostly they use some herbal medicines, and a few perform rituals along with these medicines. Similarly, 34 of the 40 healers said that they treat swelling and pain in joints. In addition to herbal medicines and rituals, healers used massaging the affected part with oils, including different animal fats for the treatment of joint pains. All traditional healers offer treatment for jaundice, except two healers from Karnataka. Most healers consider jaundice a serious ailment; hence, the treatment is also complex by using different kinds of rituals, herbs and materials. Repeated illnesses are mostly considered the effect of the bad eye, evil spirits or curses, and sometimes the result of black magic. Though a few healers treat infections with herbal medicines, most healers perform different rituals and advise patients to tie amulets (*yantra*). Regarding stroke among children, very few healers (seven out of 40) from Madhya Pradesh, Gujarat and Andhra Pradesh treated stroke patients. They have been treated by using herbal medicines and massaging the paralysed part with oils and herbal ointments. Most healers informed that they advise people to seek treatment from tertiary-level modern health facilities for serious illnesses, including stroke. Sometimes, they refer patients with the conditions mentioned above to local PHCs.

Perceptions on the government SCD programme

All traditional healers expressed that initiating an SCD programme is a welcoming decision by the government. Many healers acknowledged that the people are poor; hence, support from the government is essential in treating and curing this illness. Though SCD is not curable, some healers believe that the modern medical system can cure SCD. The bottlenecks, the healers perceived, are poor community awareness and people's inaccessibility to health facilities. All healers mentioned that government should conduct community awareness programmes, and proper treatment and medicines should be ensured at the local government hospitals, including PHCs. Traditional healers suggested that people in their area are to be screened in villages to identify the people with SCD. Healers further said that many people are suffering from anaemia, and they linked anaemia with SCD. Thus, most of the healers highlighted the need for screening. Other suggestions are making blood transfusion available under the SCD programme and the availability of treatment in nearby government hospitals. The healers know that the SCD patients have to go farther (to cities) for the treatment of SCD. Furthermore, they suggested including Ayurveda in these hospitals. Ayurveda, the Indian traditional medicine, is one of the World's oldest medical systems, dating back to 3000 years ago. It is practised in the countries of the Indian subcontinent. The treatment under this system combines herbal products (sometimes metals and minerals), diet, exercise and lifestyle. Traditional healers from Gujarat suggested that a separate hospital be set up in tribal areas, as patients go to distant urban areas to seek SCD treatment. The reason for suggesting a separate SCD hospital was that travelling to urban areas is costly and time-consuming.

A traditional healer from Karnataka said, "As it is for the benefit of our people, it is a welcoming move".
A healer from Gujarat said, "A separate clinic should be set up for this disease. More attention should be paid because there are more sickle cell patients in this area".

When healers were asked how they support the government SCD programme, all said that they feel privileged to participate in the government-run programme. They further said that the programme should recognise the role and importance of traditional healers when implemented in tribal

areas. All healers said they help mobilise the people and inform them about the programme. Traditional healers said they would refer the patients to government hospitals if treatment was available. Some traditional healers said they help gather herbs from the forest needed to treat the patients. And a majority of healers suggested using traditional medicine in the programme. Only one healer has denied supporting the programme, as it affects their profession. The healers from Andhra Pradesh said that they would learn about the disease through the programme, and subsequently, they would treat the patients if required.

> A healer from Gujarat said, "I can help in a government programme that I know about it; If there is a need to gather people or inform people about the disease, I can do that. I also help spread awareness about the disease".

Discussion

The present study reports the traditional healers' knowledge and practices related to SCD from tribal areas of five Indian states. This study is the first of its kind from India. Information on SCD-related knowledge and practices of traditional healers is unavailable from India and scarcely available from other endemic communities (Olatokun 2010). In India, a few traditional healers know about SCD, though they are aware of general anaemia and other symptoms like spleen enlargement, joint pain, jaundice and stroke. They are not aware of the causes. Instead, they have some misconceptions about the cause of SCD. Though none of the healers has treated SCD, they offered symptomatic treatment for some of the symptoms associated with SCD. A similar study from Nigeria revealed that a few traditional healers sought information and used modern diagnoses and remedies in dealing with SCD cases (Olatokun 2010). About 10% of healers have claimed to use haemoglobin electrophoresis to confirm that patient had SCD (Olatokun 2010).

Traditional healers play a crucial role in the pluralistic health-care sought by Indian tribes. These healers are more readily available to tribal members than any other type of healthcare provider. Traditional healers' practices related to illness management and treatment are indigenous. These traditional healers are not under the public health system, and their practices are beyond the scope of modern medicine. During 2007–10, about 12% of people in India reported that the most frequent care provider was traditional healers and about 19% of people used traditional medicine in a year (Oyebode et al. 2016). Thus, traditional healers have acceptance and credibility among the tribal communities. The healers' position is located at the interstices of magic, religion and tribal social system, and hence they attained an important position in the tribal communities (Landy 1974). The traditional healers can play crucially in informing the people to accept the SCD programme, particularly the screening and treatment. If traditional healers are not taken into confidence during programme implementation, the tribal communities may not accept the SCD programme encouragingly.

Several efficacious therapies and strategies are available for the treatment and management of SCD (Nardo-Marino et al. 2020). Such treatment modalities are in use in some countries to manage vaso-occlusive crises and other morbidities related to SCD (Nardo-Marino et al. 2020). However, they are not available in the present study PHCs and other tribal areas in the country (Geethakumari et al. 2021). In all these PHC areas, births with SCD are prevalent (Babu et al. 2021a). Also, these people are unaware of the problem and lack adequate knowledge of SCD (Babu et al. 2021b). The government of India is going to institute the SCD programme in the country. Under the SCD programme, the PHCs and their facilities are to be equipped for screening and managing SCD. The simple screening/diagnosis techniques are standardised and are to be made available at the PHC level (Babu et al. 2021a, 2022). Such techniques are feasible to implement in these communities (Nimgaonkar et al. 2014; Desai et al. 2016; Babu et al. 2021a, 2022). Though the SCD programme-related draft documents identified some important components to implement, they lacked community and health systems approaches. The proposed programme has not taken the realities of the Indian tribal community into consideration. The tribal healthcare system and its institutions and community resources, like the services of traditional healers, are ignored. Though the programme is to be implemented by the government health system, communities are to be informed and prepared to accept the programme. The care-seeking behaviour of patients is to be promoted through local healthcare institutions. Community engagement strategies are to be used to mobilise the community for the acceptance of the programme. During these efforts, the traditional healers' role is crucial, particularly in generating awareness about the programme and acceptance of the services. All traditional healers in the present study sites expressed concern about the problem and are willing to support the government's initiation. They offered some suggestions and agreed to mobilise the people. In order to achieve the involvement of traditional healers in the SCD programme, the traditional healers should be knowledgeable in identifying SCD patients through common symptoms. Traditional healers should be involved in guiding the patients to approach the primary healthcare system for diagnosis and treatment. The traditional healers are to be made aware of the importance of screening and subsequent treatment and care of the affected. Hence, educational programmes meant explicitly for traditional healers are to be part of the SCD

programme, and these programmes are to be organised by the health system routinely. The programme should recognise the role and importance of traditional healers in tribal health. Such involvement and education empower the traditional healers in guiding the people concerning SCD care appropriately.

Thus, this study provides the SCD-related knowledge and practices of traditional healers, who are an essential part of the pluralistic healthcare of the Indian tribal population, hitherto unavailable in India. However, the limitation of this study could be the fact that there is some likelihood of social desirability bias while eliciting the responses from the traditional healers. For instance, all healers welcomed the initiation of the SCD programme by the government. Usually, people support the government's decision, and healers might have perceived the research staff as government representatives. Hence, they might have said in support of the SCD programme, which might be a courtesy bias. The SCD treatment and care are supposed to be initiated at the primary healthcare institutions; subsequently, the referral and other services are to be available through the local PHC. The regular and community health workers will facilitate these services, and the availability of traditional healers' services is an opportunity for better implementation of the programme in the community. By virtue of traditional healers' important position in the tribal societies, they can play a bridging role between the local health system and the community. These healers are able to counsel and guide the patients to approach the health system. Such models involving traditional healers are to be studied to optimise the success of the SCD programme.

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Author contribution BVB conceived the study; all the authors designed the study protocol; PS, SBS, DB, JS and GS carried out the data collection and preliminary analysis; BVB and YS carried out the analysis and interpretation of the data. BVB drafted the manuscript; all the authors read and approved the final manuscript. BVB is the guarantor of the paper.

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Data availability Data will be available on reasonable request.

Code availability Not applicable.

Declarations

Competing interests The authors declare no competing interests.

Ethics approval The institutional ethics committees of the institutes of the authors (PS, SBS, DB, JS and GS) approved the protocol. Each of the five committees approved the study for the corresponding district. All the study participants were informed about the study's purpose, and their consent was obtained before conducting interviews.

Conflict of interests The authors declare no conflict of interest/competing interests with their work.

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