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Knowledge of Healthcare Workers about Sickle Cell Disease in India: A Reality Check

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ABSTRACT

India ranks second in sickle cell disease prevalence worldwide. Government has rolled out National Sickle Cell Anemia Elimination Mission 2023, aimed at prevention, early diagnosis and management, the knowledge of healthcare workers (HCW) is one of the most important drivers of healthcare interventions, especially when investigations and treatments are made accessible according to standard treatment guidelines. This study was undertaken to assess the extent of healthcare professionals' knowledge of SCD. This was an observational cross-sectional study. The questionnaire was a slightly modified DFConhecimento instrument that was sent to the HCW using a web tool to be filled through a link. A total of 416 HCW participated in this survey. The median age of the participants was 34 years, and 190 (45.7%) were male. The majority had experience of working long-term in medical facilities-38.2% (159/416) had worked for more than 10 years. On assessing the knowledge, 52 (12.5%) had good (adequate) knowledge and 364 (87.5%) had poor (inadequate) knowledge. In the prevalent zone, only 14.7% of the HCW had adequate knowledge, and in the non-prevalent zone, only 2.6% had adequate knowledge. The study has attempted to cover major aspects related to the knowledge of healthcare professionals on sickle cell disease and conclusively established the inadequacy of knowledge. This alarming situation requires urgent attention from all stakeholders. With the government rolling out a massive mission to eliminate SCD, the poor knowledge of healthcare workers is likely to serve as a major roadblock.

Keywords: Healthcare workers; Sickle cell disease; SCD patients

INTRODUCTION

Sickle Cell Disease (SCD) is a genetic, mono-mutational blood disorder of the hemoglobin molecule with autosomal recessive transmission and is associated with increased morbidity and mortality. It is one of the most common blood disorders prevalent worldwide, including India [1]. The global burden of SCD is increasing and requires well-designed public health planning [2]. The World Health Organization, (WHO) has recognized it as an important global public health problem in terms of mortality, morbidity, and socioeconomic impact [3]. With more than 300000 births per year in the world with SCD and approximately 50,000 births in India, it ranks second after Nigeria [4-6]. The incidence of abnormal genes varies from 0 to 40% in different pockets of the country. It significantly contributes to infant mortality, maternal mortality, and anaemia [7]. Sickle cell disease is responsible for the highest all-cause mortality; 50%-80% of homozygous sickle cell children in Africa die before the age of 5 [8-10].

Studies in the USA have indicated that appropriate interventions, such as screening and, intervention at a very

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early age with vaccinations, medical support, transfusions, and disease-specific modifications, lead to not only improvement in quality of life but also increased survival. It can prevent up to 70% of the deaths caused by SCD [3,11]. The interventions were conducted by the healthcare workers (HCW). Appropriate knowledge of care pathways is of the utmost importance in all medical interventions [12,13]. Limited knowledge among health professionals, despite the availability of treatment and standard treatment guidelines, is one of the major reasons for the poor performance of healthcare interventions, likely contributing to the high childhood mortality of 50%-90% in sub-Saharan Africa [14-19]. The disease is prevalent in the tribal population of India (104 million, 9% of the total population), and is classified as having a low socioeconomic status. Nearly ¾th of the abnormal sickle haemoglobin population belongs to the tribal group [20,21]. Gaps remain in context-specific knowledge for action in several parts, as well as evidence gaps across several health system building blocks, including governance and financing of care [22].

The government of India has rolled out multiple programs, the most recent of which is the National Sickle Cell Anaemia Elimination Mission 2023, aimed at early diagnosis, prevention, and reduction of morbidity and mortality [23]. The proposed program will be implemented with the involvement of healthcare workers in areas with higher prevalence. The delivery of information and patient care is influenced by the behavior of these professionals [24,25]. SCD related knowledge plays an important role in the successful implementation of national programs besides acute care, and professionals must be well-versed with the follow-up of these patients, including vaccination schedules, prophylactic transfusions, and special investigations such as brain MRI and cranial ultrasound. They should have adequate knowledge of hemoglobin electrophoresis. The prescription of hydroxyurea, the main disease-modifying agent, is crucial. One of the studies from tribal-dominated districts of India reported the inadequacy of SCD-related knowledge among HCW [26]. The lack of knowledge was related to both preventive activities and treatment. This study evaluated community and peripheral healthcare workers. Data on the knowledge of more skilled professionals such as nurses and physicians are lacking in the literature. This study was undertaken to assess the extent of knowledge of healthcare professionals about the treatment and management of SCD in various parts of India, including a few with a high prevalence of sickle cell disease and a few with a low prevalence of sickle cell disease.

MATERIAL AND METHODS

This was an observational cross-sectional study. This study was conducted among staff of the public healthcare system in various districts of India. Of the hospitals surveyed, some were in a high prevalence zone of sickle cell disease, and some had low sickle cell but high thalassemia prevalence.

Collecting qualitative data through survey forms and interviews remains a challenge and should be performed using validated instruments [27,28]. In this study, data were obtained using a slightly modified validated self-administered questionnaire adapted from Brazil [16,29]. The questionnaire was administered using a web tool and filled through a link. The questions were in a multiple-choice setup, and participants had to choose the best response for each question. The questionnaire comprised three sections:

- Socio-demographic data, including gender, education status, district of residence, professional category
- Place of health service, and number of years working
- The DFConhecimento instrument [29].

Multiple-choice questions were included regarding the disease, covering

- Newborn screening program,
- Sickle cell disease
- Sickle cell anemia genotype
- Sickle cell trait
- Clinical manifestation
- Acute events
- Conditions favoring red blood cell hemolysis
- Science of sickle cell disease
- Medications
- Prophylaxis
- Adolescence
- Pregnancy
- Prevention of leg ulcers. This instrument has been validated and used in multiple studies [16,30].

The instrument presents dimensions composed of items compatible with themes indicated as priorities for knowledge on sickle cell disease by health professionals (diagnosis, treatment, and prevention of complications).

The instrument scores were calculated with one being assigned for correct answer and zero for incorrect answer (0-13) for the 13 questions copied from the original instrument. To calculate the overall knowledge of SCD, the sum of all correct answers was calculated using the following knowledge score ranges: >7 (more than 54% accuracy) as good and ≤ 7 (54% or less accuracy) as poor. The analysis was also performed using the prevalent and non-prevalent zones. A prevalent zone refers to areas classified as having a high incidence of SCD, where a non-prevalent zone indicates areas where occasional cases could be seen.

The minimum number of enrolled participants was calculated using the following formula: $N=(Z\ \alpha\ 2\ (p \times q)/\Delta 2$. where Z α represents the level of confidence, p represents the probability of an HCW having good knowledge of SCD, q=1-p represents the probability of an HCW having inadequate knowledge of SCD, and L represents the margin of error. The values of Zα and Δ were 1.96 (95% CI) and 0.05, respectively. The values of p and q are both set to 0.5. We could not find a focused study of HCW on SCD in India; therefore, we took p as 0.5. Following this calculation, a minimum of 384 participants needed to be included in the study.

Data were analyzed using the Statistical Package-SPSS (version

11.0), Armonk, NY, USA. Continuous variables were summarized as median, mean, standard deviation, and minimum and maximum values. Categorical variables were described using percentages relative to all enrolled cohorts and were evaluated using the chi-square test. The qualitative variables-gender, education number of years working in healthcare, and type of healthcare service are summarized using absolute and relative frequencies. The scores obtained with the instrument are summarized as the mean and standard deviation.

Univariate binomial logistic regression analyses were performed to identify variables significantly associated with the level of knowledge, as measured by the estimated odds ratio (OR) with a 95% confidence interval (95% CI). Variables that showed a trend toward statistical significance were further analysed using a multivariate logistic regression model. Statistical significance was set at $p<0.05$. This study was approved by the hospital ethics and research committee as an overall program designed for sickle cell disease.

RESULTS

A total of 416 HCW participated in this survey. The median age of the participants was 34 years, and 190 (45.7%) were male. **Table 1** depicts the demographic characteristics of the participants. Of the total respondents, 43% were physicians (179/416), and 57% were nurses (237/416). Nearly 46% were from government run district hospitals, and rest were from other health facilities like medical colleges (7.7%), community health centers (10.3%), primary health centers (4.8%) (**Table 1**). 274 (65.8%) participants reported providing healthcare services to patients with SCD. 59 participants (14.2%) underwent SCD training. The majority had experience of working long-term in medical facilities-38.2% (159/416) had worked for more than 10 years. More than half of the surveyed (65.8%), were coming across patients with SCD.

Table 1: Baseline characteristics of healthcare workers on patients with SCD (n=416)

Characteristics	Number (Percentage) (%)
Median Age (SD)	34 (10)
Gender Male	190 (45.7)
Female	226 (54.3)
Education Graduate	315 (75.7)
Post graduate	101 (24.3)
Type of hospital	
Government	393 (94.5)
Private	23 (5.5)
Health professional	
Doctor	179 (43)
Nurse	237 (57)
Type of facility	
Primary Health Centre	20 (4.8)
Community Health Centre	43 (10.3)
District Hospital	190 (45.7)
Medical College	32 (7.7)
Others	131 (31.5)
Work experience (years)	
<3	131 (31.5)
3-6	87 (20.9)
7-9	39 (9.4)
>10	159 (38.2)
Do you see patients of SCD	
Yes	274 (65.8)
No	142 (34.2)
Have you received short term training on SCD	
Yes	59 (14.2)
No	357 (85.8)

On assessing the knowledge, 52 (12.5%) had good (adequate) knowledge and 364 (87.5%) had poor (inadequate) knowledge. In the prevalent zone, 14.7% of the HCW had adequate knowledge, and in the non-prevalent zone, only 2.6% had adequate knowledge. **Table 2** summarizes the overall mean knowledge based on the participant demographics. Male HCW, physicians, and HCW with postgraduate qualifications had higher knowledge scores than did male HCWs. No changes were attributable to SCD training in the overall group. Irrespective of their association with SCD, their knowledge levels were low and not significantly different (p=0.432). Higher education levels were associated with better knowledge scores (**Table 3**), such as number of years of experience (p=0.001).

Table 2: Analysis of overall knowledge based on the demographics and characteristics of the participants.

Variables	Mean (SD) total score of knowledge	p- value
Male	4.75 (2.98)	0.001
Female	3.49 (2.42)	
Doctors	5.3 (2.9)	0.001
Nurse	3.15 (2.29)	
Graduate	3.83(2.63)	0.023
Post graduate	5.12(3.05)	
Government institute	4.08 (2.8)	0.66
Private Institute	4.43 (2.69)	
Do you see patients of SCD	-	-
Yes	4.58 (2.75)	0.432
No	3.16 (2.6)	
Have you received short term training on SCD	-	-
Yes	5.32(2.86)	0.553
No	3.8 (2.73)	

Table 3: Distribution of adequacy of knowledge based on the demographics and characteristics of the participants

	Adequate Knowledge (%)	Inadequate Knowledge (%)	p-value
Male	37 (19.6)	152 (80.4)	0.01
Female	13 (5.8)	212 (94.2)	
Doctor	43 (24)	136 (76)	0.001
Nurse	9 (3.8)	228 (96.2)	
Government	49 (12.5)	344 (87.5)	1
Private	3 (13)	20 (87)	
Graduate	28 (8.9)	287 (91.1)	0.001
Post graduate	24 (23.8)	77 (76.2)	
Work experience (in years)	-	-	-
<3	9 (6.9)	122 (93.1)	0.001
3 to 6	9 (10.3)	78 (89.7)	
7 to 9	1(2.6)	38 (97.4)	
>10	33 (20.8)	126 (79.2)	
PHC	1 (5)	19 (95)	0.016
CHC	4(9.3)	39 (90.7)	
DH	32 (16.8)	158 (83.2)	
Medical College	7 (21.9)	25 (78.1)	
Others	8 (6.1)	123 (93.9)	
See patients of SCD	46 (16.8)	228 (83.2)	0.001
Don't see patients of SCD	6 (4.2)	136 (95.8)	
HCW received STT in SCD	14 (23.7)	45 (76.3)	0.005
HCW not received STT in SCD	38 (10.6)	319 (89.4)	
HCW practicing in prevalent areas.	50 (14.7)	290 (85.3)	0.002
HCW practicing in non-prevalent areas	2 (2.6)	74 (97.4)	

HCW- Healthcare workers, SCD- Sickle cell disease, STT- Short term training

On assessing the knowledge of individual questions, two questions about sickle cell disease were correctly answered by >50% of HCW. Knowledge about the diagnostic, treatment, and prevention aspects assessed by another questionnaire was inadequate **Table 4**.

Table 4: Response of individual questionnaire of DFConhecimento instrument by healthcare workers and stratified by HCW practicing in Prevalent and Non-prevalent zones

	Correct answer (%)	Prevalant areas (%)	Non prevalent areas (%)	p-value
Question-1	108 (26)	96 (28.2)	12 (15.8)	0.025
Question-2	213 (51.2)	176 (51.8)	37 (48.7)	0.67
Question-3	222 (53.4)	194 (57.1)	28 (36.8)	0.001
Question-4	100 (24)	91 (26.8)	9 (11.8)	0.006
Question-5	122 (29.3)	105 (30.9)	17 (22.4)	0.1411
Question-6	142 (34.1)	120 (35.3)	22 (28.9)	0.2911
Question-7	183 (44)	163 (47.9)	20 (26.3)	0.001
Question-8	117 (28.1)	105 (30.9)	12 (15.8)	0.008
Question-9	84 (20.2)	76 (22.4)	8 (10.5)	0.02
Question-10	129 (31)	110 (32.4)	19 (25)	0.21
Question-11	74 (17.8)	64 (18.8)	10 (13.2)	0.24
Question-12	95 (22.8)	82 (24.1)	13 (17.1)	0.188
Question-13	115 (27.6)	97 (28.5)	18 (23.7)	0.393

On univariate analysis, male sex (OR (95 CI)=3.97 (2.04-7.72)), doctors as HCW(OR (95 CI)=8.010 (3.787-16.943)), postgraduate educational status(OR (95 CI)=3.195 (1.753-5.824)), experience of >10 years ((OR (95 CI)=3.550 (1.631-7.729)), and healthcare workers who received short training in SCD (OR (95 CI)=(2.612 (1.313-5.195)) were associated with adequate knowledge. On multivariate analysis, doctors as healthcare workers (OR (95 CI)=4.891(2.174-11)) were associated with adequate knowledge, as depicted in **Table 5**.

Table 5: Univariate analysis and multivariate analysis of adequate knowledge of HCW on SCD

Knowledge of HCW	Univariate analysis		Multivariate analysis	
	OR (95 %CI)	p-value	OR (95 %CI)	p-value
Gender	-			
Male	3.97 (2.04- 7.72)	0.01	0.998(0.397-2.5)	0.996
Female	1			
Education	-			
Post graduate	3.195 (1.753- 5.824)	0.01	1.816 (0.914-3.60)	0.089
Graduate	1			
Healthcare worker	-			
Doctor	8.010 (3.787-16.943)	0.01	4.891(2.174- 11)	0.001
Nurse	1			
Institute	-			
Government Hospital Private Hospital	0.950 (0.272 -3.314)	0.935	-	-
Level of experience	-	-	-	-
< 3 years	1	0.364	1	
3-6 years	1.564(0.595- 4.112)	0.336	0.873 (0.305-2.49)	0.8
7-9 years	0.357 (0.044-2.907)	0.001	0.192(0.22-1.656)	0.13
≥ 10 years	3.550 (1.631- 7.729)		1.534(0.638-3.688)	0.33
HCW received training of SCD	2.612 (1.313- 5.195)	0.006	1.362(0.625-2.97)	0.437
HCW didn't received training of SCD	1			

DISCUSSION

Sickle cell disease in India is regarded as a significant target for the Indian healthcare system, with the launch of the National Sickle Cell Anemia Elimination Mission 2023 [31-34]. At this juncture, it is extremely important to analyze the knowledge of healthcare workers on sickle cell disease. The mission objective necessitates that healthcare workers be up-to-date, as they are important pivots of any health system.

SCD-related interventions, including investigations and disease-modifying treatments, have become easily accessible; however, their delivery remains challenging. The final goal can only be met through the involvement of multiple layers in society [35-40]. A scoping review of social determinants of health in sickle cell disease found that poor access to health care, stigma and discrimination, low educational attainment, and economic stability are all associated with poor medical outcomes [41].

HCW must have in-depth knowledge of all aspects of the disease [38,42]. Moreover, care must be delivered to the far-flung socially inequitable underserved population. HCW can play multiple important roles [43].

The country is divided into states and states into districts that host nodal hospitals, controlling all health activities. The staff of this hospital remains one of the most important factors in a country's health system. Sickle cell disease is not exclusively followed by specialists, every healthcare professional may have to follow any patient and provide inpatient admission for patients in need. Every healthcare provider encountering such patients is required to offer medical services. General medicine specialists and paediatric experts are available, but patients are attended to by the available healthcare workers and not by specialists. There may be dedicated day-care transfusion areas in a few district hospitals, but there are no dedicated in-patent facilities. In areas with a high prevalence of SCD, districts have dedicated registries for patients with SCD who offer free drug supplies.

In this study, we evaluated SCD knowledge using a validated questionnaire. Measuring the skills and knowledge is an important task. Creating an exact checklist for this type of qualitative research is challenging [28]. The DFConhecimento instrument has been validated and used by many investigators. We used the same method, adding a few small questions related to the local situation.

In the present study, we found a substantial lack of knowledge regarding SCD among healthcare workers in India. A study from India reported inadequate knowledge and management experience of health workers working in primary healthcare institutions and the community in tribal-dominated SCD-

endemic area [44]. Multiple studies across the world have tried to assess the knowledge of HCWs on sickle cell disease [16,44,45]. In a study from Tanzania, a good level of knowledge was observed in 25.1% of HCW [16]. A study from a developed country (US) reported that 78% of physicians did not display confidence in treating patients with sickle cells [45]. The level of knowledge in the present study was inferior to that in African countries. Furthermore, their knowledge was lower than that of healthcare workers in West Africa, particularly in the DRC and Nigeria, where 80% and 37.9% of healthcare workers, respectively, were found to have good knowledge of the nature of the disease, recognizable features, early SCD diagnosis, ideal timing for screening, and efforts to prevent SCD crisis [19,46]. The low level could be attributed to the low level of focus on sickle cell disease in previous years. This may be explained by the differential coverage of SCD in training curricula for health sciences, which is more extensive for medical practitioners than nurses, especially at the degree level and above [47].

Healthcare workers who are exposed to SCD have a slightly better knowledge of SCD. Similarly, prolonged exposure to medical practices has improved their knowledge. Similar to our results, a study from Africa recognized that HCW with less than six years in practice are also less likely to communicate about SCD results [48].

In our study, approximately 14% of HCW had undergone short-term training for SCD, but no difference was observed in their level of knowledge. In contrast, previous studies in the USA, Brazil, Nigeria, and Ghana have reported a significant influence of short course on SCD [47,49,50]. In the present study, the level of medical training was associated with a higher knowledge of SCD. Regarding professional qualifications, nurses fared worse in their understanding of SCD, with 96.2% having a poor score. Nurses are frontiers of healthcare delivery in districts, communities, and primary healthcare centers. Inadequate knowledge of nurses could be a significant barrier to sickle cell disease elimination program. However, participants with a Master's degree demonstrated better SCD knowledge. Similar to our observations, a study from Tanzania found a significant difference in knowledge based on variables such as duration since graduation, level of education, professional cadres, and years of practice. For example, participants who had graduated more than five years ago (84.2%), held a master's degree (69.2%), were clinicians (41.8%), and had more than 10 years of practice (25.1%) were more likely to have good knowledge (score>7). Conversely, all the certificate holders and a high percentage of nurses (93.9%) showed poor knowledge of SCD [16].

Community health workers, who are not a direct part of health department machinery but assist health care workers, are increasingly recognized as useful for improving health care and health outcomes in a variety of chronic conditions. Community health workers play a vital role in facilitating the continuum of care by acting as a bridge between community and health facilities. Community health workers can provide social support, navigation of health systems and resources, and counselling. The social and cultural alignment of community health workers with the population they serve is an important aspect of community health worker intervention. Community health worker interventions have been shown to improve patient-centered outcomes in underserved communities [43].

In India, traditional healers more prominently advocate tribal areas that play an important role in health care. Therefore, the role and importance of traditional healers should be recognized. Necessary education regarding SCD should be provided to the healers [26]. Such involvement and education will empower healers in appropriately guiding people with SCD.

There is a need to deeply analyze Indian sickle cell disease, which is likely to be different from African SS [14,15,51]. This may provide clues for early interventional strategies such as the adoption of vaccinations and various investigations.

There is an urgent need to design programs to train healthcare workers in SCD-prevalent tribal areas. The proper training of HCW will improve outcomes related to SCD, improve utilization of available services, improve care, and ultimately the quality of life of patients [13,52-54]. This would reduce morbidity and mortality and reduce the ultimate cost of health systems. The attitude of HCW also needs to be appropriately changed [55].

The major limitation of this study was that the analysis was based on a limited number of questions. A validated instrument was used, which includes many aspects but still has limited coverage.

The study has attempted to cover major aspects related to the knowledge of healthcare professionals on sickle cell disease and conclusively established the inadequacy of knowledge.

CONCLUSION

For the SCD mission to be successful, the focus should shift to the immediate time-bound training of HCW. As it is difficult to train each healthcare worker on care approaches, it is better to design a vertical model in which education and training are imparted to a selected healthcare worker, and patients are then directed to them. Training should involve two distinct targets: One should focus on general awareness and screening, and the other should focus on the care of diagnosed patients. Barriers to accessing healthcare through proper coordination and comprehensiveness should be focused on at all levels, from the primary to the tertiary level. Improvements in the knowledge of HCW are pivotal for the success of the Sickle cell elimination program. Proper management of training and meaningful participation of all stakeholders will possibly impart appropriate knowledge and skills to healthcare workers, which would ultimately lead to improvement in quality of life and reduction in morbidity and mortality of patients with sickle cell disease.

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AUTHORSHIP CONTRIBUTION

DP and GN were equally involved in the planning, designing, data collection, analysis, manuscript preparation and final review.

CONFLICTS OF INTEREST

Both the authors have no conflicts of interest to disclose.

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The study did not receive any funding.

DATA ACCESS

All relevant data are within the paper.

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