



Knowledge, awareness, and attitude of premarital screening with special focus on sickle cell disease: a study from Odisha

Basanta Kumar Bindhani¹ · Naorem Kiranmala Devi¹ · Jayanta Kumar Nayak²

Received: 29 January 2019 / Accepted: 10 June 2020 / Published online: 18 June 2020
© Springer-Verlag GmbH Germany, part of Springer Nature 2020

Abstract

Sickle cell disease (SCD) is a genetic disorder with an estimated 5200 live births each year indicating towards a major public health issue in India. Although SCD has been described in India in numerous ethnic groups, it is most prevalent in tribal community. Prevalence of sickle cell gene is 5 to 34% in tribal communities, who have a high prevalence of socioeconomic disadvantage and are frequently medically underserved. The objective of the present study is to explore the knowledge, awareness, and attitude of premarital genetic counseling and screening for sickle cell hemoglobin among individuals of Koraput district. A cross-sectional study design was employed and a total of 152 individuals were recruited using multistage sampling technique, including 43 individuals with sickle cell hemoglobinopathy. Data was collected using a pre-tested, self-administered questionnaire and analyzed using SPSS-20. Though people are aware of SCD and SCT, majority believe that sickle cell carriers transmit the disease and they do not know that marriage between sickle cell carriers need to be avoided.

Keywords Premarital counseling · Sickle cell disease · Knowledge · Attitude · Awareness

Introduction

Sickle cell disease (SCD) is one of the most common monogenic disorders globally with an autosomal recessive inheritance (Serjeant and Serjeant 1992). Homozygous sickle cell (SS) disease occurs in an estimated 312,000 births annually (McGann 2014), and all forms of sickle cell disease are likely to exceed 400,000 births annually in the world (Serjeant et al. 2017). SCD has a high prevalence in India, especially in the tribal populations, and poses a considerable health burden (Rao 1988; Jain et al. 2012). Although it is now well established that Orissa is at higher risk for sickle cell and thalassemia hemoglobinopathies, there is a lack of appropriate approach to initiate a large-scale population-based study with a dedicated genetic counseling aim (Mohanty and Das 2011). Koraput district is one of the underdeveloped districts of Odisha and predominantly inhabited by tribal people.

Moreover, earlier studies suggested a high prevalence of SCD in this district (Bindhani and Nayak 2018). Therefore, Koraput district was considered for the present study.

The objective of the present study is to explore the knowledge, awareness, and attitude of premarital genetic counseling and screening for sickle cell hemoglobin among individuals of Koraput district.

Materials and methods

A pilot survey was carried out in 2 villages of Koraput district of Odisha. Furthermore, snowball sampling method was used with the help of Anganwadi workers and villagers to identify other villages having a high number of SCD patients. Villages ($N = 7$) that were remote and where medical facilities were not easily accessible were finally chosen for the present study. In total, 9 villages were selected for the present study.

A descriptive cross-sectional study design was carried out among 152 individuals of both sexes (males = 70 and females = 82) and aged between 4 and 48 years, who were recruited by using a multistage purposive sampling technique. Of the total participants, 43 individuals were affected with SCD and remaining individuals were their family members and relatives. Also, a qualitative case study approach has been

✉ Basanta Kumar Bindhani
bkbanthro@gmail.com

¹ Department of Anthropology, University of Delhi, New Delhi 110007, India

² Department of Anthropology, Central University of Orissa, Koraput 763004, India

employed among 43 SCD-affected individuals, who were confirmed as sickle cell homozygous through their medical cards, in the age group of 4–18 in Koraput district of Odisha.

Data was collected using multidimensional interviews, and pre-tested and self-administered schedules. Based on the previous literature, scoring scales and schedules were developed and modified for the assessment of knowledge, awareness, and attitude. In this study, the overall average score of < 50% was considered as poor and $\geq 50\%$ considered as good. Data were analyzed using SPSS-20 software. Frequency distribution tables were constructed; cross-tabulations were done to examine the relationship between the categorical variables. All statistical analysis was set at 5% level of significance, $p \leq 0.05$ (i.e., 95% confidence level).

Results

The purpose of this study was to explore the knowledge, awareness, and attitude of premarital genetic counseling and screening for sickle cell hemoglobin among individuals of Koraput district. Of the 152 subjects recruited, 92.76% were heard about sickle cell anemia and 30.26% have indicated on hearing of premarital screening. Analysis to understand the extent of knowledge, awareness, and attitude towards premarital screening of various diseases which focused on sickle cell disease reveals that only 30% of the patients and their family members were aware of premarital screening for SCD. This analysis reveals that people are more aware of screening of SCD before marriage than screening after marriage; however, the percentage of the former category is not high (about 29%). Around 32% of the total subjects believed that premarital screening is not only for SCD but also for other various diseases, whereas 10% of them believed that premarital screening is exclusively for SCD. About 58% of them have no idea or opinion on the premarital screening of diseases. Regarding diseases other than SCD, the majority of the participants were aware of HIV (almost 40%), and both HIV and hepatitis (about 44%). Almost 60% of the individuals believed that premarital screening can prevent SCD; however, 31% did not have any opinion. Concerning the premarital screening in the prevention of SCD, 90% have the opinion that carriers cannot transfer the disease and 80% believed that sickle cell screening knowledge helps in avoiding incompatible partners.

Though the majority of them are aware of disease and trait, 100% of them are not aware of disease on genetic level, i.e., none of them knows their genotypes. Also, the present study found that only about 7% of the married respondents have been tested for any disease before marriage. About 33% of the SCD patients relied on traditional medicine, and about 42% relied on both traditional and allopathic, whereas only about 26% depends upon allopathic (Table 1).

Also, this study found that the overall good knowledge, attitude, and awareness among patients (72.09%) is significantly higher than their family members (33.9%) ($p < 0.001$) (Table 2).

Discussion

Based on the findings, it is evident that many individuals still lack good knowledge, attitude, and awareness concerning premarital screening and SCD in the studied area. Many shortcomings have been addressed in all three aspects. Although most of the participants in this study have heard about SCD (about 93%), the majority (about 70%) of them were unaware of premarital screening. This corroborates with findings of earlier studies (Al-Qattan et al. 2019; Bindhani and Nayak 2018).

The present study found that all the participants (100%) are not aware of their hemoglobin genotypes. Similar studies have reported that more than half of married couples enter into marriage unaware of their hemoglobin genotypes (Odunvbun et al. 2008; Acharya et al. 2009; Ameade et al. 2015). The findings reveal that more than 50% of the participants reported that the decision of marriage rests upon their family members and community regardless of their sickle cell hemoglobin status. Almost 30% of the individuals had a strong opinion that sickle cell carriers should not marry each other. About 88% of the participants believed that the government should prohibit marriage between incompatible couples. This supports with findings of previous studies (Mason et al. 2016; Ugwu 2016). Only 2.63% disagree with the statement that the government should prohibit marriage between incompatible couples, out of which some believed that subjecting self to genetic counseling before marriage demonstrated a lack of faith in God. This is similar to the findings reported from other studies where the majority of the respondents correctly believed that sickle cell was inherited from parents rather than from any supernatural phenomena (Olakunle et al. 2013; Treadwell et al. 2006). Out of 109 married respondents, the majority (92.89%) of the recruited participants have not tested for the disease before marriage. And 58% of the total participants showed a positive attitude of the fact that they will go for sickle cell screening, which corroborates with previous studies (Ugwu 2016; Al-Farsi et al. 2014). This study also reveals that continuous and extensive hospitalizations and health care services, and inconsistent insurance coverage were major factors of economic burdens for the families of SCD patients. Similar findings based on the economic burdens of SCD patients to the family were also reported (Olatunya et al. 2015; Adegoke et al. 2014). The present data explores that 32.56% and 41.86% of the subject depends on traditional medical practice and both traditional and allopathic respectively. According to

Table 1 Sex-wise distribution of assessment of knowledge, awareness, and attitude of premarital screening

Queries	Total (N= 152)		Male (N= 70)		Female (N= 82)		p value
	No.	(%)	No.	(%)	No.	(%)	
Have you ever heard of sickle cell anemia?							
Yes	141	92.76	65	92.86	76	65.00	0.96
No	11	7.24	5	7.14	6	5.00	
Have you ever heard of premarital screening?							
Yes	46	30.26	22	31.43	24	29.27	0.63
No	106	69.74	48	68.57	62	75.61	
Premarital screening is							
Screening for relevant diseases before marriage	44	28.95	21	30	23	28.05	0.77
Screening for relevant diseases after marriage	15	9.87	8	11.43	7	8.54	
Do not know	93	61.18	41	58.57	52	63.41	
Do you think premarital screening is only for SCD?							
Yes	16	10.53	8	11.43	8	9.76	0.17
No	48	31.58	27	38.57	21	25.61	
Do not know	88	57.89	35	50.00	53	64.63	
If not for SCD, which other diseases (N= 48)?							
HIV	19	39.58	13	46.43	6	30	0.95
Hepatitis	0	0	0	0	0	0	
Ebola	0	0	0	0	0	0	
HIV and hepatitis	21	43.75	12	42.86	9	45	
HIV and Ebola	0	0	0	0	0	0	
Ebola and hepatitis	0	0	0	0	0	0	
HIV, hepatitis, and Ebola	0	0	0	0	0	0	
Do not know	8	16.67	3	10.71	5	25	
Do you think premarital screening helps in the prevention of SCD?							
Yes	90	59.21	44	62.86	46	56.10	0.64
No	15	9.87	7	10.00	8	9.76	
Do not know	47	30.92	19	27.14	28	34.15	
How does premarital screening helps in the prevention of SCD? (N= 90; male = 44 and female = 46)							
Knowing status helps in avoiding incompatible partner (N= 90)	75	83.33	38	86.36	37	80.43	0.70
Determine ones Hb status (N= 90)	41	45.56	23	52.27	18	39.13	
Carriers cannot transmit disease (N= 90)	81	90.00	41	93.18	40	86.96	
Others (N= 90)	17	18.89	11	25.00	6	13.04	
Do you know your hemoglobin genotype?							
Yes	0	0	0	0	0	0	1.00
No	152	100	70	100	82	100	
Would you screen yourself and your partner before marriage? (including married respondents)							
Yes (for both)	87	57.24	42	60	45	54.88	0.57
No	29	19.08	15	21.43	14	17.07	
Myself only	19	12.50	7	10.00	12	14.63	
My partner only	17	11.18	6	8.57	11	13.41	
Why not your partner? (N= 36)							
Community are not informed	15	41.67	5	38.46	10	43.48	0.69
He/she may not understand	2	5.56	2	15.38	0	0.00	
He/she will do his/her own	14	38.89	5	38.46	9	39.13	
Others	5	13.89	1	7.69	4	17.39	
Would you encourage others to screen for SCD?							
Yes	125	82.24	58	82.86	67	81.71	0.85
No	27	17.76	12	17.14	15	18.29	
If you and your partner are AS, would you go ahead with your marriage							
For sure we will	11	7.24	3	4.29	8	9.76	0.71

Table 1 (continued)

Queries	Total (N = 152)		Male (N = 70)		Female (N = 82)		p value
	No.	(%)	No.	(%)	No.	(%)	
We will never	43	28.29	22	31.43	21	25.61	
We may	16	10.53	6	8.57	10	12.20	
Not known	82	53.95	39	55.71	43	52.44	
Do you think the government should prohibit marriage between incompatible couple?							
Yes	133	87.5	64	91.43	69	84.15	0.36
No	4	2.63	0	0.00	4	4.88	
Do not know	15	9.87	6	8.57	9	10.98	
Have you been tested for any disease before marriage? (N = 109 for married respondents only, male = 52 and female = 57)							
Yes	8	7.34	4	7.69	4	7.02	0.89
No	101	92.66	48	92.31	53	92.98	
Screened for which disease/s? (N = 12)							
SCD	5	62.5	3	75	2	50	0.94
HIV	0	0	0	0	0	0	
Hepatitis	0	0	0	0	0	0	
HIV and SCD	0	0	0	0	0	0	
HIV and hepatitis	0	0	0	0	0	0	
HIV, hepatitis, and SCD	1	12.5	1	25	0	0	
Do not know	2	25	0	0	2	50	
Which type of medicine did you use? (N = 43; male = 19, female = 24)							
Traditional/desi	14	32.56	7	36.84	7	29.17	0.82
Allopathic	11	25.58	5	26.32	6	25.00	
Both traditional/desi and allopathic	18	41.86	7	36.84	11	45.83	

them, traditional medicines are low cost and effective, and hence, they were more inclined towards it.

The understanding level is significantly higher among SCD-affected individuals than their family members and relatives ($p < 0.001$). This indicates that patients themselves were much aware of the disease during the process of diagnosis. Furthermore, educational level is also found to be positively associated with the knowledge, awareness, and attitude towards premarital screening. All other variables were not significantly different from each other ($p > 0.05$). Despite poor knowledge of SCD among the subjects, the majority (82.24%) agreed to encourage others to screen for SCD. In other words, the participants exhibited a high level of acceptability for premarital screening, genetic counseling, and mandatory implementation of screening programs by the government. This shows the understanding of the potential importance and

benefits of premarital screening as a preventive measure to control SCD, which also supports earlier findings (Laskey et al. 2003). In general, most of the participants showed a positive attitude towards premarital screening for sickle cell hemoglobinopathy indicating the work of earlier studies (Olatona et al. 2012; Ameade et al. 2015).

Conclusion and suggestions

Despite various government-funded screening and counseling programs, there appeared to be the awareness, the socio-economic, and the biological burdens of SCD are not widely known to the communities where the prevalence of sickle cell hemoglobinopathy is high. In developing countries like India where the illiteracy rate is high and cultural norms are stronger, just screening and counseling may not be very effective in reducing the burden of SCD. Further research and awareness programs regarding genetic diseases specifically in terms of SCD should be initiated.

Compliance with ethical standards

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with comparable ethical standards.

Table 2 Graded score for knowledge, attitude, and awareness of the patients and their family members

Score	Patients (N = 43)		Family members (N = 109)		p value
	No.	%	No.	%	
Poor	12	27.91	72	66.06	< 0.001
Good	31	72.09	37	33.94	

Conflict of interest The authors declare that they have no conflict of interest.

References

- Acharya K, Lang CW, Ross LF (2009) A pilot study to explore knowledge, attitudes, and beliefs about sickle cell trait and disease. *J Natl Med Assoc* 101(11):1163–1172
- Adegoke SA, Abioye-Kuteyi EA, Orji EO (2014) The rate and cost of hospitalisation in children with sickle cell anaemia and its implications in a developing economy. *Afr Health Sci* 14(2):475–480
- Al-Farsi OA, Al-Farsi YM, Gupta I, Ouhtit A, Al-Farsi KS, Al-Adawi S (2014) A study on knowledge, attitude, and practice towards premarital carrier screening among adults attending primary healthcare centers in a region in Oman. *BMC Public Health* 14(1):380
- Al-Qattan HM, Amlih DF, Sirajuddin FS, Alhuzaimi DI, Alageel MS, Bin Tuwaim RM, Al Qahtani FH (2019) Quantifying the levels of knowledge, attitude, and practice associated with sickle cell disease and premarital genetic counseling in 350 Saudi adults. *Adv Hematol*:2019
- Ameade EPK, Mohammed BS, Helegbe GK, & Yakubu S (2015) Sickle cell gene transmission: do public servants in Tamale, Ghana have the right knowledge and attitude to curb it?
- Bindhani BK, & Nayak JK (2018) Quality of life among individuals with sickle cell disease: a study from Koraput district, Odisha
- Jain DL, Sarathi V, Upadhye D, Gulhane R, Nadkarni AH, Ghosh K, Colah RB (2012) Newborn screening shows a high incidence of sickle cell anemia in Central India. *Hemoglobin* 36(4):316–322
- Laskey SL, Williams J, Pierre-Louis J, O’riordan M, Matthews A, Robin NH (2003) Attitudes of African American premedical students toward genetic testing and screening. *Genet Med* 5(1):49–54
- Mason K, Gibson F, Gardner RA, Serjeant B, Serjeant GR (2016) Prevention of sickle cell disease: observations on females with the sickle cell trait from the Manchester project, Jamaica. *J Community Genet* 7(2):127–132
- McGann PT (2014) Sickle cell anemia: an underappreciated and undressed contributor to global childhood mortality. *J Pediatr* 165(1):18–22
- Mohanty D, Das K (2011) Genetic counselling in tribals in India. *Indian J Med Res* 134(4):561
- Odunvbun ME, Okolo AA, Rahimy CM (2008) Knowledge of sickle cell disease among parturiant mothers in Benin City and their attitude to newborn screening. *Ann Biomed Sci* 7(1–2)
- Olakunle OS, Kenneth E, Olakekan AW, Adenike OB (2013) Knowledge and attitude of secondary school students in Jos, Nigeria on sickle cell disease. *Pan African Med J* 15(1)
- Olatona FA, Odeyemi KA, Onajole AT, Asuzu MC (2012) Effects of health education on knowledge and attitude of youth corps members to sickle cell disease and its screening in Lagos state. *J Community Med Health Educ* 2(7):163
- Olatunya OS, Ogundare EO, Fadare JO, Oluwayemi IO, Agaja OT, Adeyefa BS, Aderiye O (2015) The financial burden of sickle cell disease on households in Ekiti, Southwest Nigeria. *ClinicoEconomics Outcomes Res* 7:545
- Rao VR (1988) Genetics and epidemiology of sickle cell anemia in India. *Indian J Med Sci* 42(9):218–222
- Serjeant GR, Serjeant BE (1992) Sickle cell disease, vol 3. Oxford university press, New York
- Serjeant GR, Serjeant BE, Mason KP, Gibson F, Gardner R, Warren L, Jonker M (2017) Voluntary premarital screening to prevent sickle cell disease in Jamaica: does it work? *J Community Genet* 8(2):133–139
- Treadwell MJ, McClough L, Vichinsky E (2006) Using qualitative and quantitative strategies to evaluate knowledge and perceptions about sickle cell disease and sickle cell trait. *J Natl Med Assoc* 98(5):704–710
- Ugwu NI (2016) Pre-marital screening for sickle cell haemoglobin and genetic counseling: awareness and acceptability among undergraduate students of a Nigerian University. *Int J Med Biomed Res* 5(1):43–49

Publisher’s note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.