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Knowledge, Attitude, and Health Care Practices of Sickle Cell Patients

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ABSTRACT

Background: Sickle cell disorders are the most common single genomic disorder among people all over the world. According to the World Health Organization, 5% of the world's population has genetic abnormalities, with sickle cell disease accounting for 1-44 percentage of the population in India. Sickle cell disease (SCD) is noted for its painful crises, which usually require hospitalization. Organ failures, leg ulcers, priapism, and vision-related issues like retinopathy among other things, are common among SCD patients.

Objective: To elucidate the factors those contribute to people's ignorance of SCD and the consequences of it among SCD patients and their family members. The impacts of culture and belief systems on health care practices of SCD patients.

Area and people: The study was conducted in the five villages of Nandahandi Block and Nabarangpur Block of Nabarangpur District, Odisha, India. The study population was heterogeneous in nature includes General (UR), Scheduled Caste (SC) and Other Backward Caste (OBC). All the participants belonged to Christian and Hindu community.

Methods and Material: This is a cross-sectional study. The study is an interview based on 45 respondents. The research tools were Household survey and research schedule. The interview schedule included the self-prepared questions according to the objectives of the study. SPSS and Microsoft Excel software were used for statistical analysis

Results: Unawareness on SCD has been increasing the ambiguity of SCD patients and social problems are found to be common among them.

Conclusions: The social problems of SCD patients are proportional to the unawareness of the common people. SCD can be preventable by changing public purviews with the help of proper medical guidance.

Key-words: Sickle Cell Disease (SCD), awareness, health care practice

I. INTRODUCTION

Worldwide sickle cell disorders are found to be the most widely spread single genomic disorders among people. According to the World Health Organisation, 5% of the world population carries genomic disorders and, in India, the prevalence rate of sickle cell is found to be 1-44% [1]. Sickle cell disease (SCD) is known for its painful crisis which causes the patients to be hospitalized frequently. Often the organ failures, leg ulcers, vision-related problems like retinopathy, and priapism, etc. are commonly found among SCD patients [2].

SCD is caused by the abnormal shape of the haemoglobin, which causes frequent acute pain episodes and leads to several other health problems such as organ failures is one of them. This disease is found usually in the Mediterranean countries such as Turkey, Greece, and Italy; Sub-Saharan Africa, South America, Cuba, Central America, Saudi Arabia, and India. Migration played a crucial role in spreading SCD across the globe [3]. Since time immemorial migration is also seen among the Indian population and the practice of inbreeding prevailed in all the religious groups' in terms of cultural and regional contexts [4,[5]. The origin history of sickle cell disease in India roots back to 1952, reported by Dunlop KJ and Mazumder UK. It is first observed in Assam among the migrant labourers of Bihar and Odisha [3].

In the case of SCD the crucial factors, people need to be aware of such as early detection, neonatal screening, health education, counselling, consanguinity and endogamy, healthy lifestyles, and uplifting their quality of life by improving their economic condition [6]. The carriers of SCD are normal and healthy [7]. But, the anaemic conditions of the patients due to SCD leads the patients to many infectious diseases throughout their lives, and that increases the mortality and morbidity rate [8].

The literatures indicate that in the study area there is a need for research on awareness issues and health care practices. Because the study area is accommodated with illiteracy, low-income rate, unemployment, and inadequate amount health care facilities. The people of the study area need awareness about the disease; presently there is no possible cure for it, so the better way is prevention. Due to the lack of knowledge about the disease, the sickling patients are also lacking knowledge on the proper health care practices.

Objectives: To elucidate the factors those contribute to people's ignorance of sickle cell disease and the consequences of it among SCD patients and their family members. The impacts of culture and belief systems on health care practices of SCD patients.

II. MATERIALS & METHODS

This is a cross-sectional study. After the consent of the Pondicherry University and District Headquarter Hospital of Nabarangpur the fieldwork carried out. The District Headquarter Hospital of Nabarangpur stores the data of SCD patients from all over the district; the data retrieved with permission from the authorities. Lists of SCD prone zones identified and five villages selected from the list. A separate list of 45 SCD patients selected randomly from the list and all participants came under the age group of 1 year to 45 years. The research tools include Household survey and research schedule. The household survey included the basic amenities of a house, their occupation, and other personal details. The researcher personally met the patients for the interviews. The interview schedule included the self-prepared questions according to the objectives of the study. An informal group discussion carried out with the patients and with their family members for rapport building. The respondents thoroughly interviewed after the rapport building with their family members. When it comes to children their parents interviewed as their caretakers. The secondary methods of data collection included the medical report, census report, libraries, and online data. SPSS software and Microsoft Excel software used for analysis of the data.

III. RESULTS

Findings	Frequency	Percentage
Total Population	45	100%
Males	28	62%
Females	17	38%
General Category (affected)	34	74%
Other Below Caste (affected)	10	22%
Schedule Caste (affected)	1	2%
Christian Community	41	91%
Hindu Community	4	9%
Unmarried	30	67%
Married	15	33%
Primary Level Education	17	38%
Secondary Level Education	17	38%
Higher Education	9	20%
Unemployed	14	31%
Students	13	29%
Basic Knowledge Of SCD	30	67%
No Idea About Causes Of SCD	27	60%
Diagnosed in the Infancy Period	10	22%
Diagnosed in the Early Childhood	6	13%
Diagnosed in the Middle Childhood	6	13%
Diagnosed in the Adulthood	5	11%
Diagnosed in the Adolescence Period	18	40%
Family History Of SCD	20	44%

No Family History Of SCD	25	56%
Families Undergone SCD Screening	32	71%
Did not do Screening	13	29%
Practise Consanguineous Marriage	26	58%
Do not Practise Consanguineous Marriages	19	42%
Could be Curable	16	36%
Cannot be Curable	22	49%
Biased About Cure	7	16%
Consanguineous Marriages is Cultural Practice	23	51%
Biased on Consanguineous Marriages	3	7%
Preventable	35	78%
Biased on Prevention	7	16%
Prevention Is Not Possible	3	7%
Careful towards their Lifestyles after diagnosis	21	47%
Normal Lifestyles after diagnosis	13	29%
Felt Isolated after diagnosis	11	24%
SCD is most Common Health Problem	43	96%
Other kinds of Treatments	12	27%
Use Allopathic Medicines	33	73%
No Side Effects	42	93%
Seek advice from the Medical	44	98%
Advice on Food Habits and Preventive Lifestyles	25	56%
Prevention is not Possible	3	7%
Preventable by Careful towards Food Habits	8	29%
No Idea On Prevention	11	39%

IV. DISCUSSION

Infectious diseases are very common among SCD patients due to their weak immune systems. The incidence of infectious disease is lower in countries where resources are abundant and the quality of life is higher, whereas resource-poor regions suffer the most from SCD [9]. According to the respondents in the study area, the common infectious health problems are malaria, typhoid, and diarrhoea. Tuberculosis, paralysis, hypertension, and jaundice are found among people. The study area is prone to SCD, 96% of respondents have opinions of it.

There are several (four) types of sickle cell disease, it is complicated to understand the several types of the disease but for the convenience of common people, we divide it into sickle cell patients and sickle cell carriers. So basically it can be said that it is of two types. The majority (67%) of the respondents have precise knowledge in terms of basic knowledge about SCD such as names and types of SCD. The biased respondents are who know only about the genetic disease in terms of the genetic disease stays in the family for generations, but they lack knowledge on how it spreads among relatives, and how it spread across the population.

The unawareness among the people, absence of proper medical equipment, and inadequate or poor quality research, and the lethargic attitude of the health care system towards spreading the awareness among the people makes the SCD a serious challenge; it affects the public purviews regarding SCD and many communities go unreported. There is no report that people are eagerly going with the medical follow-ups [10,[11]. The school children can be made aware of SCD from the early adolescent period along with the implementations of periodic screenings, prenatal diagnosis, premarital counselling, therapies, haemoglobin tests, vaccinations, and encourage them to adopt prophylactic measures in their lives [11,[12,[13].

Out of the total respondents, 98% showed willingness towards medical advice. It could have been helpful if the health workers such as the ‘Asha Karmis’ and the ‘Anganwadis’ were proactive in their responsibilities towards spreading the awareness regarding SCD. The respondents are not backing away to try different kinds of medicines such as Ayurveda, Ethno-medicines, and Homeopathy along with allopathic treatments. 93% of respondents have no side effects of the medicines whether it is Allopathic, Homeopathic, Ayurveda, or Ethno-medicines. Those who have used different kinds of medicines have found that allopathic medicines are the best in terms of treatment compared to other medicine. Every kinds of treatment such as Ayurveda, Homeopathy, Ethno-medicines, or Allopathic treatment has its advantages; sometimes what the allopathic treatment can not cure that can be cured by other methods of treatment. But at the same time, one cannot ignore that Allopathic treatment has done remarkable progress in the case of treatment especially during the

crises of sickling patients [14,[15]. Blood transfusion is proven to be significant in maintaining the haemoglobin level in blood in SCD patients; however, the use of indigenous medicines has proven to be effective in reducing the frequency of blood transfusion [16]. Taking more than one kind of medication needs strict medical attention and there need proper studies to attain this purpose.

The factors such as consanguineous marriage, the disease forms, and traits forms of the SCD are some of the important factors people should be aware of to prevent the spread of the disease. That implies the respondents are lacking adequate knowledge of SCD. The territorial endogamy and the marriage among blood relatives are quite common among some communities in Odisha due to the socioeconomic and property incentives. In the western and southern pockets of Odisha; SC (Schedule Caste), ST (Schedule Tribe), OBC (Other Backward Caste), and general categories of people practice the consanguineous marriages for various reasons; which is severely increasing the homozygosis frequencies for SCD in those regions [17]. It results in forming genetically isolated groups and increases the homozygosis among the people which is quite inevitable due to the lack of demographic data on genetic homozygosis. It encourages inbreeding and favours the genetic loads or homozygosis; the SCD is an autosomal recessive disorder and the chances of getting SCD increases when a genetically homozygous couple reproduces [18,[19]. Even if the population is large and the mating is random, but inbreeding could take place if the large population is following the consanguineous marriage practice for a long time; this way the population is susceptible to SCD [10,[19]. The consanguineous marriage practice is very common in the study area. The people of the study area are unaware of the way SCD spreads across the population in a community. People are not sure whether the members of their family are the carrier of the disease or not. This situation is being an obstacle for the people in terms of precaution measures of the disease. This makes the community vulnerable in tackling the disease.

In general, SCD is termed incurable, but it is highly preventable. The doctors advise that the early diagnosis of this disease makes the sickling patients live normally and the people who have late diagnoses suffer the most. 78% of respondents agreed upon that the SCD can be preventable; regarding prevention, the respondents have various opinions. The majority of the people are concerned with their food habits, lifestyles, and medical check-ups.

There are some superstitions on food habits in society; food habits do not cause SCD, but it happens due to genetic mutation or alteration of the genetic composition at the molecular level. SCD is not confined to lower castes, tribes, or higher castes, but it is prevailing across the consanguineous population who has a history of SCD in previous generations [10]. More than half of the respondents are found to be misguided or have vague ideas regarding the cure of SCD. Consanguineous marriage has been a serious issue in the study area, 58% of respondents are agreed upon that they are marrying among their relatives. The provoking reason for the consanguineous marriage has been the cultural beliefs of family bonding through the marriages; as 51% respondents are the opinions of this. After the diagnosis of SCD, social stigma was experienced by the respondents, as 24% of respondents felt isolated. The genetic disease comes with the burden of social stigma along with it, the sickling patients feel it as shame to be an SCD patient and they are hesitant to disclose their identity as a sickling patient [20]. Stigma due to SCD is there in society, one cannot simply overlook it. Unawareness creates the vacuum of uncertainty further psychologically as well as culturally among the SCD patients. Therefore, social stigma is very common among SCD patients [21].

The family members of 29% of respondents' have not been screened despite knowing one of their family members has been suffering from SCD. A total of 40% of the respondents have been diagnosed in their adolescent period. Accessing health care facilities, healthy foods, or other amenities regarding SCD requires healthy earnings. Studies show that when it comes to crises or hospitalization due to SCD, the burden of monetary expenses tends to exploit the people. Illiterate and unaware people suffer more in terms of exploitation and discrimination which further push down their quality of life [12]. The spreading of SCD, awareness and preventive measures correlates with belief systems, education, income, misinformation, ignorance, ineffective treatment, myths, exploitation, discrimination, frustration, and social stigma [15,[21,[22]. According to medical science human beings' perception, culture, and belief system should be considered first before explaining human beings as anatomical and physiological beings [15]. The people of rural areas in India have their specific kind of health care systems and the health care practices of the people are largely influenced by cultural factors such as their religious beliefs, customs, or ethics, etc. These beliefs largely defy the behaviours of the people in terms of the treatments they want to follow [12,[23]. The people are out of dismayed opting for something new for the cure of SCD [12]. The desperation of the people makes them believe that the sorcerer or the tribal medicine man has the power to connect with the supernatural force of nature for the

healing of various diseases. Unaware and illiterate people often follow sorcerers with the hope to get cure for SCD. Usually, in rural areas of India, these kinds of practices still is prevailing [24].

The therapeutic properties of herbal medications were identified and had been widely used long before the advent of modern Allopathic treatment. In terms of affordability, cultural practice, beneficial properties, and easy accessibility it was also reliable among people for a long time especially in India and used widely across the globe [15,[25,[26]. Looking at all these beneficial nature of the indigenous medicines; proper steps should be taken to study the combined use of modern and indigenous medicines [15]. The study was not confined to a particular age group; rather all sets of age groups have been included. Prospects for the future research of SCD can be based on a particular gender and age group.

Conflicts of Interest- None declared.

V. CONCLUSION

Human beings are simply not just physical beings, the cultures, and beliefs are equally important when defining human beings. The health care practices of humans are affected by their feelings and belief systems; so for the betterment of society, awareness should be spread not only regarding SCD but also for eradicating the superstitious beliefs that come along with the disease. Consanguineous marriage is an important aspect when it comes to prevention, but demographic analysis in terms of genes is needed for the communities to prevent the genetic loads. The demographic analysis would make people aware of their genetic status briefly. All the traditional medicines do not have side effects for SCD, so proper studies should be carried out to implement those medicines along with the Allopathic medicines. The interlinked social problems due to SCD like discriminations, exploitations, and stigmatization of SCD should be eradicated for a healthy society. SCD is an expensive disease to handle; monetary assistance is needed or exempts the medical expenses for the SCD sufferers. In the end, the government should take proper steps from the grassroots level.

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