# EXPLORATORY ASSESSMENT OF TREATMENT CHALLENGES AND SOCIAL BURDEN AMONG SICKLE CELL ANEMIA PATIENTS IN DURG DISTRICT, CHHATTISGARH

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## ABSTRACT
*Sickle cell anemia (SCA) is highly prevalent in central India and is associated with significant morbidity, frequent health-care utilization, and social constraints. Evidence from district-level settings on barriers to care, treatment adherence, and social burden remains limited. In this study we conducted pilot study at Pandurang Ramarao Dongaokar District Hospital Durg, (c.g.) Date on 04/01/2025 at morning time, sample size was 5. This research projects aim was to identify challenges in access to treatment, social issues, adherence to treatment and complications and to associate selected socio-demographic variables with the challenges in access to treatment, social issues, adherence to treatment and complications we conducted main study on 29/04/2025 at morning time at Pandurang Ramarao Dongaokar District Hospital Durg, (c.g.) This study found that there is significant relationship between frequency of hospitalization and gender.86.67% was on regular treatment, 36.67% patients have more than one symptom (including joint pain, headache blurring of vision, dyspnea etc.*

***Keywords**: Sickle cell anemia; treatment access; adherence; complications; stigma; social burden.*

## INTRODUCTION
Sickle cell disease is an inherited disorder of hemoglobin, characterized by formation of long chains of hemoglobin when deoxygenated within capillary beds, resulting in sickle shaped red blood cells. This disease occurs when a person inherits two abnormal copies of the beta globin gene that make hemoglobin, one from each parent. The gene occurs in chromosome 11.

An estimated 3,00,000infants are born annually world-wide with sickle cell disease. Most individual with sickle cell disease live in Sub-saharan Africa, India, mediterranean and middle-east. As of 2015, about 4.4 million people have sickle cell disease while an additional 43 million have sickle cell trait. About 80% of sickle cell cases believed to occur in Sub-saharan Africa. In 2015, it resulted in about 4800 deaths. According to world Health Organization(WHO), 3,00,000 to 4,00,000 children are born with sickle cell anemia every year and it is established that 50-90% children will not survive to adulthood. Sickle cell disease affects approximately 2.3% of the population of India, with higher rate in certain communities. In India sickle cell disease is mainly restricted to tribal and schedule caste population where carrier frequency ranges between 5-40%.

In Chhattisgarh, high frequency of sickle cell gene has been reported. In Rajnandgaon as well as in Durg district prevalence of sickle cell gene was found 9.15% & 8.88% respectively. Highest percentage of sickle cell was reported from Sahu community (12. 34%).

Chances of getting complications from sickle cell anemia are- Anemia (80-90%), Infections (50-70%), kidney damage (20-30%), stroke (5-10%), chronic pain (50-

70%), Osteoporosis (10-20%), delayed growth and development (20-30%) and increase risk of mortality (1-5%).

**Need for the study**

The tribal population of India, as per 2011 census, is 10.43 crore, constituting 8.6%of the total population. Despite of the highest population of indigenous people in India, there is a very little and scattered knowledge about the actual burden and frequency distribution pattern of disease in this underprivileged group of the society.

In the state of Chhattisgarh, where 30% of the total population is contributed by indigenous people, there are limited studies with large scale as per study done by Lad H et all (2022). Twelve districts in Chhattisgarh falls into sickle cell of the state, the sickle cell trait prevalence was more than 10% in Abhujmaria, Gond, Halba tribes and Ghasia, mahar and Ganda Schedule caste communities in Chhattisgarh.

**Problem Statement**

An exploratory study to assess the challenges in access to treatment, social issues, complications and adherence to treatment among patients with sickle cell anemia attending medical OPD at Pandurang Ramarao Dongaokar District Hospital Durg, (C.G.).

**Objectives**

1. To assess the challenges in access to care, social issues, complications and adherence to treatment among sickle cell anemia patient.
2. To associate the selected socio-demographic variables with the challenges access to treatment, social issues, complications and adherence to treatment

## LITERATURE REVIEW

**Sani A.H. et al (September, 2024)** stated that this study aimed aimed to assess the socioeconomic impact of sickle cell disease on families of patients receiving care at the SCD clinic of Aminu Kano teaching hospital in Kano, northwest Nigeria. The research adopted a descriptive cross-sectional approach, involving the participants of 273 individuals selected through a multi-stage sampling method. Data was gathered using semi-structured interviews. The study achieved a 100 % response rate with 84% of the participants being female and a significant proportions (79.9 %) reported a monthly income of thirty thousand naira or less. The findings of the study revealed that SCD had a notable social impact, affecting 93.5 % of participants and 5.8 % most of the time. Furthermore substantial financial burden was experienced by 54.2 % of respondents most of the time and 45.1 % occasionally.

**Adigwe O. P. (Feb, 2023)** stated that sickle cell disease is a genetic disorder with its higher prevalence in Nigeria. This study aimed at assessing views of health practitioners in Nigeria on policies and practices in the area of access to health care services for sickle cell disease. A cross-sectional study was undertaken amongst health care professionals in Nigeria. Data were collected using a self-administered questionnaire. A significant proportion of participants (42.8%) disagreed that relevant legislative framework exists to facilitate optimal access to high quality health care services for persons with sickle cell disorder in Nigeria. two –thirds of the study cohort were of the opinion that public health surveillance towards sickle cell disease was sub optimal (61.2%). Also, more than three – quarters of the respondents (78.7%) indicated that the cost

of managing sickle cell disease was not affordable to majority of affect Nigerians.

**Young M et al (July 18, 2022)** studied that SCD is a hemoglobin-pathy with increasing global prevalence resulting in pain episodes and multi-organ complication. There are an estimated 1,00,000 individual in the U.S. alone with SCD. Hydroxyurea (HU) & other disease modifying therapies have demonstrated to significantly improve clinical outcome in patients with SCD. Low adherence have been shown to increase disease burden and healthcare utilization. Hence HRQOL (Health related quality of life) measures can serve as an effective evaluator of disease burden. This intends to determine the association between adherence to disease modifying therapies and HRQOL in patent with SCD.

**Kanter J et al (12 Aug, 2020)** found that SCD is the most common blood disorder in the united states, affecting ~1,00,00 individuals. To define the most important element of an SCD center, a convenience sample of 14 established adult SCD treatment center in United States and United Kingdom was sent via e-mail with, a qualitative survey with with several questions. Access to adult sickle cell care is poor in many parts of united-states, resulting in increased acute care utilization, early mortality for patients. As more clinicians are trained in providing focused SCD care, center designation will enhance the ability to undertake quality improvement and compare outcomes between SCD centers. Activities will include an assessment of the clinical effectiveness of expanded access to care, implementation of SCD guidelines, and efficacy of newly approved targeted medications.

**Leger R. R. et. Al (2018)** sickle cell disease associated stigma impacts health related quality of life and community participation. Stigma in adults living with sickle cell disease and family member was appraised via pilot study for paired (adult and family) instrument development, face validity and psychometrics. 42 adults from United States and Nigeria participated in the study. Nigerian report higher stigma ($r=.60$, $p<.01$). Adults from both countries "fear that their significant others will reject them."

## METHODOLOGY

Methodology of research refers to investigation and ways of obtaining, organizing and analyzing the data. Methodology studies, address the development, validation and evaluation of research tool or method. This chapter deals with the methodology adopted to assess the challenges in access to treatment, social issues, complication and adherence to treatment among patients with sickle cell anemia attending medical OPD at Pandurang Ramarao Dongaokar District Hospital Durg.

### Research Design

A researcher's overall plan for obtaining answer to the research question or for testing the research hypothesis is referred to as the research design. It spells out the basic strategies that the researcher adopt to develop information that is accurate and interpretable.

### Sample

Sample was drawn from patients with sickle cell anemia attending medical OPD at Pandurang Ramarao Dongaokar District Hospital Durg. In this study sample comprises total of 30 patients with Sickle cell anemia.

### Sampling Technique

In present study Non Probability Convenient sampling technique was used.

### Variables

In the present study variables were: Access to treatment, Social issues, Complication & adherence to treatment.

**Selection & Development of Tool**

Based on the problem statement and objectives of the study, following steps were undertaken to select and develop the data collection tool.

**Selection of Tool**

Selection of tools used self – structured questionnaire and checklist to assess the challenges access to treatment, social issues, complication & adherence to treatment among patients with sickle cell anemia.

**Development of Tool**

The tool was developed after:

- Extensive review of research literature.
- Formal discussion with expert guidance
- Formal & informal discussion with peer group.

**Description of Tool**

Self – structured questionnaire and checklist were constructed by the investigator to assess the challenges access to treatment, social issues, complication & adherence to treatment among patients with sickle cell anemia.

**Data Analysis**

Data analysis is defined as the process of systematically applying statistical & logical technique to describe, summarize and compare data.

The collected data was analyzed in terms of objectives by using both descriptive and inferential statistics. The plan for data analysis is as follows:

1. Data tabulation
2. Frequency and percentage distribution were used to study the sociodemographic variable of patients such as age, sex, educational qualification, monthly income, area of residence, source of information regarding sickle cell anemia, marital status, occupational status, family - status, number of children and history of any illness in family and clinical data about sickle cell disease.

**DATA ANALYSIS AND INTERPRETATION**

Data analysis and interpretation include compilation, editing, coding, classification and presentation of data. This chapter contain analysis and interpretation of the analyzed data collect to identify the challenges in access to treatment, social issues, adherence to treatment and complication in patients with sickle cell disease.

**Distribution of subjects according to socio-demographic variables in frequency and percentage**

**Table 1: Distribution of samples according to history of any illness in family**

**N = 30**

| S.NO. | History of any illness in family | Frequency | Percentage |
|---|---|---|---|
| **1.** | Yes | 12 | 40 % |
| **2.** | No | 18 | 60 % |
| | Total | 30 | 100 % |

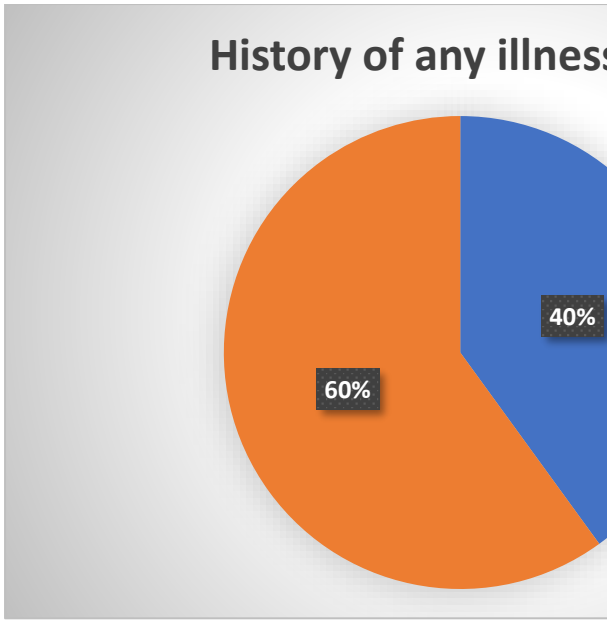


**Figure 1**

Table 1 & Figure no. 1 shows distribution of samples according to history of any illness in family which shows that maximum 60% (18) patients do not have history of any illness in family whereas 40% (12) patients have history of any illness in family.

**Table 2:** Findings related to clinical data among patients with sickle cell disease

| S. No. | Items | Response | Frequency (f) | Percentage (%) |
|---|---|---|---|---|
| 1. | Diagnosis of disease (in years) | 1 – 4 years | 16 | 53.34 % |
| | | 5 – 8 years | 10 | 33.33 % |
| | | >08 years | 4 | 13.33 % |
| 2. | Are you on regular treatment | yes | 26 | 86.67 % |
| | | no | 4 | 13.33 % |
| 3. | History of hospitalization for sickle cell disease | yes | 21 | 70% |
| | | no | 9 | 30% |
| 4. | Frequency of hospitalization for sickle cell disease in a year | 0-4 times | 18 | 60% |
| | | 5-8 times | 8 | 26.67 % |
| | | 9-12 times | 4 | 13.33 % |
| | | >12 times | 0 | 0% |
| 5. | Number of days of absenteeism from work or educational place due to hospitalization or sickness in a year | 2-4 times | 11 | 36.67 % |
| | | 5-8 times | 10 | 33.33 % |
| | | 9-12 times | 7 | 23.33 % |
| | | >12 times | 2 | 6.67 % |
| 6. | Symptoms | Joint pain | 11 | 36.66 % |
| | | Dyspnea | 3 | 10% |
| | | Head ache | 3 | 10% |
| | | Blurring vision | 0 | 0% |
| | | More than 1 symptom | 13 | 43.34 % |

| | | | | |
|---|---|---|---|---|
| 7. | Duration of symptoms | Seasonal | 14 | 46.66 % |
| | | Persistent | 16 | 53.34 % |
| 8. | Do you consult your doctor regarding your disease in emergency condition | Yes | 29 | 96.67 % |
| | | No | 1 | 3.33 % |
| 9. | Amount of water taken per day (in liter) | 1-2 | 22 | 73.34 % |
| | | 3-4 | 6 | 20% |
| | | >4 | 2 | 6.66 % |

**Table 2** shows that with regard to diagnosis of disease maximum 16(53.34%) were diagnosed within 1-4 years, 10(33.33%) were diagnosed for about 5-8 years whereas only 4(13.33%) were diagnosed for more than 8 Years. In response to regular treatment majority 26 (86.67%) said that they were on regular treatment whereas 4(13.33%) were not on regular treatment.

In response to history of hospitalization for sickle cell disease maximum 21(70%) patients said that they had history of hospitalization whereas 9 (30%) patients said that they do not had history of hospitalization.

In response to frequency of hospitalization for sickle cell disease in a year majority of 18 (60%) patients hospitalize 0-4 times in a year, 8 (26.67%) patients hospitalize 5-8 times in a year and 4 (13.33 %) patents hospitalize 9-12 times in a year.

With regard to number of days of absenteeism from work or educational place due to hospitalization or sickness in a year maximum 11 (36.67%) patients absent 2-4 times in a year, 10 (33.33%) patients absent 5-8 times in a year, 7 (23.33%) patients absent 8-12 times in a year and only 2 (6.67%) patients absent more than 12 times in a year.

In response to what symptoms they had majority of patients 13 (43.34%) hade more than one symptoms, 11(36.66%) patients had joint pain, 3 (10%) patients had dyspnea and 3 (10%) patients had headache.

With regards to duration of symptoms maximum 16 (53.34%) patients had persistent symptoms whereas 14 (46.66%) patients had seasonal symptoms.

By asking do you consult your doctor regarding your disease in emergency condition maximum 29 (96.67%) patient response yes and only 1 (3.33%) patient response No

In response to amount of water taken per day (in liter) maximum 22 (73.34%) take 1-2 liter water in a day, 6 (20%) patients take 3-4 liter water in a day and only 2 (6.66 %) patients take more than 4 liter water in a day.

**Table 3: Finding related to assessment of social issues**

| A. Stigma and discrimination/Social isolation | | | | |
|---|---|---|---|---|
| S.no. | Item | Response | Frequency (f) | Percentage (%) |
| 1. | Do you feel isolated and alone in social | yes | 1 | 3.33% |
| | | no | 29 | 96.67 % |

| | | | | |
|---|---|---|---|---|
| | places due to this disease | | | |
| 2. | Do you get any help from community for treatment and maintenance of health | yes | 19 | 63.33 % |
| | | no | 11 | 36.67 % |
| 3. | Do you think that sickle cell disease affect your relationship with the society | yes | 1 | 3.33% |
| | | No | 29 | 96.67 % |
| 4. | Whether you are accepted or you are understood in your community | yes | 28 | 93.33 % |
| | | no | 2 | 6.67% |

**Table 3** shows that in response to do you feel isolated and alone in social places due to the disease majority of 29(96.67%) patients do not feel isolate or alone in social places whereas only 1 (3.33%) feel isolate and alone in social places. On asking patients do you get any help from community for treatment and maintenance of health majority of 19 (63.33%) response yes whereas 11 (36.67%) response No. In response to do you think that sickle cell disease affect your relationship with the society maximum patient 29 (96.67%) response No whereas 1 (3.33%) patient response Yes. On asking patients whether you are accepted or you are understood in your community majority 28 (93.33%) patient response Yes and 2 (6.67%) patients response No.

**Table 4: Findings related to assessing access to treatment & adherence to treatment**

| A. Access to treatment | | | | |
|---|---|---|---|---|
| S. No. | Item | Response | Frequency (f) | Percentage (%) |
| 1. | Do you feel any difficulty in reaching hospital or health center | Yes | 1 | 3.34 % |
| | | No | 29 | 96.66 % |
| 2. | Is ambulance or transport facility available in case of emergency | Yes | 28 | 93.34 % |
| | | No | 2 | 6.66 % |
| 3. | Distance (in Km) to the nearest | 0 – 5 Km | 10 | 33.34 % |
| | | 6 – 10 Km | 14 | 46.66 % |

| | | | | |
|---|---|---|---|---|
| | health facility | 11 – 15 Km | 3 | 10 % |
| | | > 15 Km | 3 | 10 % |
| 4. | What medical facilities available in your area | HWC | 0 | 0 % |
| | | PHC | 7 | 23.34 % |
| | | CHC | 2 | 6.66 % |
| | | District hospital | 21 | 70 % |
| | | Private hospital | 0 | 0 % |
| 5. | In case of any emergency/illness who accompanies or who will accompany you to the medical facility | Family member | 27 | 90 % |
| | | NGO | 0 | 0 % |
| | | Friends | 1 | 3.34 % |
| | | Social worker/ ASHA | 2 | 6.66 % |
| | | Others | 0 | 0 % |

**Table 4** shows that in response to do you feel any difficulty reaching hospital or health center majority of 29 (96.66%) patients response that they do not feel any difficulty in reaching hospital or health center whereas 1 (3.33%) patient fell difficulty reaching hospital or health center. In response to is ambulance or transport facility available in case of emergency maximum 28 (93.34%) patient response yes whereas 2 (6.66%) response No. With regards to distance (in KM) to the nearest health facility maximum 14 (46.66%) patients response 6-10 Km, 10 (33.34%) patients response 0-5 Km, 3 (10%) patients response 11-15 Km and 3 (10%) patients response more than 15 Km. With regards to what medical facility available in your area maximum 21 (70 %) patients response district hospital, 7 (23.34%) response primary health center, and 2 (6.66%) response community Health center.

**Table 5: Association between help from community for treatment and maintenance with area of residence**

| Items | Rural | Urban | Total | $\sum x$ | Df | Table value | level of significant | Total sample size | Inference |
|---|---|---|---|---|---|---|---|---|---|
| Yes | 12 | 7 | 19 | 0.8925 | 1 | 3.84 | 0.05 | 30 | **Not significant** |
| No | 5 | 6 | 11 | | | | | | |
| Total | 17 | 13 | 30 | | | | | | |

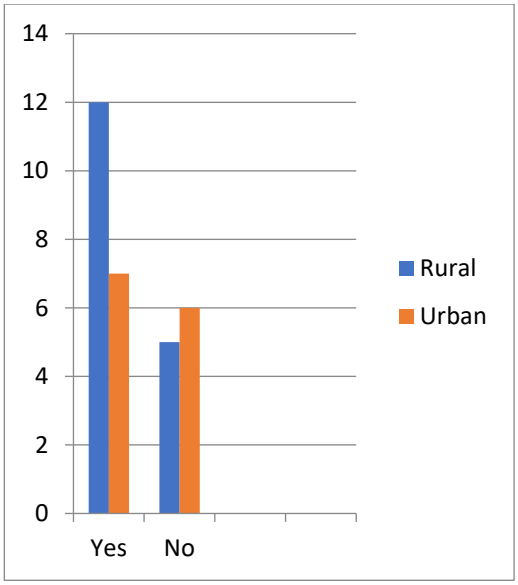


**Figure 2**

Table 5 & figure 2 shows that association between getting help from community for treatment and maintenance with area of residence was found to be 0.8925 at the Df 1 which is lower than the table value of 3.84 hence it was not significant at 0.05 level of significant.

**Table 6: Association between extreme pain and gender**

| Items | Male | Female | Total | ∑x | Df | Table value | level of significant | Total sample size | Inference |
|---|---|---|---|---|---|---|---|---|---|
| Yes | 5 | 22 | 27 | 3.426 | 1 | 3.84 | 0.05 | 30 | **Not significant** |
| No | 2 | 1 | 3 | | | | | | |
| Total | 7 | 23 | 30 | | | | | | |

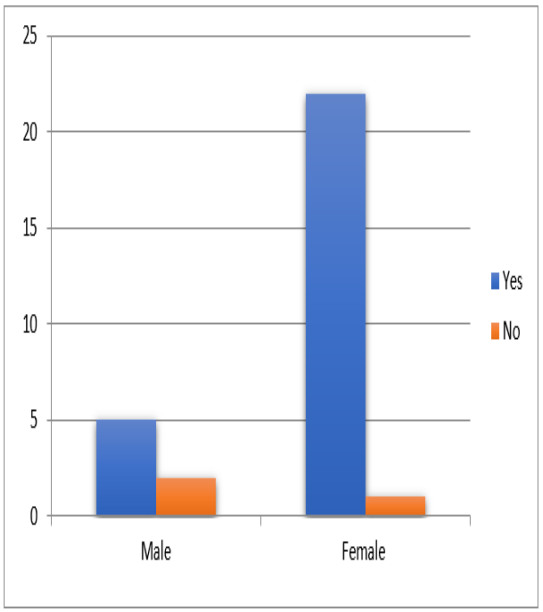


**Figure 3**

Table 6 & figure 3 shows that association between extreme pain with gender was found to be 3.426 at the Df 1 which is lower than the table value of 3.84 hence it was not significant at 0.05 level of significant. On asking in case of any emergency/ illness who accompanies or who will accompany you to the medical facility majority 27 (90%) response family member, 2 (6.66%) response social worker/ASHA and 1(3.33%) response friends.

**Conclusion**

This present study was undertaken on 30 sample and descriptive(exploratory) method was applied and the findings revealed that majority 56.6% were of the age group 18 to 28 ,majority 76% were female, majority of sickle cell disease patients 53.34% were diagnosed within 1- 4 years, majority of respondents (50%) reported annual treatment expenses between ₹500-₹1000,most participants (

96.66% ) reported no difficulty in accessing hospitals , all respondents (100%) had written medicine schedule and can access required medications at the hospital , the majority of individuals experienced extreme pain (90%), and powerlessness(83.33%) , indicating these are the most common complications.

**Limitation**

- The study findings are limited to 30 samples, hence the generalizeability of findings in small.
- The participants under data collection were available during the limited period so the findings cannot be generalized to a larger population.

**Recommendation**

- For further study on the topic it is recommended to take a much larger sample size for the study when association is to be found.
- Further studies can be done to identify the complications among the sickle cell patients for better problem solving among those suffering from the disease.
- Similar study can be done using an experimental design.

## REFERENCES

1. *Basavanthappa B. T. text book of nursing research and statistics, 3rd edition, published by JAYPEE BROTHERS medical publisher private ltd. page no. – 184, 480.*
2. *KhanalArunBhadra text book of Mahajan's method in biostatistics 8th edition published by JAYPEE BROTHERS medical publisher private ltd. page no. – 404, 213.*
3. *Sharma Suresh K. text book of Nursing research and statistics, 4th edition published by ELSEVIER page no. – 138, 246.*
4. *Suddharth's&brunner text book of medical surgical nursing, 12th edition, published by Wolters kluwer, page no. – 48-53*
5. *AI-Salem Ahmed text book of medical surgical complications of sickle cell anemia, published by Spinger, page no. – 329-338, 57-89*
6. *Lews E. Marilyn text book of sickle cell disease;genetics, management and prognosis, page no.- 95.*
7. *Williams S Linda & Hopper D paula textbook of medical surgical nursing fourth edition, published by JAYPEE brothers medical publishers private ltd. Page no. 569 – 570*
8. *Lewis Driksen, Heitkemper & Bunchertextbook of medical surgical nursing ninth edition, published by ELSEVIER, page no. 644 – 645.*
9. *Chugh S N textbook of medical surgical nursing part – II, published by Avichal publishing company, page no. – 537*
10. *Black Joyce M &Hawaks Jane Hokanson textbook of medical surgical nursing 8th edition, published by ELSEVIER, page no. – 3o23, 2022-2026.*
11. *IgnataVicius& Workman textbook of medical surgical nursing Volume – II, 8th edition published by ELSEVIER, page no. – 800, 801-802.*
12. *Christensen &Kckrow textbook of adult health nursing 4th edition, published by Mosby, page no. – 266.*