Review Article

Community-Based Mapping and Screening of Sickle Cell Disease in Rural Balaghat District, Madhya Pradesh, India: A Cross-Sectional Pilot Study

Prakalp Pandey[1], Dr. Rajesh Mujariya[2], Dr. Manjeet Singh[3], Dr. Disha Chouhan[4], Dr.Atul Bisen[5], Manjusha Shandilya[6]

[1]*Research Scholar of Institute of Pharmaceutical Science & Research, Balaghat*
[2]*Professor & Principal of Institute of Pharmaceutical Science & Research, Balaghat*
[3]*Executive Director of Institute of Pharmaceutical Science & Research, Balaghat*
[4,5,6]*Associate Professor of Institute of Pharmaceutical Science & Research, Balaghat*

ABSTRACT

Since SCD found as a global burden. Study was executed under the guidance of principal scientist of ICMR.. A cross-sectional screening study of 289 participants in Balaghat district identified 1 SCD case, 20 SCT cases, 3 BTD cases, and 1 BTT case. Awareness was poor in 95% of participants. The study supports targeted screening and counseling. Routine screening and awareness programs are recommended.

KEYWORDS

ICMR, SCD, hemoglobin S (HbS), Sickle Cell Anemia (SCA), WHO

I. INTRODUCTION

SCD is an inherited hemoglobin disorder common in central India. Sickle Cell Anemia (SCA) is a hereditary hemoglobin disorder characterized by the presence of abnormal hemoglobin known as hemoglobin S (HbS). It is an autosomal recessive genetic disease, meaning that an individual must inherit the defective gene from both parents to develop the condition. Sickle Cell Anemia is one of the most common monogenic disorders worldwide, particularly prevalent in Africa, India, the Middle East, and parts of the Mediterranean region.

Sickle cell disease (SCD) is one of the most common inherited hemoglobin disorders worldwide and represents a significant public health burden, particularly in low- and middle-income countries. Globally, it is estimated that 300,000–400,000 infants are born each year with SCD, with the majority of cases occurring in sub-Saharan Africa, followed by India, the Middle East, and parts of the Mediterranean region. High prevalence in these regions is attributed to the selective advantage conferred by the sickle cell trait against Plasmodium falciparum malaria, leading to persistence of the mutant hemoglobin S (HbS) gene in endemic areas.

In Africa, SCD accounts for a substantial proportion of childhood morbidity and mortality, with some countries reporting carrier frequencies of 10–30%. Without early diagnosis and appropriate medical care, childhood mortality remains high. However, implementation of newborn screening and comprehensive care programs has significantly improved survival in high-income countries. In the United States and Europe, SCD primarily affects individuals of African, Caribbean, Middle Eastern, and South Asian descent. Due to advances in neonatal screening, prophylactic antibiotics, vaccination, and disease-modifying therapies, life expectancy has markedly improved, with many patients now surviving into adulthood.

In India, SCD is a major genetic disorder, particularly prevalent among tribal and socially disadvantaged populations. High frequencies of the sickle cell gene are reported in states such as Odisha, Chhattisgarh, Maharashtra, Madhya Pradesh, Gujarat, Telangana, and parts of Tamil Nadu. The carrier frequency in certain tribal communities ranges from 5% to 35%, making SCD an important public health concern in the country.

II. MATERIALS AND METHODS

Community camps were conducted in rural Balaghat villages using point-of-care screening and questionnaires.

This study were supported by indian council of medical research (ICMR) with coordination with National Institute Of Research In Tribal Health, Jabalpur & Sardar Patel University, Balaghat. For awareness & mapping program principal investigator was hired i.e. Dr. Anup Kushwaha &

Dr. Ramswaroop Uikey. To complete these study team was required hence scientific staff, principal staff & coordinators was chosen. Detail of participants member is incorporated in annexure-I.

For execution of blood sample analysis, sickle solubility kit was collected from district hospital, Balaghat.

Study Design

A cross-sectional, survey as well as analysis based observational study was conducted to assess knowledge, clinical status, disease burden, and management practices related to Sickle Cell Anaemia. Six days duration was decide to execute these studies.

Study Area

The study was carried out in selected hospitals, clinics, community health centers and rural/urban populations in the chosen region i.e. Village-Madanpur, Teh.-Waraseoni, Dist.-Balaghat (MP), Village-Nevergaon, Teh.-Waraseoni, Dist.-Balaghat (MP), Village-Dongria, Teh.-Lalbarra, Dist.-Balaghat (MP), Village-Alejhari, Teh.-Waraseoni, Dist.-Balaghat (MP).

Study Population

The study was include:

- Confirmed patients diagnosed with Sickle Cell Anaemia.
- Parents/guardians of pediatric patients.
- General population for awareness assessment.
- Healthcare professionals (optional).

Sample Size & Technique

Approximately 300 participants depending on availability, resources, and statistical requirements were planned. SOP were prepared for solubility test & Electrophoresis (annexure-II). Upon recommendation of ICMR, solubility test & Electrophoresis Kit were collected from district hospital, Balaghat. Instrumental method for haematological & biological estimation are well defined in (annexure-III).

Inclusion Criteria

As per ethical aspect, Consent letter (annexure-IV) were collect form all volunteers before execution of study.

- Individuals diagnosed with Sickle Cell Anaemia.
- Age above 18 years (or guardian consent for minors).
- Willing to participate and provide informed consent.
- Exclusion Criteria
- Participants unwilling to participate.
- Individuals with severe mental or communication limitations.
- Incomplete questionnaire responses.

Study Tool (Questionnaire Design & Blood sample analysis)

Day wise Protocol for the study was prepared. (annexure-IV)

A structured questionnaire (annexure-V) was prepared containing the following sections:

Section A: Demographic Details

- Age
- Gender
- Residence
- Education
- Occupation
- Socioeconomic status

Section B: Disease History

- Age at diagnosis
- Family history
- Frequency of pain crises
- Hospital admissions
- Blood transfusion history

Section C: Clinical Symptoms

- Fatigue
- Jaundice
- Joint pain
- Fever
- Breathlessness
- Weakness

Section D: Awareness of Pathophysiology

- Knowledge about hereditary nature
- Understanding of sickling mechanism
- Triggering factors
- Preventive care

Section E: Treatment and Management

- Use of Hydroxyurea
- Folic acid supplementation
- Vaccination status
- Follow-up practices
- Lifestyle modifications

Section F: Quality of Life Assessment

- School/work absenteeism
- Physical activity limitation
- Emotional stress
- Financial burden
- After blood collection & analysis all individual blood report (annexure-VI) were arranged and evaluated against SCD parameter.

Validation of Questionnaire

- Questionnaire were pretested on a pilot group (10–15 subjects).
- Necessary modifications were made for clarity and reliability.

Data Collection Procedure

- Participants will be interviewed directly or questionnaire forms will be distributed.
- Responses will be recorded confidentially.
- Local language assistance may be used.

Ethical Consideration

- Institutional Ethics Committee approval were obtained.
- Written informed consent was taken from participants.
- Confidentiality and anonymity were maintained.

Data Analysis

- Data entered into MS Excel
- Results expressed as:Percentage

III. EXPECTED OUTCOME

- To assess awareness, disease burden, symptoms, treatment adherence, and socioeconomic impact of Sickle Cell Anaemia.
- To identify gaps in knowledge and healthcare management.

Note: Regarding the awareness camp on SCD prior intimated to CHMO- Balaghat & concern Head of Gram Panchayat through Annexure-IX & Annexure-X respectively, for effective & smooth conduction of program

IV. RESULTS

This pilot study demonstrate that feasibility of using the sickle SCAN test to gather knowledge about the prevalence of sickle cell. After blood collection & analysis all individual blood report as per annexure-VI were arranged and evaluated against SCD parameter. Finally summary of all analysis results were framed into annexure-VII. i.e. SCD analysis summary report.

Screening was done for 289 participants from the surrounding village of Balaghat i.e. Village-Madanpur, Teh.-Waraseoni, Dist.-Balaghat (MP), Village-Nevergaon, Teh.-Waraseoni, Dist.-Balaghat (MP), Village-Dongria, Teh.-Lalbarra, Dist.-Balaghat (MP), Village-Alejhari, Teh.-Waraseoni, Dist.-Balaghat (MP) were tested using SCAN point of care test. A study was admistered to assess demographics, diseases awareness, prior diagnosis, and family history. Testing took over the course of 5 days. Out of 289 individual 0.35% (n=1 were identified as having SCD & 7% (N=20) had SCT, BTD 1% (N=3),BTT 0.35% (N=1). 95% of all participants had no knowledge of sickle cell anaemia, Among the respondents, 9% reported a family member with the trait and diseases, while 53% were unsure of any familed diagnosis.

In 6 day program total 289 blood sample (Male=129,Female=160) are randomly collected & screamed. Different village i.e. Madanpur, Nevergaon, Dongria, Alejhari, Kaspur of district Balaghat was covered for the study. Our awareness & medical team were reached door to door & spread awareness & provide information regarding sickle cell anaemia as well as thalassemia. (annexure-VIII).

Sickle cell volunteer data is usually not shared publicly because of privacy, ethics, consent, legal rules, and misuse concerns. Hence in attached annexures Volunteers/Patient details were available in secrete code. Carrier prevalence and poor awareness indicate need for interventions.

V. CONCLUSION

This pilot study demonstrate that feasibility of using the sickle SCAN test to gather knowledge about the prevalence of sickle cell. Screening was done for 289 participants from the surrounding village of balaghat Madanpur, Nevergaon, Dongria, Alejhari were tested using SCAN point of care test. A study was admistered to assess demographics, diseases awareness, prior diagnosis, and family history. Upon comparison with WHO survey report and our pilot study, it was concluded that "The higher apparent sensitivity of the Malajkhand belt toward SCD compared to Waraseoni block may be attributed to differences in population genetics, tribal distribution, migration, endogamy, environmental stressors, and screening intensity."

"Focused screening, awareness, genetic counselling, and healthcare strengthening are urgently recommended in the Malajkhand belt due to its higher sensitivity toward SCD compared to Waraseoni block."

"The present study provides baseline data; future research should incorporate larger populations, genetic testing, long-term follow-up, and targeted public health interventions to reduce the burden of SCD in affected regions."Routine screening and awareness programs are recommended.

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