Epidemiological Analysis of Sickle Cell Disease in Badwani District, Madhya Pradesh: A Comprehensive Study Based on Recent Data

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Abstract— Sickle cell disorder (SCD) remains a significant health concern in various regions globally, including Badwani District, Madhya Pradesh, India. This research paper presents an in-depth epidemiological analysis of SCD utilizing recent data from the district. The study aims to characterize the prevalence, distribution, and severity of SCD cases, providing valuable insights for healthcare planning and intervention strategies in the region. Through an interdisciplinary lens, the paper examines the socio-cultural context, healthcare infrastructure, and public policy responses to SCD, highlighting the need for holistic approaches to mitigate its adverse effects on affected populations. This research paper explores the sociological impact of SCD in Madhya Pradesh, inspection its effects on individuals, families, and communities

Index Terms- Sickle cell disorder, healthcare planning, intervention strategies, individuals, families, communities.

I. INTRODUCTION

Sickle cell disorder (SCD) is a congenital traits blood disorder characterized by the presence of abnormal haemoglobin, leading to various clinical manifestations. In Badwani District, Madhya Pradesh, SCD poses a substantial health burden, necessitating a thorough understanding of its epidemiological characteristics. This paper examines the latest data on SCD in Balwani District to assess its prevalence, distribution, and severity

Sickle cell disease (SCD) is the umbrella term used to describe a host of inherited disorders known as hemoglobinopathies, and blood diseases affecting haemoglobin, including sickle cell anaemia. SCD refers to a disorder distinguish by a predominance of haemoglobin, including sickle cell anaemia (1). Introduction to Sickle Cell Disease (SCD) and its prevalence in Madhya Pradesh. Overview of the research problem, objectives, and methodology. Importance of understanding the sociological dimensions of SCD for effective intervention and support. worldwide, sickle cell disease constitutes the general monogenic disorder(2,3).

1.1Sickle cell history in the India

Sickle haemoglobin was first discovered by Lahmann and Cutbush about 50 years ago among the tribals of Nigiri Hills of Southern India. Later, Following studies conducted by several researcher reported its high density throughout Central India and parts of Southern India (Bhatia and Rao, 1987, Kar, 1991 and unpublished reports). (4).

1.2The tribal residents of the India

India has the largest concentration of tribal populations globally. They are believed to be the early settlers in the country. And considered to be the original in habitats. According to the Consist of India 2011. The tribal population of India is 8.6 percent of the total population which is about 67.8 million people(5). Madhya Pradesh is one of largest population of tribal residents in the India. Most tribal population has live isolation and depends on nature for food and livelihood.

1.3 Sociocultural Context of Sickle Cell Disease in Madhya Pradesh

- Analysis of socio-cultural beliefs, practices, and stigmas associated with SCD in Madhya Pradesh. Examination of traditional healing practices, religious perceptions, and group frame of mind toward

individuals with SCD.Exploration of how socio-cultural factors influence health-seeking behaviors, treatment adherence, and social integration among SCD-affected individuals.

1.4. Impact on Individuals and Families

Evaluation of the physical, psychological, and economic burden of SCD on affected individuals and their families. Analysis of challenges related to healthcare access, affordability, and quality of care for SCD management in Madhya Pradesh. Discussion on coping mechanisms, resilience, and support networks among SCD-affected individuals and their families.

1.5.Community Dynamics and Social Support Systems

Examination of the bit part of community-based organizations, support groups, and advocacy networks in addressing the needs of SCD-affected communities in Madhya Pradesh.

Assessment of community-led initiatives, awareness campaigns, and educational programs aimed at reducing SCD-related stigma and promoting health-seeking behaviours.

Identification of gaps in existing social support systems and recommendations for strengthening community resilience and solidarity.

1.6 Healthcare Infrastructure and Policy Responses

Examination of the healthcare infrastructure for SCD management in Madhya Pradesh, including the availability of diagnostic facilities, treatment centres, and trained healthcare professionals. Evaluation of government policies, programs, and initiatives aimed at addressing SCD prevalence, prevention, and treatment . Discussion on challenges in policy implementation, resource allocation, and coordination among healthcare stakeholders in combating SCD in Madhya Pradesh.

1.7. Gender Dynamics and Sickle Cell Disease

- Exploration of gender disparities in SCD prevalence, diagnosis, and treatment outcomes in Madhya Pradesh. Examination of the intersectionality of gender, socio-economic status, and access to healthcare services among SCD-affected populations. Examination of gender-specific challenges and vulnerabilities faced by women and girls living with SCD, including reproductive health concerns and caregiving responsibilities.

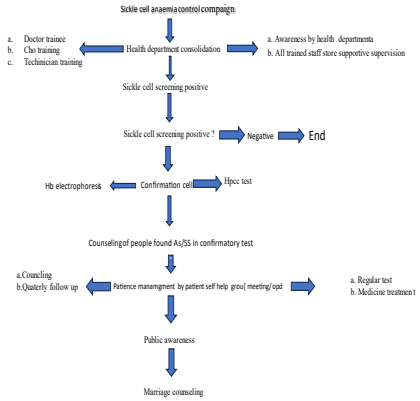
II. METHODOLOGY

Data Source: The study utilizes epidemiological data collected from healthcare infrastructure like including hospitals, clinics, and health centres, across Badwani District.

Study Period: Data collection spans a specified timeframe to capture recent trends and variations in SCD prevalence and severity.

Data Analysis: Descriptive statistical analysis is performed to quantify the prevalence of SCD and categorize cases based on severity levels.

Model description in research



III. PREVALENCE AND DISTRIBUTION OF SICKLE CELL DISEASE

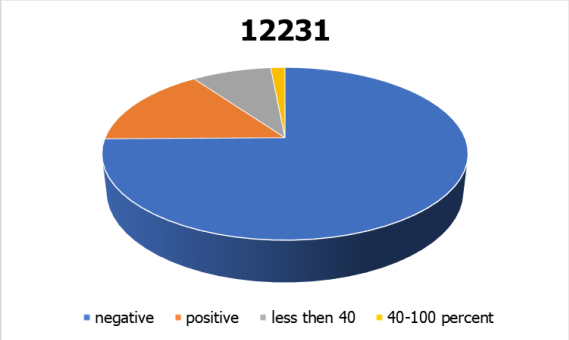
Total Tests: A total of 12,231 tests were conducted for SCD screening or diagnosis in Badwani District during the study period.

Positive Cases: Out of the total tests, 1,883 were identified as positive for SCD, indicating an overall prevalence rate.

Spatial Analysis: Geographic information system (GIS) mapping techniques may be applied to visualize the distribution of SCD cases across different regions

within Badwani District, identifying areas of high prevalence and potential clusters.

Total test	12231
negative	9198
positive	1883
less then 40	1032
40-100 percent	185



IV. SEVERITY CLASSIFICATION

Less Than 40% Sickle Cells: Among the positive cases, 1,032 individuals exhibited less than 40% sickle cells, indicative of milder forms of SCD or carriers of the sickle cell trait.

40-100% Sickle Cells: A subset of 185 cases demonstrated 40-100% sickle cells, suggesting more severe manifestations of SCD requiring closer monitoring and specialized care.

V. IMPLICATIONS FOR HEALTHCARE PLANNING AND INTERVENTION

Resource Allocation: Understanding the prevalence and severity distribution of SCD in Badwani District is dire for allocating healthcare assets effectively, including diagnostic facilities, treatment options, and supportive care services. Education and Awareness: Community-based health education programs aimed at raising awareness about SCD, its inheritance patterns, and available preventive measures can help mitigate the burden of the disease and improve health outcomes.

Primary prevention Awareness

Multiple stages shall be utilize for awareness for preventing and control of scds enhance utilization of prenatal screening , premarital genetic counselling , screening of up to 40 year of age. Counselling and awareness focusing of prevention. There are some stages to focus on prevention sickle cell.

In individual leval / Household level awareness
Ashas community health volunteers, local NGOs, etc, shall be engaged in raising awareness towards scds through have visits asha as per her routine population and identified scd patients with in her catchment area. As per routine activities asha are already preparing list of eligible couples which may be linked with the programs to identify and provides genetic counselling and mobilize the couples to the nearest ayushman bharat mission and wellness centre for screening, preventing and clinical management.

Individual with know or detected scds would also be encouraged to register on sickle cell disease support corner, which is moto initiative to bridge the gap between patients and health care services in tribal area.

In community level
Community level platform is working as monthly village health sanitisation and nutrition community Arogya samiti meetings village , urban , health sanitation and meeting at Anganwadi , jan Arogya samities , Arogya sabha , self help groups(SHG), youth clubs, parent- teacher meeting school etc. To sanitize people and cleanliness importance of sickle cells disease and screening service available at AB-HWCS. To compliment these shall be engaged for rural areas and urban slums areas places w2ith gathering suach as haat bazaar , fixed day market may also include for gathering awareness amongst community member on scds locally relevant awareness modalities such as street plays , writing painting , quizzes etc.shall be undertaken to raise community awareness of sickle cell disease and national mission to eradicate this disease from world. Patients support group would be formed facilitate by asha or other frontline workers to improve treatment compliance and engaging not only with these disease condition but also family member also.

Community platform such develop mechanism for community level referrals for per martial and pre

conceptional screening backed by genetic counselling service as.also , at the community level all individual detected to know as carries or patients extended family screening is to be learned.

In health care facility level

Primary health centre is primarily responsible for counselling services for all individual diagnose positive with sickle cell disease. The existing counselling shall be leveraged at phc-hwc and shall be trained on sickle cell disease genetic counselling. Primary health care teams including CHOs, ANMs, Asha, medical officer and staff nurses will trained on all aspects of scds prevention, control, counselling and management. They will organize community awareness events on scds regularly. The platform of Rastriya Kishor swasthya karayakram and its adolescent friendly health clinic shall be used for reaching out to adolescents for awareness generation, screening and genetic counselling's.

All the eligible individual couple identify as positive or at risk at community level or at Shc-HWC/UHWC would be referred to the counsellor at PHC-HWC/UPHC for further advice. It also given advice to couple for pregnancy or not for safer or prevention identified as carriers. Higher center would also engaged in providing counselling services to walk in patients or patients referred from lower level facilities .

Sickle cell cards holder:

Sickle cell card provide to councillor by primary health care centre for purpose for of premarital and pre conceptional counselling by matching the cards of prospective matching. Matching of cards would show the chances of there children being born with SCD or SCT . Every individual who is screened for SCD will provide a sickle cell card. These card would show status of individual by noirmal , carries or diseased. The card holder are color coded separately for male (blue) and female (pink). It is help for individual for receive treatment and counselling based on card status. The card holder has details such as gender, test reports, sickle cell disease , sickle cell carries, normalon the front side of the card .

There is rear side of card has detailed on possible outcome of conception if any person with either sickle cell disease or carriers marries.

If matching the card or they should placed together and held against the light the holes coinciding would given the possibilities of having diseases or traits in the child.

a. If there is between individual having sickle cell disease marry, there is 100 percent chances there children would be born with SCD.
b. If there is a sickle cell disease individual and sickle cell trait individual marry , there is 50 percent chances that their children would be born with 50 percent chances there that children will be carriers.
c. If there is a diseases individual and the normal individual and normal marry , there is a chances of 100 percent chances that t their children would with sickle cell traits.
d. If there is two individual having sickle cell traits marry, their children have 25 percent chances of being diseased , 25 percent of being normal and 50 percent chances of being carries.
e. If there is a sickle cell diseases trait and normal individual marry, their children have 50 percent chances of being normal and 50 percent chance bof being carries.

Role of NGOs and CBOs

Non governmental organization is workings as spread awareness among community like tribal people , rural areas, urban slums areas etc. Ngos is also arrange camp regularly to aware and check sickle cell diseases sample regularly on remote area where it is not easy to aces for government body. Ngos has objective to eradicate and spread awareness to these disease has provided fund by government so it extend there hand and area to collect data from ngos. Government has benefits to make schemes according to proper data collected of sickle cell.

Sickle cell monitored through mobile application

Mobile application has data captured by national information centre due generation of every individual being screened or provide healthcare. The same would be stored in central database linked to MOHFW portal and ayushman bharat digital mission.

The application has follow featured.

Beneficiary register on the portal.

Test details included.
Integration with abha ID.
The application on contains following details.

1. Registration – To record screening person's details.
2. Screening test details- to record result and solubility.
3. HPCL/Electrophoresisi test details – To record the HPCL electrophoresis test details.
4. Syncing – the sync offline(Local database) data with contan the server data.

Web portal of sickle cell

The role of web portal of sickle cell is to facilities a dashboard , creation of various level of users, download various portal. In home page citizen those screening test sickle cell could download own's certification. Dashboard also get various information sickle cell.

The web portal has following features

1. user must get his/her government email id registered through concerned user/state admin will be able to login only if has/her government email registred.
2. People can get various type of information related to sickle cell mission from home page. It consist of various like manual, gallery, contact us ,user manual, your report.
3. People can download their sickle cell certification from Know your report. Menu. They could be provide mobile no their can be provide during registration. Otp would be send to same registration mobile no and after successful verification can get sickle cell certification.
4. User can get the cumulative and daily count of total , registered , screened , negative, diseased and carries nation wide.
5. State and district user could edit details entered from mobile application in case of any mismatch typing done during the registration . for that they would have to click on patient edit list and click on edit button present against each record.
6. User could get the details of patient whose screening test is done he / his is found to be positive but confirmation test is not conducted yet . They could also download it in pdf.

Pregnancy-related sickle cell illness management carries an increased risk of complications for the baby and the expectant mother who has sickle cell disease. Every pregnancy must be treated as if it were high risk. It is best to have a full physical examination, anaemia treatment, and medical attention prior to conception. Vitamin D should be provided as a supplement throughout pregnancy, and folic acid should be taken regularly both before and after conception. Risk while expecting thromboembolic events and infection.

A rise in unplanned pregnancies.
Elevate the risk of gestational hypertension and pre-eclampsia.
early labour and excruciating, severe crises during pr egnancy. limitation on foetal growth. Antepartum bleeding. Mother Death higher perinatal death incidence.
Women who intend to become pregnant should cease taking hydroxyurea three months before they hope to conceive.
Steer clear of iron chelation medications since they m ay have teratogenic effects.
Stopping these medications before to pregnancy is ad vised.
In the process of preparing for conception, the couple should get treatment if there is evidence of iron exce ss.
Since iron deficiency is a possible side effect of sickl e cell disease.
It has to be handled in accordance with pregnancy gui delines.

SICKLE cell disease:
Alpha and beta haemoglobin subunits are included in ordinary human haemoglobin A (HbA), also known as person haemoglobin (Haemoglobin A1 or $\alpha 2\beta 2$). In human children and adults, the genes should function normally and in concert to produce regular haemoglobin. When normal haemoglobin (HbA) is replaced by faulty haemoglobin, the person may have sickle cell disease or be a sickle cell carrier. One might have normal sickle cell disease or be a sickle cell carrier.

haemoglobin (HbA) is changed by faulty sickle haemoglobin. Sickle haemoglobin (HbS) is a result of a point mutation within the beta-globin chain. If only one subunit of beta globin is affected, the person has a

trait, and if both are affected, the character has sickle cell ailment. patients with sickle mobile trait inherit HbS from one figure and HbA from the other, making them heterozygous and vendors of disease. patients with sickle cellular sickness inherit genes that code for HbS from both dad and mom, making them

homozygous. At times a patient may also inherit the beta thalassemia gene from one parent and the sickle mobile gene from another parent The most commonplace kinds of Sickle mobile hemoglobinopathies are – HbSS, HbS Beta Thalassemia, and sickle cellular trait.

HbSS: people who've the HbSS form of SCD, inherit sickle cellular genes ("S"), from both dad and mom. This is usually referred to as sickle mobile anaemia / disease and is generally the most severe shape of the ailment.

HbS beta thalassemia: humans who've this shape of SCD, inherit one sickle cellular gene ("S") from one discern and one gene for beta thalassemia, some other type of hemoglobinopathy, from the alternative parent. people with HbS beta thalassemia generally have a excessive shape of SCD.

Advice

The research findings lead to the following recommendations being put forth:

1. Strengthening Screening Programs: To guarantee early detection and intervention, increase the reach of SCD screening programs, especially in indigenous areas.

2. Improving Access to Healthcare: Increase the availability of medical services, including the provision of specialised treatment for people with sickle cell disease, in remote regions.

3. Increasing Awareness: Launch community-based initiatives to inform people about sickle cell disease (SCD), its signs and symptoms, and the value of early detection and care.

4. Training Healthcare Professionals: To enhance the handling of SCD cases, teach nearby healthcare professionals with an emphasis on early diagnosis, available treatments, and patient care.

5. Policy Implementation: Make sure that state and federal health policies incorporate SCD management techniques and provide ongoing financing and support for them.

CONCLUSION

The epidemiological analysis of SCD in Badwani District, Madhya Pradesh, based on recent data highlights the significant prevalence of the disease and its varying severity levels. By elucidating these epidemiological characteristics, this study come up with treasures cognizance for healthcare planning and intervention strategies tailored to the needs of the local population. Summary of key findings and insights from the research on the sociological impact of Sickle Cell Disease in Madhya Pradesh. Reflection on the interconnectedness of socio-cultural, economic, and policy factors shaping the experience of SCD-affected individuals and communities. Recommendations for multi-sectoral interventions, policy reforms, and community-based approaches to address the socio-economic burden of SCD and promote inclusive healthcare in Madhya Pradesh.

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