



# Health System-Led Multimodal and Multilevel Interventions to Reduce Sickle Cell Disease-Related Stigma Among Tribal Populations in India: An Implementation Research Protocol

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## Abstract

**Background** Sickle cell disease (SCD) is a chronic, inherited blood disorder with significant clinical and psychosocial consequences. In India, particularly among tribal populations, SCD is compounded by health-related stigma, which impedes treatment adherence, timely healthcare access, and quality of life (QoL). However, there is no evidence of structured, health system-led stigma reduction strategies tailored to the Indian context.

**Objective** To develop, implement, and evaluate a health system-led, multimodal and multilevel intervention to reduce SCD-related stigma among patients and caregivers in five SCD-endemic districts of India.

**Methods** This implementation research adopts a pre-post intervention design and is guided by the Theory of Change framework for intervention and Proctor's Conceptual Model for evaluating implementation effectiveness. The intervention comprises six core strategies: policy advocacy, capacity building of healthcare providers, individualized and family counselling, peer support groups, school-based awareness campaigns, and community mobilization through IEC activities. The study targets key stakeholders across the health system, community, and household levels. The impact will be assessed using the Indian Council of Medical Research-SCD Stigma Scale for India (ISSSI), alongside standardized tools for QoL (SF-36, PedsQL), resilience (CD-RISC 10), well-being (WHO-5), coping (Brief COPE), stress (PSS), and healthcare utilization.

**Expected Outcomes** Primary outcomes include the reduction in overall and domain-wise stigma scores. Secondary outcomes include improvements in QoL, resilience, coping strategies, perceived stress, and utilization of SCD-related health services. The findings will inform policy recommendations and the integration of stigma reduction interventions into the national SCD program.

**Conclusion** This study presents an innovative, contextually grounded approach to address the hidden burden of stigma in SCD care. The intervention has the potential for scale-up and may serve as a model for addressing stigma in other chronic and stigmatized health conditions in low-resource settings.

**Keywords** Sickle cell disease · Stigma · Intervention · Implementation research · Tribal health · Quality of life

## Introduction

Sickle cell disease (SCD) is a chronic inherited hematological disorder that is highly prevalent worldwide [1]. Patients with SCD experience a broad range of clinical

manifestations. However, severe, unpredictable, and episodic pain is a characteristic attribute of the disease [2]. Comprehensive care plays a crucial role in reducing hospitalizations and improving quality of life (QoL) among SCD patients [3]. However, the disparity in the availability of medical care is associated with the stigma attached to the illness [4]. Stigma related to SCD may arise from physical complications, including comorbid conditions affecting bones and joints, impaired physical functionality, and psychosocial, racial, and behavioural aspects [5].

Stigma negatively influences health through multiple mechanisms at various levels through processes like

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experienced, enacted, internalized, and perceived stigma [6]. Health-related stigma results in a form of devaluation, judgement, or social disqualification of SCD patients based on an illness affecting their physiological, psychological, and social well-being [7]. Not only this, but stigma also limits access to resources, including healthcare, which leads to serious health complications [8]. Thus, stigma has implications on the overall well-being of patients, including QoL, treatment adherence, and self-management of the disease [9]. In addition, stigma related to SCD has direct implications in the lives of SCD patients in the form of discrimination at work or school or within families [10]. SCD patients with perceived self-stigma are at risk of negative self-evaluation, loss of self-esteem, anxiety, and social withdrawal, which negatively affect the SCD outcomes [11]. Some studies found a significant association between stigma and depressive symptoms and hospitalizations for SCD pain crises [12].

SCD-related stigma is multifaceted and rooted in societal perceptions, cultural beliefs, and the healthcare system and requires a comprehensive approach to mitigate it [13]. Hence, stigma reduction intervention strategies need to be developed by targeting the multiple drivers of stigma, focusing on controlling or treating target health problems with informed health and social policies, countering the disposition of perpetrators to stigmatize, and supporting those who are stigmatized to limit their vulnerability and strengthen their resilience [7].

Despite the burden of stigma related to SCD and its significance on the lives of SCD patients, there is very limited knowledge of SCD-related stigma, its impact on health outcomes, and stigma-reducing interventions among SCD patients. Hence, this study aims to develop health system-led multimodal and multilevel intervention strategies to reduce SCD-related stigma among SCD patients and their caregivers and assess their impact on health outcomes. This paper reports the protocol of this study.

## Aim of the Study

The aim of the study is to reduce the SCD-related stigma and its impact on patients and their families by addressing it through health system-led multimodal and multilevel intervention strategies.

## Objectives

### Primary Objective

To reduce the SCD-related stigma among SCD patients and caregivers through an implementation research with health system-led multimodal and multilevel strategies.

## Secondary Objectives

1. To reduce the burden associated with stigma among SCD patients, their families, and the community.
2. To improve the utilization of healthcare services by SCD patients, increasing the availability and accessibility of quality healthcare services.
3. To improve QoL and coping mechanisms among SCD patients and caregivers.
4. To reduce perceived stress among SCD patients and caregivers.
5. To evaluate the effectiveness of stigma reduction interventions among SCD patients and their caregivers, in terms of reduction of stigma and improvement in QoL.

## Methodology

### Study Design

This study will be an interventional study with pre- and post-intervention comparison design. It will be conducted in two phases, namely, the intervention phase and the evaluation phase. Interventions will be developed and implemented using the “Theory of Change” (ToC) framework [14]. The evaluation of implementation effectiveness will be conducted using Proctor’s model [15–17].

### Study Setting

This study will be implemented in five SCD endemic districts in India, and they are Alluri Seetharama Raju (ASR) (Andhra Pradesh), Chhotaudepur (Gujarat), Kandhamal (Odisha), Mysuru (Karnataka), and Udalguri (Assam). These districts, which represent different geographical zones, are tribal-dominated and endemic for SCD. The demographic and epidemiological details are available elsewhere [18].

### Study Area

The study will be conducted in 10 primary health center (PHC) areas across five districts/states mentioned above. The focus of the intervention will be on about 300 confirmed SCD patients recruited purposively from the cohort of patients identified earlier during an Indian Council of Medical Research (ICMR) multi-centric study conducted by us between 2019 and 2022 [19, 20]. The people with SCD diagnosed through the screening by the local public health system will also be included. Thus, all the people with SCD and their families living in these 10 PHC areas will be covered. The activities at the community and health system levels will be limited to these 10 PHC areas. This is feasible and in line with implementation research norms.

### Formative Research Phase

The formative phase of the study will focus on assessing the impact of SCD among patients and caregivers of these 10 PHC areas using a mixed-method study design. The number of people with SCD will be finalized after excluding unwilling participants, those who have migrated or passed away due to the disease. If the patients’ age is < 18 years, then their parents or immediate caregivers will be recruited. Along with patients, an equal number of age, gender, and occupation-matched controls will also be recruited from the same villages. Disease impact will mainly be assessed across the dimensions of stigma and health-related QoL. In addition to that, pain episodes, self-management strategies, and coping strategies adopted by the patients and their families will be captured. In the absence of a comprehensive SCD stigma scale for India, the Indian Council of Medical Research (ICMR)-SCD Stigma Scale for India (ISSSI) was developed and validated by this research team [21]. The ISSSI is pertinent to the Indian context and is available for use [21].

At the community level, the general community, traditional healers, students, school teachers, and community platforms such as the gram panchayats (village councils) and village health, sanitation and nutrition committees (VHSNCs) will benefit. At the health-system level, medical officers, community health officers (CHOs), frontline

health workers (FHWs), community health workers, also referred to as Accredited Social Health Activists (ASHAs) and SCD counsellors, will be involved. It will also include public healthcare administrators at the block, district, and state levels, who will be targeted through advocacy for a sustained supply of drugs and implementation of interventions. Mapping of probable stakeholders will be done and schematically shown in Fig. 1.

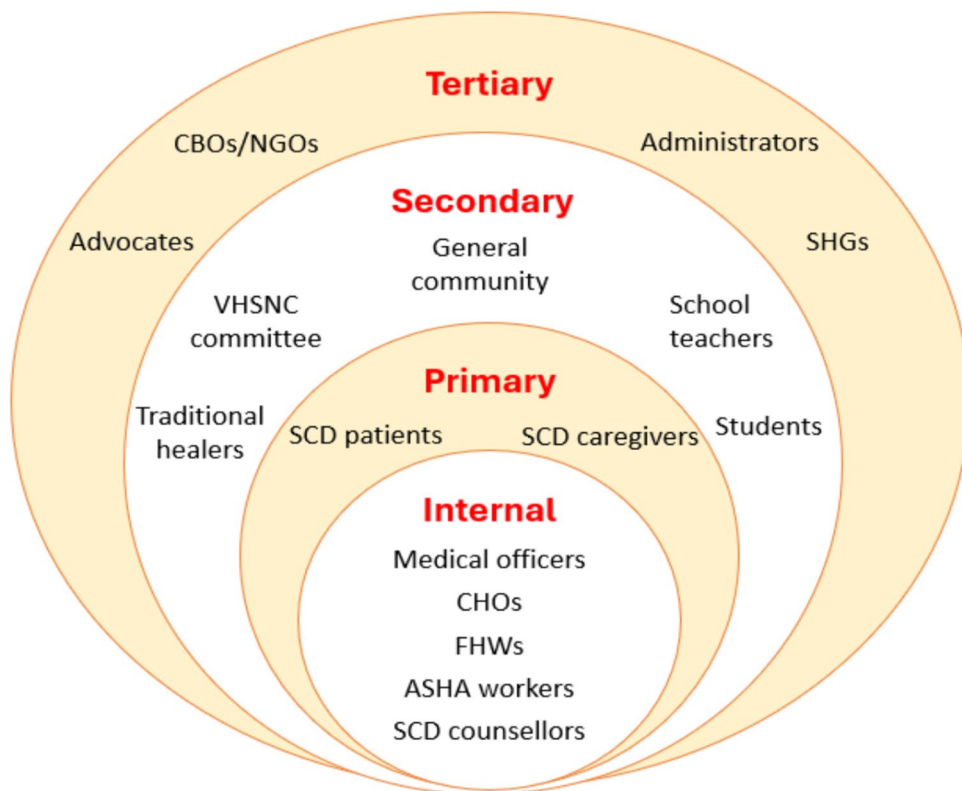
### Intervention Phase

Interventions will be co-developed and co-implemented through the active collaboration of stakeholders and subject experts applying the “Theory of Change” (ToC) [14]. ToC aids researchers in determining long-term goals and intermediate outcomes and then formulating potential interventions to achieve those desirable outcomes. For ease of understanding, the logic model of ToC is presented graphically (Fig. 2).

### Implementation Strategies

This phase will be continued for 12 months. Indicative implementation strategies will be implemented in selected PHCs during this phase and are listed (Fig. 2). These strategies will comprehensively address SCD-related stigma and poor disease outcomes among SCD patients through a multi-pronged approach at the healthcare, community,

Fig. 1 Stakeholder mapping



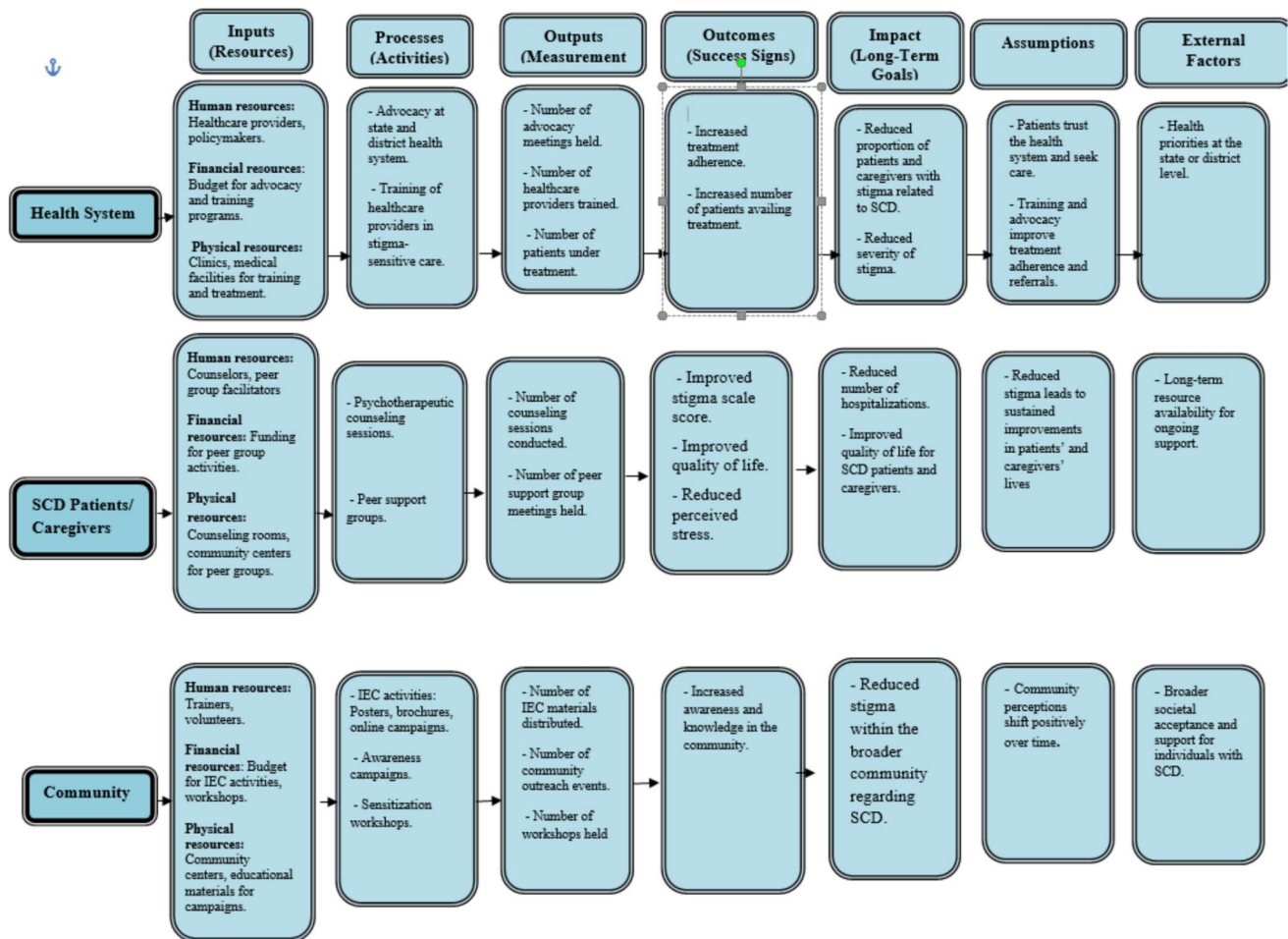


Fig. 2 Intervention activities at three levels of stakeholders

and individual levels. These interventions are carried out as described in similar stigma reduction interventions [22]. Advocacy, standard treatment, counselling, cognitive behavioural therapy, empowering patients, group counselling, promoting self-help, and forming support groups are proposed strategies targeted at individuals [10]. Community education is the primary strategy at the community level. Some of the appropriate strategies relevant to the study setting have been included. The outcomes of these implemented strategies will be reviewed intermittently by periodic monitoring, and if needed, they will be redesigned iteratively to achieve expected outcomes.

## Advocacy

For the successful implementation of this health system-led, multimodal, and multilevel interventions at the ground level, advocacy and collaboration with the health system and other allied departments at the state, district,

and PHC levels are of utmost importance. The purpose of the study, planning, and implementation of interventions will be explained to all these decision-makers and administrators, and necessary revisions will be made.

## At the State Level

At the state level, the SCD program, the heads of health and tribal affairs will chair the committee and engage in advocacy. This committee will further guide and direct the district and block-level officials. Representatives from the department of primary and secondary education will be included in this subcommittee and will also be engaged in the interventions at the primary and secondary schools. Health department officials will also advocate for including SCD-related indicators in the Health Management Information System (HMIS) portal to improve reporting and availability of real-time data.

## At the District Level

A committee on health at the district level, chaired by the district collector or district magistrate, will be contacted for support and to direct the administration to support the intervention. A committee related to SCD-related activities will be formed under the chairpersonship of the district medical officer and with other officials as members. This committee will oversee and guide the next level of officials.

## At the Sub-District/Block/PHC Level

At the sub-district level, the block development officer, block education officer, and medical officers in the block/PHCs will be engaged at this level. Microplanning of implementation strategies will be co-developed and shared with stakeholders at this level. Block education officers and primary and secondary school principals will be engaged in conducting school teachers' training and awareness campaigns for students related to SCD.

## Training of Healthcare Providers

Capacity building of the healthcare providers of the primary healthcare system will play a crucial role in addressing the health-related stigma of SCD. The training sessions will be performed according to the various cadres of healthcare providers. Details of which are as follows.

### Capacity Building of Medical Officers

At the PHC level, medical officers will be trained to address SCD, its diagnosis and treatments/management, and its related consequences at the healthcare and community level. These training sessions for medical officers will be conducted biannually with periodic monitoring throughout the intervention phase. Training sessions will be for 2 days, and they will be conducted by the coordination team of ICMR. In these sessions, medical officers will be oriented in the following areas of SCD by clinicians, preferably by the hematologists.

- Introduction to SCD and its causes
- Clinical manifestations and diagnosis of SCD
- Medical and non-medical holistic management of SCD and the continuum of care
- Monitoring and reporting
- Stigma types and causes
- Busting myths and misconceptions
- Coping strategies
- Psychosocial support and counselling techniques
- Mental health first-aid toolkit

- Capacity building of other healthcare workers

Resources: Training manuals, booklets, treatment algorithm charts/job aids, videos on patient-centric approaches, and assessment toolkits will be used as resources during training.

### Capacity Building of Community Health Officers (CHOs)/SCD Counsellors

Health and Wellness Centres (HWCs) function as frontline facilities below the PHC level, offering community-based services and referring patients to PHCs for more advanced care. Training of CHOs and SCD counsellors located at HWCs will be conducted at the HWC level. These two-day trainings will be conducted quarterly with periodic monitoring. Training sessions will be conducted by medical officers and research staff physically at PHCs. At the end of the session, healthcare providers will also be allowed to conduct pilot counselling sessions in the presence of trainers so that the challenges they face can be discussed and trained to resolve. Capacity building of CHOs and SCD counsellors will be done in the following areas.

- Basic information on SCD
- SCD screening and counselling
- Referral for diagnosis and management
- Community awareness generation related to SCD
- Stigma and discrimination related to the disease
- Types of stigmas and its drivers
- Busting myths and misconceptions
- Psychosocial support and counselling techniques
- Demonstration of counselling

Resources: Training manuals, booklets, and videos on patient-centric approaches will be used as resources during training. The content of the training modules will be kept illustrative and easy to grasp in the local language.

### Capacity Building of Frontline Health Workers (FHW)

Training of FHWs will be conducted quarterly for 2 days with periodic monitoring. Training sessions will be conducted by medical officers and research staff physically in PHCs. Sessions will cover the following areas related to SCD.

- Basic information about SCD
- Screening and early diagnosis
- Counselling
- Awareness generation related to SCD
- Busting myths and misconceptions

Resources: Presentation, group activities, and booklets will be used as training material. The content of the training modules will be kept illustrative and easy to grasp in the local language.

### Community Health Workers (CHWs)

Training of CHWs will be conducted quarterly for 2 days with periodic monitoring. Training sessions will be conducted by medical officers and research staff offline. Sessions will cover the following areas related to SCD.

- Basic information about SCD
- Symptom recognition and referral to the nearby HWCs
- Awareness generation related to SCD
- Busting myths and misconceptions
- Counselling and guiding patients and their families

Resources: Role plays, group activities, booklets. The content of the training modules will be kept illustrative and easy to grasp in the local language.

### Community Mobilization Through Health Communication Activities

Sensitization of communities to SCD is of utmost importance to promote healthcare knowledge by busting myths and misconceptions related to the disease. However, evidence suggests that educational campaigns that provide information about the genetic aspects of an illness may sometimes have unintended stigmatizing consequences. It intensifies negative attitudes and emphasizes differentness. Hence, this will be taken into consideration while planning awareness campaigns. This study will be conducted by conducting health communication activities targeting the general community. CHWs will carry out these activities with the support and monitoring of CHOs and research staff. They will be conducted through various outreach mediums.

#### Print Material

Print material will be developed for targeting different stakeholders of this health system-led, multimodal, and multilevel intervention mentioned below. All materials will be developed in the local languages, and they will be validated and adapted following standard methods to ensure cultural and linguistic relevance. All the materials will be field-tested, which ensures that the contents of the material are complete and comprehended. Feedback from community members, including patients and their families, will be obtained to understand the content and any difficulties they

encountered in its comprehension. Based on the feedback, these materials will be revised and revised appropriately.

**For general community:** Pamphlets will be distributed to the general community and community leaders. HCWs will also distribute pamphlets to them. Poster pasting, banners, and wall paintings will be done at the community's main meeting spots, such as crossroads, healthcare facilities, gram panchayat offices, local shops, and market areas. Some volunteers from the villages will be involved in these activities if they are willing to participate. These materials will be in the local language, and most of the content will be with graphics. These activities will be conducted quarterly. The content of these materials will include the following:

- Basics of SCD
- Causes and symptoms of SCD
- Diagnosis and management at healthcare facilities
- Preventive measures
- Stigma related to SCD
- Myths/misconceptions related to SCD

**For SCD patients and caregivers:** Along with the general community, SCD patients will also be targeted separately. Among SCD patients, pamphlets and calendars will be distributed by ASHAs with supportive supervision from CHOs. These materials will be in the local language, and most of the content will be graphic. These activities will be conducted quarterly. The content of these materials will include the following:

- SCD symptoms
- SCD management at healthcare facilities
- Self-management of SCD at home
- SCD management during the crisis, and in routine
- Recognition of cues of pain crisis episodes
- Availing social security schemes
- Myths/misconceptions related to stigma
- Dealing with stigma related to SCD

**Health facility level:** Standees with information on SCD and its care will be placed at health facilities such as PHCs and HWCs for the general community and SCD patients. The content of the standees will be as above. It will be in the local language, and most of the content will be graphic. It will be given once during the intervention.

**Audio-visual media:** Audio-visual media will be utilized to target SCD patients and caregivers, especially. They will be engaged through various means, including sharing YouTube videos, research team-made Shorts and Reels, and WhatsApp messages. The main focus of this content sharing will be to empower SCD patients and caregivers to better manage their illness by providing access to the information. The photovoice technique will be used to share positive

outcomes of the patients. Research staff will share content on a one-to-one basis with the active involvement of SCD counsellors so that it can be sustained later on. These activities will be continued throughout the intervention phase. Awareness generation among the general community will also be achieved by mobile LED screens throughout the entire village. Its content will be the same as mentioned above.

Resources: YouTube videos, Shorts/reels, WhatsApp messages, LED screen.

### Outreach Programs

The general community will be reached in community events such as weekly markets and fairs. Street plays related to SCD will also be performed to generate awareness.

### Counselling of SCD Patients and Caregivers

Psychosocial counselling of SCD patients and caregivers will be done at each phase of the disease cycle to provide support in the form of informational, emotional, and affirmational support and guide them in dealing with their illness. These sessions will be conducted once a month by CHOs or SCD counsellors under the supervision of MOs and research staff. These counselling sessions will be conducted by using resources such as videos, photo voice, and lived experiences by proxy. Counselling sessions conducted at each phase and their components are described as follows:

#### Counselling During Screening/Diagnosis

Patients screened by ASHAs as potential cases of SCD and undergoing solubility or confirmatory tests will be counselled first before undergoing the tests. The components of the counselling will be the following:

- General information about the disease
- Diagnostic procedures
- Possible outcomes and their interpretation (trait/disease)

Once the patients have undergone diagnostic procedures and if the results are positive, they will be counselled again about clinical manifestations and their management as per their disease status (SCD trait/disease).

#### Pre-conception Counselling

It will be conducted in couples before conceiving a child who is at risk of having an offspring with a sickle haemoglobin gene. Couples will not be denied their right to conceive a child; instead, the focus would be to give them adequate

information to make an informed decision. The components of it will be the following:

- Effects of the sickle haemoglobin gene on newborns
- Inheritance pattern
- Adoption and other options

#### Pre-natal Counselling

Pre-natal counselling will be given to pregnant mothers and their spouses. Pretest counselling will be given to pregnant mothers going for antenatal screening for SCD. If the screening test result for the mother is positive, individual and couple post-test counselling will be provided to the patient and her spouse. The carrier status of her spouse will also be investigated. If the spouse also carries a sickle cell gene, then the couple will be counselled for prenatal diagnosis, which will help identify SCD genetic mutations in the fetus. Based on this result, counselling will be provided to the couple to make informed reproductive choices.

#### Pain Crisis Management Counselling

Adequate knowledge of the disease and its management in patients and caregivers is necessary to mitigate internalized and health-related stigma attached to it. This counselling will be focused on educating patients and their caregivers about:

- Recognition of critical symptoms and cues of the onset of crises
- Phases of pain crisis episodes
- Healthcare-seeking decisions and treatment information
- Understanding providers' instructions and information to be communicated to them
- Medication adherence and self-management
- Coping strategies
- Busting myths and misconceptions
- Diet and stress management

An interventional study by Jenerette et al. implemented a care-seeking intervention (CSI) to decrease health-related stigma among young SCD patients aged 18 to 35 [23]. The intervention component included 8-min videos on SCD patients' experiences, sharing challenges they faced while seeking care, and another video that included phases of SCD pain crisis and assertive communication skills. The study's findings suggest that the CSI was associated with significantly increased awareness of perceived total stigma and stigma by doctors compared with the attention control group [23]. Similar interventions will be conducted in the proposed study.

## Peer Support Groups

Peer support groups of SCD patients in each village will be established and facilitated by CHOs through supportive monitoring by research staff. This will provide a platform for the patients to connect with other patients dealing with similar illnesses. A safe space will be created through support groups for the patients to share their experiences and provide each other comfort and emotional support so that they can stay resilient during stressful circumstances. Support group meet-ups will be conducted once a month. Initially, the project will be planned and supported by project staff. Proactive patients, among those willing, will be encouraged to take the lead. Patients will be engaged through educational pamphlets, YouTube videos, and experience sharing.

## Awareness Campaigns at the School Level

Primary or secondary school teachers and other school staff play an essential role in the lives of school-going children with SCD. Hence, their training will be conducted to generate awareness regarding SCD and related issues and how to manage them. It will be conducted biannually by MOs and CHOs under the supportive supervision of research staff. The components of the training will be as follows:

- Basics of SCD
- Pain episodes
- Prevention of pain episodes
- Things to do if a student with SCD is unwell
- Identification of early symptoms of crisis
- Impact of SCD on patients' lives
- Academic performance of students with SCD, including absenteeism
- Role of teachers in helping students with SCD academically and socially

Once the teachers are trained, then awareness campaigns for students will also be conducted in schools, facilitated by school teachers, CHOs, and medical officers under the monitoring of research staff. These campaigns will be conducted biannually.

Resources: Educational pamphlets, presentations, videos, posters.

In addition to this, the progress of each of these implementation strategies will be assessed through Key Performance Indicators (KPI) and, at the end, through outcome indicators (Table 1). Details of each of these health system-led, multimodal, and multilevel interventions are given below.

## Process Evaluation

Conducting a comprehensive process evaluation is essential to gauge the impact and effectiveness of the health system-led, multimodal and multilevel intervention to reduce SCD-related stigma and enhance the quality of life for affected individuals [16]. The process evaluation will begin by closely examining the intervention's planning and design phases, assessing the alignment of goals and strategies with the intended objectives. This will include thoroughly examining the intervention's theoretical framework, intersectionality, intervention fidelity, and the coherence of its components. These details are presented in Table 2. The intervention explicitly integrates a gender-sensitive approach by engaging women peer supporters and ensuring that community meetings and counselling sessions address stigma and barriers specific to tribal women with SCD. Intersectional vulnerabilities, such as low literacy and geographic isolation, will be addressed by using culturally appropriate materials, flexible engagement strategies, and family-level education. These measures will ensure inclusive access and participation, particularly for women and marginalised groups. In addition, intervention fidelity will be monitored through regular field supervision, standardized training manuals, and use of fidelity checklists across sites. Monthly review meetings, documentation audits, and periodic site visits by the central implementation team will help ensure consistency and adherence to protocols. Any deviations will be addressed through retraining and corrective support.

Implementation processes will be rigorously scrutinized to identify challenges or deviations from the intended plan. Additionally, any adaptations made during implementation will be documented to discern their impact on outcomes. Mechanisms of change, or the underlying processes through which the intervention is expected to achieve the desired outcomes, will be explored. This involves a detailed analysis of the causal pathways, including how specific activities or elements contribute to changes in SCD-related stigma and improved quality of life for individuals with the disease. Quantitative measures, such as changes in stigma levels and quality of life scores, will be analysed alongside qualitative data, including participant feedback and experiences. This multifaceted approach will provide a comprehensive understanding of the intervention's impact on the target population.

The process evaluation will serve as a critical tool for assessing the overall success of the health system-led, multimodal and multilevel intervention to reduce SCD-related stigma and enhance the quality of life for affected individuals. By systematically examining the intervention's planning, implementation, mechanisms of change, and outcomes, we can gain valuable insights into its strengths and areas for improvement, ultimately informing future interventions and

**Table 1** Key-performance indicators and corresponding outcome indicators

Target population		Implementation strategy	Key Performance Indicator	Outcome indicators
Healthcare system	State, district, block health department	Advocacy	Reporting of number of sickle cell disease (SCD) patients and related indicators	Availability of SCD data
	Medical officers, Community health officers, SCD counsellor	Training sessions	- Number of medical officers and health workers attended training sessions	Improvement in SCD management
	Frontline health workers	Training sessions	- Number of training sessions conducted	Number of SCD patients under treatment and treatment adherence
	Community health workers	Training sessions	- Number of times health-care workers contacted patients/community - Competency assessment-pre vs. post	No. of referrals
SCD patients and caregivers		Psychotherapeutic counselling sessions	- Number of counselling sessions - Number of patients who attended counselling session - Duration of each session attended	- Number of patients under treatment - Improved quality of life - Improved treatment adherence - Reduced number of hospitalizations
		Peer support groups	- Number of people attending group meetings - Number of group meetings - Number of beneficiaries availing scheme	- Improvement in Knowledge, attitude and practices among the SCD patients - Improved score of stigma scale
Community	Gram Panchayat/village health, sanitization and nutrition committee	Awareness campaigns	- Number of key members involved - Number of meetings	Improvement in knowledge
	At schools	Awareness campaigns (for students) Training sessions (for teachers)	- Number of schools, teachers, students involved in activities - Number of activities related to SCD taken up by schools	- Improvement of awareness among children - Acting as change agents to carry messages to the parents
	General community	Health communication activities	- Number of people engaged, - Number of events conducted	Improvement in knowledge and awareness
	Traditional healers	Sensitization workshops	Number of traditional healers attended	Improvement in knowledge

contributing to the ongoing effort to address the challenges associated with SCD.

### Evaluation Phase

The evaluation of the study will be conducted for 3 months. The impact of this health system-led, multimodal and multilevel interventions will be assessed for stigma as a primary outcome and QoL, perceived stress, coping, and healthcare utilization as secondary outcomes. The 3-month evaluation period refers specifically to the measurement of outcomes

after the intervention rollout. This does not represent the full duration of intervention implementation or follow-up. Details of these assessment tools are given as follows. Baseline and endline assessment results will be compared to assess the impact of the interventions, finalize the strategies for incorporating them into the routine healthcare system, and scale up to other districts and states. Healthcare staff will then be encouraged to integrate into the system without operational or technical support from the research team. In contrast, the monitoring team will still concurrently monitor process outcomes throughout. Moreover, reports,

**Table 2** Details of process evaluation

Component	Advocacy	Capacity building of healthcare providers	Awareness generation and sensitization in general Community	Psychosocial support to the SCD patients and caregivers
Name	Policy advocacy for sickle cell disease (SCD) management and stigma reduction	Skill development training for SCD management	Public awareness campaigns on SCD	Individualized and family counselling facilitated peer support groups
Definition	Systematic detailed description of engagement with stakeholders to create policies enabling SCD management programs	Structured training to enhance skills and knowledge of healthcare providers or caregivers	Educating the public about SCD to reduce stigma and increase awareness of symptoms	Providing emotional and informational support to SCD patients and caregivers. Organizing regular peer-led group sessions for mutual support and experience sharing
Actor	Public health researchers, SCD experts, and community representatives	Healthcare trainers, subject experts, public health officials	Public health officials, local influencers, media agencies	Trained counsellors, healthcare providers, psychologists, peer educators, trained facilitators, social workers
Action	Conduct stakeholder meetings, present evidence-based recommendation and draft policy briefs	Develop training modules, conduct interactive sessions, and provide hands-on demonstrations	Design and disseminate culturally relevant health communication materials through multiple platforms	(How) Provide culturally sensitive counselling sessions for patients and families. Facilitate group discussions, share coping mechanisms, and create a sense of community
Action Target	State and district-level health officials, healthcare institutions, and policymakers	Healthcare workers, teachers, caregivers, and community health workers	General public, schools, workplaces, local communities	Individuals with SCD, family members, caregivers. SCD patients, caregivers, and other affected individuals
Temporality	Quarterly advocacy meetings and follow-ups during policy revisions	Biannual sessions with refresher training every 6 months	Year-long campaigns with special focus on World SCD Day (19th June)	Continuous, with structured sessions during healthcare visits. Monthly or biweekly group sessions with ongoing virtual support
Dose	At least three interactions per stakeholder group per policy cycle	5–7 h of training over 2–3 days, depending on module content	3–4 events per year, complemented by weekly media messages	Minimum of one session per patient or caregiver, with follow-up as needed. Two-hour sessions, conducted biweekly for 6 months, followed by quarterly follow-ups
Implementation outcome	Improved partnership and participation of stakeholders from different health and non-health sectors	Improved healthcare provider knowledge and skills, better patient care practices	Increased awareness, reduced stigma, and greater screening participation	Better emotional well-being, enhanced understanding of disease management. Increased emotional support, reduced isolation, and improved coping strategies
Justification	Advocacy is evidence-backed to influence resource prioritization for SCD care	Builds capacity for long-term improvement in healthcare delivery for SCD	Awareness is critical to reduce stigma and increase early diagnosis and care-seeking	Counselling addresses the psychological burden and promotes better care practices. Peer support enhances resilience and empowers individuals with shared experiences

manuscripts and policy briefs will be developed to disseminate the knowledge generated by this implementation research to policymakers and implementers.

**Proctor's Conception Model of Implementation Research (CMIR)**

In order to map an essential implementation science outcome and its inclusion during the planning phase, Proctor's CMIR was utilized. This proposed model distinguishes key implementation processes and outcomes and links them [15, 17]. The CMIR model proposes three distinct but interrelated outcomes: implementation, service, and client outcomes [17]. This proposed model, adapted for this study, is shown in Fig. 3.

**Assessment Tools**

**a. Stigma assessment scale—Indian Council of Medical Research (ICMR)-SCD Stigma Scale for India (ISSSI):** SCD-related stigma will be assessed by the ISSSI [21]. There are two versions of the tool—ISSSI-Pt for patients and ISSSI-Cg for caregivers. This is an interviewer-administered tool originally developed in English. The patient version of the tool is a 16-item survey tool to be administered in SCD patients aged above 18 years to assess stigma across the five

domains of Social Disclosure Stigma (2 items), Interpersonal Stigma (3 items), Familial and Reproductive Stigma (5 items), Illness Burden Stigma (4 items), and Healthcare Interaction Stigma (2 items). The caregiver version of the tool is for caregivers of SCD patients younger than 18 years of age. It consists of 17 items across four domains, namely, Perceived Blame and Social Judgement Stigma (8 items), Illness Burden Stigma (4 items), Judgement and Dependency Stigma (3 items), and Healthcare Interaction Stigma (2 items). This scale has been developed by our team [21].

**b. QoL assessment tools—Medical Outcomes Study Short-Form Health Survey (SF-36) and Pediatric Quality of Life Inventory (PedsQL):** SF-36 is a 36-item generic instrument assessing health-related quality of life; it has eight multi-item scales, namely, (i) physical functioning (PF), (ii) role limitations due to physical health problems (RP), (iii) bodily pain (BP), (iv) general health perceptions (GH), (v) vitality, energy, and fatigue (VT), (vi) social functioning (SF), (vii) role limitations due to emotional problems (RE), and (viii) general mental health covering psychological distress and well-being (MH) and one single item scale on health transition [24]. This scale has been validated for use in India for SCD patients [25]. This tool will be administered to adult patients above 18 years of age.

Pediatric Quality of Life Inventory (PedsQL) will be administered to children and adolescents with SCD, aged

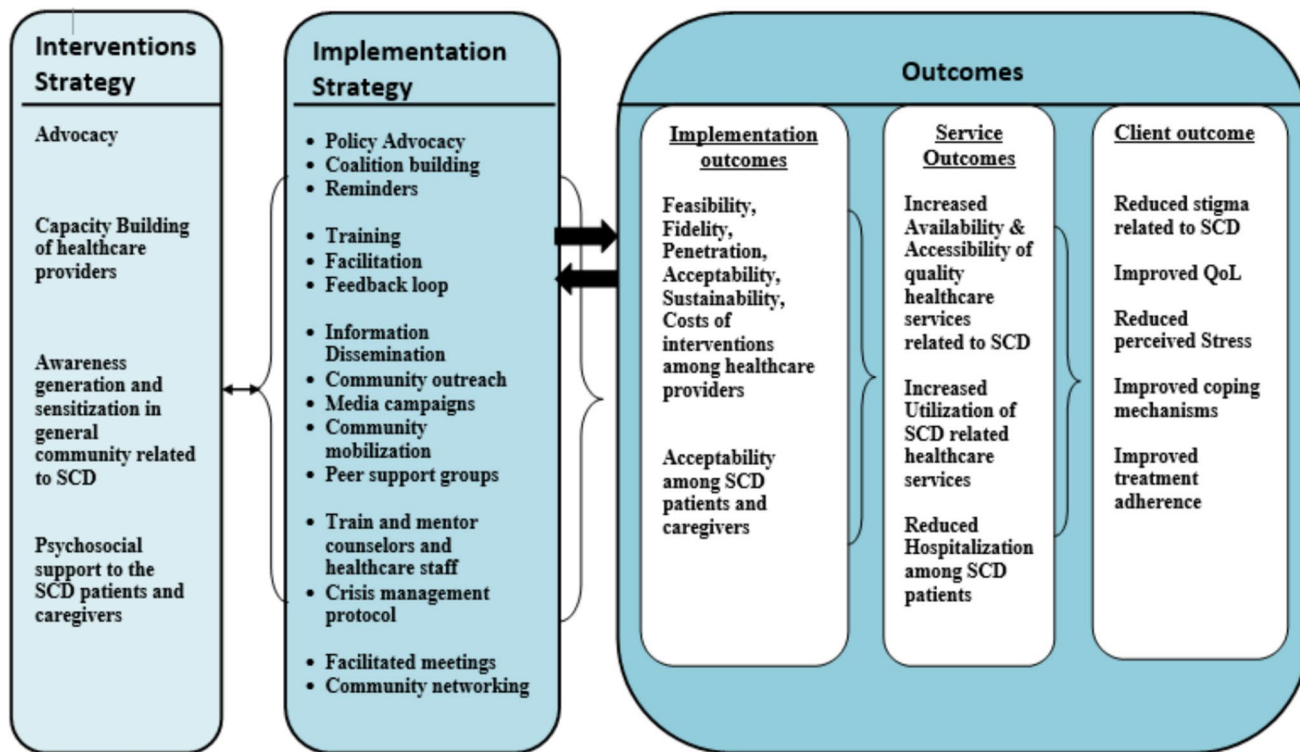


Fig. 3 Proctor's conceptual model of impact evaluation

2–18 years [26]. To assess the quality of life in diseased children and the impact of the disease on parents and family, the SCD module and Family Impact Module (FIM) will be administered, respectively [27, 28]. PedsQL 36-item Family Impact Module measures the impact of the health condition of the children on parents and family across six scales for parent self-reporting functioning, namely, (i) physical functioning, (ii) emotional functioning, (iii) social functioning, (iv) cognitive functioning, (v) communication, and (vi) worry, and two scales for parent-reported family functioning, namely, daily activities and family relationships. PedsQL SCD module consists of four versions for different age groups: Teen report (13–18 years), child report (8–12 years), young child report (5–7 years), and parent report for toddlers (2–4 years). It assesses the impact of SCD on QoL of children and adolescents across the domains of pain, pain impact, pain management and control, worrying, emotions, treatment, and communication.

**c. Subjective well-being assessment—World Health Organization-Five Well-Being Index (WHO-5):** The WHO-5, a self-report instrument measuring mental well-being, will be utilized to assess perceived QoL [29]. It consists of five statements relating to the past 2 weeks. Each statement is rated on a 6-point scale, with higher scores indicating better mental well-being. It encompasses negative aspects, in the form of depression and anxiety, and positive aspects, including contentment, satisfaction, and happiness.

**d. Stress coping/resilience assessment—Connor-Davidson Resilience Scale 10-item (CD-RISC 10):** The CD-RISC 10 is a unidimensional self-reported scale of 10 items measuring resilience [30]. The CD-RISC 10-item version with a score range of 0 to 40 comprises items 1, 4, 6, 7, 8, 11, 14, 16, 17, and 19 from the original 25-item scale, where higher scores reflect greater resilience. The reference period of the tool is 1 month.

**e. Coping strategies assessment—Coping Orientation to Problems Experienced Inventory (Brief-COPE):** Brief-COPE is a 28-item survey tool which measures strategies to cope with the consequences caused by the disease across 14 scales, namely, (i) active coping, (ii) planning, (iii) positive reframing, (iv) acceptance, (v) humor, (vi) religion, (vii) using emotional support, (viii) using instrumental support, (ix) self-distraction, (x) denial, (xi) venting, (xii) substance use, (xiii) behavioural disengagement, and (xiv) self-blame. All of these scales assess coping styles primarily across three subscales: (i) problem-focused coping, (ii) emotion-focused coping, and (iii) avoidant coping [31]. It will be administered by an interviewer to adult SCD patients aged above 18 years.

**f. Perception of stress assessment—Perceived Stress Scale (PSS):** The Perceived Stress Scale (PSS) is a 10-item tool for assessing the perception of stress [32]. The scale contains direct queries on current levels of experienced

stress. This scale contains questions on feelings and thoughts during the previous 30 days. It will be administered in adult SCD patients aged 18 years or above to assess perceived stress.

**g. Healthcare utilization assessment—Semi-structured questionnaire:** Utilization of SCD-related healthcare services will be assessed pre- and post-intervention by semi-structured interviews with all SCD patients and caregivers. It will highlight the impact of targeted health promotion interventions, including addressing self-stigma and healthcare-related stigma, as well as busting myths and misconceptions among SCD patients and their caregivers, thereby increasing healthcare service utilization.

The above tools are self-reported and will be administered by research staff. To minimize social desirability bias in administering these tools, respondents' anonymity and confidentiality will be ensured. This will encourage honest responses. Questions will be made such that they are neutrally worded and non-judgemental, avoiding sensitive or leading phrasing. Additionally, normalizing behaviors within the question context can help respondents feel less pressure to answer in socially approved ways. The research staff, who administer these tools, will be trained accordingly.

## Ethical Consideration

This study was approved by the institutional ethics committees of five institutes. These institutions are responsible for this study in the corresponding study area. All the study participants, patients, and caregivers will be informed about the intervention, and their consent will be obtained before their involvement. All data will be handled with strict confidentiality. Participants' responses will be de-identified and stored securely. Interviews involving sensitive topics, such as reproductive counselling, will be conducted in private settings by trained, gender-sensitive staff.

## Expected Outcomes

The primary expected outcomes of the study include a reduction in both the overall mean stigma score and individual domain scores as measured by the ISSSI, as well as a decrease in the proportion of individuals experiencing severe stigma and the severity of stigma among them. The intermediate outcome anticipated is an increase in the utilization of healthcare services related to SCD within the community, facilitated by improvements in the quality of service delivery. Secondary expected outcomes of the study include improved QoL, well-being, and resilience among individuals with SCD and their caregivers, reduced perceived and experienced stress levels among adult patients, and enhanced coping mechanisms for managing SCD-related challenges.

## Discussion

Despite the growing recognition of SCD as a significant public health concern in India and elsewhere, there remains a critical gap in addressing the psychosocial dimensions of the disease, particularly the pervasive stigma faced by individuals living with SCD and their caregivers. While the clinical burden of SCD has been well documented, the stigma attached to the illness continues to influence healthcare access, delay treatment, and diminish quality of life [1, 4, 6, 13]. Existing stigma reduction efforts in India have primarily focused on awareness generation or disease control without structured health system–led interventions that target stigma at multiple levels. This study was therefore conceptualized to develop, implement, and evaluate a comprehensive, health system–led, multimodal intervention aimed at reducing SCD-related stigma, with the ultimate goal of improving patient outcomes and strengthening the continuum of care.

The stigma associated with SCD is complex and multifactorial, rooted in sociocultural beliefs, structural healthcare inequities, and a lack of public and professional awareness [4, 5, 7]. Prior studies have shown that stigma manifests across various dimensions, including enacted stigma within healthcare settings, internalized self-stigma, and perceived societal judgment—all of which contribute to adverse health outcomes, psychosocial stress, and reduced health-seeking behavior [6, 8, 9, 13]. The findings of Jenerette et al. and Bulgin et al. underscore the strong associations between stigma and depressive symptoms, poor self-management, and increased hospitalizations among SCD patients [4, 12].

To address this, our study will employ a multilevel implementation approach rooted in the ToC framework [14] and will be evaluated through Proctor’s CMIR [15–17]. The intervention will integrate six core strategies—policy advocacy, provider training, community mobilization, counselling, peer support, and school-based awareness activities—each tailored to address a specific layer of stigma and mapped to key stakeholders. Pre- and post-intervention outcomes will be assessed using a robust set of tools, including the ISSSI for stigma, SF-36 and PedsQL for QoL, WHO-5 and CD-RISC 10 for well-being and resilience, and the Brief COPE and PSS for coping and stress evaluation, respectively. These measures reflect the study’s commitment to evaluating both clinical and psychosocial dimensions of impact.

Engaging policymakers and program managers at the district and state levels enables the institutionalization of stigma-sensitive practices, such as screening, stigma-reducing communication, and counselling provisions, within the National SCD Elimination Mission [33]. Previous efforts in reducing HIV and leprosy stigma demonstrate that sustained policy engagement can drive systemic change [22, 34, 35].

The emphasis on training healthcare providers is a key element in combating enacted stigma within the health system. Educational interventions have consistently improved knowledge, attitudes, and patient-provider interactions [36–38]. By delivering structured training sessions to medical officers, CHOs, SCD counsellors, and CHWs, this intervention will leverage frontline healthcare staff as change agents to improve care quality and reduce discriminatory practices. A randomized pretest/post-test study reported improvement in providers’ attitudes toward SCD patients after watching an 8-min educational video [36]. Interprofessional-focused educational modules implemented for nurses and nursing staff also reported enhanced knowledge post-intervention, influencing providers’ perceived attitudes toward SCD patients [37]. An integrative review conducted by Reich et al. included nine intervention studies conducted to improve providers’ attitudes and perceptions of SCD patients [38]. Even though they implemented different modes of interventions and measured their impact differently, they all concluded that educational interventions improved providers’ knowledge and/or attitudes [38].

Community-based IEC activities and peer support groups played an important role in addressing perceived and internalized stigma. Unlike traditional awareness campaigns that may inadvertently reinforce stigma through biomedical framing, this intervention used participatory methods such as photovoice, storytelling, and culturally adapted materials to emphasize lived experiences, resilience, and inclusion [7, 22, 39]. The consensus study report, “Addressing sickle cell disease: A strategic plan and blueprint of action,” highlighted the role of public education and awareness in demystifying an illness [39]. Community-wide interventions are essential for addressing enacted stigma and shifting cultural norms [40]. Leveraging the influence of local leaders, religious figures, and health volunteers has reduced stigma in diseases such as leprosy, TB, and HIV in India [7, 41]. For SCD, where local myths about inheritance, reproduction, and contagion persist, culturally grounded mobilization is vital to promote collective empathy and support, and these efforts are expected to create attitudinal shifts within the community and build collective ownership around SCD care.

Counselling interventions have proven effective in reducing internalized and familial stigma, especially when tailored to cultural and gender contexts [22]. For SCD, counselling helps individuals and caregivers reframe the illness, address myths about reproductive risks, and build resilience [36, 42]. In India, counselling is often underutilized in non-HIV settings, making this component particularly innovative and necessary [34].

School-based interventions are essential for addressing stigma early in life by shaping the knowledge, attitudes, and behaviors of children and adolescents. These interventions

are particularly relevant for genetic conditions like SCD, which are often misunderstood and stigmatized due to myths surrounding ancestry, contagion, and disability. Evidence from HIV, epilepsy, and leprosy-related stigma interventions shows that school-based health education can significantly reduce discriminatory attitudes and increase empathy and inclusion. For SCD, targeting school environments is critical because children with SCD often face bullying, absenteeism, and educational disruption. Teachers and peers may misinterpret symptoms (e.g. fatigue, pain crises) as laziness or disinterest. Educating peers fosters an inclusive environment and reduces enacted stigma. Engaging teachers as advocates further reinforces stigma-free practices and normalizes chronic illness management in educational settings.

Peer support is a well-documented, cost-effective strategy for addressing internalized and perceived stigma and enhancing self-efficacy among individuals with chronic conditions [43]. In SCD, peer interactions provide a safe space for shared experiences, emotional support, and identity affirmation. Research from the USA and sub-Saharan Africa suggests that peer-led interventions improve self-management, reduce isolation, and foster resilience in people with SCD [8, 10]. In the Indian context, peer support is particularly impactful in tribal and rural communities where formal mental health infrastructure is limited and stigma is reinforced through social silence.

While this health system-led, multimodal and multilevel intervention is innovative and grounded in implementation science, a few limitations warrant mention. The study's focus on five SCD-endemic, predominantly tribal districts may limit the generalizability of findings to urban or non-tribal populations. Moreover, although strong efforts have been made to institutionalize the intervention within existing healthcare systems, long-term sustainability will depend on continued political will, cross-sectoral collaboration, and integration into routine public health programs and the SCD care program. Another issue is that the absence of a comparator or control group limits the ability to attribute observed changes solely to the intervention. However, given the real-world, systems-level nature of this implementation research, a pre-post design is considered appropriate in implementation research to evaluate feasibility and preliminary outcomes of the interventions.

Despite these limitations, this research provides a replicable model for stigma reduction in chronic illnesses through the health system. As all patients and their families are covered within the study area, there will be limited risk of generalizability within the study area. By centring the intervention on stakeholder engagement, contextual adaptation, and rigorous evaluation, it offers a pathway to scale and sustainability. Although the proposed health system-led, multimodal, and multilevel intervention is resource-intensive and includes multiple components, its design emphasizes

feasibility and sustainability. Key strategies—such as integration into existing public health systems, task-sharing with health workers, and the use of community-based peer groups—enhance scalability and reduce long-term costs. While a formal cost-effectiveness analysis was not conducted in this study, leveraging existing infrastructure and aligning with national health programs are likely to support cost-efficient implementation in resource-limited settings. The findings from this study will contribute to national policy and programmatic planning for SCD, with broader implications for addressing health-related stigma in other low-resource settings and stigmatized conditions.

## Conclusion

This study will demonstrate that a health system-led, multimodal, and multilevel intervention can effectively address the complex stigma associated with SCD in India. By integrating policy advocacy, provider training, community mobilization, culturally grounded counselling, peer support, and school-based education, the intervention will target stigma at individual, interpersonal, and structural levels. The use of implementation science frameworks will ensure contextual adaptation and stakeholder ownership, contributing to the feasibility and acceptability of the approach. While challenges remain in ensuring long-term sustainability and broader applicability, the findings will offer a replicable model for embedding stigma reduction into routine health services. This approach will have significant implications for advancing person-centred care and improving outcomes for individuals living with SCD and other stigmatized chronic conditions.

**Author Contribution** All authors made a significant contribution to the publication, including input into the conception, study design, implementation, data collection and/or analysis, and interpretation; participated in drafting, revising, or critically reviewing the manuscript; agreed on the journal to which it has been submitted and approved the final submitted version; and agreed to be accountable for all aspects of the work.

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**Data Availability** Data/material will be available on request to the corresponding author, with a reasonable request.

**Code Availability** Not applicable.

## Declarations

**Ethical Approval** This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics

Committees of the respective authors' institutions, and all these ethics committees approved the study protocol for these study districts.

**Consent to Participate** Informed consent was obtained from the participant included in the study.

**Consent for Publication** The authors affirm that the participant provided informed consent for publication of information/quotes in this study.

**Conflict of Interest** The authors declare no competing interests.

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