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Sickle cell anaemia control mission: Implementation of a comprehensive care model in Anuppur, Madhya Pradesh

Sickle Cell Anaemia Control Mission Technical Group[#]

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***Background & objectives*: Sickle cell disease (SCD) is a common genetic disorder, predominantly found in the tribal population of India. The examples of models providing comprehensive care and management to individuals with SCD in public health facilities are sparse. The Sickle Cell Anaemia Control Mission is one such model implemented by Jan Swasthya Sahyog, a non-profit organization in collaboration with the National Health Mission in the Anuppur district of Madhya Pradesh. This article aimed to identify the key learnings from this programme that can guide the public health system strengthening with respect to SCD.**

***Methods*: The Sickle Cell Anemia Control Mission Programme included door to door screening for anaemia, SCD and blood group. SCD cases were included in the programme and other individuals with Anemia were referred for further care. Care for individuals with SCD included counselling, provision of hydroxyurea, regular follow up of clinical parameters and management of complications. Care for individuals with SCD was provided through monthly patient support group (PSG) meetings and regular outpatient /in-patient care at public health facilities. Quantitative data on programme design, screening and patient management collected during programme implementation were used for analysis.**

***Results*: A total of 39421 persons were screened in 18 months (August 2018-March 2020). Of these 81.9 per cent persons were anaemic, 16.9 per cent had sickle cell trait and 779 (1.98%) had SCD. Eighty-six already diagnosed individuals joined the programme for care. People from all caste categories were diagnosed with SCD. Out of 865 individuals with SCD, 157 underwent regular 9-11 months follow up and showed improvement in clinical symptoms and drug compliance.**

***Interpretation & conclusions*: Central India has a significant burden of anaemia and SCD. This study found that SCD is present in non-tribals as well. PSGs are an efficient way to deliver non-emergency care for chronic diseases such as SCD.**

Key words Comprehensive care - haemoglobinopathy - India - Madhya Pradesh - patient support group - sickle cell anaemia/disease - sickle cell disease

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Sickle cell disease (SCD) is a common genetic disorder not only in India but globally[1,2]. Individuals with this illness suffer from painful complications, including acute chest syndrome, stroke, dactylitis, bone pain, infections, and splenic sequestration crisis from early childhood. Comprehensive care and

early detection enable a normal, healthy life. So far, there have only been a few successful models for comprehensive care provision to individuals with SCD in different parts of India and across the world[3].

One of the successful models for comprehensive care for SCD is through a community-driven care network at Gudalur and Pandalur in the Nilgiri hills[3,4]. The model is run by the Non-Government Organizations Association for Community Cooperation and Rural Development (ACCORD) and the Association for Health Welfare in the Nilgiris (ASHWINI) with the help of the Tamil Nadu government[3,4]. This model had provision for hydroxyurea for all SCD-affected individuals, regular follow up, in-patient care for complications using standard protocols and a pneumococcal vaccine for children. Many aspects of this intervention involved active participation from the community. Starting from planning to organization and staffing of the services involved significant local participation. This was considered to be an important reason for the success of this intervention.

The Society for Education Welfare and Action-Rural (SEWA Rural) model[5] screened pregnant women, newborns and family members. Regular follow up of affected individuals was undertaken along with baseline and end-line surveys for clinical symptoms of the disease in this model. The care involved outpatient department (OPD) care with provision for hydroxyurea, regular follow up, penicillin prophylaxis and pneumococcal vaccination for children and in-patient care within the hospital with standard treatment protocols.

The Cuban experience is particularly relevant from a middle-income country perspective[6]. Their public health system emphasises screening pregnant women, identification of at-risk couples, and screening foetuses.

The sickle cell gene is widespread among the rural tribal community of central India[7,8]. Madhya Pradesh (MP) has 10-33 per cent gene prevalence in 27 tribal predominant districts[9]. It is estimated that 9,61,492 tribal people have sickle cell trait and 67,861 have SCD in MP[9]. Access to healthcare is poor in these tribal predominant districts of MP. Public health facilities, if strengthened and functional, are the only refuge for this population. Maternal Death Reviews conducted by Jan Swasthya Sahyog in collaboration with district government health officials in the selected districts of eastern MP (unpublished data), including Anuppur, suggested the possibility of several of these unexplained maternal deaths to be due to SCD and its complications. Anuppur is one of the marginalized districts of MP, with a 47.9 per cent tribal population. Many SCD individuals from Anuppur and other bordering districts seek care at JSS Hospital. Thus, Anuppur was selected for this intervention. JSS decided to work with the public health system to build a sustainable system for screening, diagnosis and comprehensive management of SCD rather than a parallel, non-government entity-run system.

The present study was conducted with the objectives of understanding the anaemia status, demographic profile (age, sex and caste distribution), disease presentation and severity of SCD in this selected population, the effect of PSG meetings on patient management and how to operationalize comprehensive management of SCD in public health facilities. Learnings from this work and study would help strengthen the public health system to take up this challenge.

Material & Methods

This study was undertaken as a retrospective evaluation of an ongoing programme, Sickle Cell Anaemia Control Mission by Jan Swasthya Sahyog (JSS), Chattisgarh, under the purview of the Memorandum of Understanding (MoU) between JSS and National Health Mission (NHM) Madhya Pradesh (dated January 20, 2017). As this is an ongoing programme, a part of the study findings presented in this article were published by JSS on their website[10]. The intervention was started on August 1, 2018 and is still underway and functional. This study considered the data till March 31, 2020. Quantitative data from the programme database and reports were utilized for this study. The intervention was broadly divided into the following two parts[10].

Part 1: *Screening, diagnosis and management of SCD by Project Management Unit (PMU)*: Door-to-door screening for anaemia and SCD was done in pregnant women, school children, first-degree blood relatives of solubility-positive cases and spouses of solubility-positive pregnant women in Anuppur district. Haemoglobin (Hb) estimation by copper sulphate method, blood grouping, and sickle cell solubility test were done for screening. Detailed consents were taken before blood sampling and information was collected in an offline android application, Avni (*https://play.google.com/store/apps/details?id=com.openchsclient&pcampaignid=web_share*). If Hb was less than or equal to 7 g/dl, 40 µl blood was used instead of 20 µl for solubility testing, as the presence of

fewer red blood cells in the blood of severely anaemic individuals could lead to a false-negative solubility test. All samples were stored in iceboxes/refrigerators. All positive samples were sent for Hb electrophoresis using a low-cost [Price - Indian Rupees (INR) 14,000 per test cost INR 25] agarose gel-based Hb electrophoresis machine (developed in-house). Samples where Hb electrophoresis results were inconclusive were sent for high-performance liquid chromatography (HPLC) test and revealed sickle beta-thalassaemia. Individuals who were anaemic and had a solubility test negative were referred for further investigation and management. A flowchart of the activities mentioned above has been published as picture 2 of the sickle cell disease project report on the JSS website[10].

The management of SCD individuals was facilitated by the PMU team in various ways such as counselling, patient support group (PSG) meetings, coordination in case of hospitalization and arrangement of blood whenever needed. A baseline form with the individual's clinical details was filled initially by a counsellor when he/she got enrolled in the programme. Hydroxyurea[11], folic acid and pain management drugs were provided through PSG meetings with proper counselling. In these meetings, the individual's previous month's follow up, which included clinical details such as joint pain, chronic pain, abdominal pain, shortness of breath, fatigue, fever, blood transfusion, hospitalization in the last three months and compliance to hydroxyurea were collected in the paper form which was later digitized in spreadsheets. PSG meetings are the place where individuals get a safe space to express their problems and learn from others' experiences, who were in similar situations. Those who missed their PSG meetings took their medicines from a nearby primary health centre (PHC)/Community Health Center (CHC)/ District Hospital (DH) and the counsellor visited their homes for follow up. The counsellors remained in touch with all individuals *via* telephone or through the accredited social health activist (ASHA) and tried to regularly visit those with severe symptoms. A helpline number was provided and they were assured 24×7 services.

Part 2: *Strengthening public health system for the diagnosis and management of SCD (training and mentoring)*: Before the start of the project, except few medical colleges and research institutions, there was no government health facility in the whole MP which was providing screening, diagnostics, treatment, or management services for sickle cell patients. Thus, the government health facilities were supported *via* training and mentoring of laboratory technicians, staff nurses and doctors on the diagnosis and management of SCD. Monthly data from government facilities were collected for screening, diagnosis and medicine usage. This was later analysed to build better strategies with the local officials[10].

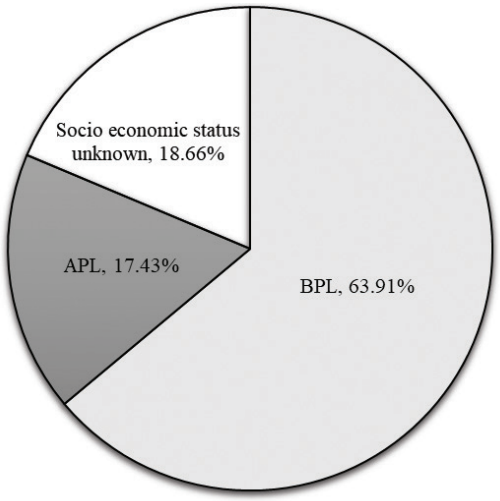

Fig. 1. Economic status of screened population. BPL, below poverty line; APL, above poverty line.

For the purpose of this study, all programme monitoring indicators were collected from previous reports and the Avni platform. Data analysis was done using Microsoft Excel (2019).

Results

Anaemia and SCD screening: Intensive screening by PMU was done over 18 months (up to March 31, 2020), in 585 villages of the Anuppur district. Anuppur district has a population of 0.749 million, according to the 2011 census[12]. As per the population growth estimates, the population in 2021 should have been 0.828 million. A total of 39,421 people were screened during the specified period. This was 4.76 per cent of the estimated population in 2021. About 63.91 per cent of screened persons were below poverty line (BPL) (Fig. 1). In all 35,296 screened participants, including cases (865) disclosed their caste status which showed scheduled tribe (ST)-51.2 per cent, other backward class (OBC)-38.3 per cent, general-8.4 per cent and scheduled caste (SC)-2.1 per cent persons.

Broadly, as per the World Health Organization guidelines[13] for the diagnosis of anaemia, 81.91 per

Table I. Anaemia status among screened persons

Type of person	Sex	Total sample	Total screened persons				Hb data not available
			<7 g/dl, n (%)	7-9 g/dl, n (%)	9-11 g/dl, n (%)	>11 g/dl, n (%)	
1. Pregnant women	Female	11,814	42 (0.36)	4125 (34.92)	6884 (58.27)	217 (1.84)	546 (4.62)
2. Children	Male	8083	6 (0.07)	828 (10.24)	4941 (61.13)	2299 (28.44)	9 (0.11)
	Female	9451	12 (0.13)	1037 (10.97)	6121 (64.77)	2268 (24)	13 (0.14)
3. Relative and other	Male	3656	20 (0.55)	645 (17.64)	1969 (53.86)	561 (15.34)	461 (12.61)
	Female	6417	29 (0.45)	2047 (31.9)	3584 (55.85)	289 (4.5)	468 (7.29)
Total sex wise (1+2+3)	Male	11,739	26 (0.22)	1473 (12.55)	6910 (58.86)	2860 (24.36)	470 (4)
	Female	27,682	83 (0.3)	7209 (26.04)	16,589 (59.93)	2774 (10.02)	1027 (3.71)
Total (male+female)		39,421	109 (0.28)	8682 (22.02)	23,499 (59.61)	5634 (14.29)	1497 (3.8)

Hb, haemoglobin

Table II. Sickle cell trait and SCD status among screened persons

Serial number	Type	Total screened persons	Sickle cell trait, n (%)	SBT, n (%)	SCD, n (%)
A	Pregnant women	11,814	1690 (14.31)	0	75 (0.63)
B	School children	17,534	2368 (13.51)	2 (0.01)	111 (0.63)
C	Family members and others	10,073	2619 (26)	5 (0.05)	593 (5.89)
Total screening (A+B+C)		39,421	6677 (16.94)	7 (0.02)	779 (1.98)

SBT, sickle beta-thalassaemia; SCD, sickle cell disease

cent (32,290/39421) of the screened individuals and 93.54 per cent (11,051/11,814) of the screened pregnant women were found to be anaemic (Table I) Copper sulphate method was used for Hb estimation at the field level, which provides Hb in ranges as mentioned in Table I (depending on the concentration of copper sulphate solution used). Solubility testing, Hb electrophoresis and HPLC found 779 (1.98%) individuals with SCD, 6,677 (16.94%) sickle cell trait and 7 (0.02%) with sickle beta-thalassaemia (SBT) out of 39,421 screened persons (Table II).

Screening first-degree relatives of SCD individuals and sickle cell trait individuals was more productive. Eighty six individuals diagnosed outside the programme were included in the programme for care. Thus, the programme had 865 individuals with SCD during the study period. The caste distribution in SCD individuals was ST-31.03 per cent, OBC-50.88 per cent, general 15.83 per cent and SC-2.26 per cent. Age distribution of SCD individuals showed that 56 per cent were below 18 yr and only 12 per cent were above 30 yr. A higher number of school children screened during this intervention could also have led to this pattern of age distribution (Table III). The management of these identified individuals was done through the monthly PSG meetings. A total of 63 PSG meetings were held at five locations, namely DH, CHC Kotma, CHC Rajendragram, CHC Jaithari and CHC Karpa. All individuals were not able to attend the meetings regularly and a few received care through regular outpatient clinics at DH and CHCs as well.

Table III. Age distribution of all SCD individuals

Age group (yr)	Number of SCD individuals n (%)
0–6	57 (7)
7–18	426 (49)
19–30	281 (32)
31 and above	101 (12)
Total	865

Out of 865 SS cases, clinical information in this period was recorded for 580 individuals with SCD. According to the information provided during the first visit at the PSG meeting or home visit for 580 individuals with SCD, the most common symptoms were joint pain (37.18%), chronic pain (12.64%), easy fatigability (49.08%), pallor (47.04 %), and abdominal pain (22.42%), shortness of breath (14.84%) and fever (28.25%). A total of 115 individuals had received a blood transfusion, and 56 received repeated transfusions

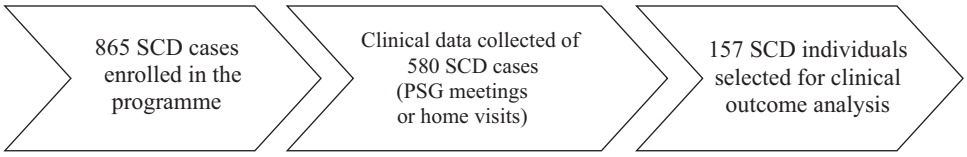

Fig. 2. Flow diagram for the selection of SCD cases for assessing clinical improvement. SCD, sickle cell disease; PSG, patient support group.

Table IV. Age distribution of 157 SCD individuals selected for assessing clinical improvement

Age group (yr)	Number of SCD individuals, n (%)
0–6	47 (30)
7–12	90 (57)
13–18	20 (13)

(>2 in the last year from the time of baseline). One hundred thirty eight individuals required hospitalization, with 63 requiring repeated hospitalizations (>2 in the last year from the time on baseline). Around 83.89 per cent of individuals with SCD were not receiving hydroxyurea or any specific management for the disease at the time of entering the programme.

For the purpose of closely analyzing the improvements in the clinical condition, a set of 157 individuals were selected on the basis of the following criteria: *(i)* at least nine months of enrollment in the programme (enrolled before June 2019), *(ii)* at least four PSG visits (may not be continuous), *(iii)* last support group meeting/home visit done between November 2019 and March 2020 (Fig. 2). Out of these 157 SCD individuals, 87 were males and 70 were females and all of them below 18 yr of age (Table IV).

We found that within 9-11 months of their enrolment in the programme, average weight increased by 8.07 per cent among these 157 SCD individuals (baseline average weight was 31.97 kg and end line average weight was 34.55 kg). Out of these 157 SCD individuals, only 34 individuals were using hydroxyurea at baseline (data not available for 15 individuals). At the end of 9–11 months of follow up, all were taking hydroxyurea regularly. Enrolment in the programme thus benefitted individuals by improving their average weights, usage of hydroxyurea, a significant reduction in their burden of symptoms and reduced requirements for blood transfusions or hospitalisation (Table V).

Status of government health facilities and other benefits: Thirty two doctors (11 from DH, 8 from 4 CHCs, 3 from PHCs, 9 from Rashtriya Bal Suraksha Karyakram (RBSK) teams, and 1 private doctor), 15 lab technicians (4 from DH, and 11 from 7 CHCs), and 20 staff nurses of DH were trained in the screening, diagnosis, and management of the disease.

As of March 31, 2020, five government facilities (1 DH and 4 CHCs) were providing screening facilities, two facilities (DH and JSS laboratory) were providing confirmatory tests and six facilities (1 DH and 5 CHCs) were providing treatment services to those diagnosed with the disease.

Fringe benefits of the intervention included *(i)* Solubility kits were brought in the State rate contract, so that they were available readily for procurement by any district *(ii)* Information Education and Communication (IEC) material was developed, such as standard treatment protocols for doctors[11], and diagnosis (testing) protocols for laboratory technicians[14] and patients counselling book (Hindi), SCD *Kundali* (Risk prediction)[15], besides flexes and pamphlets for awareness.

Discussion

Prevalence of anaemia among the screened population was found to be 81.9 per cent, which is significantly higher than National Family Health Survey-5 (NFHS-5)[16] estimates for MP. NFHS-5 mentions 52.9 per cent anaemia among pregnant women in MP, while the study found 93.5 per cent anaemia prevalence in pregnant women. This could possibly be attributed to the poor socioeconomic status of the population under study.

This study screened 39,421 individuals, which included family members of the SCD individuals and traits. A total of 6677 (16.9%) were found to have sickle cell trait and 779 (1.98 %) SCD. This screening strategy may not be representative of population prevalence in the district because of family screening. However, it does point towards the magnitude of the problem. SEWA Rural screened 7832 individuals and diagnosed 182 (2.3%) SCD cases[5]. They screened pregnant women, newborns of mothers with SCD, family members of individuals with SCD and those with anaemia and symptoms of SCD presented at their hospital. Our strategy entailed community-

Table V. Clinical symptoms reported by selected 157 SCD individuals as per the inclusion criteria

Symptoms	Baseline, n (%)	End line, n (%)	Reduction n (%)	χ^{2*}
Joint pain (last one month)	67 (47.1)	49 (34.51)	26.87	5.35
Chronic pain	34 (23.9)	10 (7.04)	70.59	6.24
Abdominal pain (last one month)	56 (39.44)	32 (22.54)	42.86	10.17
Shortness of breath (last one month)	39 (27.46)	19 (13.38)	51.28	8.2
Fatigue (last one month)	101 (71.13)	52 (36.62)	48.51	29.92
Fever (last one month)	49 (34.51)	26 (18.31)	46.94	9.13
BT (last three months)	20 (14.08)	4 (2.82)	80	9.375
Hospitalization (last three months)	24 (16.9)	7 (4.93)	70.83	10.24

P calculated using MacNemar test, $P^* < 0.05$ (comparison between baseline and endline of the clinical parameter); BT, blood transfusion

based screening of all pregnant women, school going children and family members for SCD and sickle cell trait. Meanwhile, public health facilities were equipped and underwent training to conduct testing of affected individuals and pregnant women. Since 2023 onwards, newborn screening is also planned. The non-governmental organizations ACCORD and ASHWINI screened 9646 Adivasis in Tamil Nadu, out of which 1089 (11.3%) were sickle cell trait and 137 (1.4%) had SCD[3,4]. They screened all persons below the age of 30 yr in the village.

This study demonstrates the presence of the sickle cell gene among all caste categories, including SC, OBC and other castes. This possibly has happened due to migration, inter-caste marriages and reduced forest cover. Similar results were found in a study conducted in Maharashtra and Odisha[17]. Few publications mentioned that SCD manifestations are milder in India than in Africa[9,18]. However, we found a high prevalence of severe disease manifestations like pain crises, hospitalizations, and blood transfusions. This is suggestive of the fact that there is a spectrum of disease severity and a significant number of individuals with SCD in the intervention area have serious disease manifestations. Among the 164 individuals followed up for one year by SEWA Rural, 72 (43.9%) had SCD pain crises, 59 (35.9%) were hospitalized, 43 (26.2%) received blood transfusions, and 3 (1.8%) died during one year follow up[5]. Nineteen premature deaths among 111 patients were reported by ACCORD and ASHWINI. The median age of patients who died prematurely was 23 years[3].

After enrollment into the programme, we observed a reduction in multiple clinical parameters, including pain crisis and hospitalizations. However, in the absence of a pre-post-study design, a causal association cannot be established. A significant reduction in the proportion of individuals with repeated pain crisis and hospitalization was observed by SEWA Rural after patients entered into their comprehensive care programme[5]. Peer support group meetings have been found to be useful in chronic diseases, including haematological diseases[19,20]. In our programme most participants received OPD level care *via* PSG meetings, which provided not only clinical but also psychological support and counselling that are crucial in improving quality of life. PSG meetings allowed government doctors and members of the project team to learn about the problems of these patients and through this therapeutic alliance advise and manage them.

Evidence-based SCD management is almost absent in most resource poor settings in India[19]. A cross-sectional study[8] conducted on SCD emphasises the need to develop tailor-made solutions in endemic areas like Gadchiroli, Maharashtra due to the prevalence of sickle gene among backward and marginalized communities[21]. Many population based research studies have been conducted among different communities in India[22]. Still, there are only a few comprehensive programmes for the management of SCD. SEWA Rural, ASHWINI, and JSS have such programmes for SCD patients within their community programme[3,5,10]. All the models described had a few common components like *(i)* antenatal and family screening, *(ii)* outpatient care-regular follow up, laboratory tests, amoxicillin prophylaxis, pneumococcal vaccination and hydroxyurea[23], *(iii)* in-patient care using standard treatment protocols.

Our public health system needs to be strengthened, especially in most rural and tribal regions. Another study demonstrated the gap in health systems around SCD in India[2]. The present study demonstrated the

feasibility of the implementation of a comprehensive sickle cell anaemia programme within the public health system in a remote rural tribal area of India. SCD screening, diagnosis and comprehensive management are possible even with limited resources. The support of a technical (health) civil society organization partner is crucial in implementation, especially in the initial phase when screening and management are done in mission mode as the health system ramps up its capacity. This includes training of doctors, nurses, laboratory technicians, as well as supply of essential reagents and testing equipment and drugs.

A hub-and-spoke model can be used to screen at the Health and Wellness Centers (HWC) and PHCs, while diagnostic testing and initiation of appropriate management is done at the DH and first referral unit (FRU) where facilities for Hb electrophoresis/HPLC should be made functional. Outpatient care *via* PSG meetings conducted by medical officers, staff nurses, laboratory technicians and counsellors should be provided up to the PHC level. The facilitation and coordination of these PSG meetings by counsellors can also be coordinated by the government teams under *Rashtriya Kishor Swasthya Karyakram* (RKSK) and RBSK.

Management of complications remains a challenging area for public health facilities in these remote districts, as it requires significant clinical expertise. Standard treatment guidelines and regular as well as refresher training of medical officers and specialists are key to achieving this. However, we found this to be challenging despite available standard treatment guidelines, which were disseminated to the doctors through training. Civil Society Organizations will continue to have an important role in the close follow up of these patients, providing immediate help during acute episodes through a helpline and ensuring continuity of treatment. Counselling, support and advocacy by the counsellor help to improve care during admissions.

Furthermore, some of the limitations of the present intervention were the inability to incorporate antibiotic prophylaxis and vaccination into the comprehensive care package. All pregnant women could not be screened due to their non-availability during field visits. As school screening was started later during the programme, only a small percentage of children could be screened. The approach of this intervention was targeted screening; thus the study was unable to provide population-based prevalence estimates. Part of the findings presented in this article has been published by the JSS on their website[10].

Overall, after evaluating the profile of the Sickle Cell Anemia Control Mission Programme, it was found that the targeted screening of pregnant women, children and family members of sickle cell traits and individuals with SCD is cost-effective, time-saving, and helps reach needy people in a short span. As the disease or carrier status is identified earlier in this select group, the health benefits are immediate. Agarose gel-based Hb electrophoresis is a cost-effective method of confirmatory diagnosis. Sustained training and mentoring of laboratory technicians is necessary to establish diagnostics up to PHCs. Screening and management of SCD have to go hand in hand from the beginning. An uninterrupted supply of diagnostics and medicines up to PHCs is essential to provide care. PSG meetings are cost and time-efficient techniques to deliver all aspects of care under one roof while keeping the affected individual at the centre of the care pathway. Patient education and counselling are important in care. Thus, counsellors/patient care coordinators dedicated to SCD at every block are essential to facilitate the care of this chronic disease. Continuous training and mentoring of medical officers and specialists, especially at the level of DH/FRU, is essential to manage complications. Strengthening and capacity building of the public health system, involvement of a technically sound Civil Society Organization with specific functions and community participation are the unique features of this model which make it sustainable and scalable. Screening without the provision of comprehensive care in the public health system is unethical and best avoided.

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