7th National Summit on Good and Replicable Practices and Innovations in Public Health Care Systems in India
(Category: Health Programs)

Sickle Cell Anemia Control Mission

National Health Mission, Madhya Pradesh
in technical collaboration with
Jan Swasthya Sahayog

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❖ Introduction

Sickle cell anemia is a common genetic blood disorder which not only impacts a person's normal development but could be fatal in nature if untreated early. Believed to have originated from an unnatural mutation of red blood cells to form a defense against malaria parasites, the disease is marked by the production of a greater number of sickle-shaped RBCs in an affected person's body, which survive only 15-30 days, compared to120 days for the normal RBCs. Due to the short lifespan of the red blood cell, a person with the disease often suffers from blood deficiency and may require frequent blood transfusion. Apart from inhibiting a person's natural growth, it also brings about severe pain crises, acute chest syndrome, high-grade fever, and occasional swelling in different parts of the body, limiting his activities and lifestyle severely and often leading to premature death.

❖ Need/Rationale

Madhya Pradesh has the highest burden of sickle cell anaemia in India. While working with the public health system during Maternal death reviews we found that there were a significant number of maternal deaths happening which could be ascribed to Sickle Cell Disease (SCD). In Anuppur we found that some children died with the symptoms of SCD and many women having multiple abortions, had features of SCD. But all of them remained undiagnosed because of non-availability of screening, diagnosis, counselling, treatment & management facilities for this important disorder in the public health system. Even a few patients who had been diagnosed from the private set up (mostly from bigger cities outside MP) were not receiving any regular treatment as it was not affordable, and even proper counselling was unavailable. The only life saving drug for this ailment, Hydroxyurea has also not been in the practice of doctors due to lack of awareness among them. Sickle Cell Disease and its consequences were accepted as their destiny. An ICMR study done in 2007 found that 10%-33% of the tribal population in Madhya Pradesh is sickle gene affected, & 0.70% are sickle diseased (SS/Homozygous). If proper screening & diagnosis facilities are made available then patients will get diagnosed & with proper facilities for counseling, treatment & management these affected patients can lead a normal life to contribute to their personal & country's growth and development.

❖ Model description

To manage the disease we realised the following as non-negotiable needs -

- To build the capacity of the system to screen, diagnose, counsel, & treat SCD patients. Screening alone as an activity can be misplaced and unethical until backed up with confirmatory diagnosis, reaching out to those diagnosed with counseling and treatment without impinging on their pockets.
- A community based screening of all pregnant women, aganwadi and school going children and family members of patients, as this is the most vulnerable group. Diagnosis at an early age would help in improving quality of life and prevention as well.

- Patients need support from each other, share problems and solutions as the load of patients is high and individual counseling may be difficult. As a peer support group, they can get proper counseling, & support through OPD services.

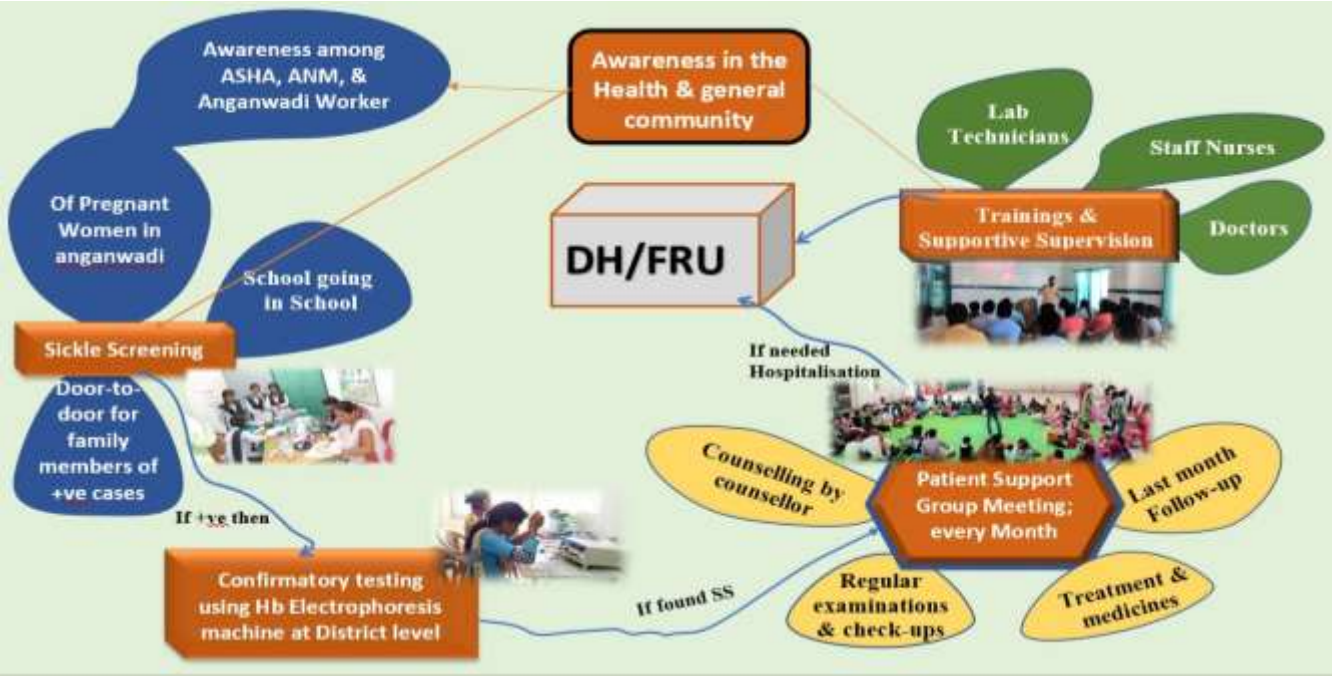


Fig: The Sickle Cell Anemia Control Mission Project

➢ **Community based Screening-**

Intensive work to manage the disease was done in the District of Anuppur – population 7.5 lacs. For screening we used contact tracing screening strategy instead of mass screening because sickle cell disease is a genetic disorder. It saves time, money, & other resources & we can reach persons with higher likelihood in shorter time. In an initial ground survey we found 100 SCD patients already diagnosed (From private hospitals). **Pregnant women with SCD are at high risk of death and other pregnancy related complications. Hence we started with door-to-door screening of all pregnant women**. Our next focus of screening were the husbands of sickle positive pregnant women. Presence of the Sickle gene in them decides the chances of SCD in their future child. If the pregnancy can result in a homozygous child then MTP was suggested to the couple by the counselor. Next we started screening school going children in the schools as also screening of all the immediate family members of screen positive cases. In the field, Solubility test was done for screening with Hemoglobin estimation using Copper Sulphate method. Positive samples were sent to the nodal lab in the district for the confirmatory testing, using Gel based Hb electrophoresis. Few cases were equivocal due to heterozygosity when the sample was sent to the HPLC lab for confirmation.

All the data is captured via an **android based application**, which provides daily reporting and relevant analysis.

➢ **Counseling, treatment, & Management of diagnosed patients-**

A SCD diseased patient (SS) needs proper counseling, regular checkup & treatment to improve the quality of life & their life span. Since the disease is going to be life-long so they also need continuous

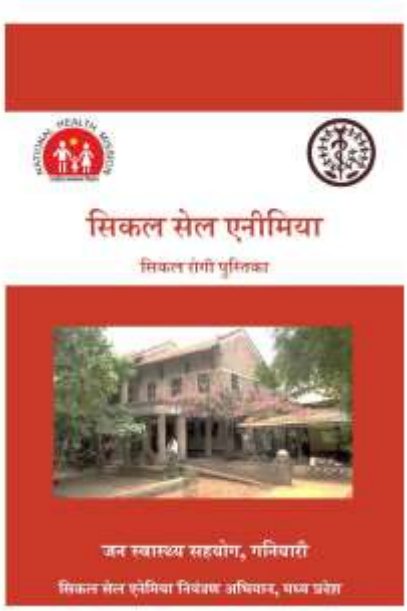
peer support. To all the diagnosed SS patients it was made available through the patient support group (PSG) meetings. In these PSG meetings-

- Each month 30-35 patients meet at or near a government health facility.
- Staff nurse does the monthly follow-up with physical examination, Lab Technicians do their regular blood checkups, counselor does counseling in groups through patient interaction sessions. Patients share their problems, stories/experiences to the group. After all these, the doctor gives the required treatment & medicines.

If a patient could not attend the PSG meeting then he can avail the treatment from OPD & join the meeting next month. This strategy reduced the load in OPD, with patients getting proper attention & improved their compliance.

A helpline number is given to all patients, especially hospitalised patients get support when they need it, & counselor attends all the calls so individual support to patients is also given whenever patients desire.

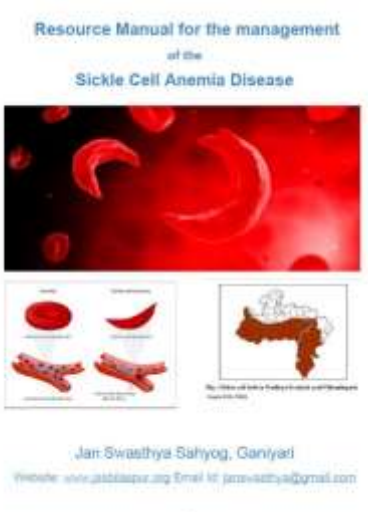
Patients are provided with information manual

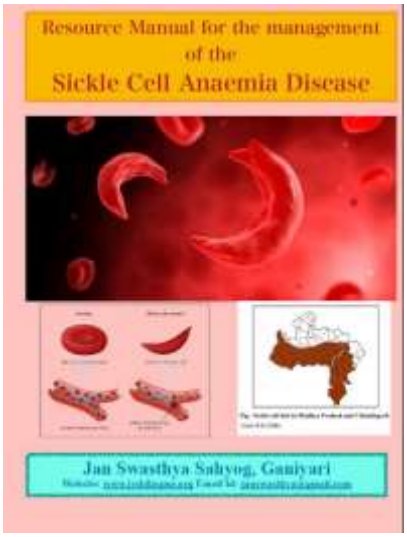


- **Capacity Building strategy of the system-**

This work was done in the 6 high priority districts (all tribal predominant) of eastern MP namely Anuppur, Shahdol, Umaria, Sidhi, Mandala, & Dindori.

- Treatment protocols, counseling checklists, & doctor's manual were developed & made available.





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- Health practitioners were made aware of the load of the disease, its management, & counseling through CMEs, sensitization workshops & duringthe celebration of World SCD day.
- To improve the screening, & diagnosis services -
    - Solubility test was made available in the state rate contract (RC), till the RC we ensured the continuous supply of screening materials.
    - For confirmatory testing of screened positive cases, JSS developed a low cost & reliable Agarose based Hb Electrophoresis machine and made it available in each of the 6 districts at the District Hospital and the FRU. JSS also ensured continuous supply of reagents & consumables because these were not in state rate contract yet.
    - Residential trainings were conducted for lab technicians by JSS and this included use of digital Hemoglobinometer for Hb estimation, which is more reliable and cost-effective. The proper use of training was ensured through supportive supervision visits to the facilities.
- NHM, DHS and District Administration converged to support this work financially, administratively and technically.

❖ **Human Resources**

Capacity Building: Project Coordinator, Lab Mentors, & District Coordinator.

Intensive work in 1 district (Anuppur): Screening, Diagnosis, & Management-

- 5 screening teams each team consisting- 1 ANM, 1 Lab Technician, 1 resource person.
- Counselors -2, logistic Managers -2, Nodal lab technicians - 2, Data Entry Operator -1

❖ **Evidence of effectiveness**

Fig 1.0: Screening data of Anuppur district (by PMU teams); From Sept 2018 - July 2020							
Type	**Screened**	**Solubility +ve**	**AS**	**SBT**	**SS**	**-Ve**	**Already Diagnosed**
Total Screening (Preg Women+ School Going + Family members)	**41,091**	**8,190**	**7146**	**7**	**905**	**32902**	**98 (SS)**

% of all screened samples	***100%***	***19.93%***	***17.39%***	***0.02%***	***2.20%***	***80.07%***	

The above chart represents the number of patients that fall in the ambit of our intervention, both screened by us and pre-diagnosed patients. With the sheer number of screenings, check-ups, counseling, provision of drugs, and regular follow-ups, the project has shown positive impacts on the health of sickle cell patients.

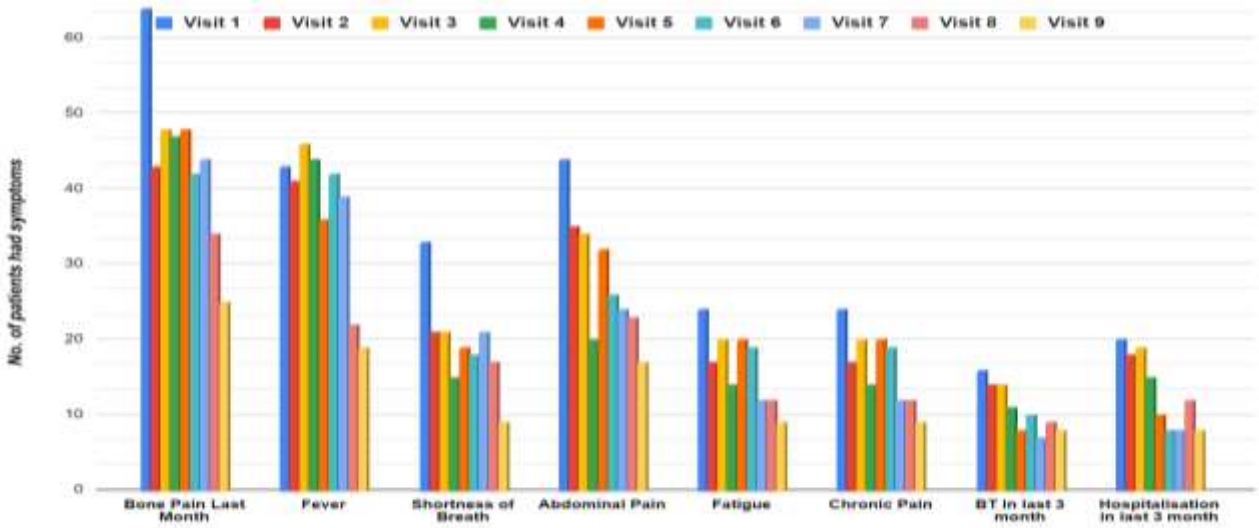

Fig 1.1: Progress of the symptoms of 142 SCD patients who attended Patient Support Group Meetings for 9 times

Fig 1.1 shows the health progress of the patients who have been regularly attending the PSG meetings facilitated by the SCACM- PMU.

Moreover, with our awareness generation programs, the community as well as health workers are now better educated about the disease and its symptoms and reach out to us (helpline number) if the need arises.

- **Budget:**

Expenses incurred in this program were very minimal (Rs 260 per patient screened, diagnosed and managed to its logical conclusion) compared to the benefits observed. These expenses occurred over 20 months which includes capacity building, intensive door-to-door screening work on targeted population, & patient management. The expenses have been supported by NHM(National Health Mission) via DHS(District Health Society) and DMF (District Mining Fund)

SN	Components	Activity	Budget	Total
1	Capacity Building	Training & Supportive supervision	4,94,285	6,64,898
2		IEC, Treatment & Diagnosis protocol manual, & Awareness	1,70,613	
3	Intensive Work in Anuppur District	PSG Meeting	1,37,504	99,09,253
4		Drugs were made available by the system		
5		Screening, & Diagnosis	24,03,150	
6		Mobility Support	20,55,670	

7		Gadgets, app, & database	8,11,795	
8		Human Resource	43,97,580	
9		Office Expenses	1,03,555	
		Total	**1,05,74,151**	

- **Summary of lessons and challenges**

The biggest lesson learned is that if proper screening, treatment, & counseling facilities are made, then not only can we save sickle cell patients, but they can also live a normal life of 60-80 years. So the screening without confirmatory testing, counseling, & management is likely to be unethical and may make 'sicklers' ostracized socially.

- The screening & diagnosis program became successful because we had a JSS (Jan Swasthya Sahyog) made diagnostic Hb Electrophoresis machine, that was able to provide reliable diagnostic testing at a very low initial (Rs 15000) and recurring cost (Rs 25 per test).
- Due to the absence of comprehensive affordable care in the public health system before this intervention, the diagnosed rural poor felt the burden of the disease severely as they faced financial crises at every stage of accessing treatment. Many of them sold their farms/meagre belongings to avail treatment from private practitioners.
- It is time to remove the 'tribal burden' tag from sickle cell anaemia because from the results of screening, out of all positives only 35% were tribal.
- In the contact tracing we found that most of the positive cases were diagnosed through the family screening.
- Android based application has been very useful in data collection in weak network areas. It also helps in quick analysis, by generating reports
- Effective convergence of departments helps in solving most difficult problems faced during implementation.

Challenges faced:

- The stocking of drugs & other consumables for this work is still not followed by district level stores, and they need repeated reminders. A system for institutionalising this needs to be put in place.
- Inadequate numbers of Lab technicians in some government facilities are causing interrupted services of diagnosis through Hb Electrophoresis.
- Blanket labeling of all anemia patients as iron deficiency can be dangerous. Daily intake of iron rich food is good for the health of a SCD patient but iron supplements can be toxic. So Iron Folic Acid tablets should be avoided for them. Hence the importance of having the right diagnosis of SCD.
- Due to lack of awareness among health practitioners, some carriers were also receiving the Hydroxyurea. This needs training of health practitioners outside the public health system.

- **Potential for scale**

There are 89 tribal blocks of 22 districts affected by SCD in Madhya Pradesh. This low cost intensive work model needs to be scaled in all the 22 districts so that we can provide succour to thousands of SCD persons.

- **Partners involved in the implementation**

The sickle cell anaemia control mission was a joint effort of JSS and SRIJAN in consultation with the Maternal Health Division of NHM, Bhopal. An initial pilot plan and PMU were set up and later collaborated with NHM Bhopal. The health care providers in the 6 districts have been actively engaged to make this endeavor successful and sustainable. The District administration under the Collector has also been extremely supportive. District Health Society has been on the forefront of the project especially troubleshooting and monitoring.