

Establishment of a Comprehensive Platform for Sustained Delivery of Yoga Therapy for Sickle Cell Anemia in Rural and Remote Tribal Pocket in India

Abstract

Background: Sickle cell anemia (SCA) is the most common inherited genetic red blood cell disorder, highly prevalent in the tribal population residing in the Central India. The affected populace are disadvantaged due to a lack of accessibility and unavailability of transportation, flawed communication systems, insufficiency of health professionals, and basic health infrastructure. **Objective:** The objective was to set up a yoga-based lifestyle intervention (YBLI) center that is sustainable, accessible, affordable, and acceptable as the part of the Integrated Sickle Cell Anemia Research Program (ISCARP) randomized control trial study. **Methodology:** By analyzing previous government screenings, the study identified remote, high-prevalence areas. Based on these criteria, encompassing 58 villages were surveyed in Maharashtra. Bijari village in Nandurbar was chosen for setting up the YBLI center. This center was equipped with basic health facilities and Information and Communication Technology infrastructure, managed in a hybrid model by ISCARP staff and incentive-based government health workers. A Central Control Center was established at SVYASA University in Bangalore to coordinate all the activities. **Results:** The YBLI center was successfully set up in Bijari village. At the center, around 69 children and adolescents got benefited during Yoga intervention. Only one subject out of 34 in intervention cohort experienced mild crisis. Their basic vitals were recorded regularly. On 11 different occasions, sever crisis of the participants was addressed which reduced morbidity and mortality rate. Furthermore, a social and health profile of these participants was created and updated regularly using sickle cell patient Information Management System, SIMS Portal. **Discussion:** Establishment of easily accessible YBLI center for providing primary healthcare, tele consultation with doctors, and maintaining electronic medical record and monitoring and recording vitals in addition to providing adjuvant Yoga therapy. **Conclusion:** By offering prompt medical help and counseling, the YBLI center reduced the psychological and economic strain of sickle cell disease on the local populace. The center also captures and stores medical health records, updated on regular basis, which is of great value to the government in deciding and designing policies.

Keywords: Primary healthcare services, remote tribal area, sickle cell anemia, yoga therapy

Introduction

Global estimates approximately 5% of the world's population carries genes responsible for hemoglobinopathies, which include sickle cell disease (SCD).^[1] Each year, over 200,000 infants are born with sickle cell globally, with the highest rates occurring in sub-Saharan Africa, India, and Mediterranean countries. As of 2021, the global prevalence of SCD was 7.74 million cases, showing a 41.4% rise from 2000, alongside an 11-fold increase in the number of deaths linked to the disease since that year.^[2] In India, the sickle cell carriers vary from 1% to 40%.^[3] The prevalence of sickle

cell anemia (SCA) is up to 44%^[4] in some pockets of central Indian tribal belt. SCA is considered as rare disease by ICMR^[5] and associated with critical crises, chronic to severe anemia.^[6] Moreover, SCA lowers the quality of life^[7-12] with high psycho-social and economic burden for thousands of tribal families and reduces the life span of the patients from 25 to 30 years.^[13] SCA allele is distributed among three socioeconomically deprived ethnic populations in India: the scheduled tribes, scheduled castes, and other backward classes.^[3,14-16] The SCA demands regular hospital visits, emergency care, and medication which, further

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escalates their economic burden.^[17,18] Globally, SCA is one of the most overlooked health issue.^[19,20] The affected rural mass is disadvantaged due to a lack of easy accessibility to proper healthcare facility and professionals and emergency services, which, over a period of time aggravates the morbidity, comorbidity, and may convert to high mortality rate.

Tribal communities live in remote areas which add to the woes in delivering comprehensive primary health-care services. There are several such pockets in the Central Indian tribal belt with very high prevalence of SCA, one such pocket is in Nandurbar district, located in Satpura mountain, in Maharashtra, India.^[21] Nandurbar has a population of 1,648,295 with majority of them from the rural areas (83.29%; urban – 16.71%) with tribal population constituting about 96%.^[22] Previous research by Kaur *et al.* in 2013, and information collected by nongovernment organisation, Maharashtra Arogya Mandal, Dhadgoan, notes that the area lacks primary health services.^[23] Similarly, Maharashtra Government resolution states that Nandurbar district as deficient in official buildings, proper accessible drinking water facilities and Primary Health Centers (PHCs) in required number proportional to the population.^[24] SCA demonstrated that there is a disease-based high morbidity,^[25,26] comorbidity^[27,28] impact on the sufferers. In spite of best intentions, the financial strain hindered the state from adopting necessary measures in proportion to the demand.^[14] This burden has a detrimental impact on society, particularly on children who experience psychological and financial challenges. Ultimately, these factors contribute to a high-mortality rate. Combinedly, the common implicated factors are lack of awareness, limited availability of health infrastructure, poor access to health facilities, paucity of communication infrastructure, lack of public transport and roads, distance from the village to health facility, inaccessibility during an emergency, nonavailability of specialist doctors, and medicines and financial unaffordability of the treatment.^[14,23,24,29] It is a challenge for state/private health-care providers to offer medical help for population residing in remote scattered areas specifically in this kind of topography. Establishing Yoga-based Lifestyle Intervention (YBLI) centers allows us to overcome geographic disparities, particularly in health infrastructure.

Alternative systems of medicine are ideally suitable for chronic diseases and where cost needs to be considered. A literature review on efficacy of Yoga and its effect on chronic diseases (in SCA and other health conditions) provided information on its efficacy in alleviating pain.^[30-33] inflammation,^[34,35] adverse cardiovascular^[36-39] and nephropathic parameters,^[40-42] and improving overall autonomic nervous system activity and psychological status.^[43-45] Information gathered led us to take up research called Integrated Sickle Cell Anemia Research Program (ISCARP) to elucidate the efficacy of Yoga in SCA.

It was also imperative to think about the feasibility of delivering such therapy to the population residing in remote scattered areas. Fulfilling both these aims was only possible by setting up a dedicated YBLI center. The current article outlines the steps taken to set up an adjuvant therapy center with a database, E-Health and integrated emergency response facilities to deliver comprehensive primary health-care services at the doorstep of the tribal population promptly and in a cost-effective manner. The center set up on pilot scale also had additional objectives to understand, (I) efficacy of yoga to address SCA manifestation's, (II) feasibility of establishing comprehensive platform in remote area and improving efficacy of delivering primary healthcare services at grass root level.

Methodology

Setting up of the YBLI center in the central Indian tribal belt, with a primary objective to evaluate the efficacy of Yoga in addressing some of the comorbidities of SCA, was a part of the pilot randomized control trial (RCT) study namely ISCARP. The center was established through a novel approach of bringing together the existing village-level basic infrastructure of several government departments along with modest supplementary and complementary insertions through ISCARP. Ethical clearance for the study was obtained by an institutional ethics committee and information was collected only after obtaining informed consent from the participants and informed ascent in case of children. Methodology followed to establish the center is described in below steps.

Screening

The project staff met District Health Officer (DHO) and Civil surgeon of Nandurbar district and, (a) collected data out of 1.1 million people screened between 2009 and 2011 by health department Nandurbar, under National Health Mission, Maharashtra [Supplementary Data 1], (b) identified four high prevalence *Taluks viz.* Dhahgaon, Akkalkuwa, Shahada, and Taloda, and surveyed 58 villages therein for understanding disease prevalence, remoteness, traditions, acceptability of alternative therapy, and available health infrastructure [Supplementary Data 2] (c) collected information on the comorbidity and mortality rates from *Taluk's* PHCs.

Based on this exercise, Bijari, a group gram *panchayat* consisting of a cluster of villages (Sirshani, Gaurya, Andharshisha, Byaravad, and Vaghbari) with a population of around 7,000 was chosen to set up the center.

Aligning and appraising human resources

Permissions were obtained from the following: (i) The Chief Executive Officer (CEO), Chief DHO (CDHO) and *Taluka* Health Officer for overall study, (ii) the civil surgeon of civil hospital Nandurbar for radiological assessments,

assigning pediatrician and physician for remote support and to cater critical emergency, (iii) and medical superintendent of referral hospital for providing access to in-patient ward at the hospital during intervention period for sample collection at referral hospital in Dhadgaon. The roles and responsibilities of existing Government human resources in facilitating the establishment and operation of the YBLI center are tabulated as Table 1. The communication protocol, attached as Supplementary Data 3, describing the aim and objective and functioning of YBLI center as well as the standard operating procedure for clinical procedures, was developed with help of CEO, CDHO, and Civil Surgeon for all interactive government, incentivized and recruited resources for smooth functioning of the YBLI center. The same was disseminated through training session for the resources throughout the study. A sample picture of training resources through Google meet was attached as Supplementary Data 4,

Village Administrative Core Team (VACT), consisting of eight members headed by *Sarpanch* (elected village head) and coordinated by Village Level Entrepreneur (VLE)/*Gram Sevak* (Government employee who keeps track of *Panchayat* activities), was formed at Bijari village. The VACT members were in charge of mobilizing participants, keeping the YBLI staff informed of every clinical situation, and assisting in any health emergencies in the relevant area. Services of incentive-based community health workers, Accredited Social Health Activist workers, was utilized to create the awareness about the disease and possible benefits offered by YBLI through door to door visits, meetings with SCA patients including their parents at *Ashramshalas* (residential schools) and *Grama Sabha* (village congregation) and placing of printed hoardings located at common places.

During these sessions, information on their health and socioeconomic status, availability, and accessibility of health infrastructure and services were recorded and further validated with the available information in the *Panchayat* (village council office, an organ of village selfgovernment) and with the office of CEO.

Central control center

Central Control Center (CCC), set up as a part of I-SCARP at SVYASA University served as the nerve center for coordinating all the aspects of the study, broadly, administration (accounts, human resource, and communication), wetlab research (sample storage, conducting biochemical, molecular, and hematological assessments), data analysis, coordinating for arranging emergency service, monitoring intervention, and clinical database of recruited subjects.

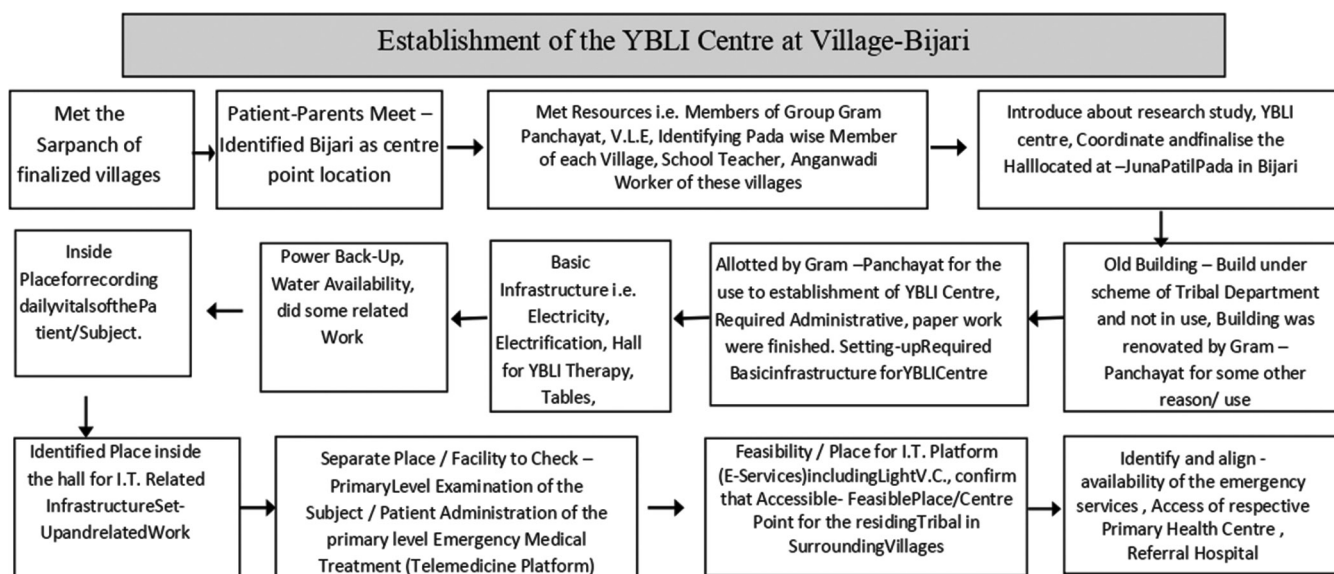
Establishment of the yoga-based lifestyle intervention center at Bijari

For administering active intervention (YBLI), the village *Panchayat* of Bijari provided an already existing built-up area with basic infrastructure such as electricity and water. Additional facilities such as power backup, Information and Communication Technology (ICT) infrastructure and facilities for checking basic vitals (blood pressure [BP], pulse, Temperature, SpO₂, and *Brahmari* time) was arranged under I-SCARP. Center also catered to arranging timely ambulance service from Chulwad *Ashramshala* with a doctor and one paramedical staff. The emergency medicine was preidentified by civil surgeon, pediatrician, and physician of civil hospital and made available to the YBLI center for prompt response to such critical crisis. Schematic Flow 1 as under:

Table 1: Officials involved in the establishment of comprehensive platform

List of government officials involved in the establishment of the center	Authority in government	Role in establishing center
Chief executive officer	Managing district administration (district development, <i>panchayat raj</i> policies)	Authorizing the use of government infrastructure and resources Instructed ACEOs and district officials to support the project
Civil surgeon	Supervises Nandurbar civil/district hospital and all referral and community health centers	Gave access to hematologists, pediatricians, general practitioners, radiologists, and medical superintendents of reference hospitals and CHC in the district for health examination and radiological test diagnosis
Additional chief executive officer (rural)	Reports to CEO. District head for local <i>panchayati raj</i> and rural governance	Permission to use Digital India/E Gram infrastructure, and other <i>Gram Panchayat</i> facilities. Instructed the <i>Taluk</i> development officer and <i>panchayat</i> resources like the <i>Sarpanch</i> , <i>Gram sevak/Talati cum mantri</i> , and VLE (authorised to work on an incentive basis) to provide human resource
Chief district health officer	Epidemic and noncontagious disease coordinator. Provides rural primary health care as public health district head under the CEO. He runs rural health programs	Instructed PHC's medical officers to get integrated with YBL centre Instructing <i>Taluk</i> health officer to support and supervise the centre The medical officer stated to provide support in utilizing the resources and existing basic health infrastructure to enhance the delivery of primary health-care services at the village level, frontline health resources, such as incentive based " <i>Asha</i> " workers (female health workers with multiple roles), to help in smooth running of the platform

VLE: Village level entrepreneur, CEO: Chief executive officer, PHC: Primary health center, YBL: Yoga-based lifestyle, ACEO: Assistant chief executive officer, CHC: Community health centre



Schematic Flow 1: Establishment of YBLI Centre at village-Bijari

Information and communication technology infrastructure

A web-based client server application “ISCARP.in” (a part of SIMS portal) was used for entering basic vitals, clinical documents, family history, details of hospital visits, transfusion events of the participants; all of which were also accessible to the treating doctor. The software had features for telemedicine, teleradiology, Health Information Management System, research module creating a comprehensive database [sample picture of the database provided as Supplementary Data 5] and remote data access to reduce the time required for providing timely medical support. The module wise access of the software was given to all the resources (both incentive based and ISCARP recruited), local service providers on the ground, and respective Government officials as per their respective requirement/engagement in the study.

The information recorded by the YBLI centre staff was communicated to the CCC and VLE of the respective villages, who further recorded that in their database.

No adverse events or critical clinical situations occurred/ were noted during the administration period of YBLI. The subjects were further facilitated with transportation services from their home to YBLI Center and back to home during the second wave of COVID-19. No infections or contagious diseases were noted/occurred in the recruited subjects during the whole duration of the research study. During the COVID-19 pandemic, YBLI was conducted with adherence to the COVID-19 protocol and guidelines. The respective primary school teachers, principals of Ashramshala were informed from time to time about the health status and clinical conditions of the recruited subjects. Procedure followed during SARS-COV2 is presented as Schematic Flow 2 below.

Results and Discussion

Establishment of the center, as explained above, fulfilled the primary objective, in addition the following secondary objectives were also achieved.

By establishing the YBLI center at Bijiri, we could address primary health care needs, counseling, emergency, and prescribe medications at the doorsteps of residents. Health service provided by the facility on 11 different occasions is provided in Table 2. Medical records of subjects, both past and current, are maintained at the center.

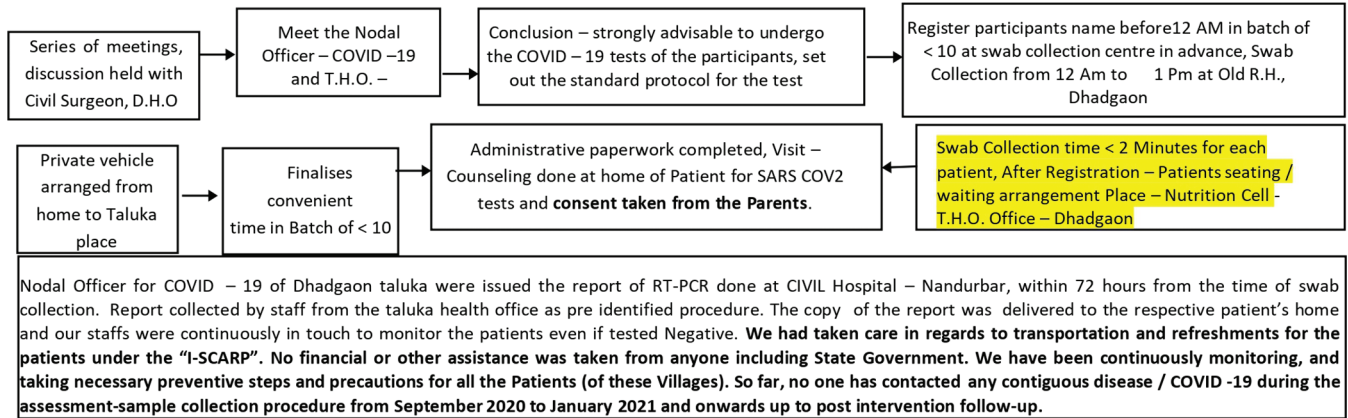
Efficacy of yoga

Thirty-four sickle cell patients in the age group of 6 years–16 years underwent YBLI therapy sessions for 70 min/day, 5 days/week along with 1 day/week of counseling by Community Health Officer [photo attached as Supplementary Data 6]. Basic vitals were recorded every day before the administering intervention, which showed an improvement in all the parameters shown in graphs below [Supplementary Data 7 and 8 attached basic vitals table and doctor checking subjects were included] in monthly average comparison.

Trend lines are the graphical tools that help identify and visualize the patterns in data sets. Linear trend lines were applied to examine the relationship between pre- and post-data of basic vitals in the YBLI group, assessing yoga’s efficacy. The X-axis represents subjects 1 through 29, while the Y-axis shows the basic vitals measured for each subject mentioned as heading of the chart. The orange trend line represents postdata, and the blue trend line represents predata. Graphical representation of basic vitals of yoga cohort is as follows.

Systolic and diastolic BP is shown improvement in post data [Figures 1 and 2]. Ideally, systolic and diastolic BP shows low in SCD patients at the steady state. Increase in

S.O.P. - RT-PCR tests for COVID – 19



Schematic Flow 2: Procedure-RT-PCR Tests for COVID-19

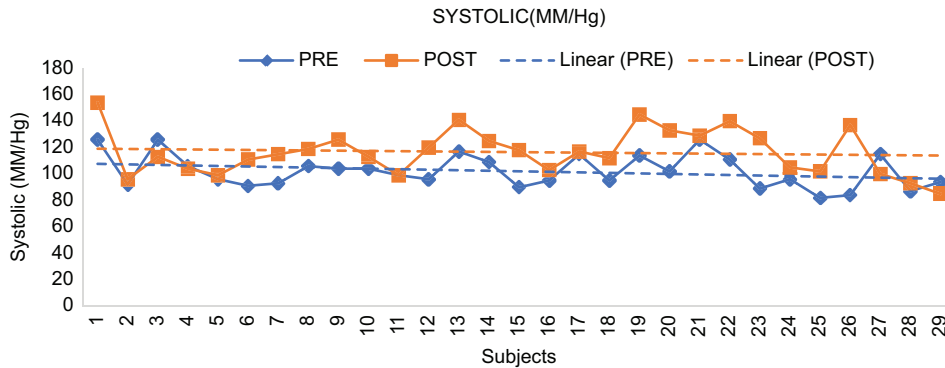


Figure 1: Systolic (MM/Hg)

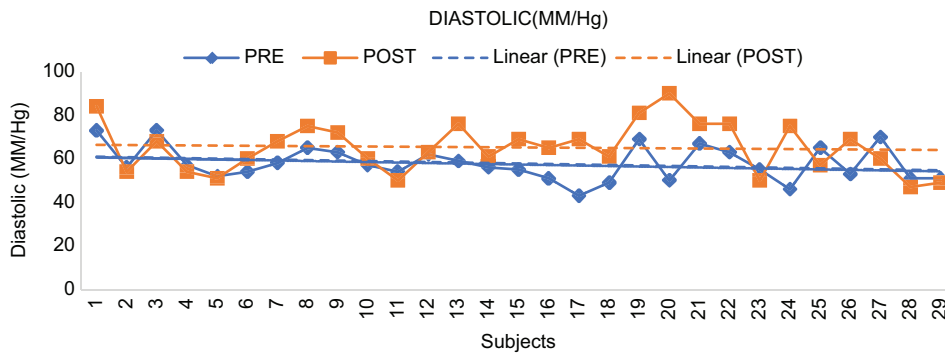


Figure 2: Diastolic (MM/Hg)

postsystolic and diastolic BP indicates Vaso dilation process regulated through YBLI.^[46]

In SCD patients, a high and fluctuating pulse rate is usually expected due to the nature of the disease. However, the postintervention data show a steady pulse rate [Figure 3], pointing to better blood circulation. This stabilization suggests that yoga helps bring the pulsation back to normal.^[46]

Pre- and postdata temperature is in normal range [Figure 4].

In SCD patients, oxygen saturation is usually unstable. However, among the yoga group [Figure 5], YBLI effectively regulated oxygen saturation.^[47]

Many studies demonstrated that increase in Bhramari time regulates metabolic and micro blood circulation in veins and arteries. In postdata, increase in Bhramari time [Figure 6] is the positive effect of yoga intervention and act pivotal role in course of disease.^[48]

Table 2: Comprehensive primary health care services delivered through YBLI center

Gender	Age	Therapy/control	Test ID	During intervention - health issue	Medication prescribed	Past clinical history	Blood transfusion histoty	Support from YBLI center
Male	6	Control	1401C1A	During March and July - 2021, suffering from cold, fever, and abdomen pain, skin itching	Tablet Cetcip-syrup Ibujesic Plus-tablet ZIFI 100 DT. Provided from YBLI centre	Duration - from 2018 up to 2020 Symptoms - Frequent episodes of severe hemolytic and occlusion crisis, pain in limb - sepsis with fever, moderate anemia Hospitalization - admitted in IPD for 3 times, private hospital Shahada Hb - 8.5, 5-4 days Medication - opioid and antibiotics	1 BT in 2019	Immediately provided teleconsultation
Male	9	Control	1701C1A	Two times pain in abdomen and joints	Syrup Ibujesic Plus was given	As per the verbal information given by the family, two times got painful crisis and treated by referral hospital - Dhadgaon	No	YBLI facilitated to reach referral hospital in ambulance
Male	12	Control	1002C2A	Suffering from joint pain	Syrup Ibujesic Plus provided	Duration - since 2016 Symptoms - frequent abdomen and joint pain. 2 times got severe crisis Hospitalization - admitted 8-5 days in IPD. One time at Referral Hospital Dhadgaon and one time in private hospital Medication - opioid and antibiotics	Not available	School dropout due to sickle cell After counseling of parents during the study, started going to school since 2021 Feedback given by parents counseling reduced their psychological stress
Female	9	Control	2701C1A	Got severe pain in abdomen and joints	Injection Diclo stat. and tablet Ibujesic Plus, tablet Meftal Spas was provided from the YBLI centre	Duration - since 2015 Symptoms - frequent severe episodes of occlusion crisis, hemolytic crisis. Abdomen pain - severe joint pain. One time converted in chronic anemia Hospitalization - three times hospitalization at Nandurbar private hospital as per verbal information from parents. Maximum for 6 days Medication - opioid and antibiotics	2 BT during hospitalization at Nandurbar	Immediate consultation with pediatrician, which prevented from converting to sever crisis
Male	13	Control	1001TC2A	Got severe abdomen pain in January-February, 2021	Tablet Cyclopam and tablet Voveran SR provided from YBLI centre	Duration - since October 2020 Symptoms - frequently pain in abdomen Hospitalization - PHC Chulwad, Referral Hospital Dhadgaon	-	YBLI center referred to civil hospital, Nandurbar, cholilithoisis CBD stone 8 mm detected. Regularly by

Contd...

Table 2: Contd...

Gender	Age	Therapy/control	Test ID	During intervention - health issue	Medication prescribed	Past clinical history	Blood transfusion histoty	Support from YBLI center
Female	10	Control	1402C1A	During March– June 2021, abdomen pain, joint pain	Tablet Meftal P and syrup Ibujesic Plus was provided from YBLI	Medication - analgesic tablet and injectable. Recommended iron and folic acid by PHC Chulwad Duration - since 2017 Symptoms - frequently got severe occlusive and hemolytic crisis Hospitalization - 2 times recorded as per available reports. For 5–3 days in IPD. 3 rd time admitted for 2 days in private hospital at Nandurbar Medication - opioid and antibiotics	NA	YBLI monitored and ensured that surgery was done free of cost in Surat civil hospital Diagnosed and provided primary medication by paramedical staff of YBLI, suspecting mild crisis referred to referral hospital
Female	10	Control		January– February, 2021 severe abdomen pain	Tablet Cyclopam and tablet Voveran SR provided from YBLI centre	Not available		Doc from CCC and referral hospital prescribed medications early diagnosis helped in preventing crisis
Male	14	Control	2902C2A	May 2021, suddenly converted in acute chronic anemia with intra hemolytic crisis due to SCD, left hip joint could be displaced/ ruptured	No medication given from YBLI centre	Duration - since 2016 Symptoms - 4 times severe crisis occurred, which includes hemolytic, vaso occlusive crisis. converted in sever chronic anemia Hospitalization - admitted at private hospital for 3 days and in civil hospital Nandurbar Medication - treated with opioid-analgesic and antibiotics. Cholecystectomy open GB stone surgery was done in 2018 at civil hospital Surat Gujarat	2 BT	Under the “I-SCARP” project, past clinical history, CBC, and radiological reports were collected at various intervals. This data, readily accessible in YBLI, was provided to the civil hospital in Nandurbar during a crisis, aiding in accurate diagnosis and immediate treatment
Male	9	Therapy	0801T1A	2021 June - suffered joint pain, 2021 December - fever - swelling with pain in left shoulder, mild vaso-occlusive crisis	Treated with oral medication - tablet Flexon MR in June 2021 Post follow up Tablet ZIFI 100 DT, and tablet Ibujesic 200 mg, tablet folic acid - opioid not required	Duration - since 2016 Symptoms - frequent vaso-occlusive, hemolytic, intra vascular hemolysis crisis and abdomen pain (3 times) in a year. Frequently converted moderate to severe anemic symptoms Hospitalization - as per available medical records - in 2018 - admitted for 3 days at private hospital - Nandurbar c/o severe vaso-occlusive	1 BT at age of 4 years severe anemia as per verbal information of family	In June 2021 tablet was provided by YBLI In December 2021 referred to pediatrician private hospital Dr Kishan Pawara, assigned by civil hospital, Nandurba

Contd...

Table 2: Contd...

Gender	Age	Therapy/ control	Test ID	During intervention - health issue	Medication prescribed	Past clinical history	Blood transfusion histoty	Support from YBLI center
Male	10	Therapy	1901T1A	April and June 2021, mild pain and fever	Cold tablet Mox - 250 Dt, Surup Meftal-P, tablet Ibujesic Plus DT, and syrup advent	<p>and hemolytic crisis - severe anemia in 2018 December severe crisis fever, severe anemia and abdomen pain admitted at civil hospital Nandurbar, for 8 days - crisis Hb - 6.7, serum amylase - 107.25, Na+ - 127</p> <p>Medication - every time he was required opioid and IPD</p> <p>Duration - since 2017</p> <p>Symptoms - frequently got severe anemia, occlusive crisis</p> <p>Hospitalization - admitted for 3 days at civil hospital Nandurbar. He is brother of Bharati Subhash Patle</p>	-	<p>Medication was provided from YBLI centre. School dropout and not able to stay in Ashramshala due to SCD crisis. After intervention and continuing with counseling, he is continuing to school and was able to stay comfortably in ashramshala</p> <p>Observation - symptomatic for conversion/vertigo -mild CI</p>
Female	9	Therapy	1302T1A	In March and June 2021, had mild abdomen pain, fever and joint pain	Syrup Meftal Spas, Syrup Ibujesic Plus, tablet PCM and tablet Diclo. Provided from the YBLI centre	<p>Duration - since 2016</p> <p>Symptoms - frequently got severe hemolytic - vaso-occlusion crisis with severe anemia</p> <p>Hospitalization - 2019, moderate anemia-crisis-abdomen pain-private doctor for 2 days at Shahda</p> <p>2020 January, admitted to civil hospital Nandurbar c/o severe anemia-abdomen pain, Hb - 5.5, treated with opioid and IV for 5 days</p> <p>2020 again converted in severe anemia for 7 days IPD - SCD crisis abdomen pain, Hb 7.2, 4 days</p> <p>Medication - analgesic-IV and oral opioid medication as inpatient. As outpatient capsule Hydroxyurea was taken since October 2020</p>	1 BT in 2019+2 BT in 2020	<p>Early stage diagnosed and treated by staff of YBLI center prevented from hemolytic anemia and not required opioids which was previously prescribed</p> <p>Based on the doctor's recommendation, hydroxyurea capsules was discontinued in March 2021 after 1 month of YBLI sessions</p>

BT: Blood transfusion, CBC: Complete blood count, CCC: Central control center, CI: Cerebral ischemia, Hb: Hemoglobin, IPD: Inpatient department, IV: Intravenous, NA: Not available, PHC: Primary health center, SCD: Sickle cell disease, YBLI: Yoga-based lifestyle intervention, CBD: Common bile duct, GB: Gall bladder, CI: Cerebral ischemia

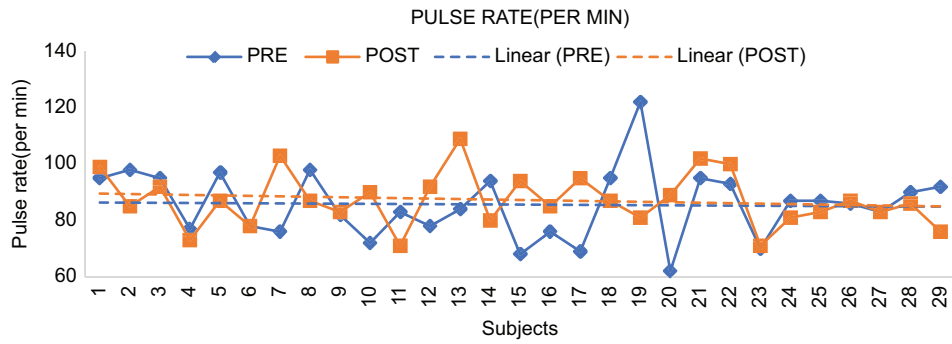


Figure 3: Pulse Rate (per Min)

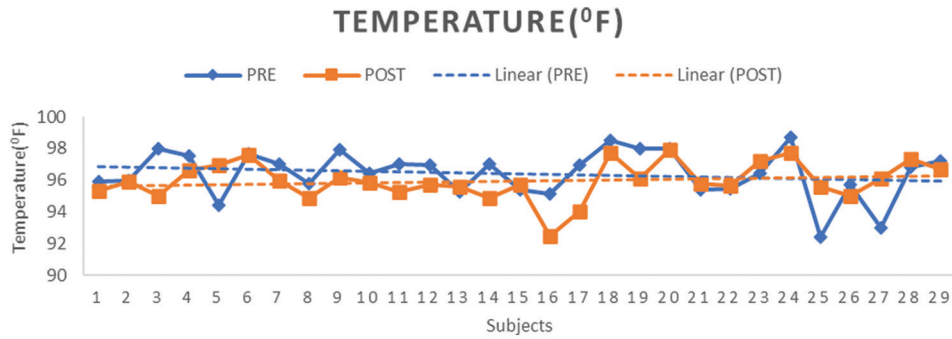


Figure 4: Temperature (°F)

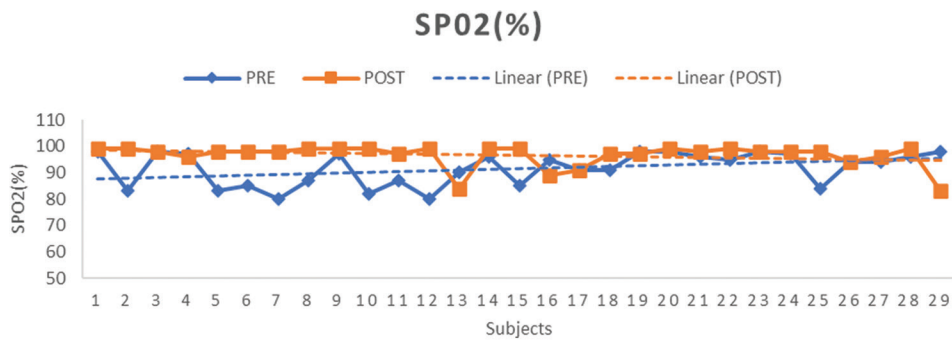


Figure 5: SpO₂(%)

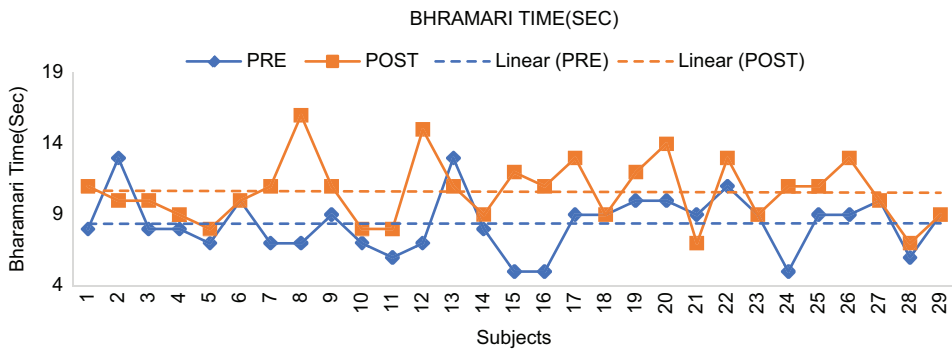


Figure 6: Bhramari Time(Sec)

Respiration rate is stable in pre and post, in fact slight decrease [Figure 7] in postdata which is positive sign of pulmonary functioning.^[49]

Yoga intervention also resulted in decreased incidences and severity of crisis among the participants. Within the 1st month of intervention, YBLI helped to reverse the

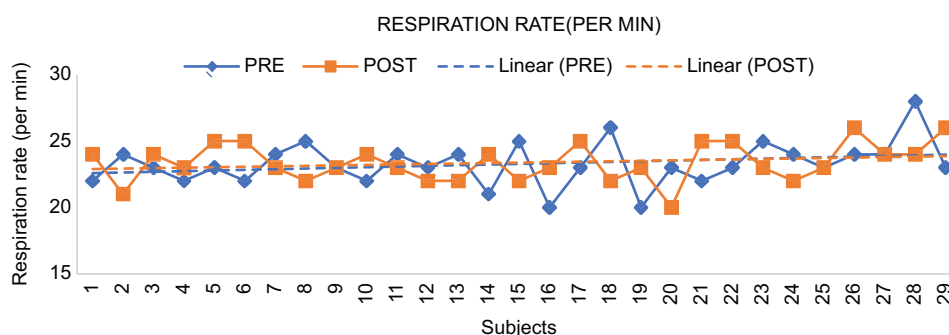


Figure 7: Respiration rate (per Min)

prescription of hydroxyurea to reduce sickling and opioids for pain management, which had been previously advised and subsequently recommended to cease by the doctor. As an example, let’s examine a detailed case study of a subject to assess the impact of YBLI (this case description and efficacy of yoga is part of another paper).

Case description

This is the case report of a 10-year-old female diagnosed with SCD in September 2019. The patient’s previous clinical records indicate a pattern of recurring crises and hospital admissions. Symptoms include lower limb pain, severe pain in abdomen, fever, and vomiting diagnosed with severe anemia, SCD with leukocytosis, pallor +++. Individual took four blood transfusions in the span of September 2019 to October 2020 [Table 3]. Till January 2020 was taking one hydroxyurea 500 mg per day and required opioids along with other oral medication.

Result

The results were promising for many reasons:

- For the entire duration of active intervention and post follow-up, there was not even a single recurrence of any crises or events necessitating BT, opioid medicines, hospitalization, and hydroxyurea capsule
- The betterment in the child was seen even as early as post 1 month of intervention by regular consultant
- The child once in July suffered from abdominal pain which got cleared with antispasmodic tablets for 2 days
- In postradiological assessment, improvement noted in gastrointestinal organs.

In previous studies also, it was evident that after 10 sessions of yoga for 1 h for 10 days helped stop the use of opioid medication for pain management.^[50] Similar positive improvement was also seen in the blood transfusion frequency, which, before intervention, was on an average one to three every 2 years. A daily certificate signed by the Sarpanch, confirming that no participants in the intervention group required hospitalization, experienced any crisis events, or faced adverse health issues during the YBLI sessions, is included as Supplementary Data 9.

Table 3: Past clinical parameters of case study

1 st admission September 2019 diagnosis with SCD by electrophoresis	
Prescription describes severe anemia and given 2 BTs	
2 nd admission January 2020 full blood count	
Hb	5.5 g/dL
WBC	14,300
Platelet	3.43 lakhs
Prescription describes severe anemia and given BT	
Post-BT blood count	
Hb	8 g/dL
WBC	10,600
Platelet	4.67 lakhs
3 rd admission October 2020 diagnosis	
Prescription describes severe anemia and given BT	
Post-BT blood count	
Hb	7.1 g/dL
WBC	9000
Platelet	3.16 lakhs

Hb: Hemoglobin, WBC: White blood cell, BT: Blood transfusion, SCD: Sickle cell disease

Feasibility of establishing the center in remote area and improving healthcare services

This study clearly establishes that setting up of therapy centers (alternative or conventional system) is most viable when done in hybrid mode, combining existing state resources with specific required resources (ex. Yoga therapist, Paramedical recruited by I-SCARP).

Feasibility was also enhanced by counseling the affected population about benefits that can be accrued from the center, surveying the villages for prevalence, health infrastructure, local customs and traditions, socioeconomic status, cost of the treatments, availability of hematology experts, screening of vulnerable population, and awareness and knowledge of the disease and therapies among patients. Routine counseling session with participants and their parents helped reduce psychosocial strain. Being the pioneer in the province, the ICT infrastructure, equipped with bandwidth services, offered free access to residents. This support enabled students from the remote regions to participate in online education during the COVID-19

pandemic. This type of meticulous planning at the micro level PHC/district wise and comprehensive medical management was advised by prior research conducted in Central India.^[51] This established platform was functional at auto sustainable mode as e-platform for delivering comprehensive services at the grass root level. This methodology can be replicated to establish additional centers in the remote areas of central Indian tribal belt to achieve desired outcome.

The key feature of SCD is acute and chronic pain where patients suffer life long.^[52-54] According to Childerhose *et al.*, a similar framework called the “Biopsychosocial Model” was suggested, highlighting mindfulness as one of its primary aspects to address chronic pain of SCD.^[55] Another pilot study involving 39 patients admitted for acute vaso-occlusive crisis (VOC)-related pain, in which 93% participated in the yoga intervention, with 79% finding mindfulness beneficial and 82% expressing interest in future involvement.^[56] This paper also quotes that yoga is low risk and low-cost intervention. Similarly, another pilot study indicates that participants hold a positive view of yoga for managing chronic pain associated with SCD and assessed the acceptance of chronic pain among adolescents with SCD after yoga intervention.^[57] Furthermore, another RCT study with children admitted to acute pain due to VOC gave positive feedback yoga practice makes them happy, feels good want to attend more yoga sessions, I could breathe well.^[32] Based on the findings from the four studies, we can conclude that yoga is beneficial for managing both chronic and acute pain in SCD patients, while also fostering greater awareness of their condition and aiding in pain acceptance. To date, research on yoga and SCD has primarily been conducted as pilot studies with small sample sizes or over very short durations of intervention; therefore, further investigations are needed to assess the efficacy of yoga in managing SCD symptoms. To the best of our knowledge, this is the first study with 6 months of yoga intervention and subsequent 12 months of follow-up in tribals outside the hospital setting in novel way and cost-effective manner. Limitation as a pilot study done in a high-prevalence pocket. Further research can be done in larger tribal areas covering many states can be advantageous.

Conclusion

Through ISCARP a model for sustainable, accessible, affordable delivery of therapy, and emergency response was successfully tested. This comprehensive platform was also able to reduce the cost and time required to obtain basic medical services and run for the long term with vision for longitudinal research on an auto-sustainable mode.

Ethical statement

The study received approval from the institutional ethics committee of Swami Vivekananda Yoga Anusandhana Samasthana (RES/IEC-SVYASA/156/2019).

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Conflicts of interest

There are no conflicts of interest.

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Supplementary Data Legends

Supplementary Data 1: SCA screening program, Nandurbar

Supplementary Data 2: Feasibility study report

Supplementary Data 3: Standardized Communication Protocol for functioning of YBLI Centre

Supplementary Data 4: Glimpse of training resources

Supplementary Data 5: Picture of ISCARP.IN

Supplementary Data 6: Picture of counseling subject and family by doctor

Supplementary Data 7: Vitals data of yoga cohort

File name	Average at	Systolic (mmHg)	Diastolic (mmHg)	Pulse rate/min	Temperature °F	SpO₂ in %	Bhramari Time/second	Respiration Rate/min
Subject-1	1 st Month	126	73	95	95.89	98	8	22
Subject-1	2 nd Month	124	72	98	96.60	97	9	24
Subject-1	3 rd and 4 th month	131	79	99	97.52	98	10	26
Subject-1	5 th month	154	84	99	95.30	99	11	24
Subject-1	5 th month 1 st to 15 th day	156	83	101	95.87	99	10	24
Subject-1	5 th month 16 th to 30 th days	154	86	96	94.83	98	12	23
Subject-2	1 st Month	104	63	82	97.95	97	9	23
Subject-2	2 nd Month							
Subject-2	3 rd and 4 th month	121	79	94	97.49	98	10	24
Subject-2	5 th month	119	75	87	94.88	99	16	22
Subject-2	5 th month 1 st to 15 th day	117	73	89	94.14	99	13	23
Subject-2	5 th month 16 th to 30 th days	122	76	85	95.62	99	19	21
Subject-3	1 st Month							
Subject-3	2 nd Month	114	59	69	98.15	98	4	28
Subject-3	3 rd and 4 th month	190	58	82	98.10	99	11	24
Subject-3	5 th month							
Subject-3	5 th month 1 st to 15 th day							
Subject-3	5 th month 16 th to 30 th days							
Subject-4	1 st Month	126	67	95	95.42	96	9	22
Subject-4	2 nd Month	123	72	98	97.89	97	12	24
Subject-4	3 rd and 4 th month	133	76	97	97.87	97	9	26
Subject-4	5 th month	129	76	102	95.78	98	7	25
Subject-4	5 th month 1 st to 15 th day	133	77	103	95.74	98	7	24
Subject-4	5 th month 16 th to 30 th days	107	68	93	96.00	95	6	28
Subject-5	1 st Month							
Subject-5	2 nd Month	84	53	86	95.69	94	9	24
Subject-5	3 rd and 4 th month	101	60	85	97.50	98	9	24
Subject-5	5 th month	102	57	83	95.60	98	11	23
Subject-5	5 th month 1 st to 15 th day	94	51	79	94.60	99	11	24
Subject-5	5 th month 16 th to 30 th days	111	64	87	96.60	98	11	23
Subject-7	1 st Month	115	70	83	93.00	94	10	24
Subject-7	2 nd Month	137	69	87	95.00	94	13	26
Subject-7	3 rd and 4 th month							
Subject-7	5 th month							
Subject-7	5 th month 1 st to 15 th day							
Subject-7	5 th month 16 th to 30 th days							
Subject-8	1 st Month	87	51	90	96.85	96	6	28
Subject-8	2 nd Month	92	55	87	97.08	93	9	24
Subject-8	3 rd and 4 th month	108	64	98	97.90	99	9	25
Subject-8	5 th month	100	60	83	96.10	96	10	24
Subject-8	5 th month 1 st to 15 th day	100	60	83	96.10	96	10	24
Subject-8	5 th month 16 th to 30 th days							
Subject-9	1 st Month	94	51	92	97.18	98	9	23
Subject-9	2 nd Month	94	45	98	98.18	99	5	26
Subject-9	3 rd and 4 th month	93	47	86	97.33	99	7	24
Subject-9	5 th month							
Subject-9	5 th month 1 st to 15 th day							
Subject-9	5 th month 16 th to 30 th days							
Subject-10	2 nd Month	105	61	92	97.40	94	8	23
Subject-10	3 rd and 4 th month	113	66	98	96.80	98	10	25
Subject-10	5 th month	96	54	85	95.88	99	10	21
Subject-10	5 th month 1 st to 15 th day	96	54	85	95.88	99	10	21

Contd...

Supplementary Data 7: Contd...

File name	Average at	Systolic (mmHg)	Diastolic (mmHg)	Pulse rate/min	Temperature °F	SpO₂ in %	Bhramari Time/second	Respiration Rate/min
Subject-10	1 st Month	92	56	98	96.00	83	13	24
Subject-11	1 st Month	126	73	95	97.99	98	8	23
Subject-11	2 nd Month	121	71	100	97.94	97	11	24
Subject-11	3 rd and 4 th month	133	74	98	97.68	98	9	25
Subject-11	5 th month	113	68	92	95.03	98	10	24
Subject-11	5 th month 1 st to 15 th day	111	65	97	94.00	98	9	23
Subject-11	5 th month 16 th to 30 th days	116	72	86	96.26	99	12	25
Subject-12	1 st Month	106	57	77	97.53	97	8	22
Subject-12	2 nd Month	104	54	73	96.60	96	9	23
Subject-12	3 rd and 4 th month							
Subject-12	5 th month							
Subject-12	5 th month 1 st to 15 th day							
Subject-12	5 th month 16 th to 30 th days							
Subject-14	1 st Month	96	52	97	94.40	83	7	23
Subject-14	2 nd Month	95	61	91	93.80	93	6	23
Subject-14	3 rd and 4 th month	90	43	118	97.90	99	10	25
Subject-14	5 th month	99	51	87	96.96	98	8	25
Subject-14	5 th month 1 st to 15 th day	99	46	88	97.07	99	8	25
Subject-14	5 th month 16 th to 30 th days	100	58	87	96.80	98	8	26
Subject-15	1 st Month	91	54	78	97.65	85	10	22
Subject-15	2 nd Month	92	58	86	96.94	92	10	23
Subject-15	3 rd and 4 th month	111	60	78	97.58	98	10	25
Subject-15	5 th month							
Subject-15	5 th month 1 st to 15 th day							
Subject-15	5 th month 16 th to 30 th days							
Subject-17	1 st Month	93	58	76	97.02	80	7	24
Subject-17	2 nd Month	85	49	76	96.70	83	9	26
Subject-17	3 rd and 4 th month							
Subject-17	5 th month							
Subject-17	5 th month 1 st to 15 th day							
Subject-17	5 th month 16 th to 30 th days							
Subject-18	1 st Month	106	65	98	95.75	87	7	25
Subject-18	2 nd Month	91	57	103	96.73	95	10	23
Subject-18	3 rd and 4 th month	102	64	98	94.81	98	9	24
Subject-18	5 th month	115	68	103	96.00	98	11	23
Subject-18	5 th month 1 st to 15 th day	114	70	106	96.10	98	9	24
Subject-18	5 th month 16 th to 30 th days	117	67	100	95.89	98	12	23
Subject-21	1 st Month	104	57	72	96.42	82	7	22
Subject-21	2 nd Month	102	53	86	97.38	91	7	25
Subject-21	3 rd and 4 th month	116	61	83	97.47	99	9	25
Subject-21	5 th month	126	72	83	96.19	99	11	23
Subject-21	5 th month 1 st to 15 th day	132	78	85	95.58	99	9	24
Subject-21	5 th month 16 th to 30 th days	121	67	82	96.68	99	13	23
Subject-22	1 st Month	99	54	83	97.04	87	6	24
Subject-22	2 nd Month	100	58	90	98.30	81	8	24
Subject-22	3 rd and 4 th month	105	62	89	98.25	99	8	27
Subject-22	5 th month	113	60	90	95.83	99	8	24
Subject-22	5 th month 1 st to 15 th day							
Subject-22	5 th month 16 th to 30 th days	113	60	90	95.83	99	8	24
Subject-23	1 st Month	96	62	78	96.94	80	7	23
Subject-23	2 nd Month	88	62	88	98.15	83	8	25
Subject-23	3 rd and 4 th month	111	50	74	97.88	98	8	25
Subject-23	5 th month	99	50	71	95.24	97	8	23

Contd...

Supplementary Data 7: Contd...

File name	Average at	Systolic (mmHg)	Diastolic (mmHg)	Pulse rate/min	Temperature °F	SpO₂ in %	Bhramari Time/second	Respiration Rate/min
Subject-23	5 th month 1 st to 15 th day	101	49	69	96.00	98	8	24
Subject-23	5 th month 16 th to 30 th days	97	50	72	94.68	97	8	22
Subject-25	1 st Month	97	53	88			13	22
Subject-25	2 nd Month	96	59	95	97.98	98	13	23
Subject-25	3 rd and 4 th month	111	65	93	97.30	93	13	25
Subject-25	5 th month	120	63	92	95.69	99	15	22
Subject-25	5 th month 1 st to 15 th day	120	61	91	95.09	99	14	23
Subject-25	5 th month 16 th to 30 th days	121	66	93	96.36	98	15	21
Subject-28	1 st Month	117	59	84	95.27	90	13	24
Subject-28	2 nd Month	114	63	79	95.93	97	11	23
Subject-28	3 rd and 4 th month	153	85	85	97.90	99	12	26
Subject-28	5 th month							
Subject-28	5 th month 1 st to 15 th day							
Subject-28	5 th month 16 th to 30 th days							
Subject-30	1 st Month	140	70					
Subject-30	2 nd Month	104	57	91	98.65	99	5	27
Subject-30	3 rd and 4 th month	125	78	96	98.73	98	7	22
Subject-30	5 th month							
Subject-30	5 th month 1 st to 15 th day							
Subject-30	5 th month 16 th to 30 th days							
Subject-31	1 st Month	56	109	94	97.00	96	8	21
Subject-31	2 nd Month	61	103	98	97.67	98	9	26
Subject-31	3 rd and 4 th month	49	89	98	98.50	99	10	25
Subject-31	5 th month							
Subject-31	5 th month 1 st to 15 th day							
Subject-31	5 th month 16 th to 30 th days							
Subject-32	1 st Month							
Subject-32	2 nd Month	106	71	83	96.23	89	9	25
Subject-32	3 rd and 4 th month	159	91	112	95.30	99	9	22
Subject-32	5 th month	141	76	109	95.61	84	11	22
Subject-32	5 th month 1 st to 15 th day	146	78	116	95.00	98	9	22
Subject-32	5 th month 16 th to 30 th days	135	75	100	96.43	66	14	22
Subject-33	1 st Month	90	55	68	95.41	85	5	25
Subject-33	2 nd Month							
Subject-33	3 rd and 4 th month	137	63	82	97.70	97	6	27
Subject-33	5 th month	125	61	80	94.86	99	9	24
Subject-33	5 th month 1 st to 15 th day	121	61	74	95.00	98	9	25
Subject-33	5 th month 16 th to 30 th days	132	63	88	94.65	99	10	23
Subject-34	1 st Month							
Subject-34	2 nd Month	95	56	89	98.05	98	11	23
Subject-34	3 rd and 4 th month	126	69	85	97.53	98	12	23
Subject-34	5 th month	118	69	94	95.73	99	12	22
Subject-34	5 th month 1 st to 15 th day	115	66	95	95.68	99	14	22
Subject-34	5 th month 16 th to 30 th days	121	73	93	95.78	99	11	22
Subject-35	1 st Month	95	51	76	95.10	95	5	20
Subject-35	2 nd Month	103	65	85	92.50	89	11	23
Subject-35	3 rd and 4 th month							
Subject-35	5 th month							
Subject-35	5 th month 1 st to 15 th day							
Subject-35	5 th month 16 th to 30 th days							
Subject-36	1 st Month	115	69	69	96.95	91	9	23
Subject-36	2 nd Month	117	43	95	94.00	91	13	25
Subject-36	3 rd and 4 th month	148	98	87	97.10	98	14	22

Contd...

Supplementary Data 7: Contd...

File name	Average at	Systolic (mmHg)	Diastolic (mmHg)	Pulse rate/min	Temperature °F	SpO₂ in %	Bhramari Time/second	Respiration Rate/min
Subject-36	5 th month							
Subject-36	5 th month 1 st to 15 th day							
Subject-36	5 th month 16 th to 30 th days							
Subject-37	1 st Month							
Subject-37	2 nd Month	95	49	95	98.51	91	9	26
Subject-37	3 rd and 4 th month	112	61	87	97.76	97	9	22
Subject-37	5 th month							
Subject-37	5 th month 1 st to 15 th day							
Subject-37	5 th month 16 th to 30 th days							
Subject-38	1 st Month							
Subject-38	2 nd Month	114	69	122	98.00	98	10	20
Subject-38	3 rd and 4 th month	136	77	92	97.80	99	11	25
Subject-38	5 th month	145	81	81	96.09	97	12	23
Subject-38	5 th month 1 st to 15 th day	145	81	79	96.03	97	11	24
Subject-38	5 th month 16 th to 30 th days	145	82	84	96.22	96	13	21
Subject-39	1 st Month	102	50	62	98.00	98	10	23
Subject-39	2 nd Month	102	50	62	98.30	98	12	21
Subject-39	3 rd and 4 th month							
Subject-39	5 th month	133	90	89	97.95	99	14	20
Subject-39	5 th month 1 st to 15 th day	130	95	88	97.50	98	13	22
Subject-39	5 th month 16 th to 30 th days	135	85	90	98.40	99	14	18
Subject-40	1 st Month	111	63	93	95.45	95	11	23
Subject-40	2 nd Month							
Subject-40	3 rd and 4 th month	110	55	99	96.85	99	11	26
Subject-40	5 th month	140	76	100	95.67	99	13	25
Subject-40	5 th month 1 st to 15 th day	140	76	100	95.67	99	13	25
Subject-40	5 th month 16 th to 30 th days	130	85	90	98.20	92	15	18
Subject-41	1 st Month							
Subject-41	2 nd Month							
Subject-41	3 rd and 4 th month	89	55	70	96.45	98	9	25
Subject-41	5 th month	127	50	71	97.20	98	9	23
Subject-41	5 th month 1 st to 15 th day	126	47	68	96.75	98	10	25
Subject-41	5 th month 16 th to 30 th days	129	57	77	98.10	97	12	20
Subject-43	1 st Month							
Subject-43	2 nd Month	96	46	87	98.70	97	5	24
Subject-43	3 rd and 4 th month	78	43	67	98.00	99	7	20
Subject-43	5 th month							
Subject-44	1 st Month	82	65	87	92.40	84	9	23
Subject-44	2 nd Month	82	65	87	95.70	83	8	25
Subject-44	3 rd and 4 th month							
Subject-44	5 th month	105	75	81	97.75	98	11	22
Subject-44	5 th month 1 st to 15 th day	110	76	82	97.50	98	10	23
Subject-44	5 th month 16 th to 30 th days	100	74	80	98.00	98	12	21

Supplementary Data 8: Picture of doctor checking subject at YBLI center

Supplementary Data 9: Certificate issued by Sarpanch