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PATIENT SUPPORT GROUPS A SHARED JOURNEY



Patient Support Groups A shared journey

© KHPT, August 2020

Publisher:
KHPT
IT Park, 5th Floor,
1-4, Rajajinagar Industrial Area,
behind KSSIDC Admin Office,
Rajajinagar, Bengaluru,
Karnataka 560 044

Ph: +91 80 4040 0200
Fax: +91 80 4040 0300
Website: www.khpt.org
Email: khptblr@khpt.org

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Disclaimer: This material is made possible by the generous support of the American people through the United States Agency for International Development (USAID). The contents are the responsibility of KHPT and do not necessarily reflect the views of USAID or the United States Government.

Acknowledgements

We sincerely acknowledge the contributions of officials of the National Tuberculosis Elimination Program (NTEP) and health facility staff in Bengaluru who supported the implementation of patient support groups. We also wish to acknowledge the support of the field staff of the THALI project who worked tirelessly to build an enabling environment in health facilities through the establishment of patient support groups.

The following individuals at KHPT contributed to the design and implementation of the intervention in Bengaluru:

Ms. Geetha K
Ms. Poornima B S
Ms. Shivaleela
Mr. Thayabullah Khan

Writing and compilation:
Ms. Bharathi Ghanashyam
Ms. Poornima B S

Editorial:
Dr. Joseph Francis Munjattu
Ms. Mallika Tharakan
Dr. Pamela Sanath
Ms. Vrinda Manocha

Layout and Design:
The Pen & Mouse

Photography:
Vrinda Manocha and THALI field staff



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ABBREVIATIONS

ADR	Adverse Drug Reaction
ASHA	Accredited Social Health Activist
AWW	Anganwadi Worker
BCC	Behavior Change Communication
CBO	Community Based Organization
CHW	Community Health Worker
CTD	Central Tuberculosis Division
DMC	Designated Microscopy Centers
DOTS	Directly Observed Treatment, Short-course
DS	Drug Sensitive
DR	Drug Resistant
IEC	Information Education and Communication
HIV	Human Immunodeficiency Virus
JEET	Joint Effort for Elimination of Tuberculosis
KHPT	Karnataka Health Promotion Trust
KOL	Key Opinion Leaders
MOs	Medical Officers
MNCH	Maternal, Newborn and Child Health
MDR	Multi Drug Resistant
NSP	National Strategic Plan
NTEP	National Tuberculosis Elimination Programme
PA	Patient Advocate
PPM	Public Private Mix
PSG	Patient Support Groups
RNTCP	Revised National TB Control Programme
SHOPS	Sustaining Health Outcomes through Private Sector
STS	Senior Treatment Supervisor
TBC	Tuberculosis Champion
THALI	Tuberculosis Health Action Learning Initiative
TU	Tuberculosis Unit
WHO	World Health Organization



PATIENT SUPPORT GROUPS AS A PEER-BASED SUPPORT APPROACH TO CATER TO CARE & SUPPORT NEEDS OF TB PATIENTS

“If it were not for Patient Support Group (PSG) meetings, I would not have understood the importance of adherence and completion of treatment. I might have risked my life and become a Multidrug Resistant Tuberculosis (MDR)-TB patient,” – Venda, TB patient, Varthur, Bengaluru Urban District.

“I found a new person and a leader in myself; this was all because of PSG meetings. I want to bring in more TBCs like me and work for stigma reduction.” - Kavitha, TB Patient cum Champion (TBC).

“If not for this PSG, I would have committed suicide unable to cope with the challenges of TB. The support I received from this group gave me hope” - Fatima (name changed), Hospet, Bellary district.

These are voices of people who have suffered and recovered from Tuberculosis (TB). They are members of PSGs for TB patients facilitated by Project Tuberculosis Health Action Learning Initiative (THALI). The PSGs are a part of the care and support initiatives of THALI. THALI is funded by the United States Agency for International Development (USAID).

THALI is implemented by Karnataka Health Promotion Trust (KHPT) in three southern Indian states covering 73 towns and 30.4 million people. It is a patient-centric family-focused TB prevention and care initiative that aims to facilitate access for vulnerable populations to quality TB services from health care providers of the patient's choice.¹

The uniqueness of the PSGs lies in the fact they are not parallel efforts, but housed within public healthcare facilities such as primary health centres (PHC) and designated microscopic centres (DMC) and actually expand on the concept of patient provider meetings (PPM) as mandated by the National Tuberculosis Elimination Programme (NTEP). This ensures that the PSGs have become more inclusive because they address the patients covered by the program. The elements fused into them are consciously designed to be patient-centred. Together they offer an empowering experience to TB patients who are struggling with symptomatic, social and economic challenges associated with TB.

¹<http://www.khpt.org/intervention/tuberculosis/>



KHPT is a not for profit entity that spearheads focused initiatives to improve the health and wellbeing of communities in India. KHPT was founded in 2003 with a single mission to reduce the prevalence of HIV in Karnataka's high priority pockets. The initiative's success made it a scalable model at national and global levels and the learnings from this large scale program has informed initiatives across themes like TB, adolescent health, maternal and child health and comprehensive primary health care.

TB - PREVENTABLE & CURABLE

Tuberculosis (TB) is a preventable, curable disease that requires long-term treatment, and yet, has continued to challenge humanity for centuries. While the spread of TB is rapid, the cure can take up to two years, depending on the form of TB (DS – drug sensitive or DR – drug resistant) which the patient has been infected with.

TREATMENT & CURE - A MULTI-FACETED PROCESS

Adherence to treatment holds the key to a complete cure from TB. It is imperative that the patient completes the entire course of treatment because failure to do so can lead to more virulent forms of drug-resistant TB and thereafter, unchecked spread of drug-resistant forms of TB. This can then involve harsh and longer duration of treatment which involve debilitating costs and impact on livelihoods. And yet, achieving complete cure from TB is not a matter of adherence alone. It is in fact an entire process that requires high levels of psycho-social, nutritional and emotional support, beginning from initiation of treatment right up to completion.

PATIENT SUPPORT GROUP (PSGs) A CONCEPT AND A FACILITY

A patient support group is a monthly, inclusive gathering of patients and caregivers visiting a particular health facility once a month. They are founded on the belief that peer support can potentially help patients deal with challenges that they face through conversations with other patients and caregivers who have been similarly affected. They address treatment-associated difficulties such as side effects, as well as social stigma and isolation from extended family members and community members.

PSGs also serve as platforms to discuss concerns about treatment with facility staff and enable mutual support through experience-sharing and easy access during the treatment phase for all patients to additional care and support services. These services are in the form of psycho-social counselling, nutrition support, provision of incentives and linkages to social entitlements for improving treatment adherence.

More importantly, PSGs afford easy physical access as they are available to them at places and times convenient to them. The PSGs offer safe, non-judgmental space for patients to air their grievances, and also serve as a learning experience for health facility staff on the importance of counselling and providing information in an informal environment.

NOT JUST A MEDICAL PROBLEM

Given the levels of support a TB patient requires beyond the strictly medical, it is now being increasingly recognized as a social issue. NTEP has universalized and standardized the TB treatment protocols and mechanisms. There are good systems in place for catering to the medical needs of the patient and in what is an encouraging trend, efforts are being made to address the non-medical needs through innovative means. PPM sets the stage for addressing the non-medical needs of a patient and are mandated as a part of the National TB Programme in India. Is this happening to its fullest extent? PSGs hold one of the answers.

BEYOND TREATMENT

Poverty, treatment access issues, fear of stigma and lack of family care and support, as well as unpleasant treatment experiences during the long duration of treatment are just some of the challenges faced by TB patients. Additionally, while they require good nutrition that can build immunity and give them the strength to withstand the treatment, the side-effects of TB treatment cause loss of appetite, nausea, temporary blurring of vision and red/orange colored urination. These are severe enough causes for them to stop treatment altogether.

PSGs offer hope to such patients. Venda says, “I am happy to be a part of a PSG because it gives me opportunities to speak freely and clear my concerns. Interacting with others like me and with doctors and experts builds my knowledge on how to care better for myself and my three children.”

PATIENT-SUPPORT GROUPS THE KHPT MODEL

The National Strategic Plan (NSP) for TB in India has included patient support in its guidelines and provided budgets for it. The guidelines specify that every patient who is on TB treatment must be given nutritional support, treatment literacy and counselling through PPM.

Dr. Prarthana B S, Project Director, JEET, KHPT, says, “PPM by its very design, adopts a one-sided approach i.e. from the healthcare provider to the patient, when the need is actually to put the patient in the centre. This is the gap that KHPT set out to fill through the PSG concept. PSG was not without precedent. Through our earlier SHOPS TB² program, KHPT had formed and run several PSGs, termed then as Prerana groups and witnessed the significant impact it had on patients who were undergoing trauma at several levels.” She continues, “They were suffering from side-effects that made it hard for them to stay on treatment. Lack of nutrition support was an added challenge. We initiated PSG to address some of these challenges. The space that they got to share their experiences made a big difference and reassured them that they were not alone. Because the meetings were held within healthcare settings, they could interact with medical experts and access correct information. Based on these experiences, the concept of PSGs was logical and indeed necessary for inclusion into THALI. Instead of creating parallel structures we fused it into the already available PPM space with encouragement from the healthcare officials.”

² <http://www.khpt.org/intervention/tuberculosis/>

THE OBJECTIVES

- ❖ Help patients overcome unpleasant treatment experiences and stigma during the treatment period using a peer support approach
- ❖ Promote patient friendly facilities by improving communication between healthcare providers, patients and caregivers to improve knowledge on TB and available services, as well as address issues related to treatment.

Ms Poornima Siddappa, Program Coordinator, Project THALI adds, “The Patients’ Charter for TB Care of WHO³, clearly states that patients are not merely passive recipients of services but active partners. They have a responsibility to gain and share information and experiences with other patients. The mandate of PPM in NTEP had already made it easy for us to reach out to patients and had the potential to move the patient to the centre. We therefore exploited that potential and made PPM more inclusive and interactive.”

³ https://www.who.int/tb/publications/2006/istc_charter.pdf



THE PROCESS, THE POTENTIAL

The process however held challenges as well as opportunities. KHPT already had the knowledge of what elements were required for a PSG through the earlier Prerana groups. A safe space for patients to engage with each other, sensitive staff at public healthcare settings and more patient-friendly facilities were mandatory requirements. An additional innovation was KHPT’s active efforts to engage local community members who could engage with the patients meaningfully and provide additional support if required. The PSGs also had the potential to identify and build capacity into pro-active individuals to become TB Champions and Advocates. TB Champions in the context of PSGs was not just a term. It meant building capacity and self-esteem into individuals with a view to building collective power that would drive positive feelings among them, give them the capacity to feel empathy and a oneness with others like them. It also meant giving them a strong voice to demand better quality services through a rights approach rather than as passive receivers.

The value of PSGs as appropriate platforms for TB patients cannot be disputed; they also hold benefits for communities at large, particularly women and adolescent girls for issues beyond TB too. This was owing to the topics and themes that were identified for discussion, which were at two levels – the mandatory and the need-based. They ranged from technical knowledge on TB and progressed to softer topics such as nutrition, well-being and attitudes (See box for details).



STRUCTURE AND FORM

While facilitating PSGs, it was important for the THALI staff to give it a basic structure, even while retaining its informal character. It was important to draw participation from patients who believed that they would gain in more ways by belonging to a PSG.

Services	
Structure and frequency	<ul style="list-style-type: none"> ⌘ Held at the DMC or PHC ⌘ Date and time of meeting already fixed a month prior in order to give enough time to patients and caregivers to plan their attendance.
Services offered	<ul style="list-style-type: none"> ⌘ Peer support, motivation & counselling ⌘ Adherence education by NTEP staff i.e. TB HIV ⌘ In person counselling by KHPT – THALI staff ⌘ Consultation with Medical Officer for adverse drug reactions ⌘ Refilling of tablet boxes, weight monitoring and supply of nutritional supplements.
Venue	<ul style="list-style-type: none"> ⌘ Held within healthcare facility close to the patient's residence, thereby providing a convenient and non-threatening space.

Agenda – topics & discussions

Mandatory	Demand-driven
<ul style="list-style-type: none"> ⌘ Information on basics of TB ⌘ Adherence education ⌘ Care and support for TB patients ⌘ Education for care givers and how to deal with weak, alcoholic or patients with co-morbidities ⌘ Interaction with medical experts for treatment literacy, management of co-morbidities and sharing of other concerns ⌘ Dealing with adverse drug reactions ⌘ Weight management 	<ul style="list-style-type: none"> ⌘ Nutrition awareness & support ⌘ Peer-support and experience sharing ⌘ Aided discussions to strengthen awareness ⌘ Interaction with donors and in-kind support for nutrition and other needs ⌘ Interaction with TB Advocates and TB Champions ⌘ IEC demonstrations

NOT A MAGIC BULLET – ADDRESSING THE GAPS

PSGs however were not a magic bullet and the true effectiveness of the groups became evident only gradually. It began with motivating people to attend and there was a need for action at several levels, which the team addressed systematically. Ms Mamata, Community Coordinator, Project THALI says, “Though we gave so much thought and care to how a PSGs would function and invested a lot of time on reaching out and inviting patients to attend the monthly meetings, there was limited pick-up in the beginning.” Patients were apprehensive; they were beset by unnamed fears of the disease, of the society and as they were already suffering, motivation levels were low. This called for intensive outreach and pointed to a need for peers to come forward and set examples. It also called for involvement of several stakeholders.



Thayabulla Khan, Community Coordinator, THALI says, “TB patients had so many needs. One way of incentivizing them to attend meetings was to fulfill those needs. So we identified local donors and invited them to the meetings. They would come and give in-kind donations, which included nutritional items. This had very good impact as the unexpected also happened. Donors became sensitized to the suffering of the patients and patients became motivated. We also intensively built-up local champions and advocates from the more vocal and active members of each PSG.”

Nutrition information was an important area of focus, given the enhanced nutritional needs of TB patients. This was done through theory and demonstration by first explaining and then teaching the patients ways to prepare nutritional supplements at home with locally available ingredients. The emphasis was on using fresh vegetables, fruits and pulses, etc, especially seasonal ones owing to the lower costs they would involve to procure. This initiative got immense response from all the stakeholders ranging from patients, caregivers, NTEP, DMC staff, district NTEP, visitors etc. Patients often quote examples of how their diets have improved. The story of Nirmala demonstrates this (see box).

INCLUSIVE IN SPIRIT AND ACTION

The other unique element lay in the manner that the PSGs responded to patient needs, even with regard to language and approach. This helped them feel comfortable and engaged. Peerambi, whose husband Peerayya has been attending PSG meetings at the K Narayanapura TU and DMC says, “I can speak and understand only Telugu; I was spending Rs150/- to take my husband to the TU and still not get the information or support I needed because I could not communicate in Kannada. After coming to the PSG meetings where information is given to me in Telugu, I am learning how to care for my husband. I feel the money I spend is worth.”

The scope of PSGs in the beginning was limited. It involved direct stakeholders i.e. patients and caregivers, and enabled interaction for them with THALI staff and healthcare providers. Involvement from NTEP functionaries was limited in the beginning but over time, when they witnessed active involvement from patients, they were enthused enough to get involved in many ways – imparting technical education being just one of them. Most importantly, other government functionaries such as medical officers (MOs) and ASHAs attended the meetings.

The PSGs also attracted interest, albeit limited from local donors from the community. Some of these members, while they did not attend the meeting, contributed in-kind nutritional support. Donor agencies and study teams visited the PSG meetings to understand how they worked with a view to replicate the concept.



A Champion – in more ways than one

Nirmala, who is now a TB Champion, was on treatment for the second time when the outreach staff of THALI met her. Aged 53, she lives alone as her son and his family live away from her, fearing she might infect them. They have moved away on her advice and still look after her needs, but as she shares, “Living alone is difficult particularly when you are sick. When the THALI staff invited me to attend the PSG meetings. I had not told anyone about my condition fearing stigma and was scared to attend the meeting. But after I went to the first one, I overcame my fears and began looking forward to the monthly meetings.”

Nirmala has now progressed to a stage where she can conduct a meeting independently. She began by helping to organize meetings and demonstrating the IEC materials and gradually progressed to becoming a TB Champion. With pride she says, “I am able to demonstrate recipes for making nutritional food like sandwiches, juices and salads which can be made at low-cost from materials available at home. I realize that awareness is very important for TB patients and will continue to do my best to spread the awareness that I have been given. I have attended state-level TB meetings.”

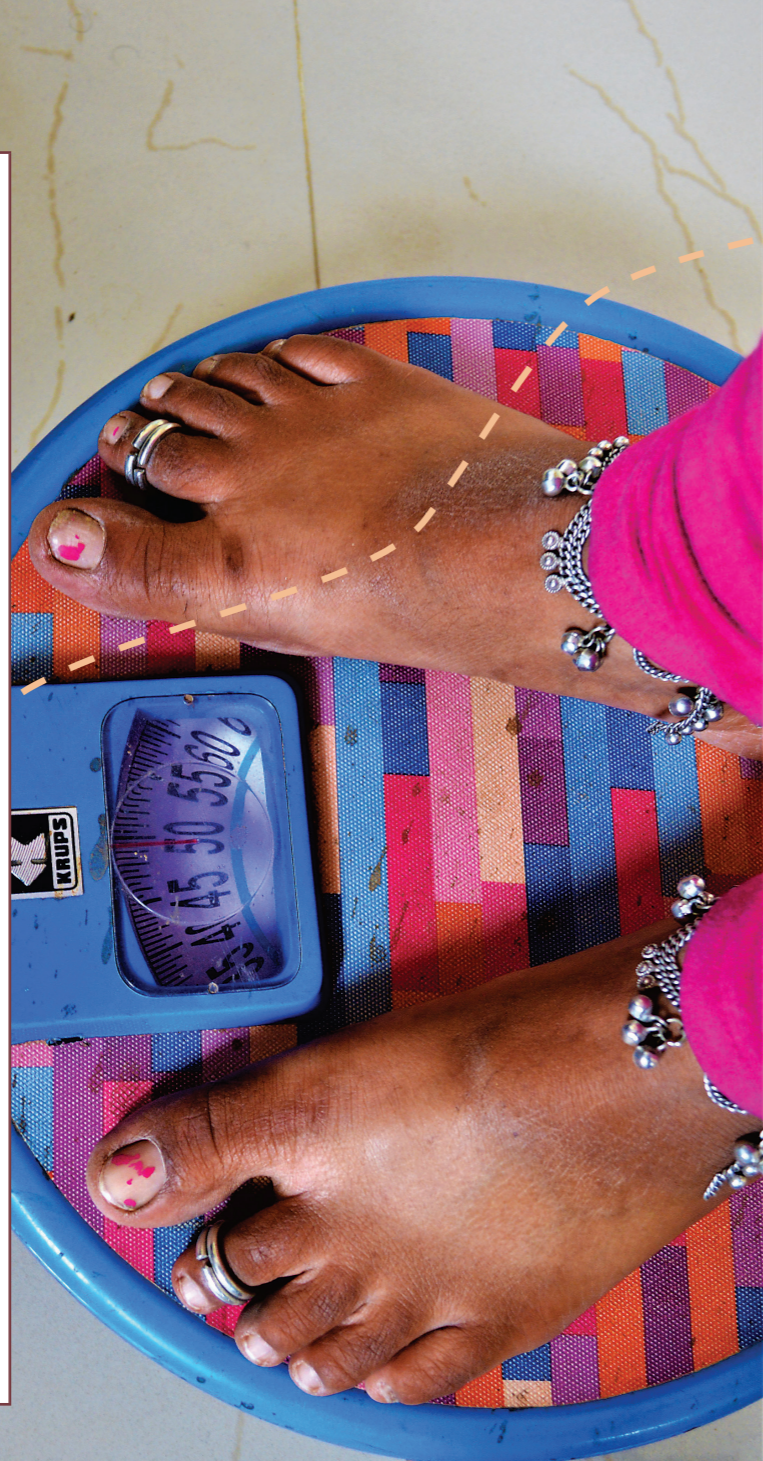
Inspiring, motivating – Kavitha’s story

“ I benefitted a lot by involving in PSG meetings and I also found a leader in myself through PSGs; I would like to work more in the field of stigma reduction in the community of TB and patients, in the coming days,” says Kavitha.

Kavitha (40) lives with her husband and two sons. She is HIV+ve and has successfully completed treatment for TB after being counselled for both TB and HIV by a THALI Community Coordinator. Having motivated her to attend a PSG meeting, the coordinator observed that she had good communication skills and convinced her to become a Patient Advocate. It began with attending PSG meetings. Kavitha says, “I went with my husband to the first meeting and we just sat and listened, too scared to talk. Then I began attending meetings regularly. I used to interact with others who came to the meeting. Then I realized that I had the skills to convince others to be adherent to treatment. This made me so proud. I also began counselling them on nutrition and management of adverse drug reactions.”

Kavitha has participated in National Level TB Champion workshops conducted by Central TB Division in Delhi and Hyderabad, and other events that encourage involvement of communities in TB control. In Hyderabad she represented Bangalore and Karnataka. She has also been a part of the State TB Forum meeting held at Vikasa Soudha in Bangalore.

Kavitha is a worthy champion!



Ensuring that benefits are shared - Goutham’s story

Goutham. C is a 33-year-old resident of Sahakarnagara, Amruthahalli TU and DMC. He lives with his sister and brother-in-law and owns a business. He had a persistent cough for three weeks and when he went to hospital for health check-up he was diagnosed with TB and put on treatment.

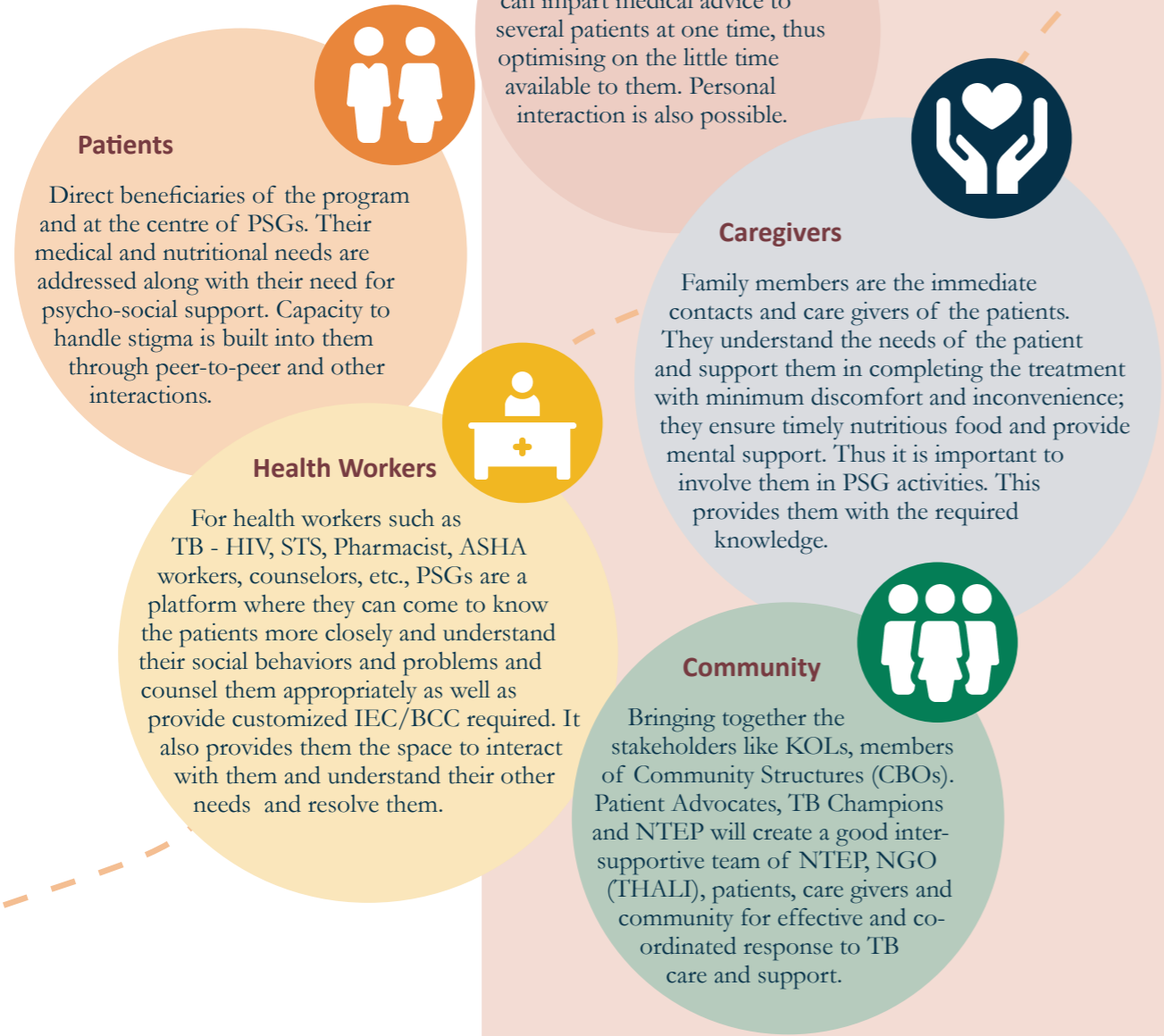
When the THALI Community Coordinator met Goutham, he was on the verge of discontinuing treatment owing to adverse drug reactions i.e. itching, vomiting and joint pains. He was motivated by the coordinator to attend a PSG meeting where he was guided on how to manage drug reactions, and given awareness on the importance of nutrition. He was also sent to Medical Officer for help on management of ADRs. He started taking medicines regularly and his weight improved from 44 to 58 Kgs. He was cured in March 2020. Now he voluntarily attends the PSG meetings, self-motivated and he facilitates the sessions on nutrition, adherence and other aspects related to TB as a Patient Advocate.

Moving from hopelessness to living with hope - Raju’s story

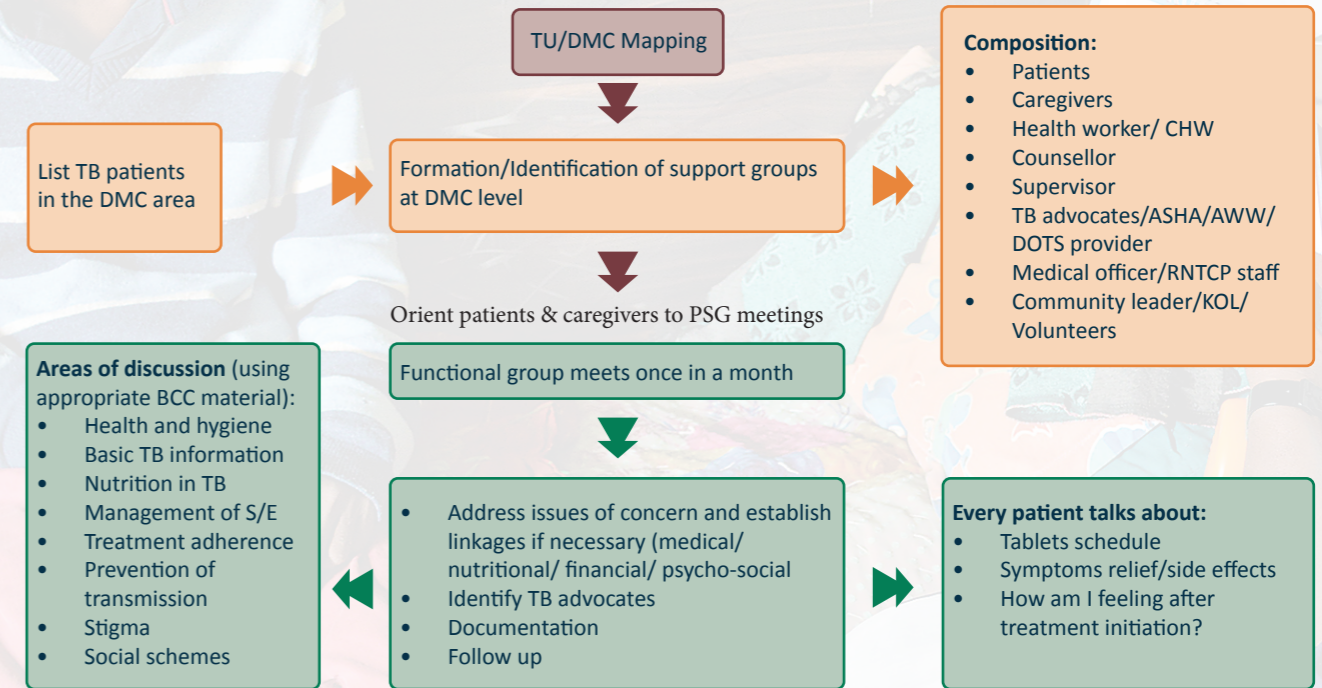
Raju (32) lives with his mother at Bangarappanagar, and is attached to the Kengeri TU/ DMC. An alcoholic since the age of 17, Raju was working in a hotel when he was diagnosed with TB. But he did not comply with the adherence and was classified as a defaulter. The THALI Community Coordinator unsuccessfully tried to get him to attend PSG meetings. With motivation from the Senior Treatment Supervisor and Health Visitor at the TU, Raju began attending meetings and interacting with other patients. He was given help to manage side effects, and given nutrition support. At the time of recovery, Raju was an active participant in PSG meetings and he had even become less dependent on alcohol. He also became familiar with the IEC material which helped him stay with treatment because of increased awareness.

THE PROGRAMMATIC BRIDGE

The influence of the PSG meeting among various stakeholders can be observed as below:



IMPLEMENTATION MODEL



WHAT WORKED, WHAT DID NOT

Over the period of the SHOPS and THALI projects, the value of PSGs as a peer-based approach had been established. It was also clear that government healthcare settings were ideal spaces given the PPM mandate. Expansion of the concept of PPM into PSGs proved impactful while enabling access to comprehensive TB services such as counselling, consultation, medicines, testing, peer support, nutrition information as well as services, etc.

PSGs actually became springboards from where patients could enhance their awareness, get their concerns addressed, and become equipped to share their learnings with other, affected and infected persons, be it in their communities, at other PSGs meetings or at high-level meetings while interfacing with policy makers and institutional donors. They became community-led advocacy models for strengthening TB care and support services and also for inclusion of community in the TB management systems at district, state and central levels.

However, there were in-built limitations. Since all the meetings were conducted within healthcare facilities, participation was a challenge in urban as well as rural settings. Confidentiality issues were equally a limitation in the meetings. Hopelessness and apathy among patients who were suffering at different levels both physical and mental was an added challenge as getting them to the meetings required a lot of effort.

Additionally, each patient was at a different level of understanding and had varied needs. Some had just begun treatment so they were manifesting severe side-effects, or were depressed and demotivated. There were others who had progressed almost to completion. This however was an opportunity because it helped in experience sharing. It was also up to the Community Coordinators to ensure that everybody got the same level of attention. The benefits thus outweighed the challenges and each challenge seemed small in comparison.



SCALEABILITY OF PSGs – VIABLE OR NOT?

Ease of scaleability of any intervention is a crucial indicator for success. PSGs have demonstrated the ease with they can be scaled up in universally available healthcare settings. While the current model of PSGs has demonstrated impact in urban and rural healthcare settings, the true results can become evident if they can be successfully conducted at community levels. While rural settings are relatively easier owing to lower levels of stigma, community-led models can be challenging in urban settings where instances of stigma are higher and space constraints exist.

A constant challenge will be the inability of affected and infected communities to attend the meetings as government services are not functional at PHC level on holidays and this is a severe limitation for daily wage labourers and other working groups. Patients were required to dedicate at least half a day to attend PSG meetings. As the benefits were so visible, patients were willing to compromise their work schedules and to attend PSG meetings. In such situations, it would be more beneficial to have community-level PSGs.

Intense effort on the part of KHPT staff resulted in increased participation of urban poor population in Bangalore Urban in PSGs. To maintain this level of effort will be a challenge while scaling up and advocacy can ensure PSG meetings are included in the reporting structure in order to ensure sustainability. Demonstration of nutritional food recipes and individual counselling by THALI field teams were the most powerful reasons that patients participated in the PSGs in Bangalore Urban District.

Other limiting factors were the residences of patients being situated very far away from facilities in few places like Varthur and Kadugodi. In a few places there was no public conveyance system; In few, patients could not afford to pay conveyance and visit the facility. In such circumstances it will be difficult for even caregivers to



participate. But given the demonstrated impact of PSG it calls for dedicated government schemes or interventions to enable patients to be part of support groups with the larger objective of better adherence and chances of cure. Failure to do this will mean limited and short-lived impact.

THE CONCLUSION BUT NOT THE END

The PSGs facilitated by KHPT were the amalgamation of learnings gleaned from the field through earlier projects such as SHOPS TB, HIV programs and maternal and new born child health (MNCH) programs. These programs had already demonstrated strongly that community-driven initiatives were more effective because they responded to felt needs. They also clearly established that such efforts were sustainable beyond the program. When communities felt that their needs were being respected and responded to, and when this response resulted in visible changes, it did not take long for them to own it and take it forward on their own.

PSGs were no different. Initiated as a part of the PPM of the NTEP, they were gradually transformed and became dynamic platforms of hope. Patients and caregivers alike were encouraged to voice their needs and concerns. While it was a small step, it had big impact. Being heard, and what is more, being heeded was more than half the journey covered. As Nirmala says, “Living alone, I was often very

lonely and would become fearful about my condition. I looked forward to the PSG meetings because I got relief on so many fronts, be it treatment support, nutrition information, or help that donors gave. In these stressful times of COVID 19 I miss the PSG meetings acutely and feel I was better off then, even though I was suffering from TB.”

Nirmala’s poignant reflection actually holds very deep meaning. It demonstrates how important it is for vulnerable and challenged people to be able to access solidarity groups such as the PSGs and how wide the scope of a PSG can actually be. PSGs hold the potential to become hubs for activities beyond TB care and support alone. While the PSGs of Project THALI were focused only on TB the KHPT team felt more could be done. Given that TB patients are encouraged to restart life after complete cure they would welcome holistic support.

PSGs can go beyond just TB and promote open communication within families to tackle societal attitudes and self-stigma. The



concept can percolate down to the community level where wider dialogues can be promoted to include women, children and youth. They also have the potential to promote focus on individual empowerment and skill building. The broader vision for PSGs is to empower patients by building their self esteem and confidence, thereby giving them the ability to negotiate for better services for themselves.

There were lessons for sustainability too. The primary lesson was they could be institutionalized into the NTEP and have standardized protocols and tools. PSGs must be included into the reporting structure in order to give them official recognition and importance. There was strong buy-in from ground-level officials and this can be leveraged to strengthen the concept and sustain it. This will ensure that PSGs are strengthened at community and institutional settings. The result of this will be cross-learning, sensitization from both community and officials to each other’s needs and challenges, and strong collaborations.

Beginnings have been made and the concept can only get stronger, given the demonstrated need.



KHPT

IT Park, 5th Floor,
1-4, Rajajinagar Industrial Area,
behind KSSIDC Admin Office,
Rajajinagar, Bengaluru,
Karnataka 560 044

Ph: +91 80 4040 0200

Fax: +91 80 4040 0300

Website: www.khpt.org

Email: khptblr@khpt.org

