



Understanding the Role of the Differentiated Care Model and Patient Support Groups on Tuberculosis Treatment Outcomes

A qualitative study in selected districts of Karnataka, Andhra Pradesh and Telangana



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Publisher

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Some of the photographs included in this report are of THALI's community engagement activities and do not represent field activities carried out during the surveys.

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LIST OF ACRONYMS

BCC	Behaviour Change Communication
CHW	Community Health Worker
CP	Continuous Phase
DCM	Differentiated Care Model
DMTB	Diabetes Mellitus Tuberculosis
DRTB	Drug-Resistant Tuberculosis
DSTB	Drug Sensitive Tuberculosis
DOTS	Directly Observed Treatment - Short course
IEC	Information Education and Communication
IP	Intensive Phase
HIV	Human Immunodeficiency Virus
MoHFW	Ministry of Health and Family Welfare
NTEP	National Tuberculosis Elimination Programme
RANA	Risks and Needs Assessment
PRI	Panchayati Raj Institutions
PSG	Patient Support Group
TB	Tuberculosis
TBHV	Tuberculosis Health Visitor
THALI	Tuberculosis Health Action Learning Initiative
WHO	World Health Organization

EXECUTIVE SUMMARY



Tuberculosis (TB) remains one of India's severest public health concerns, although there are numerous existing global and national programmes and commitments that strive to eliminate the disease. The Government of India's National Strategic Plan for Tuberculosis Elimination (NSP) (2017-2025) lays down plans to reduce the incidence, prevalence and mortality from TB, with the goal of eliminating it by 2025. One of the major barriers to these efforts is the incidence of poor treatment outcomes due to non-adherence to the long and difficult TB treatment regimen.

This is further exacerbated among certain categories of high-risk patients, such as those with comorbidities, with drug resistant TB, those using alcohol, as well as those living in disadvantaged socio-economic contexts. There is a growing body of evidence-based advocacy for incorporating patient-centric and community-based strategies to tackle these issues and to improve treatment outcomes among TB patients.

In line with this vision, the Tuberculosis Health Action Learning Initiative (THALI) was implemented by a consortium of partners, led by KHPT and funded by USAID, as a TB prevention and care initiative to support vulnerable populations' access quality TB healthcare services. Under THALI, the Differentiated Care Model (DCM) and Patient Support Groups (PSG) were developed as key patient-centric interventions to achieve successful treatment outcomes for patients and improve treatment completion and cure rates. The DCM seeks to provide customized Prevention, Care and Support (PCS) services to seven categories of high-risk patients through a cadre of trained frontline health workers, namely, elderly patients above the age of 60 years, patients living alone, previously treated TB patients, drug-resistant TB patients, those using alcohol, and patients with HIV or diabetes mellitus comorbidities.



This model provides prioritized care in the form of frequent visits and follow-ups, counselling, referral services, and linkages to welfare schemes and nutrition support, and aims to tap into the potential of family and community-based support networks to assist patients in successful treatment completion. The PSG is designed to make healthcare facilities more patient-friendly by strengthening communication channels between patients and healthcare staff and building patient advocacy networks.

After the implementation of DCM and PSG in selected districts of Karnataka, Telangana and Andhra Pradesh under the THALI project, a study was conducted to assess the effectiveness of the programme in achieving the broader goals of THALI, to understand the impacts of the two interventions on treatment

outcomes, and to evaluate these findings to further improve the two programmes. The research study was carried out in Bengaluru and Koppal districts of Karnataka, Hyderabad in Telangana and in Krishna district of Andhra Pradesh between October 2019 and March 2020. It adopted a qualitative approach, including 38 in-depth interviews with purposively sampled patients from each DCM category, Community Health Workers (CHWs) of the THALI program, and TB Health Visitors (TBHVs) of the National Tuberculosis Elimination Program (NTEP). The study also included four participant observations of PSG meetings. Findings were thematically coded and recursively analyzed using qualitative software, and this report presents these findings and analysis of data, along with a discussion of major themes and recommendations for further consideration.

Findings indicate that the CHWs under DCM played an important role in ensuring treatment adherence among DCM patients, as corroborated by patient experiences. The DCM fills an important gap in TB programs by aiding patients in the form of regular visits or phone calls from healthcare workers, who impart critical information on tests to be conducted, regular hospital visits, assistance for obtaining medication, precautions to avoid the spread of disease, nutritional advice, regular reminders to consume medication and the critical need to adhere to treatment at all costs. As narrated by patients themselves, these efforts were useful in cultivating proper treatment adherence behaviours, and contributed to their successful completion of treatment.

It was noted that a significant number of such activities undertaken by patients were enabled by the presence of supportive family members, neighbors, or friends. While this critical insight reinforces the



premise of the DCM, which aims to tap into this potential of family-based support, and provides an impetus to the programme to continue to do the same, this aspect of support was found to be insufficiently mobilized for patients who did not have existing support networks in the present implementation. Another shortcoming was the generality of treatment assistance provided by CHWs, which compromised on the ‘differentiated’ aspect of care. With CHWs often unable to identify multiple-risk categories or manage co-morbidities such as diabetes or HIV, and having difficulties with certain types of

patients such as those dependent on alcohol, further rigorous training and support could provide a more concrete foundation of knowledge and capacities for them to work.

The nature of TB literacy imparted by CHWs, though reflected in patient awareness levels, was not always comprehensive in nature, and the issues of superstitions, stigma, and discrimination around TB were persistent at the community level. For patients without existing family or other support networks, the efforts at patient care were found to be inadequate. Attempts at counselling and psycho-social support by CHWs were hindered by structural barriers such as those of gender and caste, and were also limited to individual instances of personal rapport-building. Socio-economic vulnerabilities of TB patients were highlighted in the lack of social security support and were affected further by poor functioning of government Direct Benefit Transfer (DBT) schemes, in spite of assistance in linkages in this regard by health workers. Interactions with CHWs revealed a keen theoretical knowledge of DCM categories, general TB treatment processes and the importance of counselling, but an inadequate application of these in the case of patients with comorbidities and multiple risks, as well as inadequate training to manage treatment adherence for difficult cases such as patients with alcohol use. Aside from these challenges, CHWs also cited community-level stigma, poorly functioning DBT schemes and unavailable social security support for

patients, and lack of sufficient personnel, as constraints to their work. TBHVs seemed to be functioning largely independent of CHWs, focused primarily on improving overall successful treatment outcome rates, without any specific attention to DCM category patients. Patient Support Groups saw poor and irregular attendance due to various reasons such as the illness itself, pressures of work, the stigma of being associated with TB patients, lack of availability of medical staff at meetings, and the repetitive content of the meetings. Patients also did not actively participate during these meetings as these were considered spaces for obtaining information rather than building solidarities. At the same time, the potential of PSGs was highlighted by some accounts of patients and CHWs who described them as beneficial for clarification of doubts, sharing of one's experiences of the treatment process, and building a sense of confidence among them in the ability to cure their illness through proper treatment.

Structural factors such as poverty and discrimination, which are known to constrain treatment adherence among TB patients, were also found to be hindering the effectiveness of the DCM. Although these require interventions at the institutional level, the efforts of sustained community-based and patient-centred efforts at mitigating societal issues such as stigma should not be understated. Based on prior evidence, as well as specific narratives of successful outcomes, it can be ascertained that continuous efforts by frontline health workers and PSGs have the potential to mediate and effect change at the intersection of complex interpersonal and structural factors that impact TB outcomes. Although patient support groups were also found lacking in such aspects of support, the evidence to show the potential benefits of psycho-social support groups for patients on treatment adherence and overall patient well-being, build a strong case for further developing the intervention with more robust planning and management.

Based on insights from findings, recommendations are suggested for strengthening the DCM and PSG. It is suggested that knowledge and capacities of frontline workers be improved through intensified training to tackle the difficulties of attending to comorbid, multiple-risk, and difficult-to-treat patients. Resources may be compiled at the district level and constantly updated and shared with workers to aid their efforts with social security linkages. Advocacy material for patients should similarly be prepared to address issues of stigma, superstition, and discrimination associated with TB. PSGs must be strengthened through the development of clearly delineated goals and activities, and its implementation improved through planning that involves all stakeholders, including patients, frontline health workers, medical staff, and community representatives. Active engagement of patients at meetings must be encouraged strongly within PSG design



and implementation, and this may be supported through the presence of trained counselors. For both DCM and PSG, feedback mechanisms must be created for patients and other stakeholders to provide regular inputs and contribute to continuous improvement and monitoring with patient well-being as a central agenda. Frontline health workers require support in the form of increased human resources, extensive training, and handholding to ensure smooth transitioning of the DCM into the government-run NTEP. Meetings for health workers may provide an additional component of building

collective capacities to drive the programmes. At the community-level, advocacy for TB literacy through local government institutions, linkages between the programme and existing frontline workers such as ASHAs and Anganwadi workers, and efforts towards creating accountability in social security programs will benefit the overall achievement of the goals of the DCM and PSG. Integrating these models with the larger government health system can strengthen efforts towards TB elimination by improving treatment adherence, completion, and successful cure.

INTRODUCTION



India is classified as a high-burden country by the World Health Organization (WHO), and with over 2 million active cases, accounts for 27% of the world's TB cases, higher than any other country (WHO, 2019). There exist TB programmes such as the centralized National Tuberculosis Elimination Program¹, which provides free-of-cost TB treatment through government hospitals along with other services, through DOTS - the WHO-approved international strategy for countering TB. In addition, aligning with global commitments, India reiterated its efforts to combat this national and global public health concern through renewed efforts under the National Strategic Plan for Tuberculosis Elimination (2017-2025), with the objective of reducing TB incidence, prevalence, and mortality by 2025 (Ministry of Health and Family Welfare - MoHFW, 2017).

Aside from gaps in the detection and diagnosis of the disease, one of the major challenges of TB elimination is related to treatment outcomes, in particular, poor adherence to the long treatment regimen. As early as 1962, when district TB centers were established, it was recognized that ensuring continuity of treatment was a challenge, since only 66% patients were found to be taking the drugs, and the defaulter rate - the term for patients not adhering to treatment - was 33% (MoHFW, 2015). Studies identify reasons for non-adherence to treatment as lack of attention and support at health facilities, poor interpersonal communication with health staff, inability to address drugs' side effects, equating symptom reduction with the cure, long distances to clinics, and lack of attention to everyday socio-economic constraints of patients (Jaiswal et al., 2003; Bhattacharya et al., 2018).

¹The RNTCP was renamed to National TB Elimination Programme (NTEP) in December 2019.

Furthermore, certain categories of patients are identified as being at higher clinical risks of both contracting TB and unsuccessful treatment outcomes. For instance, HIV is a well-known factor that adversely affects the progression of TB and the consequent cure process (Duarte et al., 2018). Resistance to TB drugs is another major barrier to the management and treatment of TB. Diabetes, alcohol, tobacco consumption and malnutrition also similarly accelerate TB progression and complicate its treatment (Narasimhan et al., 2013). In addition to these, emergent risk factors relating to socio-economic and behavioral aspects are also known to increase susceptibility to TB and play a major role in unsuccessful treatment outcomes (Duarte et al., 2018).

While several large scale programs exist to address the treatment needs of TB patients, these are often unable to cater to the more specialized needs of TB patients, especially those at higher risk of non-adherence to treatment. Patient-centric approaches that incorporate both clinical and psycho-social needs of patients, and deliver care through compassion and dignity remain elusive in India (Pai et al., 2014). It has been noted for instance that the role of the family in assuring patients' treatment success has received the least attention in TB programs, in spite of evidence that family support, motivation, and counselling improve treatment outcomes (Kaulagekar-Nagarkar et al., 2012)

Under the National Strategic Plan (2017-2025), community engagement for people-centric and community-led TB response is incorporated as a key strategy to address issues of TB patients and improve support systems for their care. In line with these objectives, and to address some of the prevailing issues around TB outcomes in India, the Differentiated Care Model (DCM) and Patient Support Groups (PSGs) were conceptualized and implemented under the KHPT-led Tuberculosis Health Action Learning Initiative (THALI) project. The DCM aimed to achieve successful treatment completion and cure by accounting for the differentiated needs of patients at high risk of non-adherence and adopting a framework of service delivery that centres patients and families within their community contexts. Within this framework, seven categories of high-priority DCM patients were provided intensive care, services, and counselling through a cadre of trained frontline health workers. PSGs further supported this exercise by providing spaces for patients to access healthcare staff and build patient advocacy.

Based on a research study of the DCM and PSG initiatives, the present report seeks to understand their impact on treatment outcomes for patients and examines the effectiveness of implementation by frontline health workers. Before describing this research study, an overview of the DCM and PSG programmes is provided in the following section.

BACKGROUND

The THALI project (2016-2020), implemented by a consortium of partners led by KHPT and funded by the United States Agency for International Development (USAID), is a patient-centered TB prevention and care initiative to support vulnerable populations' access quality TB healthcare services. After an initial scaled approach, in the fourth year of its implementation, THALI took an approach for focused interventions in fewer districts. Based on learnings from the previous years of implementation of THALI, innovative initiatives for in-depth intervention were designed to prevent and control TB at the community, facility and systems level, in partnership with TB Alert India (TBAI). DCM and PSG comprise two of the patient-centric interventions.

i Differentiated Care Model

Based on the evidence of high risks associated with certain categories of patients, the Differentiated Care Model provides customized Patient Care and Support (PCS) services to these patients via trained frontline community health workers (CHW) to ensure improved treatment adherence and successful outcomes. PCS services comprise a range of services in the form of medical, nutrition, infection prevention, psychosocial, and financial services for TB patients and their families. These were customized for DCM patients through additional elements of counselling to address patients' psychosocial needs; increased frequency of follow-up to support treatment adherence; linkages to treatment, care and support for specific complaints/conditions; and support to the patient to register for Direct Benefit Transfer (DBT) payments under the NTEP's Nikshay Poshan Yojana scheme.

The specific objectives of the DCM were as follows:

- To improve treatment adherence, leading to course completion and cure of high priority patients, thereby reaching more than 90% successful treatment outcomes.
- To create a specialized cadre of frontline workers who are trained to provide customized PCS services to patients according to their needs.

The following seven categories of patients were identified as being at higher risk of poor treatment outcomes, and thus in need of prioritized care with additional PCS services:



Elderly patients (above 60 years): These patients are at higher risk of other age-related illnesses and social exclusion. Medication for multiple health problems may create complexity and confusion of adhering to treatment regimens. Under DCM, CHWs strive to assess support systems for possible neglect, ensure caregivers take responsibility for the patient, facilitate screening for other age-related disorders periodically, provide linkages for medicine access to reduce travel burdens and facilitate pediatric screening for children in close contact with the patient.



Patients living alone or without family support: Living alone or lack of family support among patients is found to be highly correlated with other risk factors such as being elderly, consuming alcohol, having HIV or diabetes, or being previously irregular to treatment. Under DCM, CHWs assess reasons for living alone to see if disclosure to the family is possible, facilitate alternative support systems such as counselling groups or trusted sources like ASHAs, friends, trusted neighbors, etc. and set up reminder systems such as alarms for treatment adherence.

03



Patients previously irregular to TB treatment: These patients are at high risk of non-adherence due to non-compliance, lack of follow-ups, and lack of or loss of belief in medication. Under the DCM, the CHW attempts to ascertain reasons for irregular treatment, provides relevant treatment literacy if necessary, ensures DST (drug sensitivity testing) to check for drug-resistant TB, facilitates nearest linkages for injectables to reduce the frequency of travel, facilitates screening for underlying conditions such as HIV or diabetes and treatment linkages for the same if required.

04



Patients with drug-resistant TB (DR TB): Drug-resistant patients are at a higher risk of death due to failure of medication, and can also transmit the same to others. Under the DCM, the CHW ascertains the duration of treatment required and provides literacy for the same, does regular follow-ups to check adherence, facilitate referrals and linkages to welfare schemes other required medical interventions.

05



TB patients using alcohol: Patients using or dependent on alcohol are known to have poorer treatment adherence, and may also have strained family relationships due to which support may be reduced. Under DCM, the primary goal is to ensure treatment adherence and not deaddiction; if addiction/intoxication interferes with adherence then counselling for deaddiction and linkages with possible services for the same are to be provided. Other efforts are aimed at ensuring that the primary caregiver takes responsibility for regular treatment, and in case of alcohol-related domestic abuse of caregiver, facilitating community-based support for them as well.

06



TB patients with HIV (TB-HIV): This group has very high mortality rates, with TB being the most common presenting illness among HIV patients, as well as the major cause of HIV-related deaths. Several complications arise from comorbidities due to the high pill burden, co-toxicity, and drug interactions. As part of DCM, services included referral and linkages to HIV treatment and support, educating family members to maintain patient-friendly medication schedules, and counselling.

07



TB patients with diabetes mellitus (TB- DM): Reduced immunity due to diabetes puts patients at higher risk for contracting TB. Further, both disorders worsen the patient's clinical condition and require careful management of treatment. Under DCM, specific objectives included an early screening of, and referral for diabetes, regular evaluations by medical officers, counselling on healthy diet and lifestyle, and ensuring patient-friendly medication schedules.

ii Patient Support Groups

The NSP (2017-2025) suggests patient networks as key stakeholders to improve planning, implementation, and monitoring of TB program, as well as to create networks of support, mentoring, and advocacy. With these objectives, PSGs adopt a patient-centric approach to centre their needs and experiences of TB treatment. With the primary goal of improving the treatment experiences of TB patients at government health facilities, PSGs attempt to build self-esteem and confidence among patients, counter stigma, address issues of unpleasant treatment experiences, and create effective communication channels between patients, caregivers, and medical providers.

Though no standardized protocols exist for conducting PSGs, they were designed to include patients, caregivers, health workers, ASHA, medical staff, and community-level representatives such as PRI members and community structure members. Discussions, while encouraging patients to speak about their own issues, were to revolve around key themes of health and hygiene, basic TB literacy, nutrition, management of drug side-effects, treatment adherence, overcoming stigma and social schemes to support patients.

iii Operationalization of DCM and PSG under THALI

- The DCM and PSG, under THALI, were implemented in selected districts of Karnataka (Bengaluru, Koppal, 6 TUs of Bellary), Telangana (Warangal district, and 19 TUs of Hyderabad city) and Andhra Pradesh (Krishna district and 4 TUs of Vishakhapatnam city).
- In coordination with district NTEP staff, an initial Risks and Needs Assessment Analysis (RANA) was carried out to identify high-risk patients within the seven DCM categories, preferably at the time of diagnosis or treatment initiation. The RANA is to be carried out monthly to draw up a list of high-priority patients for each district.
- Capacity building was conducted for project team staff, including for the frontline workers (community health workers - CHWs) on the DCM.
- CHWs were provided advanced training on communication, counselling, stigma reduction, referral services, and linkages. The training was based on tools of Behaviour Change Communication (BCC) and was implemented during regular PCS visits to patients during both the intensive phase (IP) and continuous phase (CP) of treatment.
- Information Education and Communication (IEC) material was developed for regular use by high priority patients to effect behavioral change.
- The organizational structure of the project team included District Coordinators, Block Coordinators, and Community Coordinators to manage, monitor, and supervise the work of CHWs.



OBJECTIVES

This qualitative research study was conducted to understand the role of the DCM and PSG in fulfilling the broader goals of THALI, and in particular, to understand their impact on overall TB treatment adherence and outcomes among high-priority patients. The specific objectives of this study were:

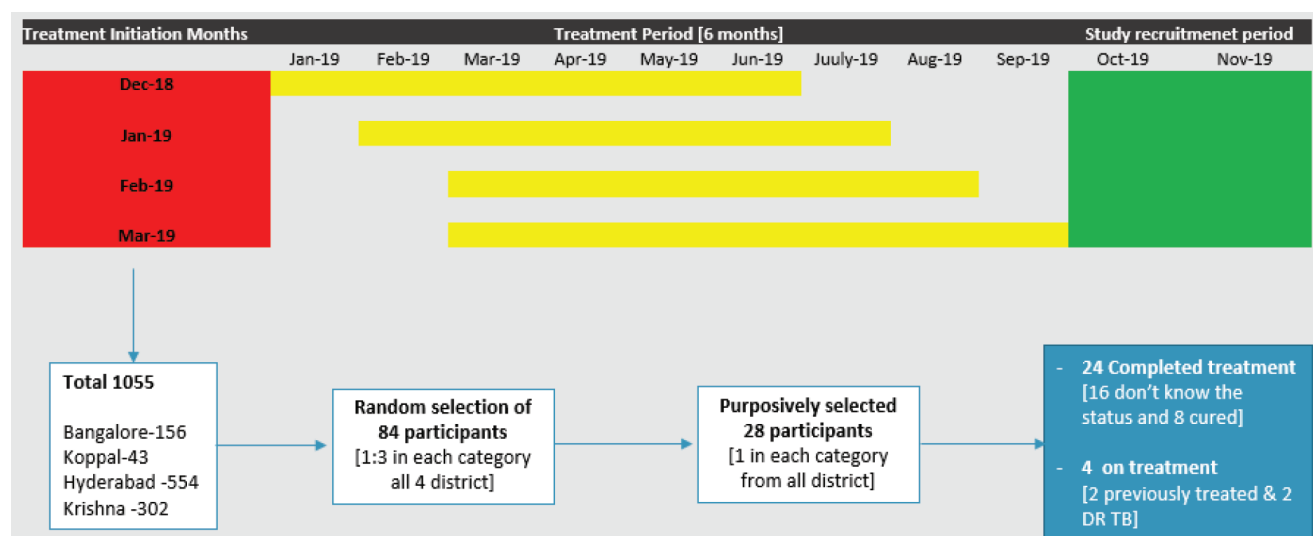
1.
 - (a) To explore how intensive in-person care and counselling through the DCM approach by front line workers influences treatment adherence, and supports TB patients and their family members for their other relevant needs.
 - (b) To explore how well the frontline workers have internalized the DCM messages, their experiences, and perceived changes in TB control programs.
2. To describe the role that patient support groups (PSG) play in enabling TB patients to have better adherence and a quality healthcare experience during TB treatment.



METHODOLOGY

i Research design and sampling

The study was carried out between October 2019 and March 2020. TB patients who initiated the treatment from December 2018 to March 2019 were considered for this study. A total of 84 respondents from the line list of 1055 were randomly selected and among them, 28 participants were purposively selected after the interviewer visited them in person. The data collection for this study was carried out from October to November 2019, and at the time of data collection, 24 patients completed their treatments and four continued to take treatment. Also, five community health workers and five TB Health Visitors were interviewed as part of this study. The following figure depicts the process of sampling and recruitment of study participants.



The study adopted a qualitative approach with in-depth interviews and participant observations with key stakeholders of the DCM and PSG programmes. These were carried out in four of the project sites, namely:

- **Bengaluru (Karnataka)**
- **Koppal (Karnataka)**
- **Hyderabad (Telangana)**
- **Krishna (Andhra Pradesh)**

The study adopted a qualitative approach with in-depth interviews and participant observations with key stakeholders of the DCM and PSG programmes. These were carried out in four of the project sites, namely:

- Patients from each of the seven categories of the DCM, namely - elderly or above 60 years of age living alone; those consuming alcohol; previously treated for TB; those with drug-resistant TB (DR TB); those with HIV TB; and those with Diabetes Mellitus TB (DM TB).
- CHWs recruited under THALI from each
- TB Health Visitors (TBHVs) who are part of the NTEP program

Table 1 below shows the site-wise distribution of the number and type of respondents.

Table 1: Site-wise distribution of number and type of respondents sampled for in-depth interviews

Respondent type/Site		Bengaluru	Koppal	Hyderabad	Krishna	Total
DCM patients	Elderly or 60+ years	1	1	1	1	4
	Living alone	1	NA	1	2	4
	Using alcohol	1	1	1	1	4
	Previously Treated for TB	1	1	1	1	4
	DR TB	1	NA	1	2	4
	HIV - TB	1	1	1	1	4
	DM - TB	1	1	1	1	4
Community Health Workers		2	1	1	1	5
TB Health Visitors		2	1	1	1	5
Total		11	7	9	11	38

In-depth interviews were conducted face-to-face and audio-recorded by trained researchers after obtaining explicit permission and written consent from all participants. Interviews were semi-structured and probed questions around the following themes: 1) Patients' socio-demographic information 2) Knowledge and attitude on TB 3) Testing for TB 4) Treatment process 5) Treatment adherence 6) Counselling 7) Stigma and discrimination 8) Coping mechanism 9) Support structures at family and community level 10) Patient support group meetings and 11) Prioritized care by the frontline worker².



In addition, a total of 4 PSG meetings, one in each site, were studied through participant observation. Researchers attended the PSG and passively observed attendance, interactions, and discussions to obtain a deep understanding of both the explicit and

implicit aspects of patient participation and experiences of PSGs. These observations along with informal interactions with patients after the PSG meetings were noted down in the form of field observation notes.

ii Analysis

Data collected through in-depth interviews were transcribed and translated to English and reviewed for accuracy and completeness. Transcribed and translated documents, along with field observation notes, were then imported to Nvivo 11, a software for qualitative data management and analysis. Data were thematically and recursively coded to include initial themes from interview guides, as well as incorporate emergent themes from subsequent analysis, and thematic saturation was noted. Writing of extensive memos was done in order to compare, contrast, and interpret the data.

iii Ethical considerations

The consent process was administered by trained researchers, and explicit written consent was obtained from all respondents. Prior to obtaining consent, participants were informed and assured that participation was voluntary and that their decision would have no bearing on their involvement with the local programme or accessing its services. Signed consent forms were stored in a locked cabinet in the KHPT office in Bengaluru. The anonymity of participants and confidentiality of data was maintained by assigning unique study IDs to each participant. Study data was retained and stored on a password-protected computer for the entire duration of the research. The study protocol received ethics approval by the St. John's Ethical Review Board, Bengaluru.

²The interview guides for DCM patients and frontline health workers (CHWs and TBHVs) can be found in the Annexure 1 and Annexure 2 respectively.

FINDINGS



Table 2 below shows the socio-demographic details of all the patients interviewed. This gives some insight into the socio-economic composition of the patients. It can be seen that although a roughly equal number of men and women were selected, all patients within the DCM category of alcohol use were male, reflecting a more general social trend of the gendered nature of alcohol usage. Of 28 patients, 89 percent were seen to belong to either Schedules Castes (36 percent) or Other Backward Classes (53 percent). A majority of patients (64 percent) were either illiterate or had only attended up to the primary school level. Most patients (46 percent) were not employed during the time of the interview, while another 20 percent were engaged in wage labour.

Table 2: Socio-demographic details of patients interviewed

Details		60+	Alcoholic	DRTB	Living alone	Previously treated	Diabetes	TB-HIV	Total
Gender	Male	3	4	2	2	2	1	1	15
	Female	1	0	2	2	2	3	3	13
Age	>25	0	0	0	1	1	1	1	4
	26-35	0	2	1	2	2	0	1	8
	36-45	0	1	1	1	0	1	2	6
	46-55	0	1	1	0	0	0	0	2
	56-65	2	0	1	0	0	2	0	5
	66+	2	0	0		1	0	0	3

Marital status	Married	3	4	2	1	2	1	2	15
	Unmarried	0	0	0	2	1	1	1	5
	Widow/er	1	0	2	1	1	2	1	8
Caste	SC	0	3	0	2	2	1	2	10
	OBC	3	1	2	2	2	3	2	15
	General	1	0	2	0	0	0	0	3
Education	Primary	1	3	2	2	0	1	0	9
	High school	2	1	0	0	0	1	3	7
	Graduation and above	0	0	0	1	2	0	0	3
	Illiterate	1	0	2	1	2	2	1	9
Occupation	Not working	3	1	3	1	1	2	2	13
	Agricultural labour	0	1	0	0	1	0	0	2
	Business	1	1	0	0	0	1	1	4
	Wage labour	0	1	1	3	0	1	0	6
	Private	0	0	0	0	2	0	1	3

The findings from the research are discussed in relation to each of the specific objectives.

1(A) Intensive in-person care and counselling through the DCM approach by the frontline workers

Assistance with treatment processes



Across districts, it was reported by patients that frontline workers, or CHWs, played a significant role in their treatment process. Although the relative importance of their role differed depending on the context of the patient, their overall impact was nonetheless positive and useful to the patients. For some, the presence of the CHW critically determined a positive treatment outcome by virtue of providing all necessary information and support related to the process, as expressed by the following patient who felt indebted to the CHW:

“ At that time someone told me madam’s (CHW’s) name. She saved me like a God. I was so worried; I have no one to take care of me [...] now I am cured only because of her. (Female, 37 years; DCM -Living alone, Krishna district, Andhra Pradesh)

”

For others who had some form of existing family support, CHWs eased the treatment process and provided important information to effectively harness existing support. The major modes of care provided by the CHW were through regular visits, which would range from once weekly to once a month, or through regular phone calls. During these interactions, the CHW was most often reported to emphasize the importance of adherence to TB medication, and to ensure that the same was being followed by the patient through constant reminders and procurement of tablets if required, as instantiated below:

“They (CHW) used to come near the house and ask how am I, if I am taking tablets, count the tablets to check - this has helped me. They used to visit our home and do all these things [...] once in a week [CHW] used to come. If they couldn't come, then they used to call and ask. If the tablets were over they used to deliver, they said not to stop, they forced me till I took tablets and finished the course [...] they used to come and give us the tablets and they used to take the used empty strips from us back. [...] I used to sweat also. But I didn't give up I had promised that I will complete the treatment. Most of the patients will quit the tablets because of this problem only. I am completely alright today because of these 3 madams. May God bless all these people. (Male, 60 years; DCM -Elderly, Bengaluru)

“They told me that if I stop taking tablets I will get TB again. They used to speak to me for one hour or one and a half hours. They even gave examples of patients of other localities. So after listening to them I continued the tablets. (Male; DCM-Alcohol use, Koppal district, Karnataka)



Advice on the importance of a healthy and nutritious diet was another aspect of information that was regularly shared and a habit that was encouraged among patients, along with the need to consume the nutrition powder provided by them, as noted by the following respondents:

“She came, she gave information like ‘eat like this, greens, grains, sprouts vegetables, eat everything you like, anything you need, ask us, I'll come to your house anytime. (Male, 40 years; DCM – Drug-resistant TB, Bengaluru)

“Eat nicely when were you feel hungry, eat nicely’ [CHW] madam told me. Chicken, mutton, eat egg daily. Eat eggs every day, one in the morning and one in the evening is what she would tell me. (Female, 45 years; DCM Diabetes, Bengaluru)

“They told me [powder] will give strength, ‘Mix it with milk. You look weak this powder will help you’, they said. (Male, 40 years; DCM – DR TB, Bengaluru)



CHWs also provided help in the form of following up on the general health of the patient, checking weight, collecting sputum samples for testing or guiding patients at hospitals with testing procedures, and wherever possible, helping patients to deal with side effects of medication. Except in the case of Krishna district, CHWs informed and called patients for Patient Support Group (PSG) meetings, and provided nutrition powder to them, alongside instructions on how to consume it.

Patients largely provided positive accounts of the support they received from the CHWs in terms of assistance with treatment-related processes. This is reflected in the successful treatment adherence, treatment completion, or cure in a majority of the cases.

While relatively successful at ensuring a broad level of treatment adherence for TB, CHWs fell short in identifying more specific needs of patients who required specialized assistance. This was, for example, elucidated by the following patient who was over 60 years of age, had diabetes, and had also been previously treated for drug-resistant TB, and thus fell into multiple categories of the DCM:

“My TB is fine now, I completed my course, and this [CHW] madam always used to remind me to take medicines, so I never missed but you know my sugar is a big problem, it's just not getting under control, because of which doctor says I started having problems in my kidney. Even though I am taking insulin injections daily, I leave for work at 6 a.m.. and 10 a.m. I eat something outside and carry this injection in my pocket and I just take it myself. (Female, 62 years; DCM – Elderly, Diabetic, previously treated for drug-resistant TB; Hyderabad, Telangana)

In this case, the CHW was unable to manage the co-morbidities of the patient and provide appropriate linkages for the patient to follow up on. Similarly, there were instances wherein the CHW was unable to effect lifestyle changes required to manage co-morbidities. This is illustrated below by an elderly patient suffering from both diabetes and BP, along with TB, upon being asked what measures he took to manage his sugar problem, because of which his eyesight was affected:

“We did nothing. I wasn't able to see anything. [He ate only roti and ragi mudde for a few days] I followed this for a few days, now why do dieting in old age so started eating everything again. [...] For sugar tablets, the doctor suggested I take some 4 varieties of tablets, it was costing around 1000 rupees. Here we have a medical shop, we showed him the report and we told him that we can't pay 1000/month, what do we do? Then he chose only one sugar tablet and asked me to take it. For 12 years I have been taking the same tablet. I told madam this once, she said just continue taking medicines. (Male, 60 years; DCM – Elderly; Koppal district, Karnataka)

Though CHWs ensured treatment adherence and consequent cure of TB in this case, the problem of diabetes received scant attention, both in terms of necessary dietary advice as well as assistance with accessing affordable health services for treatment.



Accounts also revealed that for patients there was a lack of information regarding the need to conduct follow up tests, as well as confirmation tests after treatment completion. For instance, the following patient's husband, describing the first time she got cured of TB, was unaware of the need to do tests, and as a likely consequence she developed a second round of drug-resistant TB:

“No, they didn't do any tests after the [first] treatment [...] [we got to know she was cured because she was feeling better and we could see that in her behavior as well. (Mother of a female patient, 32 years; DCM – Drug-resistant; Hyderabad)

Other patients similarly reported not having conducted confirmation tests after the treatment period, and neither the health facilities nor the CHW in these cases has to follow up with the same. The following patient upon being asked if he conducted a cough test after his six months of treatment, responded:

“No. Just left [medication] after six months, didn’t even go to the hospital, they said I am healthier now so no need to take tablets now [...] I have not given that [sputum] test. Because when we went there to get tablets for the last week, they didn’t inform me of any test and also told us to stop taking tablets. (Male, 60 years; DCM – Elderly; Koppal)”

TB literacy



CHWs played a role in explaining TB transmission to patients, and also guided them on basic precautionary measures, as can be seen from the examples shared by respondents below:

“if there are children you should not spit anywhere, you should keep the house clean, while talking we should cover mouth - like that [CHW] madam told. (Female, 45 years; DCM – Diabetes; Bangalore)”

“[CHW] mentioned it, when he came home he mentioned [...] If we talk generally then nothing will happen if we cough with high pressure, then we shouldn’t breathe those particles [...] We should not pass through a cough or spit, should not inhale the same air, we should not eat from the same plate. (Female, 30 years; DCM – Previously treated; Koppal)”

“I went to the hospital and took her [CHW] to my house (house visit) [...] Then she (CHW) asked me to open the windows, keep the windows open, and told me that the front of the house should also be kept clean. (Male, 33 years; DCM – Living alone; Bangalore)”

The need for general cleanliness and hygiene seems to have been internalized by patients. In addition, patients were also aware of the role of alcohol and tobacco in exacerbating the chances of contracting TB, as well as affecting the treatment and recovery process adversely. Though this was more difficult to manage with patients with alcohol dependency, a basic awareness around the harmful impact of alcohol existed, as explained by an alcohol-dependent TB patient’s relative:

“He (patient) did not even know about hospitals and tablets and all. His routine was just having food, consuming alcohol, and sleeping, that’s it. He used to come home after having alcohol and used to beat the kids and his wife. After that he got affected by TB. [...] They used to give him counseling for 1 to 2 hours and tried all the ways that were possible to them. [...] They told him to avoid those 2 things [alcohol and beedis] and take the treatment regularly to get cured. If he consumes alcohol and tobacco again then TB may attack him again and it may lead to his death. They asked him to leave the alcohol for life. [...] [After he contracted TB] he left consuming alcohol for some 3 months [...] Still he takes the alcohol but he has become better than before. (Uncle of the male patient, 42 years; DCM – Alcohol use; Koppal)”

In the above instance, though the patient was unable to resolve the problem of alcohol dependency, the counselling efforts of the CHW aided in reducing alcohol consumption for a short duration. Moreover, the combined efforts of the CHW and the family members ensured that, despite the continued alcohol dependency, the patient practiced treatment adherence till he was cured successfully.

In spite of efforts at TB literacy, not all patients seemed to be fully aware of how the disease is transmitted, and some even expressed a lack of clarity or misinformation in this regard. As an instance of misinformation, one patient, upon being asked how people get TB, responded as follows:

“It may be because of more cough and from mosquitoes. (Male, 35 years; DCM – Alcohol use; Koppal)”

More worryingly, superstitions around the disease continued to persist at the community level. There were some patients who shared how they had believed the cause of TB to be due to black magic. As one respondent explained:

“People said it was some superstition, there is this Saheb, he also told us that it was black magic [...] Like someone might have done some ‘Maata Mantra’ [...] For that there is this ‘tolaga’ (practice to remove the black magic) [...] I would have gone to hospital but we listened to what people said and went to Baba’s place because we thought it must be black magic [...] made us spend a lot of time, when we ran out of money, then we came to know that it is TB. Now I am cured of TB [at government hospital] where zero money was needed. (Female, TBDM, 21 years, Koppal)”

Such practices were potentially harmful and were also often causes for delayed diagnosis among many other TB patients as well. Though this was a problem occurring before the DCM care stage provided by CHWs, it is heartening to know that once on treatment, these patients were able to be successfully integrated into proper medicinal regimes, and were able to adhere to the same with full conviction in its effectiveness.

Family involvement

One of the striking observations from patient interviews was their dependence on networks of support, of family or other close friends, for adherence to the treatment process. This help took on several forms, ranging from reminding patients to take their tablets regularly and everyday care work such as cooking and cleaning, to arranging for, and accompanying patients for hospital visits, and even filling the role of primary breadwinners for the family when the patient was unable to continue with work. For example, this diabetic TB patient expressed her gratitude at how her two sons were able to care for her in every possible way during her illness:

“Whatever we want my sons will get for the house, they press my legs, hands, and anything I want. If I want hot water they get one tumbler hot water, they will do everything madam, God has given me good children. Other children will say leave my mother, have got some disease, what to look after, they would say. God has made me lucky to have had such children, that’s all. (Female, 45 years; TBDM or DCM diabetes term; Bangalore)”

Such observations reinforce the basic premise and potential benefits of the DCM, which adopts a patient and family-centric approach, and seeks to tap into the potential of family support. Since many patients had existing support-networks of this kind, it is difficult to comment upon the effectiveness of the CHW in

facilitating this kind of support. Observations indicate a mixed account, where CHWs were able to build a rapport with extended family members and friends in some cases, and not with others.

Usually, if family members were themselves invested in the patient's health, this task for the CHW was easier to facilitate. For instance, in the earlier case of the diabetic TB mother, she explained how the CHW would guide her son to take care of her well:

“If I call [CHW] madam she would tell ‘go get her injection [respondent's son].’ She knows my son, ‘get her one injection she won't be able to bear (pain), like this, will happen for two months when she takes tablets. She doesn't have strength’. [...] ‘take care of your mother, this is (TB) dangerous, give her healthy food, give her something to eat timely, you should look after her well not only now but in the future also’. (Female, 45 years; DCM – Diabetes; Bangalore) ”

In another instance, a patient described how the CHW shared a good relationship with her mother and had during home visits provided patient-care advice to her as well:

“My mummy knows her [CHW] really well [...] [CHW told her mother] give tablets correctly, don't miss giving tablets, if one tablet is missed again from the beginning she should take. (Female, 26 years; DCM – Previously Treated; Bangalore) ”

In another case, a patient explained how the CHW would motivate family members through moral support as well:

“My mother was very upset and worried, but she [CHW] always used to motivate her also. I started taking tablets on time, whatever she suggested to us, we followed her, and now by the grace of Allah, I am fine. (Female, 21 years; DCM – Diabetes; Koppal) ”

There were however cases where the patient did not have a primary caregiver or a strong available support network of this kind, and in such cases, CHWs were reported to have minimal, or no interaction with family, friends, or neighbors who might be able to support the patient. For example, the following patient living alone in Bangalore, who depended upon a work assistant for his meals, since his wife and family lived in his native village, explained:

“No one has spoken, I have not given any one's link (contact of family members) [...] Nobody asked if they had asked I would have given but they didn't ask. I had told [the CHW] every week I go to my native village and come, here I stay alone. [...] My assistant, they didn't ask about [...] they (CHW) have spoken to nobody. Only me they have spoken to. (Male; 33 years; DCM – Living alone; Bangalore) ”

It is a serious matter of concern that for such patients, who had no means of support during their treatment process and were thus in most urgent need of assistance, the CHWs did not invest in actively mobilizing any forms of family or alternative support.

Interestingly, in one case, a respondent from Bangalore described the isolating experience of city-life, remarking on its lack of community-based support when compared to a village:

“For patients, the city is not suitable, the village is the best environment. [...]If I was in my village, all are known people, I could sleep or they will ask if I had coffee, tea or food. Here (city) no one will ask. It is difficult. There (village) I can sleep under the tree it will be cool, in this (city) environment I can't do anything. (Male, 40 years; DCM – Drug-Resistant TB; Bangalore)

This particular instance not only brings to the fore the experiences of migrant workers who live without their families in cities, but also the specific role that positive community-based relations and basic caregiving can play in emotional well-being during the treatment process. This again underscores the need for CHWs to prioritize attending to the needs of certain categories of patients such as the elderly or those living alone, who are most likely to lack familial or community-based support during their treatment.

Psycho-social support and counselling



There was a strong overall element of positive messaging to keep patients motivated to persist with their treatment along with an assurance that they will get cured if they do so. The following excerpt from an interview aptly summarizes this aspect of emotional support received by patients in relation to the fears engendered by contracting the illness:

“She (CHW) would always say [...] So young you are to have been diagnosed with TB, don't worry too much about anything, still you are a kid, this is your time to play, take care of yourself, we will cure your TB, just take tablets on time, if you skip taking them then you have to take for years, so be careful. That's why I took tablets every day without missing any [...] like don't take tension, don't bother about what others say, you should ignore what people say, don't get hurt, take medicines every day, eat good food. Everything will be alright, Allah (God) is there, you should not worry, you should see the face of your abba ammi (parents), how much they love you, stay strong, this is the kind of information she gave.” (Female, 21 years; DCM – Diabetes; Koppal)

This kind of counselling however requires a certain level of personal rapport building, which was found to be mediated strongly by social relations, notably by community, caste, and gender relations. The above example, for instance, was likely made possible due to the fact that both the CHW and the patient's family belonged to the same religious community. Thus, it was not always possible to build the trust required for effective communication. For instance, a female patient expressed her hesitation at interacting with the male CHW as:

“Sometimes I felt awkward, you never know what people will think and doubt. What is this, he (CHW) comes so often to my home, who is this man, so, people may start thinking bad things about me and wonder what the reason for it is...so I have told him that I will call him if I need the medicines or anything (Female, 30 years; DCM – Previously Treated; Koppal)

In this case, the norms of appropriate gender relations were seen to govern the extent to which interaction was possible between the patient and the CHW, and acted as a barrier to building a relationship in which one may be able to share personal problems. In this manner, social structures of gender, age hierarchies, and caste hindered the ability of CHWs to meaningfully carry out their designated duties.

Another barrier to providing psycho-social support was the lack of adequate training for CHWs to carry out this kind of counselling. Patients most often reported not sharing their concerns with CHWs, and did not seem to view this as lying within the ambit of their responsibilities as health workers. One patient, when asked if he shared her personal concern relating to the illness with the CHW, he responded:

“Even if I share, they won’t help, like this, they interview and go. I lost the hope which I had.
(Male, 60 years; DCM – Drug-Resistant TB, Elderly; Krishna)

”

CHWs themselves did not seem to be equipped with managing the problems of certain patients, as evidenced in the following response from an alcoholic-dependent patient who said he does not share any personal issues with the CHW:

“I have informed to madam [CHW] also that I will drink, then madam told me that when you drink, don’t take the tablets. If you want to drink, when you don’t take the tablet, on that day you can drink how much ever you want. (Male, 28 years; DCM – Living Alone; Hyderabad)

”

This lack of training was in particular visible in the case of difficult patients such as those with alcohol-dependency. As also discussed in further sections, CHWs themselves reported how alcohol-dependent patients were especially difficult to interact with and would often not be willing to follow directions for proper treatment despite constant efforts.

Socio-economic security and support



Though CHWs were able to provide counselling and boost patient morale in relation to TB-related anxieties, other forms of support, which involved patient’s personal anxieties or difficulties with not only the medical aspect of TB, but also the associated social or financial struggles that it brings along, were less frequent, or completely absent. Several narratives of respondents belonging to lower socio-economic strata described the financial hardships brought about due to the loss of daily wage work during the prolonged period of the painful illness, physical weakness, and emotional trauma.

One female respondent who had three children to take care of, and an alcoholic husband who refused to pay for the family, described her ordeal of having to continue to work as an agricultural labourer even when she was sick:

“Who will take care [...] Was taking tablets and was going for work [...] otherwise we can't live our life, we didn't ask for a single penny from anyone, while waiting for these tablets start working and start curing me, for food I kept my Jhumki and one necklace, as a mortgage. After that, I started working [...] Jhumki I kept for 5000 rupees, 3000 rupees for the necklace, one pair earrings. So many I had but to be able to have at least one penny, I mortgaged everything, leave sir it's better to not talk about that time [...] It was only with that mortgage money we paid electricity, gas bills, current bill, food bill. (Female, 30 years; DCM – Previously Treated; Koppal)

”

Under such difficult circumstances, the necessary linkages with government or NGO support were not always made possible. Some respondents expressed this dissatisfaction with the forms of support received, especially those living alone. They noted that merely information regarding TB, food, and medicines was insufficient for them when they had no means of survival:

“I want to live sir. If someone could help me out in some form like giving money, I can buy rice, daal, milk, etc. I can eat food well, can take medicines. I don't get any social entitlements. Somehow I am sustaining by begging here and there. Many days I don't eat food out of frustration, thinking how long others will pity me. (Female, 37 years; DCM – Living alone; Krishna)

”

“She came 3-4 times in the last 6 months, she told me the same things that doctors say... don't miss medicines and eat healthy foods like sprouts, egg, milk... I had asked her about my problems in getting the RNTCP card, I told her I need the support that government gives to all TB patients... but she never helped me in any of these. (Male, 33 years; DCM – Living alone; Bangalore)

”

In the second instance above, the respondent refers to the direct bank transfer that is provided to TB patients under the RNTCP scheme. It is worth noting that in many instances, the CHWs did provide information and assistance in linking patients' bank accounts in order to avail the monetary benefits of the scheme, as they share during their interviews (in the next section) as well as shared by patients:

“She [CHW] asked whether I gave my bank details. She told me that I will get money, so I asked my daughter to check the account. My daughter told me that there are some two thousand rupees [...] excluding all the [previous balance] I only got only fifteen hundred rupees. [...] I used that money to buy medicines, and also used it for household expenses. (Male, 57 years; DCM – Diabetes; Krishna)

”

The amount of INR 500 per month provided to TB patients undergoing treatment under the RNTCP scheme was in this manner significant in managing several expenses. In particular, for poorer families, this was critical for offsetting the unintended costs of the illness, such as loss of work. However, in spite of having linked their bank accounts to avail this benefit, most respondents shared that they had not actually received payments under the scheme, or had only received part of the amount. As the husband of a TB patient explained:

“They told us that we will receive the money, but we have not received it yet. And the income that I am getting is not enough for our expenses like kid's school fees, home rent, and all. And I am the only one who earns in the family. She can't work now, and I am the only one to work and earn. It was very difficult for us in those 5 months because she could not even prepare food. And I used to do all the household work and my work. (Husband of the female patient, 62 years; DCM – Diabetes, Elderly; Hyderabad)

”

While for some respondents, the money was a small amount and they did not feel the need to claim it, for other disadvantaged sections, it was a major loss. Another patient explained this difficulty and insufficient help in this regard:

“What can I eat sir? I asked her [CHW] why the promised money of Rs 1000 or Rs 500 per month is not deposited in the bank account for nutritional support. She said that they might have forgotten, but they will deposit, don't worry. (Male, 67 years; DCM – Previously Treated, Elderly; Krishna) ”

While it was not possible for the CHW to ensure governmental efficiency in this regard, efforts at the individual or collective demands for accountability in the government program were absent on their part. Linkages with other government schemes or NGO programs were also rare.

Stigma and discrimination



Experiences of the stigma associated with TB patients were commonly expressed by respondents, such as in the following case:

“Here people would not allow me to sit near their houses, not even near shops, they will ask me to get up and go. It is so humiliating and that is why I have completely stopped going out. What to do, whom to tell all our feelings to. (Male, 40 years; DCM – Drug-Resistant TB; Bangalore) ”

Respondents spoke of the fear of sharing the news of their illness with relatives or neighbors due to the perceived threat of discrimination:

“Earlier for TB, Leprosy they used to keep people outside the village [...] we didn't tell anyone. Who knows what they would think? Obviously, they would be disgusted. If I tell them I have TB then they may not mingle with me, and they will speak among themselves about it. (Male, 60 years; DCM – Elderly; Koppal) ”

“No we didn't tell anyone[...] even when somebody comes to ask about her (for marriage proposal), people in our area if we tell them one thing, they will add something and say 10 more things (cook their own story) and spread rumors, that's why we have not told anyone [...] Even to these ASHA workers we have informed not to reveal this in front of others [...] now we are in a rented home, so if they get to know then they would not let us stay [...] They doubt us, sir, they don't call us, they say: you don't come because you have TB, we have children at home (Female, 21 years; DCM – Diabetes; Koppal) ”

In certain instances, the behaviour of staff at health facilities also demonstrated a discriminatory attitude, as in the case of the following patient describing the insensitivity of nurses at a hospital:

“I felt so bad, if I go to collect tablets, [the nurse would say] “Eh, wear a mask and come, if you forget at least tie kerchief” somewhat uncaring they are. (Male, 33 years; DCM – Living Alone; Bangalore) ”

These accounts also reveal a deeply internalized sense of stigma, wherein respondents, though they expressed fear, also did not explicitly counter the discriminatory beliefs shared by others around them. There does not appear to have been any efforts on the part of the health workers either in such cases at addressing the instances of discrimination.

At the same time, there were some examples of overcoming discrimination with the help of health workers, notably, in the case of an HIV-TB respondent from Koppal, who had consequently become a social worker herself. In her words:

“ She took me to one office and there they said that we will give a job as a community worker for HIV work. I faced a lot of emotional trauma, one side I was carrying a baby, and no Mangalsutra was there, so I face discrimination everywhere including during fieldwork. During fieldwork, many said many bad words, but this madam [CHW] kept motivating me, she said I am no less and I deserve a better life. Today I go around and talk to TB and HIV patients. I am better now and somewhere I feel I can influence people. (Female, 35 years; DCM – HIV; Koppal) ”

She further went on to encapsulate the particular significance of non-discriminatory, inclusive, and supportive elements for moral and emotional support during TB treatment:

“ In TB or HIV, for these, more than treatment, people’s support is important. I mean there should be people who speak with touch, [...] we often think - ‘why should we live, let’s die, living like this with HIV or TB, what is the point of living, it is better to die’ - this kind of pettiness we feel about ourselves. We feel pity for ourselves. A doctor or counselor, outreach worker, DTO sir, etc., if all of them support us then we feel ‘so many people are there to support me, forget about people in the neighborhood, why worry about them, I will take treatment and feel healthy (Female, 35 years; DCM – HIV; Koppal) ”

The benefits of community and institutional support are outlined insightfully in the above excerpt, making a strong case for investing further in countering stigma around TB and other illnesses through providing assistance through community health workers.

SUMMARY

- CHWs have played a significant role in ensuring treatment adherence among DCM patients and this is reflected in positive patient narratives and successful treatment outcomes. At the same time shortcomings remain in certain areas such as identification and specialized management of patients with co-morbidities or multiple DCM risks, ensuring follow up testing and confirmation testing after completion of medication.
- TB literacy among patients is provided by CHWs but sometimes remains cursory in nature and misinformation regarding transmission, in particular through superstitions and stigma around the disease, is still prevalent in communities.
- While CHWs have managed to mobilize existing networks of family support, they were unable to find adequate support networks for those without family help, such as those living alone or migrant workers.
- Psycho-social support extends to personal rapport-building efforts by some CHWs but is limited by several factors such as social institutions of gender/caste and lack of training for counselling provision, especially with difficult patients.
- In light of the poorly functioning DBT entitlement of the RNTCP scheme, the urgent need for financial support of TB patients, especially in the case of socio-economically disadvantaged patients, is brought sharply into focus.

1(B)

Internalization of the DCM messages by the frontline workers, their experiences, and perceived changes in TB control programs

Knowledge of programme among CHWs

The accounts shared by the CHWs revealed the primary focus of their DCM work to be treatment adherence and nutritional counselling, with the objective of treatment completion and cure. As summarized by a CHW:



“[Work] includes identifying the TB patients and ensuring they take the treatment. Also, taking care of them, providing counseling to them, to make sure that they take the treatment properly for 6 Months. They [trainers] said that basically we will be responsible for their treatment and getting them cured, that we have to work in the field (Female, Community Health Worker; Bangalore)”

The health workers during conversation expressed a keen understanding of the specific risks that DCM patients faced with regard to non-adherence, and this understanding was strengthened by their experience of working with both regular as well as high-priority- DCM patients on the field. As described by one health worker:

“When I joined I did the same follow-up for all of them. Only once in a month follow up. As time passed by, after 6 months, this category only, why? Because, as I understand, they are more likely to stop taking their medicines. Because of being diabetic, already a lot of medicines need to be taken. ‘Also need to take these now. Better leave this medicines’ sort of mindset is there so they have a chance of leaving medicines. Still (furthermore), alcoholic, drinking is prohibited. Once drunk they then don’t want medicines or anything else. If medicines are taken then they can’t drink, so many are like, ‘leave medicines’. Then these old folks, they may forget. They may not have any caretakers, leaving them (patient- alone at home, family members) go for jobs. they have poor memory. Previously treated, they are afraid of side effects. Earlier (previously) they have left tablets. They have stopped treatment in half, MDR patients, why we have a follow up every 15 days is because they have many medicines. They are fed up with injections.... many are like.... ‘This way or that way we will die... leave (medication) it. Let’s see what happens. So these patients we follow-up every 15 days, sir. (Male, Community Health Worker; Bangalore)

”

CHWs expressed an awareness of sensitivity when it comes to stigma, as explained by a CHW:

“Precautions should be taken before we converse with them, we should not discriminate, for example, if I stay far and talk then it would hurt them. So I should be close to them while talking and I should be one among them in their family to get a good response. (Female, Community Health Worker; Koppal)

”

They also demonstrated an understanding of the need for counselling, and the potential benefits of attending PSG meetings, as expressed below:

“Counselling is very important sir... why counselling is needed is sir...they are fed up with ‘do we need to take so many tablets’, ‘(why) should this disease happen to me only. No one else got it’... pity... when we speak to them they get some (peace) ... little it comes sir, acceptance of the situation. (Female, Community Health Workers; Bangalore)

”

Interactions with the CHWs on their responsibilities as part of the DCM aligned with patient narratives of the kind of help offered to them by the CHWs. The CHWs understood their role under DCM as that of counselling DCM patients and their families to impart knowledge on the importance of adherence in the treatment of TB and being available in every way possible to ensure the same takes place. Aside from this, they sought to provide necessary information on diets, nutrition, testing, cleanliness, hygiene, and DBT provision under the scheme.

Implementation of DCM by CHWs

While they were all provided training on the essentials of communication and sensitivity in counselling, there remained constraints in the application of this theoretical knowledge.

The specifics of how to deal with more complex or difficult cases posed major challenges for CHWs. For instance, as also described in patient narratives, CHWs lacked sufficient knowledge to manage patients who had co-morbidities or fell within multiple DCM categories. One CHW explained on how they dealt with TB patients with diabetes as:

“I suggest to them that they take TB medicines in the morning and for diabetes in the night.... that’s it. (Female, Community Health Worker; Bangalore)

”

The expertise to identify patients falling within multiple categories of DCM, and advise such patients accordingly, was found to be lacking among the health workers.

Further, patients with alcohol-dependency were commonly reported to be difficult to manage in terms of ensuring their adherence to treatment:

“Now I go to (their)home, do some counselling Sir, ‘you shouldn’t drink, I am not asking you to quit, but at least not to consume while on drugs(medication). When I say so ‘ok madam’ (they would reply). I would sit there for one hour and tell it’s a lot of trouble for your family. Your wife and children suffer. You will be fired from your job. No one will respect you... when told so... they (the patient) listen carefully and say ‘Ok madam! Ok, madam!’ Then after I leave.... in the evening about 6-7-8 the wife would call and tell me ‘they (he- for husband) are drunk and sleeping. You were saying so much.’ Then what do we do? Will we be told a bit more about this, can something be done? (Female, Community Health Workers; Bangalore)

”

As remarked towards the end by the CHW in the above example, they felt under-equipped to deal with such cases and would require further training to be able to do so.

CHWs also faced difficult decisions in relation to patient concerns about the stigma associated with TB. Though they are provided training on the importance to counter stigma, the practical implementation of this proved difficult due to its deeply embedded nature. As explained by a CHW:

“Door to door [visits], we don’t do because patients don’t feel comfortable to have us inside, for some it affects their family honor (Female, Community Health Worker; Hyderabad)

”

When a patient shared their fears and anxieties around societal stigma, the CHW did not have a choice but to respect their wishes, as in the following cases:

“Few say that our visit to their home is bringing discrimination for them in the society, and then we spoke with them and said that if that is the problem, we won’t visit you at home, we will be in contact over the phone, and you can come to the hospital to meet us. But if our coming is a problem then I will not come. (Female, Community Health Worker; Koppal)

”

“Don’t tell them... Don’t tell Anganwadi, don’t tell ASHA workers’, they request.)’ Please madam... there is ASHA worker next to my house; I don’t want to tell her...I will not take medicines from her/ him, only from you. Even if you come to my house, call me ... I will come wherever you are’ they say” (Female, Community Health Worker; Bangalore)

”

Such a scenario creates a conflicting situation wherein the CHW has to respond to the individual patient’s concerns over the larger objective of countering social stigma. This decision is appropriate considering the primary goal of ensuring individual patients’ treatment adherence but simultaneously reinforces the existing patterns of stigma surrounding TB. For this purpose, perhaps community-level awareness would be required rather than individual counselling of TB patients.

In fact, as narrated by a CHW herself, she encountered instances of stigma even within her own family when she informed them about having taken up the job:

“Then I also discussed at home, that I have this kind of job. There being villagers.... We come from a village... villagers say... ‘Oh! This disease! No, no... we will also catch it up.... You can search for some other job right?’ They said all these things. I did not listen to them, attended training, attended classes, participated in workshops, I learned that it, Sir, doesn’t attack us that immediately. When I became aware I became more confident. (Female, Community Health Worker; Bangalore)

This reveals the deep-rootedness of the issues of stigma, and how training and awareness programmes are crucial to counter it at multiple levels from the health workers themselves to patients, health facilities, and community-based groups.

Another challenge faced by CHWs was in relation to the creation and linkages of bank accounts for DBT under RNTCP. Though instances from patient interviews revealed their dissatisfaction with this aspect of the program, some interactions with CHWs showed how despite constraints, they were attempting to help patients to the best of their capacities. For example, a CHW from Bangalore described the various efforts he put into the process:

“Earlier it used to be a problem to create the bank accounts. When I was in Laggere there was a patient who had no bank account, so I had to get it created [...] I told them that there is a TB patient who has no account, so we must create a zero-balance account to him. [...] There we created accounts for 2 to 3 patients. And DBT linked to those accounts and they have received the amount as well. [...] Even in Bank account cases, I used to go to their home to get the account details by telling them that they will be getting this DBT support. [...] so to make the use of it, I used to link their bank accounts here. (Male, Community Health Worker; Bangalore)

It is likely that with their existing workload, it was not possible for each CHW to follow up on bank paperwork closely. In fact, the same CHW suggested that a higher number of health workers would help in reaching out and following up in a more comprehensive manner with all TB patients. Another CHW expressed the same concern regarding the workload of managing multiple TB patients, due to which attending to the specific needs of DCM patients was a major task:

“I am responsible for 650 patients and among them, 165 are DCM. (Male, Community Health Worker; Krishna)

Perspectives from TB Health Visitors (TBHV)

Interviews with TBHVs revealed a scant understanding of the DCM categories and they did not report having received training for the same. Their designated role was to attend to all TB patients for help with diagnosis, testing, and counselling regarding treatment adherence. As explained by one TBHV:

“Success rate is more important to us so, when we provide them the treatment they have to utilize it and because of the treatment they should get cured and the disease should not spread, that is the more important thing that we inform the patient during counselling. We can’t talk much about their personal things, but we can talk about the treatment and facilities that we provide here. (Male, TB Health Visitor; Bangalore)

Specialized care thus appeared to remain outside the ambit of their responsibilities. They did note however that the presence of CHWs reduced their workload:

“CHWs were very supportive to us as they do follow-ups after we do the entry. As I have to spend my whole day in PHC sometimes looking after online work like HIV status and some such cases. So I will take the CHW’s help for follow-ups. I used to give the details to CHW then they used to visit patients to give feedback. They do work well. (Male, TB Health Visitor; Bangalore)”

The scope of work of TBHVs did not seem to be as decentralized as that of CHWs, and they reported how linkages with ASHA and Anganwadi workers allowed them to monitor cases in their areas:

“We can’t go to everyone, sir. We have ASHA workers, they keep a check. They are always in the field and they keep a check and continuously monitor. (Male, TB Health Visitor; Krishna)”

The limited involvement with the community in part seemed to be a result of limited manpower, which was cited as one of the challenges. The major issue with treatment was identified by the TBHVs as a lack of awareness, as expressed below:

“Madam whatever we may do, unless and until people get complete awareness about TB and get all the information about this TB, whatever we do will not be effective. [...] Because people will not take the things seriously until they have knowledge about it. They just listen to us and go off. So they should have awareness mainly. (Male, TB Health Visitor; Koppal)”

Though CHWs and TBHVs broadly self-described their roles as being involved in helping patients with their TB treatment process, the scope of their work has been conceptualized differently. While TBHVs manage work at the facility level with the larger objective of improving successful outcome rates, they are not as involved as the CHWs with providing patient-centered services.

SUMMARY

- CHWs displayed an understanding of general TB treatment processes and the importance of counselling towards achieving the key objective of the program to ensure treatment adherence for DCM category patients as a whole but were unable to address specialized needs of patients belonging to different categories, or multiple categories.
- In particular, CHWs lacked the training to manage patients with multiple co-morbidities and what they termed as ‘difficult’ patients such as the elderly, or those with alcohol dependency.
- Community-level stigma around TB, delays in the government-sanctioned DBT for TB patients, and excessive workload were alluded to by CHWs as major challenges in their everyday work.
- TBHVs did not appear to be aware of the details of the DCM model and were engaged in their responsibilities largely independent of CHWs, with a focus on improving successful outcome rates.

2

Critical role of the patient support groups (PSG) in enabling TB patients to have better adherence and quality healthcare



A little less than half of the respondents interviewed (12 out of 28) had attended the PSG meeting at least once. Four patients had attended with a relative, while two had sent a relative in their place to attend the meeting. PSG meetings saw an average attendance of 12-14 patients and usually lasted for a duration of 45 minutes to one hour.

Benefits of PSG

As described by both patients, and CHWs, the PSG meetings consisted of information dissemination regarding treatment adherence, healthy diets, hygiene, and precautions to avoid the spread of TB. In addition, patients were asked to speak about their experiences, in order to generate a sense of solidarity as well as clarify any questions they may have regarding the treatment. Patients described the meetings as:

“When I was sitting in meeting (PSG) that time they would tell. You should not spread to others, you should not spit anywhere, if you have children you should keep separate plate, tumbler, and clothes, like that they would tell to my husband. (Female, 45 years; DCM – Diabetes; Bangalore)

“In TB, many ways of infections are there, not to sit in front of coughing person, through the air it spreads, in the meeting also they have mentioned. Even if I spit, then too I should use kerchief. (Male, 60 years; DCM – Elderly; Koppal)

Some patients also spoke about their experiences, for instance, in relation to the importance of adherence, a patient with DR TB shared the following experience:

“Don’t skip like me (tablets). Even I was in this state and suffered) for 2 years, take continuously, don’t miss – I have spoken this at the meeting -, Till then I didn’t know about TB, after experiencing now I know about TB. Now it’s like with great difficulty I have lived, I was in doubt (of living). If I had some other disease and died I would have been in peace. God promise my house is on the first floor, I couldn’t climb stairs and I couldn’t walk on the road easily I used to feel tired. I felt like nobody should get this disease. (Male, 40 years; DCM – Drug-Resistant TB; Bangalore)

CHWs also expressed that PSG meetings were useful for the purpose of building a sense of solidarity among TB patients:

“Conducting meetings every month also helps them to understand that - ‘till now I [TB patient] was thinking there aren’t people like me but now I have understood so many people are there’. (Female, Community Health Workers; Koppal)

“They have overcome their inferiority about themselves. They started feeling that they are not alone anymore. They are not the only ones who are cursed by God. They used to think earlier that god has cursed them alone with this. So, we used to tell them that there is nothing as a curse and make them understand that they are not only the ones who are affected by this. Even they used to share their experiences with other patients about tablet timing and regularity, also about bad habits like smoking or the consumption of alcohol and how they overcame it. [...]Which all I felt was helpful. They get to open up at that time. (Female, Community Health Worker; Bangalore)”

Such sharing of experiences and discussions are potentially useful and can help all patients by serving as both a learning experience as well as being a space for acceptance and solidarity.

Challenges for patients to regularly attend PSGs

Patients faced several challenges to regularly attend PSGs. This was explained by some patients and also a CHW as being due to the physical effects of the disease, as well as due to clashes with working hours:

“For some PSG meetings, patients can’t come, pity. They are bedridden. And then, some go to work. Then the people who care for them come, sir. (Female, Community Health Worker; Bangalore)”

Another factor for non-attendance arose from the recurring fear of stigma, as explained by one of the patients, who was also a community worker:

“Not all come sir, they think what people will think if I go there. For example: if two people from the same area come for the meeting, then the other person would get to know that I have TB so let’s skip it. (Female, 35 years; DCM – HIV; Koppal)”

Not all patients held similar views about the usefulness of PSG meetings. One cause of this appears to be that the PSG had not been appropriately communicated as space for patients to share their experiences or build a sense of community, and were hence viewed as a place to sit and listen to experts, rather than speak about themselves. As shared by a patient in response to being asked about who spoke at these meetings, he said:

“People who know the information speak. Can we speak? People like you, who know, will come and speak. How will we know what they will do in a meeting like this? They tell you about TB, what you should eat and drink. Patients won’t know anything, only after they tell you will get to know. [...] Like who knows information comes to hospital and talks. We have to listen to them. If they speak and we don’t listen to them, it will affect us. (Male, 40 years; DCM – Drug-Resistant TB; Bangalore)”

The non-availability of doctors and medical staff to participate at PSGs further reduced the patients’ interest in attending these meetings. Patients expected these meetings to serve as opportunities to seek clarifications from doctors, who they were not otherwise able to access during routine check-ups at hospitals. However, participant observations of PSG meetings revealed that medical staff was rarely present at these meetings, thus demotivating patients from continuing to attend them.

In addition, space has not been made conducive for patients to feel comfortable enough to speak up, as is evinced from the following responses about PSGs:

“they used to speak and I just used to just listen to them [...] I was actually not having the courage to speak as I was feeling that they may ask me something which I am not aware of [...] I was scared to talk over there [...] I was not confident in front of higher authority. (Male; DCM – Alcohol Use; Koppal)”

“They used to ask me how it infected me. How would I know that? They should know the answer to this. (Male, 60 years; DCM – Elderly; Bangalore)”

In an existing system of hierarchies where many patients already feel inferior due to a perceived sense of lack of awareness and knowledge, a more active effort would be required to meaningfully engage patients to have a conversation amongst each other.

As a result of such factors, patients also felt that the PSG did not serve any unique purpose, and were repetitive in the information they imparted. One patient responded, upon being asked what she thought of the meeting:

“Same information, everywhere the same information [...] only the same information they gave, but they also gave Ganji powder. (Female, 30 years; DCM – Previously Treated; Koppal)”

There appeared to, therefore, be little incentive for patients to attend the meeting, except to collect the nutritional powder, and sometimes medication, that was distributed during the meetings. Even for those who did exhibit initial interest, the meetings soon turned repetitive in nature, and did not impart any knowledge that was not already shared with them during interactions with CHWs and hospital visits.

SUMMARY

- The potential of PSG meetings was highlighted by patients and CHWs who described them as informative sessions, spaces for clarifying doubts, and sharing of difficult experiences of their TB treatment process to build a sense of solidarity.
- Yet PSGs saw poor attendance because of various reasons such as the illness itself, pressures of work, or stigma of being associated with TB patients.
- The focus during the meetings was more on information dissemination rather than the encouragement of patients to speak or to carve out space for them to express their concerns.
- The content of the meetings was deemed as repetitive in nature and did not see regular attendance by medical staff who could clarify doubts. These contributed in part to patients' perceptions of PSGs as not being significantly useful.

DISCUSSION



The major objective of the DCM is treatment adherence to ensure successful treatment outcomes, which in large part was noted to be carried out effectively by CHWs. It is important to take stock of what aspects of the DCM conceptualization as well as its implementation contributed to this success, as well as where there remains scope for further improvements.

Research in the area of TB treatment adherence identifies several levels of factors associated with low adherence, broadly lying with the domains of health systems, social contexts, and personal factors (Garner et al., 2007). However, it has been noted that relatively few interventions tackle issues at the social, community and family level, such as with the help of health workers, to counter stigma, provide TB education and ensure treatment completion (Garner et al., 2007). The DCM as a patient-centric model strives to fill precisely this gap, seeking to tap into potential support networks within families and communities through frontline workers to assist patients. The need for such forms of care, as envisioned under the DCM, was further illustrated through the research study, which noted the positive impact that directed, invested efforts by CHWs had on treatment processes. Patients often lack information on testing, treatment adherence, handling of side effects of medication, and nutritional requirements. These gaps in awareness were filled by the presence of CHWs who were adequately trained in these matters, and could thus guide patients by providing necessary inputs. The key responsibilities were efficiently implemented through regular visits or phone calls which imparted critical information on tests to be conducted, regular hospital visits, assistance for obtaining medication, precautions to avoid the spread of disease, regular reminders to consume medication and the critical need to adhere to the treatment at all costs. Along with this, CHWs also provided motivation and encouragement in the face of difficulties that patients faced, for instance when they struggled with severe side effects that may hamper their adherence. In these respects, the DCM was successfully implemented to cultivate proper treatment routines conducive to positive outcomes.

Apart from the efforts of the CHWs however, a critical factor that enabled this success was the support of family networks that offset the high costs and burdens of the treatment process. These costs ranged from physical weakness from the illness and severe side effects of medication to loss of daily wage work. The centrality of family support in the recovery of such patients took many forms. For some patients, this was the presence of family members who could cook nutritious meals, accompany them on hospital visits, and regularly remind them to take their medicines. For financially under-resourced families, it was a member who could work and earn a living for the basic subsistence of the family. Yet for others, it was simply family members who could provide emotional support and comfort during times of fear or distress. A meta-review of studies on TB treatment adherence notes along similar lines that support at the level of the family and household has the potential to counter complex barriers to treatment adherence at both structural and personal levels (Munro et al., 2007). However, in the absence of such forms of support for patients, the role of the CHW in either filling this gap or mobilizing such forms of support from extended family, friends, and neighbors was insufficient. It was precisely these patients who required more intensive forms of care, rather than those who already benefited from existing support networks. In such cases, it has been recommended that the potential of local groups or community-based support networks could be explored (WHO, 2003)

The generality of treatment assistance provided by CHWs, while effective to an extent, compromised on the idea of ‘differentiated’ needs as it is conceptualized under the DCM model. Other studies have also noted the need for customized care among patients at higher risks of non-adherence. For alcohol consumption among patients, for instance, it is suggested that modifications to alcohol-related behavior may improve treatment outcomes (Bagchi et al., 2010). Co-morbidities such as HIV and diabetes complicate the course of the disease and pose an increased risk to treatment completion, requiring specialized assistance and co-management of the illnesses (WHO, 2020). Adherence among patients with DRTB (Drug-Resistant TB) or MDR TB (Multi-drug resistant TB) is often unsuccessful due to loss of follow-ups, and have found to require additional motivational counselling, family support, social support, and nutritional supplementation to ensure treatment completion (Deshmukh et al., 2018). Such studies not only point to the differentiated nature of risks but also the need for case-specific interventions to manage treatment adherence and completion. Though such elements of differentiated care are theoretically captured in the design of the DCM, CHWs were often unable to identify multiple risk-categories or manage co-morbidities such as diabetes or HIV, and also had difficulties with certain types of patients such as those dependent on alcohol. To a certain degree, such encounters are not possible to predict and require health workers to improvise based on their general but layered understanding of the needs of patients. At the same time, however, more rigorous training would provide a more concrete foundation of knowledge and capacities which CHWs may draw on for their work.

Certain limitations of the DCM did not arise from individual-driven factors revolving around CHWs, patients or their family members, and require attention to the contexts and structural factors within, and through which differentiated medical risks operate. Such contexts of poverty, stigma, or gendered and hierarchical relations were seen to further complicate the implementation of DCM. Structural factors such as poverty and discrimination are known to constrain treatment adherence among TB patients, even when patients are themselves willing to adhere, and often these constraints on agency are obscured in patient narratives (Munro et al., 2007). Addressing these required institutional-level support mechanisms, which were not always available. For instance, issues of poverty would require effective and accountable governmental intervention programs, while social issues would require sustained advocacy and mobilization efforts within communities. Though TB health visitors were not engaged in intensive patient-centric healthcare, concerted efforts such as coordination between, and convergence of the responsibilities of TBHVs at the health facility level and the CHW at the community level could help address some of these issues. It is also important to build capacities of health workers to make visible structural constraints since they are often implicit in nature and not directly expressed by patients.

At the same time, the efforts of sustained community-based and patient-centered efforts at mitigating societal issues such as stigma should not be understated. It was found in one study for example that home visits by health personnel and participation in self-help groups called ‘TB clubs’ played a role in reducing patients’ internalized stigma (Macq et al., 2008). Personal attitudes and beliefs towards TB, though mediated by complex inter-personal and structural factors, can be reduced through continuous engagement and advocacy through the involvement of health staff, workers, patients, and community members.

Patient Support Groups serve this function well and have the potential to create an initial space where many of the individual and social-level problems of TB can be addressed. HIV programmes frequently utilize patient support groups as an intervention to address the psycho-social needs of patients and are even recommended as a strategy by the WHO to improve retention adherence to ART (Anti-Retroviral Treatment). Though less common in TB programmes, there is growing recognition on the importance of patient networks to improve treatment outcomes and experiences at health facilities and evidence to show the potential benefits of psycho-social support groups for patients on treatment adherence and overall patient well-being (see Acha et al. 2007; Kaliakbarova et al., 2013; Khanal et al., 2017).

However, observations and patient accounts of PSGs revealed that unfortunately they were not effectively performing this function of psycho-social support, and were instead only duplicating the work of information dissemination already being carried out by the health workers. While patients benefitted to an extent from hearing about other’s treatment experiences, side-effects of medication, in particular, of other patients, these meetings were by and large not perceived as spaces for patients to express their fears, problems, or anxieties. Given that the unique feature of these meetings was the opportunity to interact with other TB patients, efforts at making these spaces more active, welcoming and engaging would benefit not just the patients, but also by extension their communities, and the prevailing misinformation and stigma. Furthermore, the presence of both health staff who can provide medical guidance, as well as trained counselors for psycho-social help would be necessary to facilitate these meetings and achieve its objectives.



RECOMMENDATIONS



1. Strengthening elements of patient-care and frontline health worker capacities in the DCM

- Intensive knowledge must be provided to frontline workers on specific facets of DCM so they can identify categories of DCM, co-morbidities among patients, and patients falling within multiple DCM categories.
 - For managing these differentiated needs, the capacities of frontline workers need to be built through further rigorous training so they can address the multiple requirements of DCM patients.
 - For providing counselling to DCM patients, frontline workers must also be trained extensively in forms of individualized psycho-social care, so they can manage ‘difficult’ patients and ensure treatment adherence among them.
 - At the district level, resources for financial support and various treatment services by the government, NGOs and private providers may be identified, compiled, and updated regularly in a centralized fashion. These can be shared in the form of simple, reader-friendly hand-outs with frontline workers to aid them in their work on linkages and referral services.
- Advocacy material in the form of IEC to actively counter the stigma associated with TB can be developed and shared with patients.
- Mechanisms to incorporate patient feedback on CHWs and the DCM initiative should be created as a means for regular improvement, and to maintain the patient-centric nature of the model.

2. Improving the functioning of Patient Support Groups to achieve intended goals

- A detailed curriculum and operating protocol for PSGs must be developed to clearly delineate its purposes, tasks, and outcomes.
- Improved planning involving all stakeholders is required for ensuring the attendance of medical staff and community representatives at the meetings.
- Encouragement and motivation of patients at these meetings must be enhanced through further efforts, and actively engaging them through planned activities that foster meaningful discussion.
- In addition to existing stakeholders, the presence of a dedicated counselor at these meetings can be considered in order to attend to psycho-social aspects of patient care.
- Similar to DCM, feedback mechanisms should be created for all key stakeholders to better understand their needs and preferences, and ensure the smooth and effective functioning of the meetings.

3. Supporting frontline workers

- There is a paucity of human resources to implement the DCM as part of the RNTCP and would require an increase in recruitment of frontline health workers.
- TBHVs lack the capacities to implement the DCM in the manner done so by CHWs. The transitioning would require intensive training and handholding of TBHVs in the initial stages by CHWs.
- Meetings for health workers may be incorporated into the programme to enable the sharing of common issues, provide opportunities to learn from, and support each other's work, and build collective capacities to drive the program.
- More importantly, for the effective implementation of DCM, it is important to have a multi-disciplinary tired team-based approach, rather than overloading FWS with all the responsibilities.

4. Broader community-level efforts to counter structural contexts that impact TB treatment outcomes

- Advocacy for inclusion of TB literacy and stigma reduction through community-level institutions such as Panchayati Raj Institutions (PRIs) should be incorporated in the program.
- Strengthening linkages of frontline health workers with community-based workers such as ASHA and Anganwadi workers who have an existing rapport with community members would be useful for the implementation of DCM and PSG.
- Identification of relevant support programmes for socio-economic security and the strengthening of accountability mechanisms at the community level to ensure their functioning would be important to support TB patients.

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ANNEXURE

Annexure 1: Interview guide for DCM patients



Name of the interviewer: _____ Date of interview: _____

Name of the site: _____ Name of Tehsil : _____

I. General information

1. DCM category of respondent : _____
2. Name of the respondent : _____ Respondent ID _____
(refer sample sheet)
3. Age : _____
4. Gender : _____
5. Caste : _____
6. Education : _____
7. Current occupation : _____ Previous occupation: _____
8. Marital status : _____
9. No. of family members : _____ Male _____ Female _____
10. No. of children in the family : _____ (mention sex and age also)
11. Monthly income : _____

II. TB disease/treatment related

1. First diagnosed at : _____ (name of hospital)
2. Date of last test : _____
3. Medicines consumption (TB) : _____ (Yes/No) No. of medicines (per day) : _____
4. Duration of medication : _____
5. Injection for TB : _____ (Yes/No)
6. Name of the care giver : _____ Relationship with respondent: _____
7. Frequency of visit to hospital : _____ (in days)

III. Other health issues

1. Any other health issues : _____ (any co-morbidity)
2. Name of the hospital : _____
3. Medication for other health issue : _____ (Yes/No)
4. How long medicine consuming: _____
5. Name of the care taker : _____
6. Relationship with respondent : _____

IV. Others

1. Alcohol consumption : _____ (Yes/No). How often : _____ (day)
2. Smoking : _____ (Yes/No). How often : _____ (day)
3. Tobacco : _____ (Yes/No). How often : _____ (day)

Note: This information needs to be filled by the interviewer after completion of the interview

In-depth Interview Guideline for DCM Patients

Greetings! (Introduction and Rapport building)

IMPORTANT: Ensure the respondent has completed the consent process (signing of the consent form and consent to record the conversation) before beginning this interview. The consent form must be reviewed, understood, and signed by the respondent.

Fill the Socio-demographic information in the Master list.

Note: Use the local name known to the respondent while referring to the CHW.

Request the respondent to give examples (esp, regarding their own experiences) from time to time!

1. How are you? Tell me something about yourself, like who is there in your family, what do you do, generally how is your day like (daily routine). **(If the respondent is living alone or elderly, probe for how their life is different, their life events leading to difficulties and daily challenges they have been facing economic, support system, care, emotional support, relationship dynamics, discriminations, etc.)**

2. What do you think about the health and nutrition of people living in your area? What are the common ailments? What are the general health practices like food, cleanliness, preference for health care services, lifestyle, and medication? Where do people prefer to go for treatment? (Probe for Government versus private health care facilities). Any concerns regarding the same?

3. How is your health? What all (ailment)health problems are there? **(If the respondent is living with Diabetes, BP, HIV, or any other co-morbidities, probe for the following specific question. When were you diagnosed with HIV/BP/Sugar or any other co-morbidities? Please explain in detail. Where it was tested and when the treatment initiated? What medicines are you taking for the cure? Where are you taking the treatment? Probe for the treatment adherence, belief, and**

practices about taking treatment for a prolonged period, challenges to adhere to the treatment, what support they have, etc. (take pictures of all the medical records available with the patient- note if there is change/discontinuation in doctor, medication, etc- probe reasons for the same) How has the co-morbidities if any, has impacted your life and treatment the TB?

4. Can you please share your problems and experiences with TB treatment? When did it happen? How was it first detected? Any prior symptoms? Where was it diagnosed? **(if the respondent was previously treated for TB then probe specifically on how he/she got re-infection. Also, if a respondent is a DR-TB patient, probe specifically on how it has developed or the pathways to develop DR-TB).**
-

5. What were the next steps taken by you after the diagnosis (availed health services, rechecked the test results, ignored it initially, etc), who was present with you when it was diagnosed? What was informed by the doctor? Who helped you? What problems faced during that time? **(probe the respondent to narrate the complete history related to TB, its treatment and present situation, identify if the patient mentions about previously treatment history or DRTB)**
-

6. How TB affected your life? (probe in terms of family, social or professional life or any other financial constraints)
-

7. Who all in your family and friends knows of your TB status? How is their behavior towards you? (probe if the respondent faces any challenges (stigma, discrimination) after informing it to his/her closed ones, what kind of support they receive, from whom if not what was/is the expectation)
-

8. What do you know about TB? (Probe for how it transmits, course of treatment, preventive measures, how important is nutrition to prevent TB, etc.) Did you know all these when you first diagnosed with TB? What did you know, how is it different now? What (who) is the main source of information related to TB? (probe to understand the respondent's knowledge and perceptions on TB, reasons, symptoms, preventives, cure, treatment, etc.) Do you know of any local beliefs and perceptions related to TB? (like how it happens, what should be done, any local treatment, etc.)
-

9. What are your experiences at the health facility? Do you face any challenges? Do you think more support and assistance is required for the TB patients? If yes, what can be done? (probe questions related to accessibility, availability, and affordability) Have you shared your problems related to a health facility with anyone? Have you received any support regarding the same? What kind of support? (probe if the CHW/TB-HV has helped them and how regarding this)
-

10. Do you face any challenges in continuing the treatment? Could you please elaborate on how do you take treatment? (Probe for when and what medicine they take) How do you manage the treatment for other diseases? What are the challenges you have been facing in taking the treatment regularly?

11. Do you feel any side effects because of the TB medicines, if yes, what type of side effects? Have you discussed them with the doctor or anyone else? Do you still face similar problems? (probe, if the respondent finds it difficult to maintain the treatment regime, has the respondent stopped taking medicines and reasons behind that, is the respondent taking medicines/any treatment to address the side effects)

12. Do you think consuming alcohol and tobacco can worsen the disease or affect the treatment? How? How commonly people take alcohol and tobacco in your locality? Do you also sometimes take it? How frequently? **(if the participant is in the alcoholic category, probe for his history of alcoholism, any efforts to de-addiction, if the respondent has been informed about the adverse effect of alcohol and tobacco on TB treatment and what all support has been provided to him regarding the same by the CHW/TB-HV, what are the challenges respondent is facing due to alcohol intake like addiction, maintaining the medication regime, side effects, and other daily life problems, etc.)**

13. How is the life of TB patients in your locality? (probe around the stigma, discriminations) what are the reasons behind? What other challenges do TB patients face, please elaborate? Have you also faced something similar? (probe at family, community, health facility level, etc.)

14. Do you know/receive any services available from the govt? (probe around general and specific to TB health). Which one? How did you come to know about this? How useful it is? Did anyone help you in availing of these benefits? Who? How did they help? (probe if CHW/TB-HV has ever helped the respondent in linking with some financial assistance, government schemes, etc. probe if that has contributed in any way to the respondent's life)

15. Do CHW (xyz...mention the CHW name) visit your home? What about TB-HVs and Asha's? Who else? How often? What all she tells? Since when does the respondent know him/her and how? (If the CHW does not visit the home probe, where does she meets? Why?) (probe the respondent to tell more about the CHW, what all she covers, how frequently she come, has she helped the respondent in any way – what are those, probe if the CHW also talks to the respondent's family or immediate caregiver, what do they generally discuss)

16. Have you ever shared your personal problems with the CHW? Has the CHW tried to help you and How? Give examples. (probe if the respondent has shared any issues related to family, living alone, alcohol, support needed, problems related to the health facility, treatment adherence, experiences of stigma and discrimination or any other with CHW, whether the CHW did any counselling)

17. How much is the CHWs involvement with your family members or caretakers? Do they every time when they visit you also talk to your family members. **(in case the caregiver or family member is available, the interviewer may also briefly speak to them regarding the experiences with the CHW, has it made any changes and how) (IDENTIFY- if the patient is elderly or living alone – how CHW has helped the respondent to find the caregiver for them. How far they are involved in ensuring the treatment adherence of the patient. How does it help the patient)?**

18. How do you feel about the CHW's visit to you? (Probe around how the CHW visit have impacted on their life/health status? Which is the most important aspect of the CHW visit they feel has made a difference (seek to understand if it's the CHWs in-person care like spending time with the patients and discussing their problems, counselling or reminding the patient to go for health check-up follow-ups through visits or SMS or linking them with any medical or financial aid has impacted more)

19. Do you receive any reminder calls, SMS to take medicines or go for follows ups, etc (Probe if yes, how often, most common method)? How it helped you in treatment adherence and how? Have you seen any posters, pamphlets, or any street plays, campaigns, or any other thing that has information related to TB in your area? Do you think it is important to create awareness related to TB? What can be done about it?

20. Have you ever attended any meetings with CHWs, other TB patients, and their families, doctors, etc., outside your home? Where was it held? Did you ever attend any meeting conducted at the health services? Can you tell me your overall experience of it? (probe around when, how many, how often they have gone for the (PSG) meeting, with whom they went, what all they did there, who all are there). What all topics you discussed in the meeting? How did you feel about it? Note: whether the patient mention this meeting has been helped him in adhering to the treatment, side effects, issues with the health facility, etc. Any other concerns related to this meeting you would like to share with us? (probe if privacy, distance, venue, timings, the poor response by the health facility or any other concern discourage the patients to attend the meetings)

Thank you for taking the time to meet with me and for answering all my questions. Please be ensured that everything that you have shared with me will remain confidential. Information gathered in this research study may be published or presented in public forums, but your name will not be used or revealed anywhere. Every effort will be made to protect your anonymity.

Annexure 2: Interview guide for CHWs and TBHVs



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Name of the interviewer: _____

Date of interview: _____

Place of interview: _____

V. General information

12. Name of the respondent : _____
13. Age : _____
14. Gender : _____
15. Caste : _____
16. Place of residence : _____
17. Education : _____
18. Current occupation : _____
19. Previous occupation : _____
20. Any other work currently doing : _____
21. Marital status : _____
22. No. of family members : _____ Male _____ Female _____
23. Main source of income : _____
24. Monthly income : _____
25. How long working in this program : _____
26. No. of working hours in a day : _____
27. No. of patients reached till date : _____
28. No. of targets : _____
29. Area coverage : _____ (no. of TU's/no. of household etc.)
30. Most challenging DCM patient to deal: _____

Note: This information needs to be filled by the interviewer after completion of the interview

IDI guideline- CHW/TB-HV

Greetings! (Introduction and Rapport building)

IMPORTANT: Ensure the respondent has completed the consent process (signing of the consent form and consent to record the conversation) before beginning this interview. The consent form must be reviewed, understood, and signed by the respondent.

Request the respondent to give examples/cases of different patients from time to time!

1. How are you? How long have you been working as a CHW/TB-HV? What did you do before your engagement with the TB program? What motivated you to take up this job? Did you have any apprehensions before joining this work? Please share.
2. Did you receive any training for this program? Who provided the training? Please tell me more about the training like how was it, what all sessions were there etc. (probe for who all were involved, no. of training, duration, no. of participants, venue, sessions, and activities)
3. What were your experiences with the training? How it helped you to perform your job more efficiently? Please suggest what all can be improved in the training sessions or what additional training may require?
4. What are your major roles and responsibilities as a CHW/TB-HV under this program? Please describe each and every activity you have to undertake?
5. What do you know about the DCM approach? Please elaborate on how do you identify the DCM patients? What it is so important? (probe...on why they think giving special attention to certain patients is important, why this kind of support is generally needed by them, what are the successful outcomes of the DCM approach) What are the major components covered under this program (note which activity is given more emphasis and probe further on it. Ex. Counselling, reminders, nutrition, etc)
6. How do you come to know that the patient falls under this program (DCM) (probe on screening, RANA form, how they fill it, what all information is gathered in it, who do they notify)
7. What are things you have to do once you come to know that patient falls under the DCM category? (probe to explain the complete process, from screening to treatment adherence)
8. How many patients have you covered so far? Can you give an example of a patient that you consider has made the most progress? Can you tell me the story of how progress was achieved with this patient? What was particular about this patient? What do you that attributed to this success?
9. According to you what are the major needs of DCM patients? Do you think through this program we can address them? Do you think we need to strengthen certain aspects of this program and how?.
10. In your experience, which are the most difficult type of patients to handle and why? What are the mitigation strategies adopted to address them? Give a few case examples.
11. Have you helped any patients by linking them with any entitlements like government schemes or medical or economic aid? Give examples? What are the challenges you have faced in this regard? What support did you receive? Who supported?
12. How do you deal with patients with special needs? (probe for patients living alone, no support, alcoholic, etc.) Have you seen any changes in the patient after the counselling? (what kind) – give examples/cases?

13. There has been a focus on counselling. Tell me more about it (what all is done in counselling). How do they react when they are offered, counselling? Generally, which category of patients refuses counselling? Who all welcomes it? Do you think it makes any difference to the TB patient? What are the messages that patients are most receptive to when you go to their home for counselling?
14. Are there examples of patients you feel the counseling failed with? Any examples where you feel any in-person conversations have made things worse rather than better? What was the major issue that did not work, what were the barriers?
15. Do you counsel the family members also? If yes, generally who is the member? What all you cover with them. Do face any challenges with counseling the family members? What kind of challenges?
16. What do you know when you come to the patient is living alone with no family support? How do you mobilize others to take care of him? What are the challenges?
17. Have you faced any challenges at the community level or family level when go for visiting the TB patients or PSG meetings?
18. In this DCM program, there are many other types of support other than counselling, can you please tell me more on this. (probe PSG, CS, linking with social entitlements, etc.). How these are interlinked and contribute to the wellbeing of TB patients?
19. Do you know of any patients whom you had attended (visited) and have successfully completed their treatment? Do you still visit them? How are they doing? Do you think they will be all right and will not develop TB again? (if yes, why and if no what are the possible risk factors). What efforts are taken to continue a healthy lifestyle (probe- give an example of alcoholic, smokers, etc.)
20. Similarly, why do some people develop TB again (like previously treated and DRTB)? Probe for what were the reasons or what didn't work? What needs to be taken care of in this situation?
21. How many PSG meetings have you facilitated? With whom? What challenges have you faced? (mobilizing, finding space, sending reminders, etc.) Do you think it helps the patients and How? What are the topics patients generally discuss at the PSG meetings?
22. Can you tell me how the KHPT program is different from outreach work done by other TBHV? Do you think that giving priority to a certain patient is helpful or a single approach is enough? What do you think of the TBHVs....how is the relationship with them? According to you are there any challenges in providing quality care by the TBHVs/CHWs?
23. Are you aware of any other activities that are undertaken by the KHPT/TB-ALERT/RNTCP in the area to create awareness on TB? (probe for community structures, information centers, etc.)? How these programs are helping the community? What is your role in these programs?
24. Please share if you have any suggestions or recommendations for this program to make it more effective in ensuring the treatment adherence among the TB patients. Do you want to share any other concerns related to the program or your roles and responsibilities?



Many thanks for all of your time and help!

KHPT

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