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Mitra: A TB Careline



What is the TB Careline?

The TB Careline is a phone-based patient care and support service providing information on TB, treatment monitoring and counselling to TB patients and caregivers free of cost. Staffed by a team of counsellors, the Careline intends to improve treatment outcomes through the systematic counselling process of patients on treatment.

Background

The TB Careline was set up in 2014 under Strengthening Health Outcomes through the Private Sector (SHOPS) project, an initiative funded by the United States Agency for International Development (USAID). After the closure of SHOPS in 2015, it was operated by KHPT until 2016, when Indegene Lifesystems Pvt Ltd, a healthcare technology company, began to support operations. Initially operational in 12 districts in Karnataka, the TB Careline expanded services to the cities of Bangalore and Hyderabad under the Tuberculosis Health Action Learning Initiative (THALI). It is currently operational in districts in the states of Karnataka and Telangana.

The need for a TB Careline system

A patient diagnosed with TB is usually given a course of medication lasting for a minimum of six months. However, patients find taking every single medication as prescribed difficult for a number of reasons. TB medication can cause side effects, which are a major deterrent to continuing treatment. Patients who feel better after a month or two of treatment are also inclined to discontinue taking their medication. This raises the risk of the TB-causing bacteria developing resistance to the TB drugs. 2-3 percent of new TB cases in India are drug-resistant TB (DRTB), which is more difficult and expensive to treat and necessitates a longer treatment period which can extend to about two years.

The TB Careline serves as a treatment support mechanism, and helps address the underlying reasons for treatment discontinuation.

A large proportion of the population does not understand why TB occurs, how it spreads and how it can be prevented. As a result, TB patients are

often ostracized within their families and among society, creating a strain on the patient and affecting treatment adherence. RNTCP facilitates in-person visits by TB Health Volunteers to ensure that patients have not stopped treatment. Some patients, for the fear of the neighbours finding out, do not wish to be visited at home by TB frontline workers. The government has employed numerous approaches to remote treatment adherence monitoring including 99DOTS, VDOTS. However, these approaches do not address the barriers that TB patients face while taking treatment. None of these systems are currently available for those patients taking treatment in the private sector.

The TB Careline provides counselling services to patients who give their consent to be monitored throughout the treatment period. They explain the basic information about TB to the patient and the caregiver, advise them on when to seek medical attention for side effects, on what food they can consume and clear their misconceptions on the disease.

If the patient has not been told that he/she has TB, or does not mention that he/she has the disease, the counsellors do not mention TB, but ask if the patients are following their doctor's advice.

An important add-on to the counselling is verbal contact screening. Patients are asked if anyone in their

families have developed symptoms and to take them immediately for testing if they have. The TB Careline enables an approach to patient care and support which can be tailored to each individual's requirements and empowers the patients and caregiver to take care of themselves.

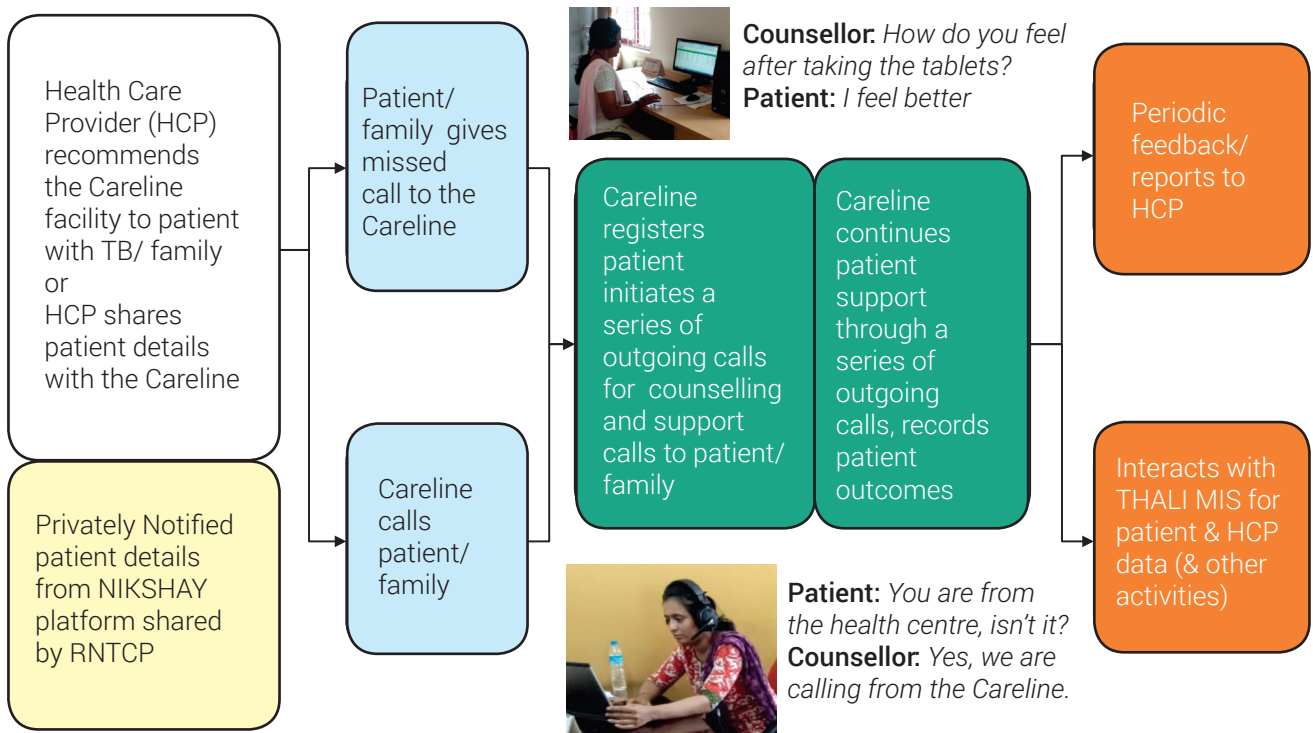
Components of Careline's Approach to Prevention, Care and Support

- ▶ Education about TB
- ▶ Treatment adherence monitoring
- ▶ Contact screening
- ▶ Counselling for psychosocial support
- ▶ Dissemination of information on benefits available to TB patients, including direct benefit transfer payments.

Structure of the Careline

The TB Careline is based in the KHPT office at Dharwad, Karnataka. It is staffed by five counsellors, each of whom has been trained in TB and counselling skills.

TB Careline – Activity framework



During the SHOPS project, a network of private healthcare providers provided their patients with the Careline number, to which the patient could give a missed call to be registered. The counsellors would wait for the call and occasionally get patients' details from the provider to call the patients and register them. At the end of each month, the providers would receive feedback on how many of their patients were being followed by the Careline, what was their treatment status, how many patients had discontinued treatment and how many patients had died. Following the closure of the SHOPS project, private providers with a high volume of patients insisted that their follow-up continue, as the Careline had proved to be a useful resource for tracking patients.

The THALI project expanded the geographical reach and the scope of the Careline to include patients notified to the government health system as well. Patients who did not prefer to receive in-person care and support from THALI community health workers were given the option of receiving telephonic support through the Careline. TB patients were given a card with the number, instructing them to give a missed call which would be returned within 24 hours.

The Careline call process

When the missed call comes to the number at the Careline office, a senior counsellor returns the call and allots the patient to one of the counsellors based on the language preferred by the caller. The call is then returned to the patient by the assigned counsellor, who introduces themselves to the patient and registers them upon consent.

The next day, the counsellor calls the patients to give post-diagnosis counselling, ask them if they have disclosed their condition, screen the close contacts of patients by asking if they are exhibiting symptoms, and address patient concerns. Subsequent to the second call, the counsellor speaks to the patient once every week in the intensive phase (the first two months of treatment) and once in two weeks during the continuation phase (the next four months of treatment). Exceptions are made in certain circumstances; if a patient has side effects or has discontinued treatment, the counsellors will call them continuously to remind them to take treatment and refer back to the treating physician appropriately.

Although the Careline functions between 10 am and 6 pm from Monday to Saturday, counsellors take calls even after hours to accommodate patient schedules. Follow-up calls on a monthly basis are made up to two years after treatment completion.

Patients also contact the Careline counsellor in order to clear any doubts they might have during the treatment period. Caregivers of paediatric patients are likely to make these calls.

Recording system

Currently call details are recorded in an Excel-based management information system (MIS), which helps the counsellors organize patient details and schedule calls for the following days.

The introduction of a software system for the Careline to help scheduling calls would be helpful in increasing counsellors' efficiency; this requires additional resources.

Value Addition

- ▶ The TB Careline maintains the privacy of patients who may not wish to receive in-person care.
- ▶ While the TB Careline has an organized call structure, the services offered during the calls are tailored to the patient's needs, offering a personalized approach to prevention, care and support. Counsellors are also trained to address specialised issues of bereavement, paediatric, geriatric and drug resistant TB.
- ▶ Careline is a system that uses technology without removing the human connect from patient care, making it acceptable to the patient and caregivers, while at the same time increasing the efficiency of the counsellors.
- ▶ The Careline is a flexible system that can be adapted to the needs of the government health system (supporting treatment notification and linkages to patient benefits) or the private sector (providing feedback on patient treatment status).
- ▶ Careline is a cost effective mechanism, the scope of which can be widened and has a potential for scale up.

Challenges to Careline operations

Communication challenges

- ▶ The onus of accessing Careline's services rests on the patient or the provider. If the patient does not wish to avail of the service, the Careline counsellor must respect his/her wishes. The counsellor must try to explain the benefits of using the service, but they only have one or two chances to do the same.
- ▶ The lack of face-to-face contact brings a set of challenges. Patients are sometimes suspicious of the Careline and do not wish to share their personal details with the counsellor. It can be difficult for the counsellors to communicate certain messages, such as the importance of avoiding alcohol during TB treatment, over the phone.

- ▶ If a patient changes his/her number, they can be lost to follow-up if they do not make an effort to share their new contact details with the counsellor.
- ▶ In many cases, especially those of women patients who do not have their phones, the counsellors cannot reach them during working hours. The calls must be made after hours, when their male family members return home from work.
- ▶ Gender of the counsellors may affect rapport building with the patients and caregivers. For example, Male counsellors may find it difficult to develop a rapport with female patients on the

phone and may face opposition from family members who do not want them to speak to female patients.

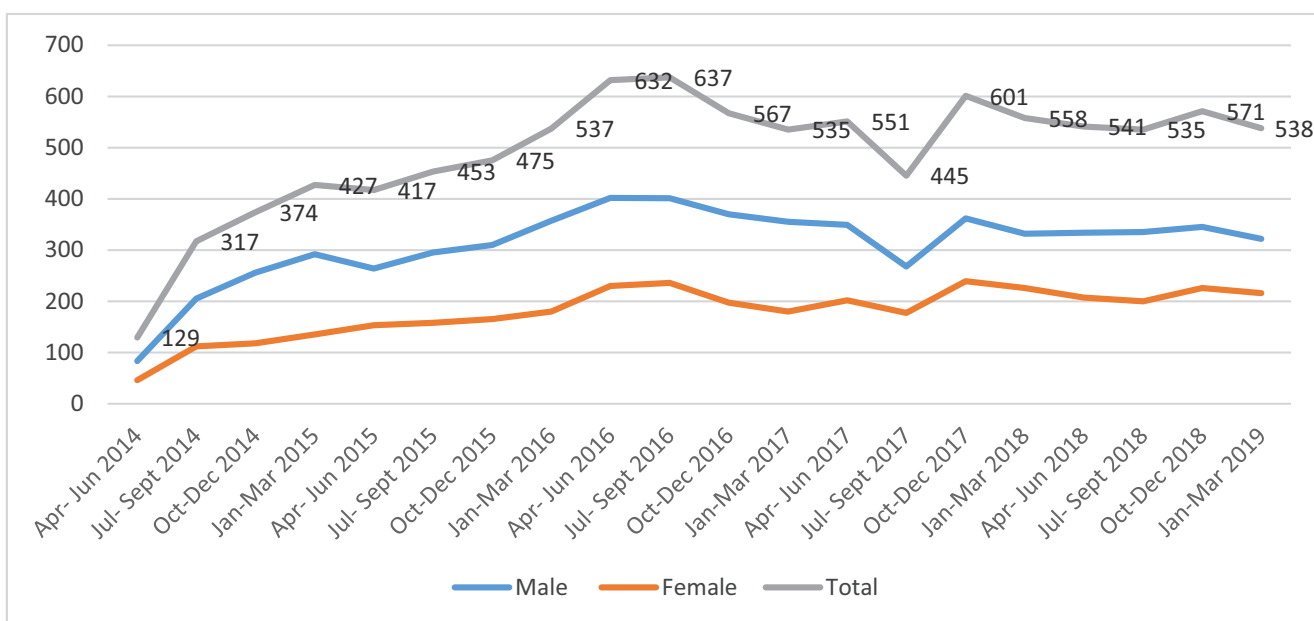
System challenges

- ▶ The current system does not automatically notify counsellors of which calls are to be made for the day. Call recording cannot be employed in the current Careline system. Employing and operationalizing these systems would be a resource-intensive endeavour. An automated dialer system for patients will help counsellors prioritize their calls and manage their patients better.

Careline Reach and Outcomes

Patient registration

The Careline has been reaching out to an average of 500 new patients per quarter since its inception.



Profile of patients registered

	4th Quarter (Oct –Dec 2018)	1st Quarter (Jan –Mar 2019)	Cumulative (April 2014- March 2019)
Number of TB patients registered	573	538	9842
Profile of patients based on sex			
Male	345(60)	322(60)	6237 (63)
Female	228(40)	216(40)	3605(37)
Profile of clients based on age			
Children (0-14 years)	89(16)	46(9)	1957(20)
Adult Population(15-59 years)	357(62)	368(68)	6295(64)

Elderly persons (60 years and above)	127(22)	124(23)	1590(16)
Profile of clients based on co-existing conditions			
HIV Positive clients	17(3)	10(2)	693(7)
Diabetic clients	35(6)	35(6)	539(5)
Profile of clients based on history of treatment			
Number of new clients without any history of previous treatment	443(77)	517(96)	9300(94)
Number of clients with history of previous treatment for TB	14(2)	20(4)	416(4)

*Numbers in brackets indicate percentages

- ▶ The male : female ratio amongst registered patients has remained constant at 60:40 over the years.
- ▶ Patients in paediatric and geriatric age groups constitute 30% of the registered patients with Careline which indicates that Careline may be a preferred choice for patients and their caregivers in these age groups.
- ▶ Patients being diagnosed with diabetes in TB has been on the increase from around 5% in 2014 to 11% in 2018.

Self-reported / caregiver-reported treatment status

Self-reported/ caregiver reported treatment status for the period	4th Quarter (Oct –Dec 2018)	1st Quarter (Jan –Mar 2019)	Cumulative (April 2014- March 2019)
Number of clients registered	573	538	9842
Treatment completed	360	592	6793
Death	14	34	577
On active care	1537	1256	-

456 patients who reported treatment rupture on call to counsellors were followed up and 214 (46.7%) of them were linked back to treatment.

Conclusion.....

At a time when Drug-resistant TB cases are on the rise, the TB Careline is a crucial mechanism to ensure that patients complete their course of treatment successfully. The Careline goes beyond asking whether people have taken their medicine, to finding out why a person is missing medicines and then addressing the underlying factors. It is a patient-centric system, which provides information and clarifies everyday misconceptions that a patient and

caregiver may have, as well as providing emotional support to patients. The TB Careline also has the potential to vastly increase the coverage of treatment adherence monitoring in a cost-effective manner. If integrated into the RNTCP's current system of patient follow-up, the counselling component of the Careline will be a particularly significant value addition to ensure that patients do not deviate from the continuum of care.

Voices

"I am happy to talk to patients, we have a relationship with them. The problems they have can't be shared with everybody. We are not doctors, but people open up to us."

– **Vijaylakshmi**, Senior Counsellor

"Patience is the most important, listening is the most important. We ask them about their home life. That is how we understand their problems."

- **Shirisha**, Counsellor

"I am thankful that they (the TB Careline counsellors) are helping me do my job."

- **A private practitioner**, Dharwad



Careline counsellors have a discussion about their experiences and challenges with the THALI program team.

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