Disrupting TB With a Phone Call: The DOTS *Mitra* Careline in Karnataka, India

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Tuberculosis: An old enemy, still with us

- Tuberculosis (TB), one of the oldest infectious diseases known to affect humans.

- 9 million cases of TB globally; 550,000 were children; 1.5 million died (2013)

- About 80% of TB cases are pulmonary TB – highly infectious, easily transmittable.

- TB is a leading killer of HIV-positive people causing one fourth of all HIV-related deaths.

- Among the top 5 causes of death for women aged 15 to 44.

Source: WHO Global TB Programme
India: 26% of the Global Burden of TB
WHO Global TB Report 2014
TB and DOTS in India

• DOTS (directly observed treatment, short-course)
  • TB control strategy recommended by the World Health Organization.
  • Standardized treatment regimen of six to eight months directly observed by a healthcare worker or community health worker for at least the first two months.

• Public health system in India instituted DOTS beginning in 1993. Standardized, high quality TB-DOTS among private health providers in India is extremely limited.

• Private sector accounts for 60% to 80% of outpatient healthcare in India.
TB and Private Providers in India’s Urban Slums

• A third of TB patients in India live in urban slums.

• Majority of urban poor use private health sector for initial care-seeking.

• TB treatment outcomes are poor when healthcare providers do not comply with national standards of TB care and when treatment supervision is inadequate.

• Leads to development of drug-resistant TB, increased transmission to contacts, relapse of TB, death.

• Adherence to the full course of 6-8 months of TB treatment essential to a cure and avoids transmission to others.
Why do people stop taking their TB meds?

- Lack of education on the need to adhere to treatment
- Side effects of drugs
- Isolation and fear of social stigma
- Lack of DOT supporter
- Feel better – Continuation Phase
- Substance abuse
What is the Careline?

A call center that provides:
• Adherence monitoring
• Counseling support

Objective:
• Support TB treatment adherence among patients in the private sector
• Improve treatment outcomes
• Reduce the spread of TB
How does the Careline work?

Missed Call
Patient calls Careline and immediately hangs up. (so that the call is free!)

Careline Calls Back
System saves the number and a counselor calls back with 1 hour.

Careline Identifies Caller
For confidentiality, the counselor does not mention TB, just asks who called.

Assess Reason for Call

TB Patient
TB Information
Who calls the Careline?

- TB patients diagnosed by private provider
- Caretakers of children diagnosed with TB by private provider
- Friends and relatives of people living with TB
- Teenagers (esp. 18-20 yrs)
- General Public
What does the Careline provide?

Highly qualified counselors provide a wide range of information and support in a non-threatening and patient-centered atmosphere.

• Scheduled calls to monitor adherence and provide counseling
• Treatment compliance status given to referring private provider

• TB patients and the general public can also call in if they have questions or need advice from a counselor (also through a missed call)
  • TB Medication side effects
  • Nutrition
  • Preventing transmission to family and friends
  • Understanding risk factors and symptoms of TB
  • Reassurance the TB can be cured
Intensive Phase (2-3 months)
Heavy dose of medication makes adherence difficult in this phase
Counselor Calls - Day 0, 1, 3, 10, 17, 24, 31, … every 7 days

Continuation Phase (4-5 months)
Lighter dose of medication eases side effects, but patients that feel better need to be reminded the importance of continuing medications
• Call every two weeks
• Confirm treatment and provide counseling

Patients can modify schedule to meet their needs.
Careline Communication with Patient’s Doctor

Registration:
- Inform doctor that patient has been registered by the Careline

End of 2 weeks:
- Inform compliance status to doctor

End of each month in Intensive Phase:
- Inform compliance status to doctor

End of Intensive Phase:
- Inform treatment stage and compliance status to doctor

1 week before each treatment monitoring test is due:
- Remind doctor about advising test (usually sputum microscopy)
- Inform compliance status to doctor

End of each month in Continuation Phase:
- Inform compliance status to doctor

End of Continuation Phase / treatment:
- Inform treatment stage and compliance status to doctor
- Inform doctor that treatment is complete

Doctor receives all messages from Careline via SMS (text message)
Where are we working?

State of Karnataka

SHOPS TB Program
- 12 Districts selected (in Consultation with State RNTCP)
- 42 Towns, 675 Urban Slums
- Population Benefitted: 15.5 Million people

Careline Pilot
- 170 providers throughout the network
DOTS Mitra Careline pilot results to date

- Careline has received more than 18,000 calls
- 1,095 registered TB patients over 13 months
Careline Case Study 1.
Caller: Father of 8-month-old baby girl diagnosed by a private provider with TB and given a DOTS Mitra Card.

Father was very angry about the diagnosis. Did not want to put the child on treatment. He was from a good family, a respected family, without any history of TB.

Could not accept that this tiny infant, his daughter, had TB when no one in his family had ever had TB.

“How can this child have TB!”

How would you, the Counselor, handle this caller?
Counselor educated about airborne transmission, that it had nothing to do with family, anyone who breathes can get it, infants and young children are highly vulnerable.

Father eventually calmed down and agreed to put child on TB treatment and asked to be contacted again by the Counselor.

A follow-up call determined that his 2-year-old child was symptomatic of TB but was being treated by a private provider for a cold and cough. The Counselor was able to explain about TB contact transmission and, again, overcome father’s resistance to having TB in his household. The father agreed to have other child tested by the private provider who had diagnosed the baby with TB. She was also found positive for TB.

Both children are currently on TB treatment. Careline Counselor is continuing calls with their father to answer questions, help him manage their side effects and support adherence to treatment. Father continues to be angry and rude, even when asking for advice from the counselor and following through.
**Case Study 2.**
**Caller: TB Retreatment patient**

Caller as a 38-year-old woman who had been through public system TB treatment and had been told she was cured.

6 months later, she began coughing up blood, went to and was put on TB treatment again by private provider who gave her a prescription for treatment and a DOTS Mitra card to contact the service.

Called and told counselor that she was upset, that she thought she had been cured and resented being on treatment again. Didn’t want to go through this again!

*How would you, the Counselor, handle this caller?*
Careline Case Study 2.
The patient called back several times to talk to the counselor during treatment.

Each time the counselor did a lot of listening and continued to reassure her that the TB was, in fact, curable. That there are many reasons for TB treatment to fail if not administered or taken correctly. Perhaps she was not given the correct dosage or quality of drugs. Perhaps she wasn’t give the right drugs to take. Perhaps there were unintended gaps in treatment.

The patient eventually agreed to go on the prescribed treatment and talked to the counselor regularly. Her fear continued but she seemed to develop a relationship with the counselor who continued to stress that adherence was best to achieve a cure and that the side effects were manageable. Also asked for information on how to not infect her family members.

The Counselor continues to work with this patient.

remained on treatment and still works with counselor.
Testimonial: Dr. H.R. Katti, private provider in Bangalkot, Karnataka

“Careline has made all the difference with my TB patients…the counselors really go the extra mile to help them get through the treatment. These patients do follow up, they do adhere to their treatment.

“And really, I’m so relieved to be able to transfer the treatment education, monitoring and follow-up, that I have no time for, to the Careline counselors.

“For TB, this is a unique and very effective service.”
Disruptive Power of the Careline

• Convenient, no-cost, and patient-centered solution to high TB treatment default rates

• Fills the private-sector DOT supporter gap – keeps TB patients on their treatment

• Disseminates correct information on treatment and treatment management and provides emotional support to support TB patients and their caregivers while on treatment

• Supports active TB case finding and contact tracing in households

• Expands geographic reach of TB treatment support services
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