Experience Using 99DOTS in Bangladesh

I feel so much better now!
If anyone saw me, they would not even believe that I had suffered from TB.

"Sonia" , 18

18-year-old Sonia (pseudonym) gulps down some medicine with a mobile phone in her hand. Once she is done swallowing the pills, Sonia does not throw the blister pack of medicine away; instead she looks into its sleeve and calls a number from her phone where she informs someone on the other side that she has taken her medicine.

Sonia was diagnosed with tuberculosis (TB) and recently completed TB treatment under the 99DOTS initiative. She lives with her mother and maternal grandparents in a small village in Niamotpur upazila of Naogaon district and attends a nearby madrassa. All was well with Sonia until August 2022 when she started losing a lot of weight, would frequently catch colds, have excruciating joint pain and suffer from fever at night. At the recommendation of the Community Health Care Provider (CHCP) at their local community clinic, Sonia gave her sputum sample for testing at the Upazila Health Complex and was diagnosed with TB. Upon hearing the diagnosis, Sonia was very scared about her health and was also concerned about her position in the community, given the stigma associated with the disease. She knew that for her treatment she would have to go to the Directly Observed Treatment Short-course (DOTS) center in person every day to take the medicines. She heard that to be fully cured, she needed to have medication for a long time, for around six months. Sonia was apprehensive about starting her treatment. Commuting to the DOTS center every day would not only be a burden on her wallet, it would also be difficult in the sweltering August heat as well as the chilly winter mornings. Moreover, Sonia was well aware of the social stigma that came as part and parcel of having TB. She was afraid that everyone in her village and locality would know about her disease if she visited the DOTS center every day and she would face ridicules, isolation and ostracization from her friends and society. However, Sonia was pleasantly surprised when she gathered up the courage to make a trip to the nearest DOTS center. The healthcare provider at the DOTS center was extremely supportive, counselled Sonia, and informed her about TB disease and treatment, about the fact that TB is curable and which precautions she needed to take. They also informed her about the possibility to monitor treatment intake using 99DOTS instead of in-person daily visits and asked if she wanted to start her 6-month treatment under this initiative.

Sonia consented to be enrolled under 99DOTS, gave her details and phone number and took home a month's supply of medicine to commence the treatment immediately. Every day for the next 6 months, once she completed taking her pills, Sonia would make a call to the toll-free number provided in the medicine sleeve to inform the DOTS provider about her medicine intake. She relates that at times, she would forget to call, but in that case, she would get an automated SMS from the system reminding her to update. Once a month, Sonia would make a trip to her DOTS center to pick up her next month's supply of medicines. In March 2023 Sonia successfully completed her treatment and is completely cured.

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Digital Adherence Technology 99DOTS

99DOTS is one of the latest digital adherence technologies in TB treatment. It is a mobile phonebased technology, in which persons on treatment can update about their regular medication intake by calling a toll-free number from their registered mobile phone. The incoming phone calls get registered in the system and treatment adherence is updated on a real-time basis. If a person on treatment fails to call/misses a dose, automatic reminders through SMS are sent to them. In the conventional system, a person being treated has to allocate time and money every day to travel to the DOTS center and to take the medicine under the observation of the DOTS provider. Although the medicines are provided free of cost by the government, traveling to and from the DOTS center regularly has a monetary cost that a person on treatment needs to bear. Additionally, this travel often leads to missed work, which may lead to increased financial costs or missed home responsibilities. Visits to the centers can also trigger stigmatizing experiences. This creates irregular adherence to TB therapy which may culminate in disease relapse and drug resistance. Direct observation of medication intake introduces challenges for the providers also. In some areas, DOT providers need to undertake frequent/daily updates from Community Workers on medicine intake by persons on treatment as they travel to their house throughout the treatment.

Digital Adherence Technologies have been proven effective in improving TB treatment adherence in similar low-resource settings, help to remind persons on treatment to take their medications, facilitate digital observation of pill-taking, compile dosing histories and triage persons on treatment based on their level of adherence, which can facilitate the provision of personalized care by the TB program based on individual risks.



99DOTS under introducing New Tools Project

I like this approach of monitoring my TB treatment.

There is a lot of stigma associated with this particular disease. Many people take it negatively. With 99DOTS, no one can know about my disease or embarrasses/ stigmatizes me. To collect medicines from the DOTS center, there is a transport cost involved daily. This cost is not incurred in this new approach. Many times, if I forget to call amidst my busy schedule, I get a reminder message immediately.

"Sonia", 18

In March 2022, icddr,b-led USAID's Alliance for Combating TB in Bangladesh (ACTB), co-supported by the Stop TB Partnership under the introducing New Tools Project (iNTP) funded by USAID, launched this innovative technology to monitor remotely in real time, the treatment adherence of persons on treatment. The scale-up of this activity in 323 DOTS centers across 16 districts spanning 4 divisions of Bangladesh (Dhaka, Rajshahi, Sylhet and Chattogram) is built on a successful pilot activity, which was the first of its kind in the country, in five icddr,b-operated TB Screening and Treatment Centers (TBSTC) of Dhaka city through the TB REACH Wave 6 project in 2019. With technical support from Everwell Health Solutions and its system integration with a local telecommunications partner, ADN Telecom, USAID's ACTB is implementing this intervention. TB and Leprosy Control Assistants (TLCA) and support staff of the NGO partners' network from the DOTS centers orient the persons with TB and enroll them into the system. Through introducing and scaling up this digital adherence monitoring system, USAID's ACTB aims to digitalize the anti-TB treatment adherence in Bangladesh and assess the feasibility and acceptability of implementing digital adherence monitoring system in urban and rural areas of the country.

The initiative has led to reduced burden for the persons on treatment as unlike the traditional DOTS, instead of traveling to a center for every dose, with 99DOTS, they can take their medicine from their home/workplace while providing real-time evidence of it, reducing the burden of cost, time and stigma that they may have faced, had they taken the traditional route

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99DOTS providers are all trained and oriented in using the platform as well as for counseling people on treatment. As related by Sonia, counseling at 99DOTS enrollment encourages persons on treatment to use the tool and gives them an understanding of the importance of treatment compliance and the benefits. In this regard, another person receiving treatment from Chattogram vouched this service saying, "I occasionally get calls from the DOTS center where they ask about me, my medication, and the benefits of this approach. This increases my enthusiasm in adhering to the rules. I think people who are taking their TB medication will not have the problem of missing doses

Most DOTS providers have also taken this initiative positively as it eases their monitoring process. The initiative allows providers to have a real-time transparent view of adherence of persons receiving treatment, which enables accurate detection, understanding and response to irregularities. Implementation of 99DOTS also helps in reducing the number of missed doses, loss-to-follow-up and recorded deaths.

In this light, a DOTS provider from Habigani district shares: "With 99DOTS, we are remotely informed if patients are taking their medicines properly. If a patient does not call, I can very easily and quickly find out the reason - whether they are okay, if they have forgotten, and what their health status is. Since an automated message is sent to the patient if they don't call after intake of medicine, there is no possibility of forgetting (to take the medicine and also to call and inform). The number of people lost to followup is reduced with this approach. I think this initiative will help the government in saving a lot of time and monetary resources."

This opinion is shared by many other providers across the country, such as the TLCA working in a DOTS center in Rajshahi who says, "I can now monitor the patients from the DOTS center and confirm if they have taken their TB medicine. If I see that someone has not called. I immediately understand and contact the patient to confirm status of medicine intake and remind them to take it."



Challenges and Limitations

The picture is, however, not all rosy, and as with any new initiative, 99DOTS comes with some challenges as well. Although the system has been functional from a technical perspective, there have been challenges in field implementation of the technology. The NTP supplied anti-TB drugs in different sizes of strips at different points in time during the project period. The lack of information in advance about the stock status and supply of drugs with various strip sizes and unavailability of specific medicine sleeves according to the strip sizes, combined with the constant shipment delay of sleeves from India, hampered the implementation of 99DOTS. The field implementation team tried to mitigate this challenge, to some extent, through redistribution of sleeves at local level and reusing of sleeves by counselling the persons on treatment, where possible. This issue regarding the mismatches between medicine sleeve and strip sizes was a huge challenge for both providers and people on treatment, who have expressed their frustration with it. A provider from Dhaka lamented on this issue and said that the difficulties in understanding the technical know-how of 99DOTS was a challenge for some persons on treatment, especially among elderly group of people.

The medicines and sleeves do not match. When the sleeves are there, then there is a different brand of medicine.

Most of the time there is a mismatch between sleeves (envelope) and blister. This causes many problems to us as well as to the patients. It's better if both are always matched

A provider from Dhaka

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The randomly-changed last 2 digits of a toll-free number are revealed when people remove pills from the blister pack each day. Some were bemused due to the fact that they have to use a new number every time they call. One person receiving treatment from Dhaka says, "The medicine sleeves (envelope) number is different every day and because of that it seems like trouble."

Insufficient knowledge about using mobile phones, and lack of ownership of mobile phones are also key barriers to successful adherence of this digital adherence technology scheme. Many people do not have the technical expertise in using mobile phones, some persons on treatment use their family member/relative's mobile phones, and some may not even be able to send or read received text messages. This issue has been reported as a barrier by many DOTS providers, such as this provider in Sylhet who says, "Since 99DOTS is a new system, it is slightly difficult to implement. Most of the patients living in rural areas are not capable of operating mobile phones. Also, there are problems such as no network and electricity, which further discourages patients and their attendants from utilizing this platform."

Moreover, especially in rural areas, poor network coverage has also been reported as a major problem by several persons receiving treatment, as this person with TB from Sylhet explained, "Sometimes, due to disruptions in the mobile network, I cannot make the calls after taking my medicine."

Even though making the call to the toll-free number is free, people receiving treatment need to have a minimum balance in their mobile phones to be able to place the call. Often times, many people from low socioeconomic conditions, do not even have that minimum balance in their registered phones, which prevents them from being able to

comply with the 99DOTS expectations for daily call-ins. A provider from Sirajganj identifies this as a major deterrence in the system and says, "If the patient's mobile balance is zero, then they can't call to the 99DOTS hub and is thus not recorded. So, it would have been better if the system could allow patients to call even with a zero balance."

In addition, local mobile phone providers have packages that offer purchase of minutes without topping up the mobile balance. Within the scheme, even if they have sufficient minutes but inadequate balance, callers cannot place their calls to the 99DOTS hub. Several people have felt that this is a barrier and one person on treatment from Bangshal expressed her frustration regarding this issue, "If we don't have enough balance on our mobile phones, then we have to spend money to top-up. Nowadays, we sometimes buy the minutes bundles that are offered – but this is not accepted for 99DOTS calls and we end up not calling. This is a hassle for me."

Conclusion

Non-adherence to anti-TB treatment poses a significant threat to a person's health and results in increased transmission rates and costs to TB programs. Medication intake, therefore, needs a strong monitoring system to improve treatment adherence, and 99DOTS can be an effective approach to mitigate this monitoring challenge while also have the strong benefits of reducing the burden upon people being treated for TB as well as the health system. However, some significant challenges in successful field implementation of 99DOTS, especially in low socioeconomics and rural settings, remain. But despite the challenges in its implementation, the benefits of 99DOTS in terms of reduced costs and convenience are very encouraging.

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For more information on the introducing New Tools Project, visit:

https://www.stoptb.org/accelerate-tb-innovations/introducing-new-tools-project





