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In this issue:

TB/HIV treatment literacy; by Theo Smart *page 2*

- Like the infection, poor knowledge about TB is endemic
- Myths and folklore
- Blaming the person with TB
- The lack of advocacy and activism
- Activities to create TB advocacy, educate and empower the community
- ACSM in practice
- Treatment literacy for treatment activism
- Moving ASCM and treatment literacy forward together
- Resources

TB/HIV treatment literacy

By Theo Smart

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"I can hear all this talk about germs, but I tell you the reason my daughter is coughing is because her uncle, who is jealous of the fact that she went to get education in Fort Hare University, sent his impundulu to kick her in the chest at night and that is why she is coughing blood. Truly, that is why."

A woman speaking at a Treatment Action Campaign (TAC) workshop in Ngqurha in Eastern Cape (excerpted from *ARVs in Our Lives*). (An impundulu is a paranormal creature, a "lightning bird" associated with witchcraft in some southern African tribes).

Overview

Knowledge and attitudes about disease, treatment and the person with the disease vary widely due to culture, religion or traditional belief systems, access to education, information and other factors. And when it comes to TB, such limited or inaccurate information has a number of serious consequences.

Appropriate health-seeking behaviour is delayed when people fail to recognise the symptoms of the TB — and levels of denial are high especially when those with the disease are stigmatised by a misinformed community. These barriers to rapid diagnosis and treatment result in an increased risk of transmitting TB to other members of the family or community — not to mention poor health outcomes in people with TB.

Meanwhile, misunderstandings about treatment have been linked to poor adherence and loss to follow-up, increasing the chances of drug resistant TB (DR-TB) and again, treatment failure and death.

Another consequence of inadequate information, fear, stigma and mistaken ideas about the respective rights and responsibilities of the person with TB vis-à-vis their healthcare providers — perhaps inadvertently reinforced by TB programmes relying on directly observed therapy (DOTS) supervised by healthcare workers or volunteers (see below) — is the difficulty in mobilising the community to take action against the disease. This has limited the TB-affected community's engagement with the health system and its interest and willingness to demand better quality health services for TB from the government (including, for example, TB infection control in health facilities).

The type of sophisticated science-based treatment activism seen in the HIV field — which has changed national and global health policy — has been rare in TB or even HIV-related TB. Until quite recently, there have been pitifully few TB/TB-HIV treatment activists.

But over the last decade, there has been a dawning realisation that, together with the HIV epidemic, the failure to engage, educate and empower the community has contributed to the failure of TB control in many resource-limited settings, particularly Africa.

Moreover, the TB research field had stagnated (failing to produce any significant new drugs or diagnostics for decades) in part because of the lack of TB research advocacy.

Again, this stood in marked contrast to how an informed and impassioned community had mobilised the world to respond to HIV/AIDS — even the once-neglected AIDS epidemic in Africa. HIV activists had worked to expedite the development of effective treatments and diagnostics, lowered the cost of treatment for resource-limited settings, demanded essential HIV services from the

government and developed community based responses providing other complementary support services.

In the meantime, a growing number of studies had begun to demonstrate that community-based support for TB treatment might work as well if not better than directly observed therapy in settings as far-flung as Ethiopia and Nepal.^{1, 2, 3}

With the launch of the Global Plan to Stop TB 2006-2015 (LINK), the STOP TB Partnership and World Health Organisation proposed a new approach: involving the community in TB control. The Stop TB Strategy called for the engagement of "people with TB and affected communities to demand, and contribute to, effective care. This will involve scaling up community TB care; creating demand through context-specific advocacy, communication and social mobilisation; and supporting development of a patient's charter for the tuberculosis community."

The Global Plan recommends "addressing social and cultural barriers to care [by] engaging former TB patients and TB support groups to advocate for services and encourage community mobilisation" and "providing opportunities for meaningful involvement of patients and communities in increasing awareness, demanding high-quality services, supervising treatment, and reducing stigma."

Advocacy, communication and social mobilisation (ACSM) are sometimes overlapping activities tailored to specific audiences to increase awareness, educate and spread key messages about TB, and to influence attitudes, behaviour and policy. According to the Global Plan, the success or failure of its efforts would "rest on the ability of ACSM efforts to generate political, social, and behavioural change at all levels." Consequently, a large number of tools and aids have since been produced to help programmes develop effective ACSM for TB (some of which are described below).

Notably, the Global Plan also stressed the importance of linking TB advocacy with other global social movements, especially the HIV/AIDS community. Activists with a background in HIV brought a critical perspective to the effort to empower the community about TB and have helped to develop treatment literacy programmes.

In *ARVs in Our Lives*, from the Treatment Action Campaign (TAC), **treatment literacy is defined as understanding the major issues related to an illness or disease — such as the science, treatment, side-effects, and guidelines — so that the patient can be more responsible for their own care and will demand their rights when proper care is not available to them.**

ACSM employs a variety of approaches (including information, education and communication (IEC)) to encourage behaviour change, while treatment literacy is about helping people understand the science well enough to make the best decisions for their own health, but both approaches could be complementary.

Not every effort is successful, so monitoring the effectiveness of activities, campaigns and IEC is essential to be certain that these activities have the greatest possible impact— especially where literacy levels are low and misinformation, myths and stigma about TB are quite entrenched.

Like the infection, poor knowledge about TB is endemic

Studies show that knowledge levels about TB can be quite low in many parts of the world — even among health workers.

For instance, an Indian survey of over 200 nurses in New Delhi found that only 40.2% of TB nurses and 10.7% of general hospital nurses had a satisfactory knowledge regarding various aspects of tuberculosis (defined as answering 75% of a multiple choice questionnaire correctly).⁴ Only 56.5% of the general nurses knew

that a mycobacterium (mTB) was the cause — 36% thought a virus caused TB. Most did at least know that transmission was through inhalation — however, only around 20% of the nurses knew the proper duration of treatment.

Another study among private general practitioners in New Delhi found that only 12% recommended sputum examinations to diagnose TB.⁵ Worse, 187 practitioners in the study were using 102 different TB treatment regimens — only 29.4% were using the regimen recommended by the national TB programme. (Note both these studies were conducted over 10 years ago, and the national TB programme in India has since launched a massive training campaign to standardise care and integrate private practitioners into its system in a public-private mix.)

Similar findings have been reported more recently in a study in Java, Indonesia, where only 40% of the nurses (general) knew the cause of TB, few could mention complications of TB and none knew the duration of infectiousness after start of treatment.⁶

In Kenya, a survey of private practitioners caring for people with HIV/AIDS concluded that “none of the interviewees had appropriate knowledge on all the areas of diagnosis, treatment, case recording, and follow up... Most doctors were not aware of the correct diagnosis and treatment of TB and many used unrecommended treatment regimes.”⁷

At this year’s Union World Lung Conference, a poster reported that nurses in Russia believed that in addition to airborne transmission, TB might be transmitted via “objects of hygiene, linens, eating utensils, kissing or intercourse.”⁸

“I went to a training in the community where I found somebody from the Ministry telling people that you can catch TB by sharing utensils,” said Carol Nyirenda, a TB/HIV activist from Zambia, speaking at the 2008 Union World Conference on Lung Health. “And some of this information actually comes from the healthcare workers themselves who don’t have the correct information.”

All of this translates to even lower awareness among people with TB, because, according to a study by Wandwalo and Mørkve in Tanzania, most TB patients learn what they know about their condition from their healthcare providers (and other TB patients).⁹

The study was conducted in both rural and urban settings in the Mwanza region of Tanzania. Only 30% of 296 TB patients interviewed had what the authors considered ‘satisfactory’ TB knowledge. This was based on answering correctly five out seven questions about the symptoms, cause, transmission, prevention and curability of TB, duration and the side effects of TB treatment.

Although 87.5% knew at least one symptom of TB (mostly cough), less than half knew the correct cause. Only about half knew how long treatment would last. The authors noted that only 10% had an educational background higher than primary school — and education levels were significantly correlated with TB knowledge.

In a survey of 85 people with TB (or their parents) in the Eastern Cape of South Africa (86.9% of whom said they thought that they were well informed about TB), most believed that TB was caused by exposure to cold (42.4%), contact with a TB patient (25.9%), smoking (24.7%) or alcohol abuse (20%).¹⁰ Only 2.4% knew that TB was caused by contact with infected sputum.

Similarly, in one recent survey of 226 nomadic pastoralists with TB in Ethiopia, almost two-thirds were found to have poor biomedical knowledge about TB.¹¹ The survey involved the use of a structured questionnaire with 12 questions about the cause, transmissibility and curability of TB and their awareness that it could be treated free of charge (the cut-off between a good and poor knowledge was answering five of the 12 questions correctly).

Poor knowledge about TB was associated with long delay in seeking appropriate medical care: with a median delay of 60 days,

and a mean delay of 130 days. One patient took almost five years to come in for care. Notably, the majority (87%) first sought care from traditional healers.

Myths and folklore

Lack of correct knowledge is only one of the challenges faced in communicating and educating about TB. Perhaps a more serious and entrenched problem is the abundance of myths and folklore surrounding tuberculosis.

Several studies have probed deeply into people’s ideas about the causes and nature of TB. In the Tanzanian study mentioned previously, Wandwalo and Mørkve noted that misconceptions about cause and transmission of TB were common among the patients, with some thinking it was inherited, passed on through blood or faecal-oral route — while other patients had more ‘superstitious’ beliefs.¹²

“Our study shows that patients’ understanding or knowledge of the disease is rather superficial—likely to be influenced on one hand by traditional ways of thinking, and on the other by apparently modern but often incorrect opinions,” they wrote.

One common superstition is that TB, HIV and other diseases can be caused by bewitchment — and this is usually related to where a person first seeks care. 10% of patients with TB in one report from a rural district in Kwa-Zulu Natal, South Africa, said that they had gone first to traditional healers who blamed their disease on bewitchment or someone having poisoned their food.¹³

Likewise, many evangelical churches attribute disease to ‘sin’ or lack of faith, or witchcraft — and claim that people can be cured by visiting a faith healer.

According to this post at the Health Dev forum from Ssanyu Teopista, a Healthdev network correspondent, “Some pastors tell people that there is nothing to worry about TB and HIV because God can heal those diseases even without any medical treatment. Such pastors claim they can cure the worshippers with just a touch. The next time you come to testify, you must give heavily in terms of tithe or even sacrifice your assets to God through them.” Of course, “many worshippers end up dying because they shun treatment thinking that they are okay.”

“Praise the Lord, brethren,” said one lady at one of the big churches in Kampala, Uganda. “I was suffering from HIV/AIDS and at the same time I went to test for TB because doctors advised me to do so. Again I was TB positive and doctors told me to adhere to my drugs and as you are aware that I came here to the man of God to pray for which he did so that I can get healed and indeed he prayed for me. I went back home few weeks later I tested negative and even TB wasn’t there.”

How common such beliefs and actions might be is unclear — according to a study conducted in the 1990’s by Edginton et al, the answer may very well depend on how one asks the question.¹⁴

When over 300 people with TB from the Tsonga and Northern Sotho tribes in the rural Tintswalo district (in what is now Limpopo Province) were interviewed by trained community workers one-on-one using open-ended questions, they rarely volunteered holding traditional (or cultural) beliefs about the cause of the disease, but when given closed (or multiple choice) questions, two thirds of them agreed with a cultural explanation for their illness.

Moreover, in focus group discussions, (with 160 people in 14 groups selected to represent a cross-section of the community, including two groups of TB patients), people were far more likely to acknowledge holding traditional beliefs about the nature of disease and its treatment.

In this particular case, the community described two forms of TB. One was a ‘Western’ form, with the classical symptoms of coughing,

sometimes with blood, weight loss and night sweats, that participants believed to be spread through close contact with sufferers (but this included sharing food, drinks, cigarettes and eating utensils) working in unhealthy environments (like mines) or having an unhealthy lifestyle (drinking alcohol excessively, cigarette smoking and poor nutrition).

Some of these ideas are not entirely off-base, since social factors such as poverty, malnutrition, working in unsafe environments and living in overcrowded inadequate housing can all contribute to the spread of TB. But, “there was ambivalence about a germ being the cause,” Edginton et al wrote.

The second form of TB participants described was almost identical to ‘Western’ TB but with a couple of other symptoms, such as swelling and ‘shyness.’ This was known as *tindzaka* (or *mafulari* or *makhuma*) in the local languages. *Tindzaka* was believed to be caused by “breaking the traditional rule that states that members of a family in which a death has occurred must abstain from sex during the period of mourning prescribed by elders,” Edginton et al wrote. This sort of infraction included, for instance, even eating food prepared by a woman who had had a miscarriage.

‘No doctor is able to cure this,’ one respondent in the focus groups said. In fact, participants said failure to consult traditional healers within the first few weeks of the illness would result in death. Notably, most of the TB patients in the focus groups said they had visited a traditional healer before coming to hospital (though only about a quarter of the TB patients individually interviewed had admitted to this).

Unless traditional healers have been trained to recognise the symptoms of TB and to refer the patient immediately to the health system, this leads to delays in health-seeking behaviour, further spread of disease and potentially, severe illness and death. Other studies in developing countries have identified similar beliefs.

Blaming the person with TB

Inevitably, a disease that is surrounded by ‘magical’ thinking, with causation attributed to individual breaches of longstanding social codes, has also been seen as a judgment in rapidly changing societies on people engaging in new or transgressive behaviours.

For instance, surveys conducted in urban and rural Zambia by Bond & Mathur found that TB was generally attributed to social and/or sexual offences.¹⁵ “Often the inference was that people were pre-disposed to falling sick with TB because of their social transgressions (smoking cigarettes and marijuana and drinking alcohol, and in particular because of sexual transgressions,” they wrote.

Such a belief system could actually be more stigmatising than thinking that TB is caused by a curse, because bewitchment can happen to an innocent person (some cultures even think you can get TB by accidentally stepping on a traditional medicine or something sacred) but people who have TB due to ‘sin’ are seen as being to blame for their disease.

“The stigma and guilt associated with TB in some cultures makes it difficult for people with TB to share their problem,” Edginton et al wrote. And with the spread of HIV – known to be transmitted during sex – people now believed in a new and doubly stigmatised form of ‘HIV-related TB.’

“TB patients are treated badly because they used to misbehave and should now solve their own problem,” according to one person interviewed in another report from Zambia, in which TB was highly associated with HIV.¹⁶

Since TB and especially HIV-related TB, is “rooted partly in judgment, blame and shame... TB-HIV stigma has serious

implications for TB outcomes and for management of HIV,” wrote Bond & Nyblade.¹⁷

Other common misperceptions or false beliefs pertain to treatment. For instance, Edginton et al reported that there was a belief that sexual contact while on TB treatment could harm one’s partner – and many focus group participants said that they would rather discontinue treatment than abstain from sex.¹⁸

In addition, the community as a whole believed that receiving directly observed therapy (DOTS) or treatment support from a stranger would simply be unacceptable: “It is difficult to receive treatment from a stranger. I will be bewitched.” Importantly, however, they would accept treatment support from someone they knew.

In other studies, people have reported believing that going on treatment will increase their appetite – a disincentive to adhere for those without food security. In a study in Ndola-Zambia, 80% of TB patients who defaulted on treatment said it was because they didn’t have enough food.¹⁹

Sometimes conflicting ideas can exist about the same treatment. For instance, in the Thibela TB study of isoniazid preventive therapy (IPT) in the mines of South Africa, rumours were spread that IPT affected sexual libido – but some were convinced it increased libido while others thought it could cause impotence.²⁰

“Health workers all too often are not aware of the beliefs and attitudes about tuberculosis of the communities that they serve, nor of the behaviour concerning illness expected by local custom,” wrote Edginton et al. “If health workers took time to find out about local beliefs and practices about TB (and other health problems), they could begin to understand their patients better.”

The lack of advocacy and activism

Programmes and healthcare workers that don’t understand people affected by TB are, of course, unlikely to engage or empower or to mobilise the affected community, or generate advocacy.

It wasn’t always this way— there was a great deal of TB activism in Europe and the UK a hundred years ago when it was seen as a disease that could affect anyone. But that was before there was treatment or TB ‘control.’ Activism quietened down with the development of curative treatment for TB in the middle of the 20th century – and TB was no longer a chronic terminal illness.

Matters did not improve with the initial DOTS strategy. “The DOT strategy when it was introduced back in ’93 didn’t mention community involvement at all. Following that, the WHO had the Community TB Care Project which was first published in 1999 – but that wasn’t really community involvement, that was about communities being providers of TB care and didn’t really address capacity building advocacy or activism within that concept,” said Dr Alasdair Reid of UNAIDS at the 2008 Union World Conference on Lung Health in Paris.

Of course, DOTS is more than just ‘directly observed therapy’ – its other elements provide the bedrock for TB control. However, supervised treatment (without education) is inherently belittling. According to TAC’s *TB in Our Lives*, “The DOTS model has its roots in paternalistic approaches where the public health official makes the decisions for the patient and the community... TB patients treated through the DOTS programmes can become dependent and not take responsibility for their treatment and health.”

HIV activism provided a different model.

“With the AIDS movement, there was this dismantling of the idea of science as something that belongs to doctors and researchers and scientists,” said Paula Akugizibwe, of the AIDS Rights Alliance of Southern Africa also at the 2008 Union World Conference. “This was

one of the most important steps to mobilising communities around HIV and we're trying to apply the same things to TB, now."

"It's one of the strangest things in history that a group of patients, living with a new disease, not only created a series of political interventions to demand healthcare but also created a demand for research and a right to research," said Mark Harrington of the Treatment Action Group and a veteran of the HIV/AIDS treatment activist movement at a 2008 meeting on engaging the community in TB research.

He went on: "Once we realised that the scientists were actually crucial allies if we could start figuring out how to talk a common language, we could work together. We could help to frame the questions, they would generate the evidence and then together we could take the evidence from those studies to policy makers and get them to actually change policy."

Activities to create TB advocacy, educate and empower the community

The idea of trying to form a similar partnership between TB-affected people and communities and the TB establishment only emerged in the last decade, with a handful of activists such as Harrington becoming involved at the international policy making level. The STOP TB strategy was then revised to emphasise community engagement, and a focus on TB-HIV and drug resistant TB.

In 2005, an Advocacy, Communication and Social Mobilisation Working Group was established to help mobilise political, social and financial resources in support of the revised strategy. The ACSM Working Group was tasked with helping to sustain and develop a global TB movement, and assisting countries to develop ACSM activities supporting TB control. To this end, quite a few materials and tools have been developed, some of which could be quite useful once one gets past the social marketing jargon (see *Resources*).

Essentially, ACSM are a number of activities that evidence suggests could affect 'behavioural change at the societal and individual level.' What that really means at the country level is that the interventions should lead to improved case detection and treatment adherence, reduce TB and TB-HIV stigma and discrimination, empower people affected by TB and help mobilise political commitment and resources for TB control.

Although activities are often cross-cutting, 'advocacy,' 'communication' and 'social mobilisation' are three distinct sets of activities with a somewhat different audience and purpose.

- Advocacy targets policy makers, thought leaders and journalists, and includes activities aimed at getting political and financial support for TB control (including all the ACSM activities).
- Communication may use a variety of media (newspapers, TV, radio) and interpersonal communication to increase awareness of and knowledge about TB in individuals or communities in order to change behaviour, such as health-seeking behaviour or discrimination against people with TB.
- Social mobilisation is supposed to bring together all the potential partners in society to engage in TB advocacy, improve TB services, and expand community support for the fight against TB.

ACSM in practice

A number of poster presentations at the 2009 Union World Conference on Lung Health nicely illustrated how some countries have put ACSM into practice, and crucially, how they are also evaluating their ACSM programmes' effectiveness.

Some common initial steps mentioned include engaging the key national players in a partnership and developing a ACSM working group and plan; starting sensitisation efforts for advocacy to secure

political commitment; and performing some initial research — a needs assessment and a situational analysis such as a 'knowledge, attitudes and practice' (KAP) survey — to establish baseline evidence to help plan, implement, and evaluate the ACSM work.

Like the studies mentioned earlier in this article, these surveys should assess current awareness, knowledge gaps, cultural beliefs and behaviour related to TB (see *Resources* for a guide on conducting KAPs).

BRAC, an NGO operating in Pakistan, has helped the national TB programme launch an ACSM programme.²¹ This began by orienting other potential partners on ACSM and advocacy efforts with policy makers, health professionals and media personnel. Baseline situational assessments were performed to assess TB awareness, health seeking behaviour and to assess which methods of communication would be most effective. Then a mass media campaign was launched with TV dramas, commercials, public service announcements, radio commercials, popular theatre with folk songs, etc.

Social mobilisation efforts involved cured (or close to cured) TB patients, orientations with village doctors and pharmacists, general practitioners, local government officials and religious leaders, school students, girl scouts and other NGOs. IEC materials have been developed and field tested. Monitoring and evaluation is ongoing and routine.

Several posters described Mexico's ACSM effort, 'Solucion TB', which is working in collaboration with the national TB programme in thirteen priority states.²²

After a six-month needs assessment, a capacity building project (empowering DOTS), health staff training on ACSM and developing ACSM plans, Solucion TB launched the country's first large KAP survey (which is still in progress) and a stigma and discrimination survey to validate TB-HIV stigma instruments adapted for Mexico.^{23, 24} The programme also implemented ACSM activities, including advocacy presentations at both state and municipal levels, as well as a TV, radio and print media campaign.

One of Solucion TB's interesting cross-cutting interventions is 'Voices and Images' which has engaged people with TB to document (with disposable cameras and diaries) their lives and challenges.²⁵

In addition to empowering participants, a gallery of their images has been produced and presented to policy makers to inform them about the human impact of disease, and exhibited in a variety of forums to increase awareness and reduce stigma. Some key themes that have emerged in their work is the need to improve the quality of health services, and the need for integrated services including nutrition and mental health services to help manage depression associated with having TB.

According to one of the Solucion TB posters, the programme has stressed the meaningful involvement of people and families affected by TB and integrated a 'person-centred' approach into state and district TB programmes.²⁶

"ACSM efforts cannot be successful without engaging persons affected by TB, not as recipients or victims or even as patients, but as decision makers, advocates, peers, highly valuable resources and keys to ultimate success," the authors wrote.

The poster also reported that, within the last four years, average case detection rates in the thirteen target states have gone up from 75.8% to 98.7%, and cure rates from 75.3% up to 84%. But the authors noted it is difficult to pin this overall success on any one intervention: "any one project or initiative, regardless of how successful, is only part of the solution."

In Kenya, a national working group was established and NGO partners were trained on ACSM activities.²⁷ In 2007-8, a mass media campaign was launched using television, radio and

newspapers; a community drama programme was conducted in a variety of venues to spread TB messages; TB community-based health workers were trained; and a school programme was started to teach children about TB.

Cross sectional surveys were conducted to assess the impact of the interventions. One involved over one thousand school children. Although levels of knowledge were uneven on different questions, 91% correctly identified that TB was airborne, 90% mentioned cough as the main symptom. 36% said that they knew somebody with TB signs and symptoms, and 94% said that they would refer people with such symptoms to a health facility for screening. (Note, at IAS 2009, Dr Helen Ayles of ZAMSTAR, a study to increase community based TB case detection, described a similar project targeting school children, which encouraged them to refer adults they know for TB screening.)

The other Kenyan survey included 1200-1300 adults (in baseline and follow-up assessments) in 13 districts, and although the baseline was not described in the poster, it reports a very high level of post-intervention TB knowledge, with 85.9% knowing that TB transmission is airborne, for example.

The most accessible communication media was reported to be radio, with the study authors recommending the use of local vernacular radio stations. Nevertheless, the researchers also noted that exposure and access to different media varied greatly: "the various channels for ACSM should be maintained to reach diverse audiences," they wrote, adding that both TB message dissemination and monitoring and evaluation of the ACSM programme need to be continuous.

In a poster from South Africa, TBFree (a joint venture between the South African Department of Health, Sanofi-Aventis and the Nelson Mandela Foundation) reports having trained over 25,000 community DOTS supporters in the last five years and launching an ACSM campaign, with adverts on TV stations, mainstream radio, and print, as well as door-to-door and school campaigns, advertisements in buses and taxis, and recently a national TB awareness road show with theatre in local languages.²⁸ The road show has reached over 30,000 people, screening many for HIV (747 people) and TB (4318 people).

The poster reports that TBFree has also found that radio is the most widely used medium — especially since many cannot afford a TV or the electricity to operate it. Local language broadcasts in either medium attract the most interest. As for newsprint, free newspapers have been found to reach a much wider audience.

Another common activity is the development of IEC materials, but a poster from ICAP in Tanzania described how evaluations are necessary because these aren't always as effective as one would hope.²⁹ Working with the National TB and Leprosy Programme, ICAP and PharmAccess developed posters and other materials on cough hygiene, TB intensified case finding and infection control. These were field tested in a few facilities before nationwide scale-up.

During this assessment, it was found that the materials were not always being displayed correctly: for instance, posters for health workers were put up in the waiting areas. Meanwhile, clients in focus group discussions told the researchers that posters targeted to people with TB were not easy to understand, and there was often no one there to explain what the posters meant. They noted that the posters contained multiple messages and the images were not realistic.

So the materials were formally revised to simplify the messages, use images that capture the audience's attention, and improve the Swahili translation. These materials are now distributed along with an explanatory guide and a better onsite orientation on how to use

them. In addition, ICAP has trained volunteers living with HIV/AIDS to conduct educational sessions in the waiting areas and wards.

There was also a discussion at the Union World Meeting in 2008 about the limited usefulness of flyers and pamphlets for IEC.

"We found that when developing IEC material in a country like ours where there are literacy challenges, you would later find those flyers scattered all over the streets because people find it difficult to read, at some point it becomes boring and whatnot," said one audience member who worked for TBFree. "Then we started branding taxis and printed messages on everyday things that people use so that at least that message stays with them and it's at a place where they are."

Treatment literacy for treatment activism

While ACSM activities are ongoing, community-run treatment literacy campaigns are needed to truly empower people affected by TB to take charge of their own health.

"The difference between treatment literacy and 'information, education and communication (IEC)' — where you communicate messages to people and you try to encourage behaviour change — is that while treatment literacy is also ultimately directed with seeing end results, treatment literacy actually empowers people to start making those realisations for themselves," said Akugizibwe at the Union World Conference in 2008. "So instead of just telling someone that they should adhere to the treatment, you enable that person to understand for themselves why adherence is important. So that message becomes something that they can own and can design in a way that will be easily understandable for other people."

"With HIV, treatment literacy has proved to be very effective and has changed medicine or in medical practice," TAC's Boniswa Seti said at the South African TB meeting in 2008. "People like myself who do not have a degree in medicine would be able to understand the whole science of HIV and be able to disseminate that information to people on the ground. We have to expand treatment literacy - not only in the field of HIV but also in the field of TB... We need to engage clients with TB themselves so that they understand exactly the impact of having to finish their treatment so that there is no chance of developing drug resistance to the medication that they are taking. This involves] breaking down the science to the level of the man in the street: what is the medication that I'm taking? Why is it good for me? How can I actually continue with the treatment so that it works and then see its benefits?"

This requires a much more involved process of education, with workshops, and ongoing education and mentoring with peer educators. It may begin at quite a basic level. For instance, TAC's TB in Our Lives describes how different people understand disease, and that people have to be ready to learn new terminology:

"Like when we learn about HIV, there are lots of new words to learn with TB and TB treatment. Some of these are difficult. We can make up songs and games and have fun learning the words in our workshops."

"I remember our first treatment literacy workshop and I saw the level of detail and in-depth science that they expected us to start understanding and applying," said Akugizibwe. "And I come from a science background but even for me, I was just like, "These people are crazy!" We were [talking about] viral life cycles, chemokines and reverse transcriptase and the vast majority of us in the room had absolutely no grounding in science. And then they talked to us about role playing and we were all going to be different parts of a cell and interact with each other to demonstrate the viral life cycle..."

"Role plays are very critical because they simplify the science," said TAC's Johanna Ncala at the Union World Conference in 2008. "Sometimes it is very difficult to explain science and we have to be

careful not to simplify science too much because you then lose the meaning of the science. Role playing makes it easier. And then the songs are very powerful - as South Africans we love singing - and so we would sing and talk about TB. There are songs for TB, songs for ARVs and also songs for other issues that are coming up in our communities. And finally, comes sharing life stories."

TAC began developing its treatment literacy programme with support from activists in the US (TAG) and UK (HIV i-Base), who came to South Africa to provide training on the science of HIV, and now, TB. The organisation then hired several staff members including treatment literacy coordinators at the national and provincial levels, along with treatment literacy practitioners and trainers who act as educators in the clinics. They have developed a number of resources and training guides (such as TB in our Lives) and worked with partners to develop videos they use in trainings.

Over time, many treatment activists become increasingly sophisticated. Globally activist organisations involve clinicians and researchers in their ongoing education.

At the CREATE meeting on engaging the community in research, Wim Vandeveld of the European AIDS Treatment Group described their treatment literacy process. "We try to maintain this continuous education of our members via lectures or training sessions given by researchers on a specific topic. For instance, before a recent meeting about a drug that may cause renal toxicity, we had a training session on renal toxicity."

"If you look at the level of knowledge and the level of confidence [of some activists] in the science of TB and of HIV now, the level in which they are able to engage with policy makers and with programme officials on this, it's really quite clear that science is not something that needs to be restricted to the domain of scientists and clinicians. Communities can really grasp it and can really apply it," said Akugizibwe. "It's very empowering, this understanding of science... it leads to the ability to engage in policy discussion... to become active players in the health response... and creates the capacity for communities to be engaged in monitoring that advocacy around programmes."

Moving ASCM and treatment literacy forward together

While most of the ASCM interventions can help elevate the level of awareness and discourse and advocacy for TB in a general way, treatment literacy work is essential to develop the sort of empowered activists who can become important allies for TB programmes and to support the implementation of TB-HIV collaborative activities. ACSM plans need to support civil society to develop treatment literacy programmes and make sure that these efforts are adequately funded.

At the same time, as many ACSM tools are targeted to national health departments, there is a danger that, despite their aim to empower the community, ACSM programmes could wind up being a paternalistic effort. There is also a danger that the focus will be on achieving TB programme indicators, losing the ultimate objective, improving health of people and communities affected by TB. Civil society and activists need to make certain that they are included in their local ACSM working groups, because community engagement is essential for the success of ACSM.

Resources

WHO STOP TB Department

<http://www.who.int/tb/en/>
Global Plan to Stop TB (English)

Resources from Treatment Action Group (TAG)

TB Activist Toolkit - TB Basics: Provides activists with fundamental information about tuberculosis in order to strengthen advocacy and scientific literacy around TB and TB/HIV. Includes [facilitators Notes](#) and [PowerPoint Slides](#).

[TAG's TB/HIV Project](#)

Resources from Treatment Action Campaign (TAC)

ARVs in our lives: TAC's guide to antiretroviral treatment aimed at people with advanced treatment literacy skills.

<http://www.tac.org.za/documents/arvsinourlives.pdf>

TB in our lives: TAC guide to assist in TB treatment literacy.

<http://www.tac.org.za/community/node/2115>

A Global Call for Action and Declaration on TB: Released by TAC, AIDS Law Project (ALP) and ARASA at the Union World TB Conference in Cape Town in 2007.

<http://www.tac.org.za/community/node/2130>

Equal Treatment November 2008: An issue of Equal Treatment that focused on TB and HIV.

<http://www.tac.org.za/community/node/2420>

[Issue 26 English](#); [IsiXhosa](#); [IsiZulu](#); [Sesotho](#)

Resources from Medecins Sans Frontieres South Africa

Community Tools (including TB posters and pamphlets).

<http://www.msf.org.za/pages.php?p=25>

TB: Time for Change <http://www.msf.org.za/tb/>

NAM resources

[HIV & TB booklet](#)

[French translation of HIV & TB booklet](#)

[Portuguese translation of HIV & TB booklet](#)

[Tuberculosis](#): more detailed treatment guide from the HIV & AIDS Treatments Directory

The Botswana Network on Ethics, Law and HIV/AIDS

BONELA's TB/HIV Advocacy Document ([link](#))

Family Health International:

[Within Our Reach: Stopping TB Together](#). A TB literacy toolkit for use by community health educators, outreach workers, counsellors and healthcare providers.

A toolkit was developed for health educators, outreach workers, counselors, and supervisors designed to educate people with TB and HIV, their caregivers, and their communities about TB and TB treatment.

["The Story of Tomas" flipchart](#) (PDF, 21 pages, 7.2 MB)

[Community Outreach Teaches the Basics of TB](#) (video clip)

[What You Need to Know About Tuberculosis](#) (PDF, 2 pages, 702 KB)

[What You Need to Know About Tuberculosis and HIV](#) (PDF, 2 pages, 702 KB)

CREATE

[Engaging the Community in Research](#)

[Research for Activists](#)

STOP TB Partnership Resources

The STOP TB Partnership provides a wide variety of publications to assist programmes, community based organisations and activists

http://www.stoptb.org/resource_center/documents.asp

Some of the key ACSM and community related documents:

[Advocacy, communication and social mobilization to fight TB: A 10-year strategic framework for ACSM activities](#)

[ACSM for Tuberculosis Control: A Handbook for Country Programmes](#): A handbook intended as a guide to support the design and implementation of effective advocacy, communication and social mobilization activities in tuberculosis (TB) control at country level.

[Time for action on TB communication: A brief on communications challenges and opportunities](#)

[What the papers aren't saying](#): A briefing for health practitioners, TB programmers, policymakers, media professionals and people affected by TB on how to improve the media's coverage of TB.

[Working with the media: how to make your messages on tuberculosis count](#): A handbook for planning and execution of media outreach: from thinking about goals, writing releases to attracting media attention.

[Community involvement in tuberculosis care and prevention: towards partnerships for health](#): Recommendations on how health policy-makers, patients' groups and local partners can include people and communities affected by TB in national strategic plans to control TB

[Advocacy, communication and social mobilization for TB control: a guide to developing knowledge, attitude and practice surveys](#): A guide on conducting and using KAP surveys in ACSM efforts.

[TB tips: advice for people with tuberculosis](#): Basic advice for TB patients.

[Networking for Policy Change: TB/HIV Advocacy Training Manual](#) A training manual for advocacy at the country and local level to accelerate the implementation of collaborative TB/HIV activities

[Networking for Policy Change: TB/HIV Participant's Guide](#): Accompanies the TB/HIV Advocacy Training Manual

[Patient charter for tuberculosis care](#): The patients' charter outlines the rights and responsibilities of a person with TB, and ways in which people and communities affected by TB can work with health providers (both private and public), and governments to improve TB care.

[Social Mobilisation at Country Level](#)

Other sites

The TB Coalition for Technical Assistance <http://www.tbcta.org>

The International Union Against Tuberculosis and Lung Disease<http://www.theunion.org>

TBFREE<http://www.tbfree.org>

ICAP's TB-HIV Resources

<http://www.columbia-icap.org/resources/tbhiv/index.html>

The Reproductive Health Research Unit's TB-HIV Resources

[TB Infection Control Manual](#)

[TB-HIV Manual](#)

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about HATIP

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For further information please visit the HATIP section of aidsmap.com