Is depression contributing to low global cure rates for multi-drug resistant TB?

Blog by Dr Helen Elsey and Ian Walker of COMDIS-HSD, a research programme consortium funded by the Department for International Development (DFID) and focusing on improving prevention and care services for communicable diseases in low- and middle-income countries.

A marathon no-one wants to run

It takes 2 years, <u>14,000 pills</u> and 6 months of daily injections before a patient can hope to be cured of multi-drug resistant TB (MDR-TB). The drugs are powerful, toxic and can cause <u>debilitating side-effects</u>, including hearing loss, kidney problems, depression and psychosis.

If treatment is erratic or interrupted, it won't work. If you are poor and live in a low-income country you are likely to have even bigger problems. Stigma and social isolation, difficulty accessing treatment centres and being unable to work are just some of the well-documented challenges patients face.



Image from a patient leaflet developed as part of the psychological support package for MDR-TB patients in Nepal. It shows a counsellor using the flipbook (also part of the package) to guide discussions with a patient and family member

Against this backdrop, how surprising is it that only <u>half of all people who start treatment for MDR-TB are successfully cured</u>? The global TB community is striving to develop better, simpler and faster-acting TB drugs. The goal, says the <u>TB Alliance</u>, is the development of 'relatively short course (6 months) of daily, all oral, affordable novel medications'. Few would argue with this priority. But is it the whole answer? Even with shorter 9-month treatment regimens now being rolled out in some countries, what about the <u>significant negative effect</u> of MDR-TB on the mental wellbeing of patients, and what impact will this continue to have on adherence and cure rates?

'I have not seen anyone surviving'

We have learned a lot from <u>our research</u> in Nepal about the wider impacts of MDR-TB. Patients have told us about the guilt of becoming a burden on their families, the financial hardship and stigma, the breakdown of family relationships and, ultimately, their sense of hopelessness.

'I think about the future. I have MDR-TB now and I think about my children. I have only seen people dying from MDR-TB. I have not seen anyone surviving.' MDR-TB patient from our study in Nepal

We are also beginning to understand the additional <u>gender-based inequities</u> faced by female MDR-TB patients, particularly married women who are frequently abandoned by their husbands and struggle to look after their children and manage their illness. What we don't yet understand is how many patients go on to have depression, when they get it and whether they are less likely to be cured as a result.

Depression and the TB timeline

The negative impact of diabetes and other long-term conditions on patients' mental health are well evidenced. The World Health Organization (WHO) states that the prevalence of major depression is <u>consistently higher</u> in people affected by chronic disease and that patients with co-morbid depression are less likely to adhere to medical treatment. Yet there is still very little data available on the psychological impacts of TB and MDR-TB. Big questions remain.

At <u>COMDIS-HSD</u>, we are working with <u>ARK Foundation</u> in Bangladesh to understand more about the timeline of depression for people with MDR-TB. We want to find out:

- How many patients have depression?
- When does depression start?
- Do depression levels fluctuate during the long treatment?
- At what point(s) do patients most need psychological support?

Together with our partners <u>HERD</u> in Nepal, we have already explored a number of psychological support interventions with patients in an effort to find which tools and methods work best in low-income settings. Strong <u>evidence</u> from India, as well as our own experience in Nepal, shows that Healthy Activity Programme (HAP) counselling is well received by patients and can be delivered by health workers and lay counsellors, with appropriate training and adequate investment in staff.

We have developed a <u>desk guide</u>, <u>flip book</u> and other information materials as part of a psychosocial support package for people receiving treatment for MDR-TB. These are the first

resources focusing on psychological aspects of MDR-TB care in Nepal and are ready for adaptation and scale-up across MDR-TB services.

In developing interventions, however, one size rarely fits all and it is crucial to tailor approaches to reflect individual, cultural and country contexts.

Giving patients a mood tool

The HAP approach, for example, helps patients identify or re-engage with activities they enjoy, eg, visiting family, talking to friends, tending to the garden or crops. It takes a gradual, problem-solving approach. Patients work with a trained health worker or non-specialist counsellor in one-to-one sessions over several weeks. Together, they identify activities the patient previously enjoyed, what might be stopping them from doing these (eg feeling afraid to go out alone) and the steps needed to get back on track. As patients do more of what they enjoy, their mood should improve and they have learned a practical way to trigger more positive thoughts when they are feeling low.

In Nepal, and other countries where MDR-TB patients are treated almost entirely in the community, this approach could be appropriate (although we know it requires considerable extra investment in staff in an already over-stretched TB programmes). But in Bangladesh, where MDR-TB patients spend an initial 2 months as hospital in-patients, it is unlikely to work. If you are lying in a huge hospital ward with 70 strangers and undergoing intensive treatment, taking a walk, gardening or visiting family are clearly off the agenda. Other approaches are clearly needed.

There is strong global evidence, including with diabetes patients in the UK, that <u>peer support</u> is helpful to patients' mental wellbeing. Other evidence points to the <u>positive effect</u> of cured MDR-TB patients talking to those still undergoing treatment. Group support approaches with current and cured patients may work better in a hospital setting and we will explore these options.

Stressed or depressed?

Language too is an important consideration when developing interventions. In contexts where mental ill health still carries a heavy stigma, we have tried to find different ways of asking patients about their symptoms. In South Asia, for instance, we use words like 'stressed' rather than 'depressed'.

Stigma can also dictate how patients are likely to present to their health services. <u>Global evidence</u> suggests that patients with depression are more likely to complain of physical symptoms, such as aches, pains or headaches, rather than talk about their feelings and mood. So, again, it is

important that screening tools use the right words and are designed to pick up on the sort of physical symptoms that may be indicating underlying depression and poor mental health.

Of course, achieving all of this will be challenging. In the context of communicable diseases, the primary focus is rightly on drugs and cure. Mental health in general remains a seriously underserved area in low and middle-income countries (LMICs).

In TB, however, the focus may be starting to shift. <u>WHO guidelines</u> are explicit about the need for patient-centred care and the importance of emotional support:

'The provision of emotional support services to patients may increase the likelihood of therapy adherence, and the acquisition of skills to deal with stigma and discrimination. This support may be organized in the form of support groups or in one-to-one counselling by trained providers.'

Mobilising the NCD workforce

Yet how do we make that happen on the ground? TB and MDR-TB are chronic infectious diseases and the evidence is clear that once you have a chronic condition you are <u>more likely to have</u> <u>depression</u>. So rather than developing counsellors within MDR-TB services, are there other ways to enhance these skills in primary care to meet the needs of a variety of patient groups?

In our current study in Swaziland we will begin to explore this model. Working with our partners at Good Shepherd Hospital, our research will look at the feasibility of delivering psychological counselling in HIV and TB treatment. We will train non-communicable disease (NCD) nurses to deliver much of the psychological support intervention.

While the race is on to develop and implement faster, simpler and more effective medications for MDR-TB, making the case for depression screening and psychological counselling is not an easy job. But it is an important one.

Much of what we are doing on MDR-TB and depression will be hugely relevant to other chronic conditions. Across all major diseases it is important every effort is made to put mental health not just on the national political agendas for LMICs, but somewhere near the top.

- For more information contact Ian Walker at: l.Walker@leeds.ac.uk
- Or visit www.comdis-hsd.leeds.ac.uk

Notes on the authors:

Dr Helen Elsey is Associate Professor in Public Health at The Nuffield Centre for International Health and Development at the University of Leeds. Helen's research interests lie in applied global public health research, particular in urban areas, developing and evaluating public health interventions that reduce risks to health and improve health behaviour.

Ian Walker is a Visiting Research Fellow and Specialty Registrar in Public Health at The Nuffield Centre for International Health and Development at the University of Leeds. A former mental health nurse, Ian has a special interest in global mental health research, particularly in the implementation of psychosocial interventions.