



A woman with MDR-TB lying outside a treatment centre in Lumbini Zonal Hospital, Rupandehi district, Nepal. MDR-TB patients need to visit the centre daily for medication




## KEY MESSAGES

1. Married women are particularly vulnerable to the social, economic and mental health impacts of MDR-TB, including isolation, financial hardship and depression.
2. Wives and mothers give crucial family support to their husbands and children with MDR-TB, but are sometimes denied even basic support from husbands and family when they are the patient.

## SPOTLIGHT ON GENDER

### Women and their mental and social wellbeing during multi-drug resistant TB treatment in Nepal

Multi-drug resistant TB (MDR-TB) and its long and arduous treatment can lead to major disruptions in physical and mental health in patients<sup>1,2</sup> and depression and poor mental health among carers.<sup>3</sup> However, our research sheds new light on the additional negative influence of gender and marital status on women's mental and social wellbeing during their MDR-TB treatment.

Our study highlights 4 key areas where women undergoing MDR-TB treatment are more vulnerable to poorer mental and social wellbeing than men: 



1: Family support



2: Poor housing



3: Financial insecurity



4: Being heard

## 1: Lack of family support

Most patients acknowledged the important role of family in the MDR-TB treatment process.

However, the extent to which this support was available was frequently determined by gender and marital status.



Parents and wives in particular were heavily involved in day-to-day care for patients, including providing food, accompanying them to the treatment centre, facilitating discussions with health workers and, most importantly from the patient's perspective, giving psychological and emotional support.

The support of wives and mothers was a common theme for male patients and, in particular, married men often had very strong support from their wives. In most cases, parents were found to be supportive of their children with MDR-TB.

However, some patients complained of not having adequate support during their treatment. This was mainly the case for married women who were either subject to stigma and discrimination or were forced to leave their homes by their husbands or in-laws after diagnosis.

'My parents encouraged us to separate, but I was determined not to leave him. I don't think it is right to be with someone when he is well and then leave him when he is unwell. I chose to be with him and to put some distance between us and my parents...I spend my whole day cooking for him, making sure he takes his medicines and washing his clothes.'

*Wife of an MDR-TB patient*

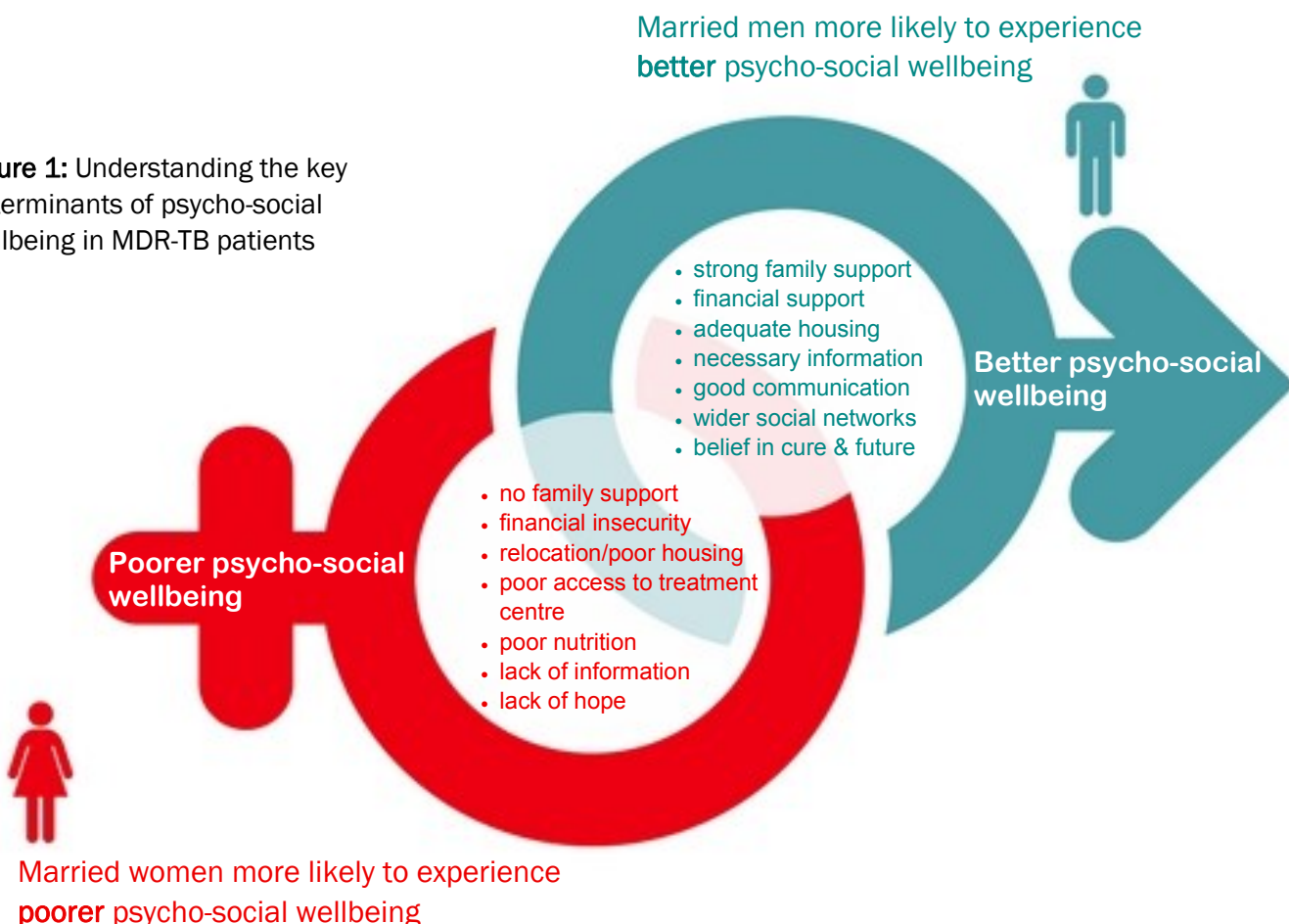
'She is my daughter, so why would I behave differently with her. Neither my daughter nor I have noticed any changes in the behaviour of our family members.'

*Mother of an MDR-TB patient*

'We often see family members abandoning people who have TB... Usually parents do support their children, but that is not always the case when it is a different family member.'

*TB health worker*

**Figure 1:** Understanding the key determinants of psycho-social wellbeing in MDR-TB patients



## 2: Poor living arrangements

The need for daily injections in the initial intensive phase of MDR-TB treatment (usually 8 months) means patients who live far from treatment centres usually have to relocate. Marital status and gender continue to influence the circumstances in which patients live during this time.

Our study showed that married male patients usually lived with their wives and families, even if this meant relocating the whole family. Some men stayed in a hostel for the duration of their treatment, but still had regular contact with their families.

Hostels tended to be occupied by more male patients (both single and married) than female patients.

Married women generally lived alone in rented accommodation. Both male and female patients said that finding a room to rent was often a challenge when their MDR-TB status was discovered.

For women with children to support, living alone without other family members was even more challenging.



‘Some people say that they do not want to rent a room to a single woman, others say that the room has already been rented out, and others say that they will not rent it to people who are sick.’ *Female MDR-TB patient*

‘When I lived with my family, they prepared food for my children. Now I am alone I have to take care of their food and all their other needs, regardless of how I am feeling.’  
*Female MDR-TB patient*

## 3: Financial insecurity

Almost all the patients said MDR-TB had a negative impact on their livelihood. Many patients had stopped work or education due to their poor physical health and the need for daily visits to the treatment centre.

- For the poorest, the inability to work undermined not just their mental health but also their means of survival. This was particularly the case for married women who had been abandoned by their husbands and families.
- Where these women were also looking after children, the effects of not being able to work could be catastrophic.
- Although most patients were aware that the National TB Programme (NTP) provided Rs1500 (\$10) each month, many identified problems with the insufficient amount, the frequency and payment distribution methods.
- While most patients were aware that the allowance was supposed to provide them with a more nutritious diet, loss of their daily income meant many had to use it for daily transport costs to the treatment centre.
- As a result, patients could become financially dependent on their families and those without family support struggled to survive.



‘Most of the patients complain about the financial difficulties they face due to the treatment. Even the local patients complain that, as they have to attend the health centre every day, their business is adversely affected.’ *Health worker*

‘I can't work either. I run a small business selling beaten rice, but it doesn't do well. I only earn Rs100-150 (about \$1) a day. How will that money help? Should I pay rent with that money or eat? It is not sufficient.’ *MDR-TB patient*

‘We have to go to Thimi (treatment centre) to receive the monthly allowance...But so far they have not given it to me and...I do not know... It's not regular.’ *MDR-TB patient*

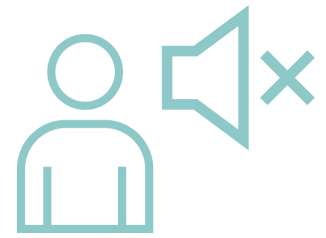


## 4: Being heard

Working with MDR-TB patients, carers and healthcare providers, we captured views and ideas on what support is needed to reduce stigma and help those most vulnerable to the psycho-social impacts of the disease. During this two-way process we found further evidence of gender bias. Specifically:

- among the MDR-TB patients we spoke to, the patients who did provide suggestions were more frequently the better-educated and male participants.; and
- the most vulnerable patients, particularly married women and those who had moved away from home, made fewer contributions.

Despite deliberate efforts to select more female patients for interview, numbers were lower than we would have liked.



However, the interviews we did do with women patients, and the focus groups, have helped ensure the voices of these women are heard.

Importantly, we continued to highlight gender issues during our study to ensure the support intervention we developed fully reflected the specific needs of women and the most vulnerable patients.

## Other findings

These gender-specific issues are drawn from a broader body of findings highlighting other important factors that can either enhance or undermine the psychological and social wellbeing of MDR-TB patients. These include:

- physical and psychological side effects of MDR-TB drugs – including loss of appetite, reduced mobility and psychiatric disorders;
- lack of knowledge about MDR-TB and its treatment - fuelling patients' anxiety and feelings of hopelessness, especially among those in the early phases of treatment; and
- social exclusion based on fear of infecting others and being infected – a particular problem for younger patients.

Read our full journal article: [Development of a patient-centred psychosocial support intervention for MDR-TB care in Nepal](#)

## References:

1. Furin J J, Mitnick C D, Shin S S, Bayona J, Becerra M C, Singler J M, et al. (2001). [Occurrence of serious adverse effects in patients receiving community-based therapy for multidrug-resistant tuberculosis](#). *International Journal of Tuberculosis & Lung Disease*, 5, 648-655
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## Next steps

Drawing on all our findings, we have worked with patients, families, health workers and the NTP in Nepal to design a psycho-social support intervention based on 2 key components:

1. training and information, education and communication materials for health workers, with particular emphasis on helping them respond to the needs of MDR-TB patients, including married women; and
2. routine assessment of all MDR-TB patients for depression and social support needs, both at diagnosis and throughout treatment.

For more information on this study and our findings, email: [sudeepa.khanal@herd.org.np](mailto:sudeepa.khanal@herd.org.np)

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