

‘Once you get TB, life changes’: post-tuberculosis experiences and care needs in East Africa

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SUMMARY

BACKGROUND: Recognition of tuberculosis (TB) sequelae is growing, and evidence regarding post-TB experiences and care needs may inform care models.

METHODS: The TB Sentinel Research Network of the International epidemiology Databases to Evaluate AIDS is a global prospective study of people aged ≥ 15 with pulmonary TB. In Eldoret, Kenya, and Mbarara, Uganda, we conducted in-depth interviews with a purposive sample of individuals treated for TB and multidisciplinary health care workers (HCWs) providing TB care, using a semi-structured guide. We conducted a reflexive thematic analysis.

RESULTS: In interviews with 25 HCWs and 61 individuals treated for TB, participants described trajectories of TB illness and recovery, and some persistent challenges after TB treatment across physical, economic, social, and

mental health domains of wellbeing. Experiences were marked by stigma and isolation. Physical illness exacerbated economic vulnerability, which compromised physical health and presented barriers to care. There was a lack of care access and need for person-centred post-TB care. Care needs included addressing potential TB recurrence, lung health impairment, and psychosocial, nutritional, and economic challenges.

CONCLUSION: Post-TB experiences are marked by persistent symptoms, economic vulnerability, stigma, and psychosocial challenges. These experiences are generally neglected in the current care paradigm, underscoring needs for accessible, person-centred post-TB care models.

KEY WORDS: PTLT; post-tuberculosis lung disease; socio-economic outcomes; health-related quality of life; qualitative research

In 2023, an estimated 10.8 million people fell ill with tuberculosis (TB) and 1.25 million people died from TB.¹ A modelling study estimated 155 million living TB survivors in 2020.² With the tremendous global burden of TB disease, post-TB sequelae may have a major impact on health.³ TB survivors are at risk for TB recurrence,⁴ have higher all-cause mortality,⁵ and have lower life expectancy than their counterparts who have never had TB, regardless of adequate treatment.⁶ Post-TB sequelae include persistent respiratory symptoms,⁷ abnormal lung function,⁸ and reduced health-related quality of life.⁹ Further, impacts from stigma, social isolation, and financial challenges may continue after treatment for TB.¹⁰ The estimated global burden of disease from post-TB sequelae is massive.¹¹ Although an emerging field of research points to lasting physical,

mental, and social effects of TB even after successful treatment,¹² post-TB care is not routine,¹³ and evidence for developing post-TB care models remains limited.¹⁴ In particular, there is limited research which directly engages TB survivors around their post-TB experiences and care needs.^{15–19} Further, health care workers (HCWs) contend with challenges of post-TB sequelae in the absence of routine post-TB care. There is a need to characterise the health and socio-economic conditions people face after TB treatment, understand their health care needs, and explore perspectives for supporting TB survivors in developing care models.

We sought to assess post-TB health and health care needs across physical, economic, social, and mental domains of wellbeing, from the perspectives of TB survivors and multidisciplinary HCWs. We conducted in-depth interviews with these groups, examining how their experiences may inform efforts to improve health and wellbeing after TB treatment.

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METHODS

This study was nested in the TB Sentinel Research Network (TB-SRN) of the International epidemiology Databases to Evaluate AIDS (IeDEA), a global prospective study of people aged ≥ 15 with pulmonary TB, with or without HIV infection.²⁰ Participants in the multiregional cohort are enrolled at TB treatment initiation, and followed at scheduled study visits during and after TB treatment.

East Africa TB-SRN sites are located at Moi Teaching and Referral Hospital (MTRH) in Eldoret, Kenya, and Mbarara Regional Referral Hospital (MRRH) in Mbarara, Uganda. MTRH serves a large catchment area of western Kenya, including urban and rural populations. MRRH serves a predominantly rural population in western Uganda. Both sites provide co-located TB and HIV services. Post-TB care is not currently routine at these sites; however, as part of the TB-SRN, participants undergo detailed clinical and pulmonary assessments and referral for pulmonary specialist care as needed.

Approach to qualitative interviews

In the emerging field of post-TB research and care, understanding both the lived experiences of individuals treated for TB and HCW perspectives on care delivery is essential to the development of post-TB care models. A qualitative interview approach was therefore selected to investigate post-TB experiences and care needs across domains of wellbeing. We conducted in-depth interviews with individuals enrolled in the East Africa TB-SRN cohort and with multidisciplinary HCWs providing TB care. Individuals with TB were purposively sampled to ensure variation in age, sex, HIV status, and disease severity. HCWs were purposively sampled to ensure a range of disciplines, including clinical officers, nurses, social workers, and peer supporters working in TB or HIV services. In-depth interviews followed a semi-structured interview guide that included investigation of post-TB experiences and care needs, as well as input on emerging post-TB care models. Individuals with TB were interviewed both during and after TB treatment to capture health experiences across this course. Post-treatment interviews were conducted within days to a year following treatment completion. While this analysis focused on the post-treatment stage, interviews conducted during treatment were included for context on care experiences and trajectories that inform the post-treatment course. Interviews were audio-recorded, and translated/transcribed into English with verification. Sample size was based on saturation of themes across sites and participant groups, and to ensure robust information power for thematic analysis.^{21,22}

Analysis

We conducted a reflexive thematic analysis. Throughout analysis, we reflexively considered the

Table 1. Characteristics of individuals with TB who participated in in-depth interviews, N = 61.

Characteristics	n (%)
Participants treated for TB	61
Age, years	
Median (IQR)	37 (26–46)
Range	15–70
Sex	
Male	35 (57)
Female	26 (43)
Study site	
Eldoret, Kenya	31 (51)
Mbarara, Uganda	30 (49)
HIV status	
Positive	31 (51)
Negative	30 (49)
Timing of interview	
During TB treatment	10 (17)
After TB treatment completion	51 (84)
Area of residence	
Urban	33 (54)
Rural	28 (46)
Education level	
None	3 (5)
Primary	19 (31)
Secondary	26 (43)
Post-secondary	13 (21)
Occupation	
Cook	1 (2)
Craftsman	1 (2)
Private sector employee	4 (7)
Public sector employee	2 (3)
Farmer	7 (11)
Housekeeper	2 (3)
Policeman/military	2 (3)
Storekeeper	6 (10)
Student	4 (7)
Truck/taxi driver	3 (5)
Retired	1 (2)
Unemployed	6 (10)
Other	22 (36)

IQR = interquartile range; TB = tuberculosis.

researchers' positionality, assumptions, and influences.²¹ The team included members in East Africa and the US with clinical and research expertise in TB. Kenya- and Uganda-based researchers were closely engaged with participants in the TB-SRN study. We familiarised ourselves with the data and developed deductive and inductive codes through close review of transcripts, discussion, and consensus. All transcripts were independently coded by multiple researchers. Themes and sub-themes were identified and refined following an iterative, collaborative process to ensure robustness of the analysis and full elucidation of themes. We used basic descriptive statistics to describe the sample. The manuscript was prepared in accordance with the Standards for Reporting Qualitative Research.²³

Ethical statement

This study was conducted in accordance with the Declaration of Helsinki. Written consent was obtained from all participants. For minors, parental consent was required in addition to adolescent assent. Ethical/regulatory approval was obtained at all sites.

Table 2. Overarching themes and select illustrative excerpts.

Theme	Illustrative excerpts
Trajectories of illness and recovery	'When I finished treatment, I still remained with some cough... Sometimes I just cough from nowhere but at least it is not like how I used to be.' – Man, aged 30–39; 'They need a lot of support... They cannot go back to who they were initially... they are not able to support themselves. Once you get TB... life changes.' – Woman HCW; 'My work was affected but from the time I got healed, I am starting to get work, and I know life will get back to normal.' – Man, aged 30–39
Stigma, isolation, and mental health burdens	'When you have a wife and they leave you, not that you have fought but they choose to leave when you are in the kind of situation I was in, it is so painful... even when you are home it feels empty.' – Man, aged 30–39; 'When they are on TB treatment, they tend to be isolated... people do not want to sit near them... other family members tend to ignore and distance themselves from that person... They are somehow neglected and depressed. Because of that, they might need some psychosocial support because of the negligence and distance their friends are creating between them.' – Man HCW
Physical illness and economic vulnerability	'I took long to go back to work and I did not have money and getting what to eat was a struggle... No one could allow giving me a job because they saw that I had no strength.' – Man, aged 50–59; 'I have been struggling ... they sent me to the chest clinic ... it became expensive to me I was not able to manage.' – Man, aged 40–49; 'The patients who have chronic difficulty in breathing after treatment... they are no longer working because... their lungs were affected... and that has even led to poverty in their families.' – Woman HCW
Lack of care access and need for person-centred care	'TB doesn't just end with the treatment. People (are) living out there with long-term complications of TB... but if we can make it routine for all the clients, not waiting for them to come back... but doing it routinely when there is sort of a protocol... Most of the time we treat, discharge and wait for complications as they come, not actively looking out.' – Woman HCW; 'They should go through counseling sessions... so... psychologically they can be able to continue with their normal lives.' – Woman HCW; 'You find that when the patients stop medication, the support also stops there, and these people ... are not able to afford for their care for their nutrition part. Though they are fully recovered, you might find them relapsing again.' – Woman HCW

HCW = health care worker; TB = tuberculosis.

RESULTS

We analysed 86 interviews from 25 HCWs and 61 people with TB (Table 1). Among individuals treated for TB, 31 in Eldoret and 30 in Mbarara, 35 (57%) were male; 31 (52%) were living with HIV; 51 (84%) had completed TB treatment; and 10 (17%) remained on treatment. Post-treatment interviews were conducted a median of 2 months from treatment completion. HCW interviews, 15 in Eldoret and 10 in Mbarara, included 3 medical officers, 3 clinical officers, 10 nurses, 2 peer supporters, and 7 others working in TB and HIV care. We present overarching themes, which intersected and reinforced one another (Table 2), followed by comprehensive themes (Figure and Table 3).

Overarching themes

Trajectories of illness and recovery

People treated for TB experienced trajectories of illness and recovery across physical, economic, social, and mental health domains of wellbeing, with many experiencing ongoing concerns across these domains. While people noted improvement from the height of TB illness by the end of treatment, TB effects lingered for some. HCWs noted that recovery takes time and requires support. Experiences across domains of wellbeing were interwoven, with recovery or challenges in one domain having cascading effects in others.

Stigma, isolation, and mental health burdens

Individuals experienced stigma, isolation, and mental health burdens during TB treatment. While treatment completion brought a sense of freedom, repaired relationships, and restored self-value for many, for others, experiences of stigma and isolation continued. Some described suicidal thinking after TB treatment. HCWs described needs for ongoing psychosocial support.

Physical illness and economic vulnerability

TB illness led to lost income and food insecurity. While physical recovery allowed return to livelihoods for some, persistent symptoms impaired economic recovery for others. Persistent physical impairments and economic vulnerabilities reinforced each other, with food insecurity, financial challenges, and stress contributing to decreased wellbeing and impeding access to health care. Amid stigma and isolation, and in the absence of dedicated post-TB care, economic vulnerability presented a major barrier to care access.

Lack of care access and a need for person-centred post-TB care

HCWs expressed needs for routine evaluation after TB treatment. For individuals who completed treatment, many did not seek care for persistent health concerns due to anticipated costs. Both groups expressed needs for comprehensive person-centred post-TB care,

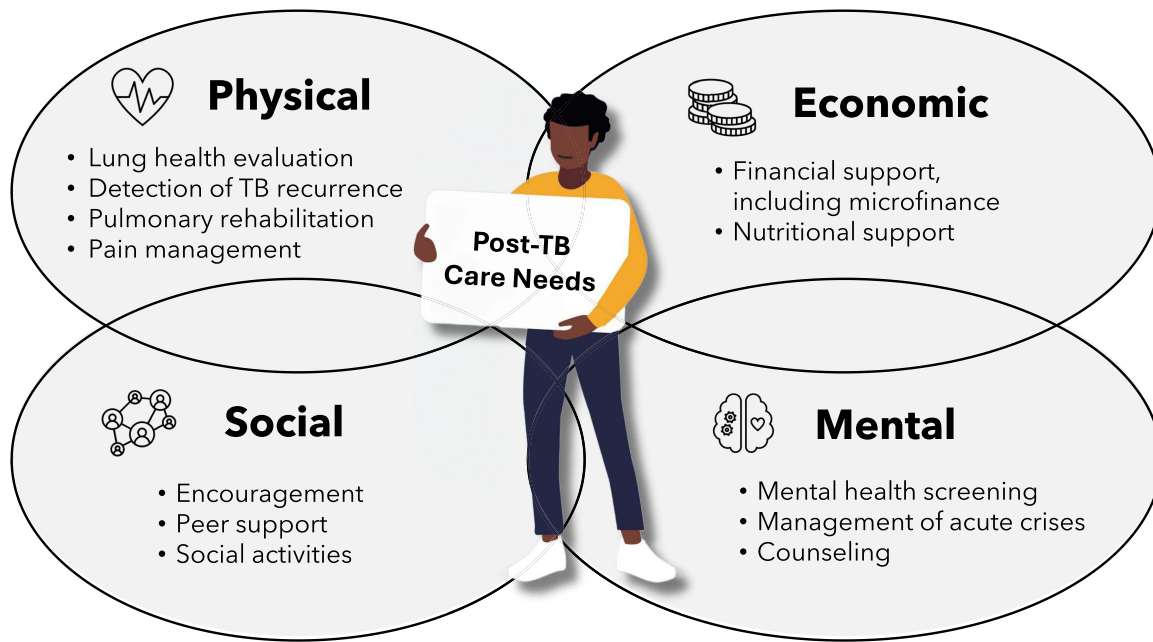


Figure. Select post-TB care needs, organised by domains of wellbeing. TB = tuberculosis.

attending to physical, economic, social, and mental health concerns. HCWs underscored needs for education about post-TB care and the rationale for follow-up. They noted needs for appropriate staffing and for patient-tracking tools/records for post-TB care, and possible opportunities for community-based care.

Comprehensive themes of post-TB experiences, by domain of wellbeing

Physical wellbeing: Individuals who had completed TB treatment described marked improvement of physical symptoms from the height of illness. Treatment side effects also resolved. However, for many, some symptoms persisted or recurred, most commonly exertional dyspnoea, fatigue/weakness, and joint or back pain. Symptoms limited functioning in activities of daily living. People with persistent symptoms were hopeful but uncertain about whether symptoms would resolve, and some worried about possible TB recurrence; yet many did not seek care.

Economic wellbeing: Improved physical health and relief from isolation supported individuals to return to their livelihoods and recover financially. For some, return to work and economic recovery were complete. For others, barriers to work, food insecurity, and financial instability persisted, particularly if physical limitations persisted post-treatment. Inability to work due to physical limitations was more commonly described among individuals without HIV. Impacts were particularly acute for subsistence farmers, whose livelihoods depended on planting and harvest seasons and required demanding physical labour.

Others struggled due to issues such as loss of clients and ongoing stigma. Some individuals reported ongoing food insecurity. Economic hardship threatened children's access to school, underlining TB impacts on all family members.

Social wellbeing: Completion of treatment relieved stigma as individuals regained health and no longer isolated themselves to avoid TB transmission or disclosure. Some experienced restored relationships. Some described becoming advocates for TB, sharing their experiences to decrease stigma and encourage TB testing. Others kept their diagnosis private and desired to move on. Many, however, found it difficult to recover after experiencing abandonment and rejection by their communities. Continued isolation and stigmatisation post-treatment was painful and not easily overcome. Ongoing stigma and isolation were more prominent in interviews with people living with HIV (PLHIV), whereas individuals without HIV spoke more often about repaired relationships and relief from stigma post-TB treatment.

Mental wellbeing: TB treatment completion yielded a sense of freedom and relief. Restored confidence was bolstered by physical recovery and returns to livelihood and to previous social activities. However, many worried about ongoing challenges. There was lingering hurt, trauma, and sadness from previous stigmatisation and isolation. Feelings of ongoing sadness, despair, and suicidal thinking were more prominent in interviews among PLHIV. Some drew strength from religious faith to cope with circumstances they found were beyond their control. Despite hardships, people

Table 3. Select themes and illustrative excerpts for post-TB experiences and care needs, organised by domains of wellbeing.

Relief/improvement from the illness period		
Physical	Marked symptomatic improvement from height of illness Recovery of physical wellbeing	'When you look at me, you cannot believe that I once suffered from TB unless I tell you'. – Man, aged 30–39; 'The situation I have gone through has not been good, the pain I had, lack of appetite but now my life is enjoyable.' – Man, aged 50–59
Economic	Return to livelihood Economic recovery	'I was strong and eating normally and working normally. I would wake up very early and start doing my gardening work.' – Man, aged 50–59; 'The income was small because I was the one to take care of my family, yet I was sick, but now that I am well, I work hard ... knowing I am completely healed and can work and get money, because those days I could not earn on my own.' – Man, aged 30–39
Social	Relief from stigmatisation Restored relationships affected by illness Relief from isolation brought on by illness	'I also used to isolate myself so that I do not spread TB to others, but I am now free.' – Man, aged 20–29; 'Some of my friends had imagined that I had gone on a very long and distant trip, because we were not meeting with most of them. It is now that we are seeing each other.' – Man, aged 30–39
Mental	Sense of freedom from the burden of illness Restored self-value	'...but those days, every time it would clock 8 pm [the time for taking medications], it felt like I was entering into hell, but now I am okay.' – Man, aged 30–39; 'When you complete your medication, you return to normal. You again associate with people you stay with, you go back to your job ... You love yourself.' – Woman, aged 20–29; 'I even have peace of mind. Have you ever heard them say, I am born again? It is as though a child has been born. You know this is like a burden ... just a load that is so heavy. But once you complete ... I feel free.' – Man, aged 30–39
Ongoing challenges to health and wellbeing		
Physical	Persistence or recurrence of physical symptoms, such as weakness, respiratory symptoms, or pain	'The strength I had earlier it's not the same as now...I don't have that energy ... a lot of problems affected my chest and, by the way, the chest is the engine.' – Man, aged 40–49 'The only challenge that I still have is to carry a heavy thing or when I don't have charcoal and I use firewood, that smoke affects me.' – Woman, aged 40–49
Economic	Challenges recovering livelihood Particularly acute impact on subsistence farmers	'It has been hard to work the way I used to; life has not been the same.' – Man, aged 30–39 'I do not have any source of income. From the time I completed treatment, I have not been able to plant any garden, and I do not have any other source of income. If it's not a season of planting where I can plant some beans in the banana plantation then there is no other source of income. I have to struggle to survive.' – Woman, aged 40–49
Social	Continued stigma Continued isolation	'I was facing stigma from people ... They start thinking that infected people do not deserve to be amidst people. It was such a discouragement, and I later chose to isolate myself.' – Man, aged 50–59
Mental	Worries about ongoing challenges Lingering trauma, hurt, sadness	'You definitely have to get negative thoughts because you have children to take care of and you cannot fail to worry about your future.' – Man, aged 30–39 'It felt like I was no longer living, reaching the point of wishing to die because it was too much.' – Man, aged 50–59
Post-TB care needs		
Physical	Lung health evaluation and rehabilitation Detection of TB recurrence	'I request that you now start treating my lungs, it's the only problem.' – Man, aged 40–49 'Not all these patients just finish treatment, and they are done, some of them ... are back again, with the same symptoms and ... you diagnose them a second time with TB. So, it would be better to enhance the follow ups because ... it will also help the patients to know themselves when they are getting reinfection.' – Woman HCW
Economic	Financial support Nutritional support	'Your job will have been lost, so you must get some support to pick up the pieces' – Man, aged 40–49; 'The nurses normally tell us to eat a lot of fruit but getting the fruit is the problem.' – Woman, aged 50–59
Social	Peer support Need for encouragement	'It's true that such a person needs help, they need to be checked on most of the time, they also need someone to keep bringing them food, someone to keep counselling them, know how they are progressing and keep assuring them that this world is not the end ... When a person doesn't have someone besides them ... these patients need to be ... encouraged.' – Woman, aged 30–39
Mental	Mental health screening Management of acute crises Counselling	'The health worker told me to relax and that all was going to be okay ... when he talked to me and opened my eyes on how there was great improvement in my life, I became strong and did not tell him how I felt like dying.' – Man, aged 50–59 '(Mental health services) are very important because after this person has suffered this TB, they still need to be encouraged that life is good, they can still live well, they can still become what they want to be.' – Woman HCW

HCW = health care worker; TB = tuberculosis.

Box 1. Key elements to consider in developing post-tuberculosis (TB) care models, based on findings from qualitative interviews among individuals treated for TB and health care workers in East Africa.

Elements of needed routine care provision after TB treatment.

Post-treatment visit(s) should be incorporated in routine TB services, to include health screening, care, and education, and linkage to needed economic or social support. Care areas include the following:

- Health screening for common post-TB sequelae and for TB recurrence:
 - Evaluation for medical complications of TB, such as post-TB lung disease, functional impairment, cardiovascular disease, or lung cancer.
 - Evaluation for TB recurrence.
 - Mental health assessments, including for symptoms of depression, suicidal thinking, or harmful use of alcohol, tobacco, or other substances.
 - Assessment for food insecurity.
- Provision of comprehensive care, through co-located services or referral, as appropriate and available:
 - Pulmonary specialist evaluation and follow-up.
 - Pulmonary rehabilitation for identified post-TB lung disease.
 - Care for other medical complications of TB.
 - Mental health evaluation, counselling, and psychiatric care.
 - Care to address harmful substance use (particularly alcohol and tobacco).
 - Nutrition support for identified food insecurity.
 - Economic support (examples include microfinance, job skills training, or financial interventions, as available).
- Education on post-TB health and anticipatory guidance:
 - Post-TB lung disease and other potential physical complications.
 - Recognition and prompt evaluation for possible TB recurrence.
 - Supporting mental health and reducing stigma.
 - Avoiding or reducing harmful substance use.
 - Considerations for avoiding TB reinfection/recurrence.

exhibited resilience and self-assurance, speaking about ways in which they were grateful and hopeful.

Themes related to post-TB care needs, by domain of wellbeing

Physical wellbeing

Individuals treated for TB expressed desires for education and reassurance around possible TB recurrence. HCWs also described needs for monitoring for TB recurrence. They described the current approach to post-TB care as passive and advocated for a proactive approach with pulmonary function and radiographic assessments. HCWs noted that some patients are managed in the chest clinic for persistent respiratory complaints, but that routine post-TB health evaluations, care referral, and rehabilitation are needed.

Economic wellbeing

Needs for financial support were prominent in interviews with people with TB and with HCWs. Many individuals had recovered the ability to work by the end of treatment but faced financial losses or lacked opportunities to return to their livelihoods. Some reported continued debt from hospitalisation for TB. They noted that small-scale financial support might allow them to leverage their skills and earn income. HCWs were concerned that food insecurity undermined physical recovery and increased risk for TB recurrence, advocating for nutritional support to ensure healthy recovery.

Social wellbeing

Individuals treated for TB and HCWs described ways in which social connection was an essential part of

recovery. After experiencing stigma and isolation, there was a need for support in returning to regular social life. The need for post-TB follow-up was seen as important not only for physical health but also for continued encouragement. Some HCWs and individuals treated for TB described key roles for TB survivors to support post-TB recovery.

Mental wellbeing

Individuals treated for TB and HCWs described that post-treatment mental health support may be critical for recovery from depression and other mental health challenges, and for regaining hope. Some described that substance use contributed to poor health post-treatment and should be addressed.

DISCUSSION

In this study, we observed intersecting and reinforcing processes by which people treated for TB experience persistent impacts on their physical, economic, social, and mental wellbeing. Persistent physical symptoms impair financial recovery, exacerbating a major barrier to seeking and accessing care. Ongoing challenges – coupled with continued stigma and isolation – worsen mental health. Despite recognised care needs, people with TB and HCWs contend with a lack of routine, accessible post-TB care. Indeed, this study makes clear that attending to the social and financial vulnerability of individuals who have recovered from TB will be critical to the success of emerging post-TB care models. The described trajectories of illness and recovery, and ongoing challenges across domains, align with other

Box 2. Considerations for development of post-tuberculosis (TB) care delivery models.

The following insights should be considered in developing post-TB care models:

- Global and national policies should prioritise accessibility and affordability of routine post-TB care services.
- Post-TB care models should proactively address economic and social barriers to recovery, such as food insecurity, mounting health care costs and difficulties returning to work, social isolation, and stigma.
- Linkages and care pathways are needed to support access to multidisciplinary services and evaluation and management of post-TB sequelae.
- Integrated care models can support care delivery by incorporating post-TB management within comprehensive care for chronic conditions.
- Medical record systems are needed which expand on current TB care visits to document and track post-TB visits and assessments.
- TB survivors and champions must be engaged as partners in developing post-TB care models.
- Multiple areas exist for incorporation of TB champions and/or peer support throughout the TB care and prevention cascade.
- Differentiated services may adapt post-TB care to patient needs, that is, with closer follow-up for those at greater risk or with identified post-TB complications.
- Innovative models might extend beyond the health system to incorporate elements of community-based care.

studies of post-TB experiences. Previous qualitative studies in Brazil, Malawi, South Africa, and Norway have described persistent physical and psychosocial challenges after TB treatment among people with drug-resistant TB or with persistent respiratory symptoms.^{16–19} In including people with and without symptoms after treatment, this study contributes to a broader understanding of post-TB treatment experiences, across two East African countries.

Our qualitative findings also lend narrative insights to previous findings of prevalent post-TB symptoms and impacts on health-related quality of life.^{24–26} A mixed-methods study in Malawi found persistent economic vulnerability and associations between physical morbidity, loss of work, and severe financial impact post-TB.²⁷ Our study further sheds light on the relationships between economic hardship and physical health, in which food insecurity and financial barriers to care impede physical recovery. These critical barriers to care access will need to be addressed as part of developing post-TB care models. Data regarding post-TB experiences of stigma are relatively limited; our findings are consistent with those of other studies reporting ongoing stigma and social impacts after TB treatment.^{10,16,17,28} Previous qualitative studies have described post-TB symptoms as a driver of stigma,^{15,17,28} and some participants in our study reported relief from stigma with physical recovery. However, others, particularly individuals with TB/HIV coinfection, experienced continued isolation, stemming from rejection and discrimination. They found it difficult to recover social connections, despite symptom resolution. Persistent isolation post-TB has also been described in South Africa.¹⁶ Our study adds evidence regarding the social impacts of TB, and furthers understanding of complex and sometimes divergent social experiences.

An emerging field of research on post-TB well-being²⁹ advocates for holistic, person-centred post-TB

care. Currently, there is limited evidence to guide post-TB care and few established care models.^{10,30} Participants in our study expressed worries about physical symptoms and possible TB recurrence, and uncertainties navigating care. Similar experiences were described in Malawi.¹⁸ Research has illuminated post-TB lung disease and needs for lung health evaluation and rehabilitation.³¹ People with TB and HCWs in our study further expanded on needs for comprehensive supports in the post-TB period, highlighting the importance of financial, nutritional, mental health, and social support to recovery. This was similarly described in a study of post-TB wellbeing and care needs in Kenya and Malawi.³² Our study further emphasises the importance of accessibility and affordability of developing post-TB care models. Taken together with previous research, our study builds the case for developing and evaluating comprehensive, accessible post-TB care models that encompass health education, screening, and care for post-TB sequelae and for TB recurrence. Findings inform needed elements of post-TB care models which should be considered by policymakers and programmes (Box 1). As described in this study, care should address not only physical health but also social, economic, and mental wellbeing (Box 2). Programmes developing post-TB care models should prioritise accessibility and affordability. Wherever possible, programmes should incorporate connections to social support and/or community-based programmes to address food insecurity and financial challenges and foster social connection.

A limitation of this study is that participation in an ongoing prospective cohort study may have influenced experiences and perspectives. Participants expressed appreciation for research evaluations extending well beyond routine care, including comprehensive lung health and psychosocial

assessments. Their experiences may not be fully representative of TB survivors who lack ongoing follow-up. In addition, social desirability bias could have influenced responses and negative post-TB experiences could have been minimised. However, rapport established between interviewers and participants allowed for in-depth conversations, including around sensitive topic areas, allowing rich data collection and nuanced narratives of post-TB experiences. The study was strengthened by a large number of participants; rigorous procedures for reflexive thematic analysis; and inclusion of individuals with TB and HCWs with a range of backgrounds and care experiences in two countries. This approach enabled a comprehensive thematic analysis of post-TB wellbeing and care needs in East Africa.

CONCLUSION

In summary, the post-TB period is marked by recovery from the height of TB illness but also ongoing challenges across areas of physical, economic, social, and mental wellbeing. These challenges include persistent symptoms, barriers to economic recovery, isolation and stigma, and mental health burdens. There is a need for person-centred, accessible post-TB care models to assist individuals navigating these challenges, to improve health outcomes after TB.

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