



Reaching Young People with Tuberculosis Care in Malawi: Empowering Lived Experience to Drive Action through Photography and Dialogue



Key messages

- ➔ Young people are being left behind in TB care. Many adolescents and young adults struggle to access TB care as programmes focus on adults and young children.
- ➔ Tuberculosis harms health, finances, and social wellbeing. Young people with TB are faced with pain, stigma, financial hardships, and social exclusion, which can delay diagnosis and treatment.
- ➔ Counselling and support help recovery. Treatment, counselling, family support, and faith all play a big role in helping young people recover from TB.
- ➔ Young voices offer valuable solutions. Experiences shared through photos and stories helped design youth-friendly TB services that meet age- and gender-specific needs.
- ➔ Teamwork is key to better TB care. Improving TB care needs youth involvement, stronger health services, integrated mental health support, social protection, and action from all sectors.

The problem and why it matters

Tuberculosis (TB) is the leading single infectious disease killer in the world which affected nearly 11 million people and caused over 1 million deaths in 2023.¹ In Malawi, ranked among the 30 countries with high TB burden globally, around 25,000 individuals were diagnosed with TB, and 1,700 died from the disease for the same year.¹ The country records one of the world's highest rates of TB-HIV co-infection, with nearly half of those affected by TB also living with HIV.¹

In 2023, 1 in 10 TB cases in Malawi occurred among young people aged 15–24, mostly in young men (56%).¹ However, 1 in 4 young people with TB remained undiagnosed, with a higher gap in young men (29% vs 21% in young women).¹ Delayed diagnosis increases the risk of poor health outcomes, including greater morbidity and long-term disability, and death. Although adolescence is a critical developmental stage, targeted interventions for young people remain limited, as TB efforts focus mainly on adults and children under five. Integrating youth-specific services into TB programmes is vital for addressing the TB notification gap in this age group and meeting their age and gender-specific needs.

For this reason, the LIGHT Consortium partners in Malawi – African Institute for Development Policy (AFIDEP), Malawi-Liverpool-Wellcome Programme (MLW), and Liverpool School of Tropical

Medicine (LSTM) – collaborated with the Malawi National Tuberculosis and Leprosy Elimination Programme (NTLEP) and the Malawi Ministry of Gender, Community Development and Social Welfare (MoGCDSW). Together, they explored lived experiences of adolescents and young adults (aged 15–24) affected by TB in Lilongwe.

What we did

The study used photovoice,² a participatory visual method inviting participants to document and share their experiences through photography and storytelling. Twelve purposively selected youth (aged 15–24) affected by TB, seven young men and five young women, from urban Lilongwe participated in the study. They included survivors, patients, and caregivers.

The study was conducted in three phases:

- ➔ **February–April 2024:** Administrative setup, researcher training, and participant recruitment.
- ➔ **May 2024:** Participants received training in photovoice and ethical photography, then spent two weeks capturing images of their experiences with TB
- ➔ **June 2024:** Participants shared their stories in workshops with healthcare workers, policymakers, and community leaders to explore barriers to care and co-develop recommendations for youth-centred, gender-responsive TB services.

What we found

The results illustrate participants' experiences along the TB care cascade – from the onset of TB symptoms through diagnosis, treatment, recovery and life post TB. Across all stages, young people described physical, economic, and psychosocial challenges, alongside coping strategies and positive experiences. They also offered recommendations for improving TB care.

Symptoms and Disease Experience

Participants described a range of physical challenges at the onset of TB. Pain, weakness, breathlessness, and fatigue during and after the early stages of illness made daily activities difficult. Young people struggled with their reduced independence.

“Before I fell ill, I could easily fetch at least 5 pails of water from the well. Now, I struggle to fill more than one pail because I get short of breath when I try to do more.” **Adolescent girl on TB treatment**

“Before I became ill, I could handle physically demanding tasks like construction and similar work. I could lift heavy blocks without difficulty... I can no longer perform this type of work, and I feel like I've lost that ability.” **Young man on treatment**

Psychosocial challenges were also prominent. Young people experienced TB stigma, were verbally abused and isolated from peers, family, and communities. They were made to eat alone, use separate utensils, or were excluded from school and household activities. Misconceptions linking TB to HIV, witchcraft, or moral failure caused deep emotional distress. Many abandoned

hobbies and lost interest in activities they once enjoyed. The compounded psychological burden led young people affected by TB to struggle with loneliness, sadness, and social exclusion; some developed suicidal thoughts.

“...The time I was suffering from TB, I was being stigmatised a lot. My family and friends did not want to associate with me. This was making me think I should just escape this scenario by committing suicide.” **Young man, caregiver and TB survivor**

Despite these challenges, support from friends and relatives, along with religion and spirituality, provided strength and comfort.

Getting a TB Diagnosis

Although TB services are officially free in Malawi, participants grappled with the significant economic burden of being ill and seeking a diagnosis. High indirect costs, such as transport fares and lost work time, made accessing care burdensome. For some, repeated visits for tests and referrals created additional financial strain.

“I didn't know what I was suffering from. I went to different hospitals. The money I can count to have spent over the time it took to get to realise that I was suffering from TB is a lot. Because I didn't know about the TB.” **Young woman who completed treatment**

TB misconceptions, fear of judgment and stigma discouraged some young people and their families from seeking care, resulting in late detection and ongoing transmission.

“When my in-law was sick... we visited the hospital several times without identifying the disease, some people were saying that this disease might be associated with witchcraft. This made us start believing and seeking help from witch doctors.” **Young man, caregiver**

Those diagnosed often described a sense of relief and reassurance in finally understanding the cause of their symptoms. However, a few young people disbelieved or avoided the diagnosis and delayed treatment initially.

“When I was diagnosed with TB, I couldn't believe it at first, so I was very confused. I used to drink alcohol and engage in other habits. Initially, I didn't take my medications properly, but after receiving counselling, I stopped those behaviours and began following my treatment regimen correctly.” **Young man on TB treatment**

Managing TB Treatment

Treatment brought both challenges and relief. Adolescents struggled with large pills, while many disliked the unpleasant taste and side effects such as nausea and appetite loss, which could affect adherence and financial strain.

“Before suffering from TB, I did not like eating Malambe anyhow... when I take medication, 10 to 15 minutes after, I feel nauseated. This makes me eat Malambe or else I could spit a lot... To avoid nausea, I just eat Malambe.” **Young man on TB treatment**



Weaknesses made travelling to health facilities exhausting, and indirect costs from transport and lost income continued to be major barriers. Long, expensive trips often led to missed appointments and interruptions in treatment.

“Trying to escort my brother-in-law to the hospital, transportation is always a problem. Sometimes we do not go to the hospital to receive the treatment because of transport.” **Young man, caregiver**

While stigma and fear of judgment could affect adherence and social participation, counselling and support from healthcare providers encouraged adherence and inspired positive behaviour change. Young people gained happiness and hope through their improved health and the love, gifts and support they received from family and friends.

“I started taking TB treatment, I am now fine. I have more energy. I am able to climb steps but then I could not. I can even run now.” **Young woman who completed TB treatment**

Recovery and Life After TB

Recovery after treatment was both a period of renewed hope and continued difficulty. Some participants continued to experience weaknesses, breathlessness, and fatigue. As physiotherapy for post-TB pulmonary rehabilitation was only available at higher level hospitals, many young people struggled to access these services.

“... on physical exercises, for some of us, Bwaila hospital is far from where we live... So, how can we manage to attend these [physiotherapy] sessions twice a week?” **Young man on TB treatment**

The economic impact endured, with disrupted education, job loss, depleted savings, and, in some cases, collapsed businesses. Caregivers also faced financial strain while supporting their relatives who lost work and income due to TB.

“Since my brother-in-law got sick, we found it difficult to find food. He was the breadwinner and stopped going to work. Finding food is hard, and also for me to eat at home it's problematic.” **Young man, caregiver**

While some regained strength and reconnected with social networks, others still faced stigma, affecting relationships and self-esteem. The ability to resume certain activities and rebuild connections fostered a sense of normalcy and optimism for the future.

Recommendations by Young People with TB for Action and Change

Participants, alongside healthcare workers, policymakers, and community leaders, co-developed the following recommendations to improve person-centred TB care for adolescents.

NTLEP and Ministry of Health to Strengthen TB Systems and Services

- ➔ Integrate mental health support into TB treatment to provide holistic care and address the gendered impacts of stigma and discrimination.
- ➔ Improve access to physiotherapy and rehabilitation during and after treatment to support recovery and well-being.
- ➔ Provide nutritional support to help young people maintain a healthy diet, aiding medication adherence and recovery.
- ➔ Expand mobile clinics and outreach services to reach adolescents and young adults in schools, workplaces, social spaces, and through decentralised drug distribution points.

MoGCDSW, NTLEP, and Ministry of Youth and Sports to Promote Youth Engagement and Empowerment

- ➔ Create youth platforms for peer support, advocacy, and information sharing among young people affected by TB.
- ➔ Ensure economic empowerment and social protection to reduce the impact of lost education, work, and income, and support family stability during TB treatment.
- ➔ Offer counselling and legal support for newly diagnosed young people to uphold their rights, dignity, and address any discrimination they may face.

All Stakeholders Must Ensure Collaboration in:

- ➔ Develop inclusive TB policies and foster multi-stakeholder collaboration that address gender and youth-specific needs in TB programmes and services.

- ➔ Implement stigma-reduction campaigns through community outreach and media, using TB survivors, community health workers, and local leaders to deliver targeted health education that challenges gendered misinformation and empowers young men and women.
- ➔ Incorporate TB awareness into schools, youth clubs, churches, and marketplaces.

Conclusion



Young people in Malawi are being left behind in TB care - a gap with serious health, social, and economic consequences. Adolescents and young adults with TB face delayed diagnoses, disrupted lives, and limited support. Their lived experiences, captured through photography and storytelling, highlight the urgent need to reimagine TB services that are not only accessible, but also age-appropriate, gender-responsive, and compassionate.

The insights from this study make clear: recovery is possible when young people receive timely diagnosis, supportive counselling, inclusive care, and social protection. By listening to youth voices and co-designing interventions with them, we can develop more effective, people-centred TB responses that restore dignity, reduce stigma, and improve health outcomes.

To end TB, we must include and empower young people as partners in the response.

References

1. World Health Organization [WHO]. Global tuberculosis report 2024. Geneva: WHO; 2024.
2. Sutton-Brown CA. Photovoice: A Methodological Guide. Photography and Culture. 2014;7(2):169-85.
3. World Health Organization [WHO]. End TB Strategy. Geneva: WHO; 2015.

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Leaving no-one behind: Transforming Gendered pathways to Health for TB (LIGHT)

LIGHT, a six-year cross-disciplinary global health research programme, funded by UK aid, aims to support policy and practice in transforming gendered pathways to health for people with TB in urban settings in several African countries. This approach leads to enhanced health, well-being, and socio-economic outcomes and contribute to ending TB.

Partners



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