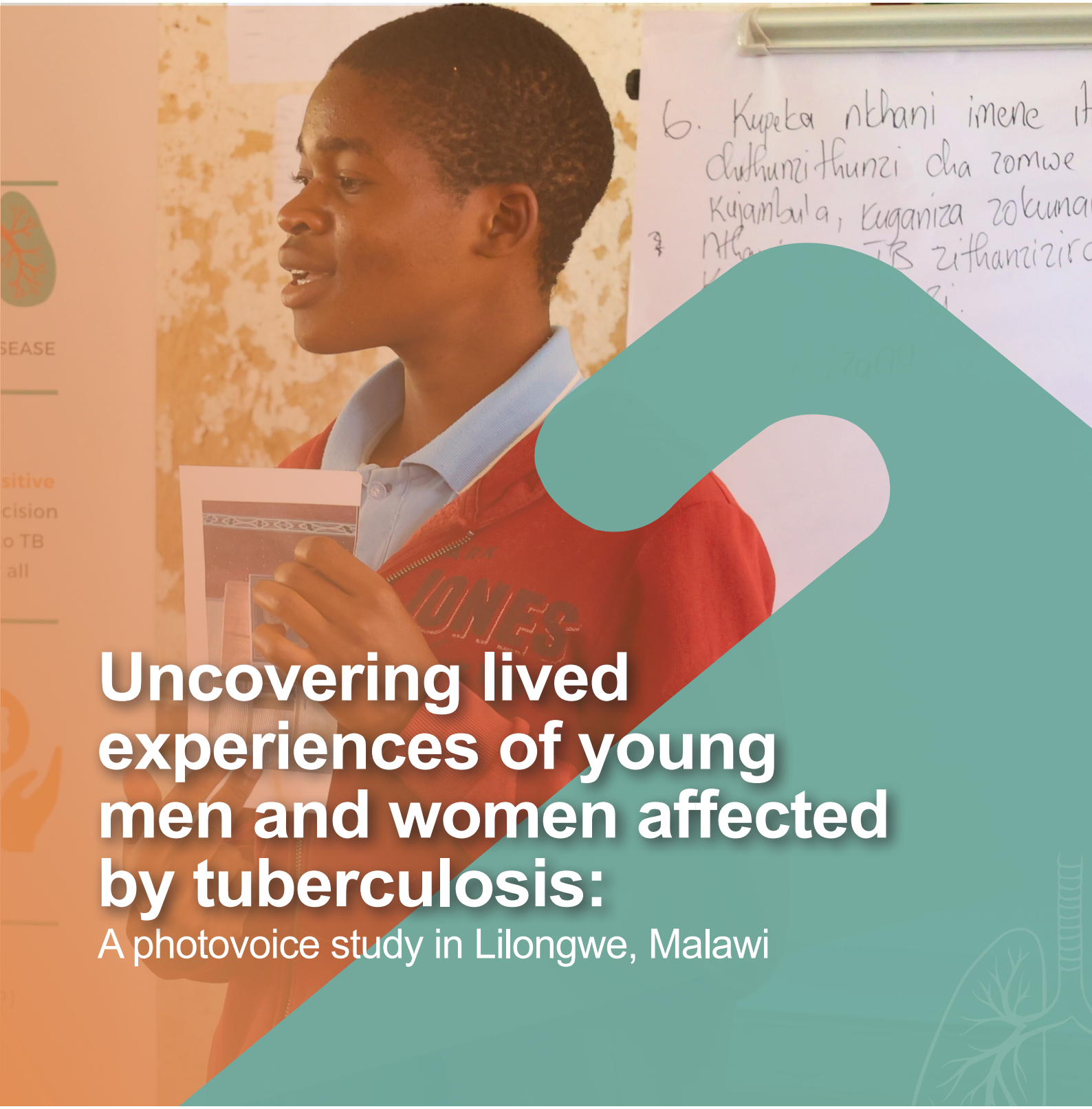
THE LIGHT CONSORTIUM

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



Uncovering lived experiences of young men and women affected by tuberculosis:

A photovoice study in Lilongwe, Malawi

Partners: AFIDEP African Institute for Development Policy; LSTM; London School of Hygiene & Tropical Medicine; mli Makerere University Lung Institute; ReSOK Respiratory Society of Kenya; Zankli Research Center

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> **A person-centred and rights-based approach, one that ensures timely access to effective tuberculosis (TB) drugs for all, regardless of gender — is essential for tackling the root causes and closing the treatment gap.**

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List of Abbreviations

AFIDEP	African Institute for Development Policy
DS TB	Drug-Susceptible Tuberculosis
DR TB	Drug-Resistant Tuberculosis
ICPHR	International Collaboration for Participatory Health Research
LIGHT	Leaving no one behInd: transforming Gendered pathways to Health for TB
LSTM	Liverpool School of Tropical Medicine
MLW	Malawi-Liverpool-Wellcome Programme
NTLEP	National Tuberculosis and Leprosy Elimination Programme
NCRSH	National Committee for Research in Social Sciences and Humanities
NYC	National Youth Council
TB	Tuberculosis
WFP	World Food Programme
WHO	World Health Organization

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Executive Summary

Introduction

In 2023, tuberculosis (TB) affected over 10 million people globally and caused approximately 1.5 million deaths, making it the leading cause of death from a single infectious agent. The year also saw a record of 8.2 million new TB cases, the highest since global TB surveillance began in 1995. The disease disproportionately affects adults, particularly men, and 87% of the global TB burden is concentrated in low- and middle-income countries (LMIC). Adolescents and young adults, 15-24 years, are often overlooked in TB prevention and treatment programmes, despite being highly impacted, due to social and economic vulnerabilities.

In Malawi, there has been a notable decline in TB incidence between 2010 and 2021, though treatment outcomes still fell short of national targets. Urban areas in the country, however, continue to show a high TB burden, emphasizing the need for localised intervention efforts. In 2023, young people (15-24 years) accounted for 10.8% of TB cases, with an estimated 2,700 cases, predominantly in young men. 25.7% of these cases (694 individuals) were missed by the health system, with a higher detection gap for young men (29.3%) than young women (21.3%). Despite this significant TB burden, tailored interventions for young people are scarce, as programmatic efforts and research primarily focus on adults and under five populations. The lack of age and gender specific TB strategies, attributed to limited resources and competing health priorities, highlights the need for further research and collaborative efforts to integrate young people into TB programmes to address their unique needs and reduce the TB burden.

Methodology

This participatory research study, implemented by the LIGHT Consortium partners in Malawi, used photovoice methodology to explore the lived experiences of young people affected by TB in Lilongwe. Twelve participants aged 15-24 years- either undergoing or having completed TB treatment, or caring for someone with TB, documented their lived experiences/journeys through photography. Their photographs' narratives were analysed alongside insights from a stakeholder workshop involving healthcare providers, policymakers and community leaders. This collaborative process facilitated a deeper understanding of the barriers young people face and fostered dialogue on potential interventions.

Findings

The study identified a range of physiological, economic, and psychological challenges faced by young individuals affected by TB. It underscored the interplay of health-related and social barriers hindering recovery and access to care. The study highlighted gender-specific impacts of TB, with young women reporting experiences of stigma and discrimination, including associations with sex work and increased vulnerability to HIV/AIDS, while young men reported challenges in fulfilling societal expectations including traditional gender roles as the income providers/ breadwinners leading to economic hardship and social isolation. Despite these challenges, participants demonstrated resilience, with narratives of recovery, support from family and friends, and behavioural changes contributing to positive outcomes. Stakeholders' engagement played a critical role in facilitating dialogue across national, district, community, and health systems, enabling the identification of targeted actions to enhance health outcomes and provide tailored support for young people affected by TB.

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Conclusion

Findings from this study highlight the urgent need for youth-centred TB approaches in Malawi, incorporating mental health, rehabilitation, and economic support. Photovoice proved to be a powerful/ effective tool for bridging gaps between young people affected by TB and stakeholders, fostering collaborative solutions.

Summary of recommendations

1. **Restoration of physical health**

   Provision of rehabilitation services including physiotherapy with well-trained physiotherapists.

   Provision of nutrition and dietary support.

2. **Mitigation of economic challenges**

   Linking young people to agencies providing loans such as NEEF, TEVET, including the social cash transfer by MoGDSW after completion of treatment.

   Strengthening mobile clinics.

3. **Preventing emotional and social harm**

   Provision of targeted TB programmes, wholistic care and mental health care for the youth.

   Incorporate TB mental health programmes into education curriculum.

   Strengthen reporting and support systems of abuse within government structures including provision of counselling and legal support for those victimised.

   Implementation of public awareness programmes by the government and partners including radio and TV stations.

4. **Promoting positive experience**

   Creation of youth TB forums for engagement and support.

5. **Strengthening TB programmes**

   Creation of a database for TB registered cases with age and gender disaggregation.

   Promote scientific research to address age specific TB issues informing programmes.

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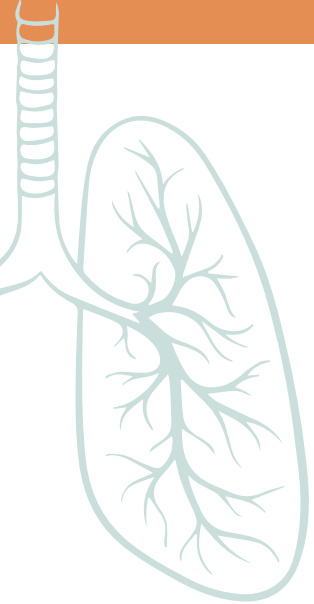
1.0 BACKGROUND



1.0 Background

In 2023, tuberculosis (TB) was reported to have affected over 10 million individuals globally (1). With approximately 1.5 million deaths annually, TB remains the leading cause of mortality from a single infectious agent worldwide (2–5). About 8.2 million individuals were newly diagnosed with TB in 2023, marking the highest number of cases reported by the World Health Organization (WHO) since the initiation of global TB surveillance in 1995 (3). Approximately 90% of individuals who develop TB annually are adults, with a higher incidence observed in men compared to women (6). Consistent with previous reports, the data indicates that 30 predominantly low- and middle-income countries (LMICs) account for 87% of the global TB burden (3,7,8) . Among the 8.2 million individuals newly diagnosed with TB in 2023, 55% were men, 33% were women, and 12% were children and young adolescents (3). Although TB incidence declined by 6.3% globally between 2015 and 2018, this fell significantly short of the 20% reduction target set for 2020 (9), and the infection has since demonstrated a concerning increasing trend in morbidity and mortality worldwide (3) .

Approximately, TB affects 850,000 adolescents (10-19 years) and 1 million young adults (15-24 years) yearly (10). TB, often linked to poverty-related factors such as substandard housing, poor living conditions, food insecurity, low educational attainment, financial hardship, and psychosocial stressors, presenting substantial barriers to accessing healthcare (11–14). Adolescents and young adults are particularly affected, as these challenges intersect with a critical developmental stage characterised by rapid biological changes and evolving social roles (10). Most TB treatment programmes predominantly target adults and children under five years of age, with limited focus on adolescents and young adults (13,15–17). This is further compounded by healthcare providers' prevailing perceptions of TB as primarily a disease affecting adults and under five children, leading to the underrepresentation of young people in TB-related interventions and services (13).

Malawi experienced a significant reduction in TB incidence in 2021, with rates declining from 338 to 132 cases per 100,000 population from 2010 to 2021 (18). Improvement in treatment was equally observed, however, still below the national TB and leprosy control strategic plan of 90% achievement (4). The 2013–2014 National Tuberculosis Prevalence Survey in Malawi estimated a rate of 1,014 per 100,000 population for bacteriologically confirmed pulmonary TB among adults aged 15 years and older, with a higher burden observed in urban areas. These findings highlighted the need for targeted TB interventions within urban settings (18).

1.1 Rationale

Age-disaggregated data suggests that about 1 in 10 TB incidences in Malawi occur in young people (aged 15-24) (19). However, specific interventions tailored to this population are lacking in Malawi. In 2023, an estimated 2,700 adolescents and young adults developed TB, accounting for 10.8% of total cases, with more cases in young men than women (19). While 2,006 cases were officially notified, around 694 young people, nearly 1

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in 4, were missed by the health system, reflecting a case detection gap of 25.7%, higher among young men (29.3%) than young women (21.3%) (19).

Young people can be overlooked in programmatic efforts to end TB (15). Research studies focus primarily on assessing TB incidence rates and documenting drivers of TB disease including programmes tailored for adults and other populations, however, TB interventions explicitly designed for young people are limited (15,16,20). The absence of age and gender specific TB intervention strategies may be attributed to constrained resources and the prioritisation of other pressing health issues (21). Further research and collaborative efforts are necessary to fill this gap and seek out age and gender-specific ways of addressing TB among young people (aged 15-24) in Malawi. Integrating young people into TB programmes is crucial for addressing their unique health needs and for effectively mitigating the TB burden within this demographic (22).

1.2 Research Aim and Objectives

The research aimed to inform and influence policy and practice by addressing gender barriers to health among adolescents and young people aged 15-24 affected by TB in the urban setting of Lilongwe, Malawi. Specific objectives included;

I. To explore barriers experienced by young people (aged 15-24) in accessing timely and appropriate TB diagnosis and treatment in urban areas of Lilongwe.

II. To understand the experiences of young people (aged 15-24) from households affected by TB and what impact it has on them.

III. To engage young people (aged 15-24) and stakeholders in leading the development of strategies for youth-friendly TB services.

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The LIGHT consortium aims to contribute to real world change through generating new evidence to inform policies that are gender-responsive and effectively actioned to improve male access to quality TB care

2.0 METHODS

2.1 Introduction

This study was conducted as part of the 'Leaving no-one behind: Transforming gendered pathways to health for TB' (LIGHT) Consortium, a six-year interdisciplinary global health research initiative funded with United Kingdom (UK) aid. Led by the Liverpool School of Tropical Medicine (LSTM), the consortium involved partnerships across Kenya, Malawi, Nigeria, Uganda, and the UK. The study aims to inform and influence policy and practice by addressing gender barriers to health among adolescents and young people aged 15-24 affected by TB in the urban setting of Lilongwe, Malawi. The study employed the photovoice approach which is a participatory research and community engagement method that allows individuals especially from marginalised or underserved communities to capture their experiences and perspectives through photography (23). The study was jointly implemented by LIGHT partners, the African Institute for Development Policy (AFIDEP), the Malawi Liverpool Wellcome Programme (MLW), and LSTM in collaboration with the Malawi Ministry of Gender, Community Development and Social Welfare (MoGCDSW) and the Malawi National Tuberculosis and Leprosy Elimination Programme (NTLEP).

2.2 Study Design

The study employed the photovoice methodology, a participatory research approach that enables participants to narrate their lived experiences through photography (23). Photovoice enables individuals from marginalised communities to visually document and reflect on social challenges impacting their lives. By facilitating the expression of often overlooked or invisible issues, photovoice fosters dialogue, empowers participants by amplifying their voices, and encourages policymakers to recognise and respond to the concerns raised. The photovoice research was conducted in 3 phases as shown in Figure 1.

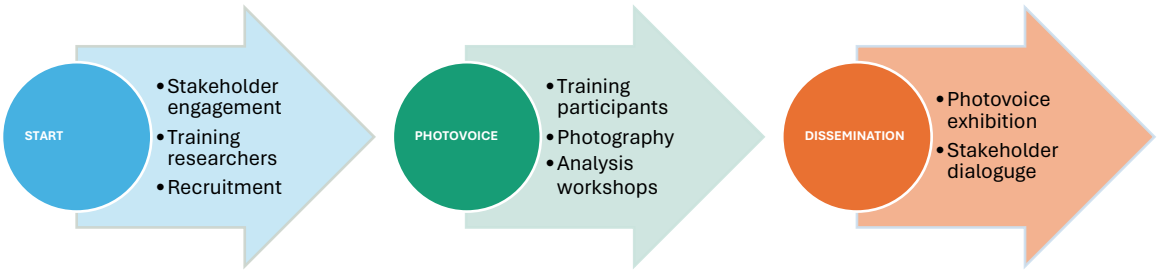

Figure 1. Three phases of the photovoice study

i. **Start Phase** (February–April 2024)

Administrative clearance was obtained from the Lilongwe District Health Office. Ethics clearance to conduct the study described in the methods section (4, subsection IV) was sought to implement the study. Co-researchers were identified from the NTLEP and the MoGCDSW. Research assistants were recruited, followed by a three-day hands-on training for the research team, which focused on essential skills and knowledge in participatory health and photovoice research. Photovoice participants were subsequently recruited.

ii. **Photovoice Phase** (April- May 2024)

Participants took part in a series of workshops, which we describe in more detail in "Data collection". Following a theoretical introduction to the research, photography techniques, and ethical considerations, they were provided with cameras to document their lived experiences through photography. In subsequent workshops, participants described the significance and context of the images they captured.

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iii. **Dissemination Phase** (June 2024)

A participatory workshop was held involving photovoice participants and key stakeholders. During the session, participants presented their photovoice exhibitions and shared their insights. Together with stakeholders, they explored the findings and identified priorities for developing youth-friendly TB services.

2.3 Study Site

The study was conducted in Lilongwe city in collaboration with Bwaila Hospital. Lilongwe developed from a fishing village (Old Town) on the banks of river Lilongwe to become Malawi's Capital City in 1975 (New Town). Today, Lilongwe has a population of about 1 million people, of whom nearly a quarter are young people (age 15-24). Research activities were conducted within the catchment area of Bwaila Hospital located close to the banks of river Lilongwe in the city's Area 2 (Old Town). Bwaila Hospital is a secondary referral centre for people from primary healthcare centres within Lilongwe and neighbouring regions, providing outpatient and inpatient services for infectious diseases, maternal and child health care, and reproductive health, among others. The facility caters to an average of 20,000 individuals monthly, including people with TB. The hospital has an inpatient capacity of around 100 beds for TB patients, both male and female, and an outpatient department providing TB screening, testing, and follow-up.

2.4 Study Population and Sample Size

The primary photovoice participants were young people affected by TB (age 15-24 years) in Lilongwe. These included young people who received TB treatment for at least two months or had completed TB treatment within the past 12 months at Bwaila Hospital; or were caregivers for persons with TB enrolled at the hospital. In addition, key TB stakeholders, including TB policymakers, healthcare providers, programme managers, and community leaders (Table 1), were engaged as secondary participants in the dissemination workshop.

The sample size of photovoice research projects tends to be small in the range of reported 10 participants as mean photovoice project size (24) and 13 participants as median photovoice project size (25). Like similar studies with young people (26), this study sought to recruit up to 16 participants to accommodate for any possible withdrawals during the study. A sample size of 20 stakeholders was determined appropriate to ensure meaningful dialogue and stimulate new possibilities for action towards improving TB prevention and care for young people in Malawi.

Participants were purposively sampled from the TB register with the support of healthcare workers at Bwaila hospital and screened for eligibility. Participants received written information about the study objectives and procedures, voluntary participation, confidentiality, and risks of participation. Written informed consent was obtained from young adults (aged 18-24 years) and assent from adolescents (aged 15-17 years) plus written informed consent from the adolescent's parent or guardian. Young people diagnosed with TB but not on treatment, or whose family member with confirmed TB was not on treatment, as well as minors whose parent or guardian did not consent were not eligible for participation. Only one affected individual was recruited per family.

The study recruited 14 participants, of which 2 were unreachable through phones after recruitment. A total of 12 young individuals affected by TB participated in the study, comprising 3 adolescents and 9 young adults, 7 males and 5 females. Among them, 4 had completed TB treatment, 4 were undergoing treatment for drug-sensitive TB, and 1 was being treated for drug-resistant TB. Three participants were caregivers of individuals

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with TB, some of whom were also TB survivors. Regarding economic activity, 2 participants were inactive, 5 were students, 1 was formally employed, and 4 operated small businesses.

A workshop with key stakeholders (Table 1), involved in managing, delivering, and promoting TB services at various levels was conducted. These included community leaders, healthcare workers, TB programme managers and officers, TB programme implementation partners, and health journalists. Researchers identified stakeholders through existing collaborations and consultations with policymakers. At the workshop, research assistants obtained formal written informed consent from stakeholders for the study.

Table 1: List of stakeholders invited for the action meeting

Level	Types of stakeholders	Number of stakeholders
National	National Youth Council TB programme manager TB programme M&E officer	3
District and community	Community leaders Community TB officers Gender Officer Community Health volunteers	7
Health care providers	Lilongwe DHSS Health care workers	4
Implementation partners	Facilitators of Community Transformation (FACT) PARADISO Patients Trust Development from People to People (DAPP)	3
Others	Journalists	3
Total		**20**

2.5 Data Collection

Data collection took place between April and June 2024 through photography and participatory workshops, drawing on methods previously piloted in LIGHT research in Nigeria and Kenya. The research team conducted workshops in the Chichewa language to ensure participant engagement, with audio recordings, field notes, and photographic documentation used to capture data.

In the first workshop, participants received training on photovoice methodology, ethics, photography skills, and planning their projects. Over two weeks, they used digital cameras to document their experiences of TB, with ongoing support from researchers. In a follow-up workshop, participants shared and discussed their photographs using the SHOWED framework: S… What do you SEE here? H… What's really HAPPENING here? O… How does this relate to OUR lives? W…WHY does this problem or situation exist? E… How could this image EDUCATE the community/policymakers? D… What can we DO about the problem or situation? (27,28). They identified themes, data gaps, and areas for further analysis. A second collaborative analysis

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workshop was held where participants refined themes, selected key images, and developed captions for the exhibition.

In June 2024, a stakeholder dissemination workshop was held in Lilongwe. Participants presented their findings to TB stakeholders through photos and storytelling, initiating dialogue on youth experiences and needs in TB care. Stakeholders provided feedback and explored actions to improve youth-friendly TB services.

2.6 Analysis

Data analysis was conducted using a participatory approach, with participants actively engaging in identifying and refining key findings. Audio recordings from research activities were transcribed verbatim, using pseudonyms, and verified by two researchers. Original audio files were deleted once transcripts were verified. Using the SHOWED method, researchers and participants jointly analysed the photographs, clustered similar issues, and developed themes while exploring potential solutions. Researchers supplemented these efforts with a framework analysis to address specific research questions, mapping and contextualising participant-identified themes. This collaborative process combined participant-driven insights with academic rigor, resulting in a comprehensive and inclusive understanding of the challenges and priorities related to TB care. The narratives of young people were drawn from the photos and captions they presented, while the policy and programmatic implications are based on discussions with various TB stakeholders during the action workshop.

2.7 Ethics, Data Management and Safeguarding

This research adhered to ethical principles and obtained clearance from the Liverpool School of Tropical Medicine Research Ethics Committee (23-046) and the National Committee for Research in Social Sciences and Humanities (NCST/RTT/2/6) in Malawi. Administrative clearance was obtained from Bwaila Hospital and Lilongwe District Health Office. Participation was voluntary, and informed consent was obtained from participants. For young people below the age of 16, their parents or guardians were responsible for the consenting on their behalf. Strict confidentiality measures were implemented throughout the study to protect participants' privacy and data. Data management adhered to strict ethical standards to ensure confidentiality and participant privacy. Photographs from the photovoice process were securely transferred to encrypted research computers, labelled with pseudonyms, and safely stored. All photo files were deleted on SD cards afterward. Safeguarding procedures were implemented to protect participants from exploitation, abuse, and harassment. All researchers underwent safeguarding and ethical practices training prior to research commencing.

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3.0
RESULTS

The findings of the study are structured around four themes encompassing the lived experiences of young people affected by TB and identified implications for policy and programmes that emerged from the stakeholder dialogue. The experiences of young people affected by TB are multifaceted, reflecting the profound impact that the disease has on various aspects of their lives. They are faced with physical health challenges (Theme 1), economic burden (Theme 2), and psychosocial harm (Theme 3). Their narratives also illustrate the ways in which they coped and found positive aspects such as support amidst their struggles (Theme 4).

3.1 Physical Health Challenges

TB-affected young people experience a range of physical health challenges resulting from their TB diagnosis and as caretakers. During young adulthood, individuals undergo significant developmental transitions as they navigate their roles within society and manage responsibilities related to daily living (29,30). This life stage is characterised by active engagement in various domains, including physical pursuits such as sports, economic activities, and the assumption of socially constructed gender roles (31). Physiologically, their bodies are typically at full functional capacity, supporting their participation in these diverse activities and shaping their motivations and behaviors (31,32). Young people in the study verbalised physiological challenges as a result of TB. These challenges significantly impacted their daily lives and physical capabilities, illustrating the severe stress that TB exerts on the health and overall well-being of young people.

a) Pain and Discomfort

Some participants reported pain and discomfort as significant physical health problems. They frequently experienced severe coughing and pain in the ribs, highlighting the chronic nature of TB symptoms and their impact on young people's well-being.

> In my photo, you can see the medication I was taking. I was very sick and coughing excessively. When my mom asked what was wrong, I told her about my severe cough and rib pain. She decided to take me to the hospital, suspecting it might be TB. After being tested at the hospital, I was diagnosed with TB. Surprisingly, I felt relieved to finally know what was wrong.

Young man on TB treatment (P7)

> These are the wastes that I used to sweep while attending Madrassa (Islamic school). The dust would often fill my nose, causing me to cough and sometimes vomit. In summary, I experienced significant discomfort.

Adolescent boy completed TB treatment (P4)

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The symptoms continue to affect individuals even as they undergo treatment and are declared cured. Addressing TB's physical symptoms requires not only effective medical treatment but also ongoing care to manage and alleviate the chronic pain associated with the disease.

b) Physical Weakness

Many adolescents and young adults reported symptoms such as weakness, pain, breathlessness, and fatigue during and post TB. These symptoms interfered with their ability to carry out routine tasks, including those associated with socially ascribed gender roles. Young women particularly highlighted the burden TB placed on fulfilling domestic duties such as fetching water and cooking which were integral to their daily responsibilities.

> Before I fell ill, I could carry two buckets of water from the well to my home. However, after getting sick, I couldn't even carry a bucket on my head. That's when I decided to seek help from the hospital. Upon assessment, it was clear I was very weak and lacked the strength to do many things

Adolescent girl completed TB treatment (P12)

While a few young men mentioned challenges with household chores, they more frequently described limitations in performing physically intensive paid work, such as lifting heavy loads or operating machinery.

> You can see on the picture it's the cylinder head of a car engine. That time, before I was diagnosed with TB, I could break this engine on the middle without problem. But now I fail to break this engine because I experience shortness of breath. So, I feel sorry that I can no longer break the engine meaning I don't have energy

Young man on TB treatment (P6

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> In this photo, you can see levelling equipment, a knife, and measuring tools, including a proper knife. Before I became ill, I could handle physically demanding tasks like construction and similar work. I could lift heavy blocks without difficulty. However, now it's challenging for me to do these tasks, especially due to the dust, like cement and others, which contributed to my illness. I can no longer perform this type of work, and I feel like I've lost that ability. Currently, I struggle with many everyday tasks.
>
> **Young man on treatment (P10)**

The loss of physical capacity was especially distressing for young men, as it undermined their perceived physical strength and interrupted their engagement in manual labour. Caregivers also noted that those under their care experienced physical weakness, with one caregiver specifically reporting:

> This photo brings back memories of the struggles I faced when my brother-in-law was suffering from TB. After his diagnosis, he became unable to walk, and we had to carry him everywhere. This is the photo I took reflecting that time.
>
> **Young man, caregiver (P9)**

Participants questioned the lack of government support for individuals with post-treatment complications like physiotherapy. Available services, commonly scheduled during school hours, were inaccessible for young people.

> The doctor used to call my people to attend physiotherapy. But we were sad because the time I was being asked to attend the sessions is also the time I am in class. Why did they put the time we are in class as the same time for attending physiotherapy? Because at that time, we miss important subjects.
>
> **Adolescent boy (P4)**

The inability to perform everyday tasks highlights the debilitating impact of the disease on the daily lives of young people. TB diminishes physical strength, even beyond the lifespan of the disease, limiting individuals' ability to perform routine tasks, thereby disrupting their overall quality of life, well-being and sense of self-sufficiency.

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c) Medication and Side Effects

TB medications, while essential, brought their own set of challenges for young people. Participants reported varying levels of struggle ranging from pill size, typically among adolescents, to nausea and change of eating habits.

> When I was diagnosed with TB, I was given very large tablets, which were too big for my age!"
>
> **Adolescent boy completed TB treatment (P4)**

> I have come with my picture. You can see I was eating Malambe, this was hard. This shows the burden of being forced to eat something. Before suffering from TB, I did not like eating Malambe anyhow. But when I was sick, particularly when I take medication, 10 to 15 minutes after, I feel nauseated. This makes me eat Malambe or else I could spit a lot. This brings discomfort to friends seeing me spit around. To avoid nausea, I just eat malambe"
>
> **Young man on TB treatment (P10)**

Medication associated challenges signify the constant dual burden of managing the illness and dealing with the side effects of the treatment, which can exacerbate their suffering among young people with TB. These challenges can further deter adherence to treatment regimens, potentially prolonging the illness and worsening health outcomes.

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3.2 Economic Challenges

Although TB treatment is provided at no cost in low-resource settings such as Malawi, individuals affected by TB often endure significant economic hardship due to income loss, a factor that has been closely associated with adverse clinical outcomes, including treatment failure and mortality (33). Young people reported significant challenges in generating income following a TB diagnosis. Some described losing employment or having their jobs terminated due to their illness, while others were unable to continue working because of physical debilitation caused by TB. Additionally, several individuals were forced to discontinue their education to care for ill family members and themselves. These disruptions collectively hindered their ability to achieve economic independence and provide financial support for themselves and their families. Young people identified the high cost of care, interrupted education, and loss of employment as key consequences of the economic burden associated with TB.

a) High Cost of Care

Financial hardship was a consistent challenge for the young people, with many incurring substantial costs associated with their illness, intensifying existing economic vulnerabilities. Lengthy diagnostic and care pathways, involving numerous medical consultations prior to receiving a definitive TB diagnosis, caused financial strain among young people and their families.

> …I visited multiple hospitals, spending a significant amount of money before finally discovering that I had TB. Since I didn't know what I was dealing with, I often sat alone, reading or doing other things, while my friends distanced themselves from me."
>
> **Young woman (P5)**

Additionally, young people's narratives illustrate how financial challenges and TB reinforced each other, with impoverishment from the disease further complicating access to health services. This was mainly due to logistical difficulties to maintain regular hospital visits throughout the course of 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 (P9)**

Experience underscores the broader economic impact of TB, where the high cost of care and transport can deplete financial resources, leaving TB-affected individuals and families vulnerable.

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b) Disrupted Education

TB markedly disrupted the educational trajectories of many young people. The combined impact of physical illness, medical expenses and financial hardship frequently led to prolonged absences from school or complete withdrawal from academic pursuits.

> This photo shows a bucket with water spilling out, symbolising my life's journey. When I was healthy, I had a strong desire to return to school. I packed my certificate, despite its poor results, and planned to resume my studies. However, when I fell ill, I had to stop attending school and remained at home. The money my husband had saved for my education and exam fees was instead used for my medical care to help me recover. This bucket and water represent the loss of everything I had worked towards. My husband lost his job, and we have been facing significant challenges due to TB. It has caused considerable strain in our marriage and disrupted many aspects of our lives."
>
> **Young woman completed TB treatment (P5)**

> …When I became ill, I had already taken my Form 4 exams in 2022 which I did not do well. In January 2023, due to my illness, I found myself repeating Form 3 instead of progressing to sit for the Form 4 exams which were scheduled for September."
>
> **Young woman completed TB treatment (P2)**

TB could also disrupt the education of young people who were caregivers. TB-related loss of household income and time-intensive care for family members with TB adversely influenced their ability to continue their education.

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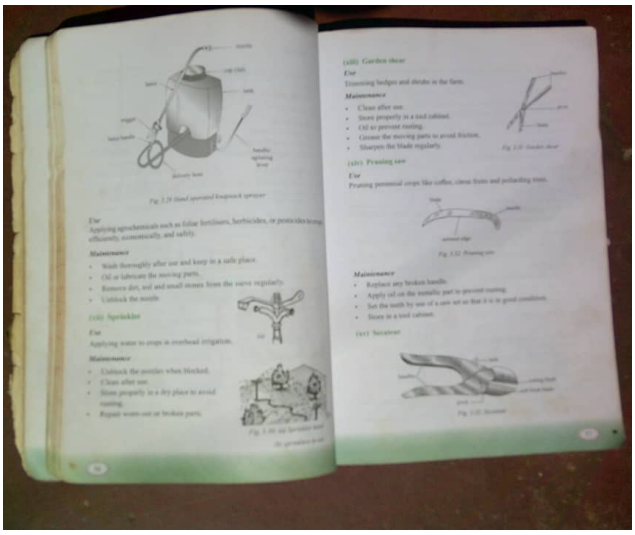

This picture represents my life before my brother became ill. I used to study late into the night or in the afternoon whenever I had free time. However, when he fell ill with TB and became bedridden, I took on the responsibility of caring for him. This included various tasks and responsibilities that left me exhausted, making it impossible to continue studying late at night or during the day when I had free time. My focus shifted entirely to caring for him, even during the afternoon hours

Young man, caregiver (P8)

…My brother, who used to provide financial support, became sick and was unable to work. This made it challenging for him to earn money while lying on a mat. It became difficult to pay school fees and to afford food. Eventually, we faced situations where we were sent home from school, and eventually, we had to stop attending altogether. I took on the responsibility of caring for him, and we endured a period of hardship together."

Young man, caregiver (P8)

Given these challenges, young individuals are at an increased risk of failing to achieve economic self-sufficiency and effectively manage their lives following TB treatment. The socioeconomic impact of the illness often leads to missed employment and income-generating opportunities, hindering personal development and potentially contributing to the broader economic burden on the country (34).

c) Loss of employment and business

Most young people were economically active before developing TB. However, TB disrupted their economic activities, with many unable to continue working or engaging in income-generating activities. Some could not work because of body weakness and lack of energy. Others lost their business after selling assets or using income to pay medical bills. Young people's loss of productivity had profound implications for their financial stability and overall quality of life.

Before I got sick, I was doing small scale business to help my brother. After I got sick, am failing to assist him in running the business and the business did not continue as the capital was used to assist me during my sickness."

Young man on TB treatment (P11)

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> This picture reminds me of how I was before being affected by TB. I was rearing a lot of chickens, but now the business has gone down because the one who had capital is not providing for the business as he is unable to walk now due to his illness."
>
> **Young man, caregiver (P9)**

The loss of economic productivity shows the broader socioeconomic consequences of TB, affecting not only the individuals but also their families and communities. The inability to work or generate income can lead to financial insecurity, compounding the challenges of living with TB (16).

3.3 Emotional and Social Harm

Poor treatment outcomes have been linked to psychological challenges associated with a TB diagnosis, particularly in contexts where individuals experience stigma (35,36). This stigma, combined with the socioeconomic impact of the disease, can severely disrupt social interactions and community engagement, further exacerbating the negative consequences on patients' overall well-being and treatment adherence (35,37). Young people experienced loss of interest in activities, sadness, stigma, social isolation and violence during the period of illness and taking care of the sick. The psycho-social impact of TB on young people was profound. Besides the physical symptoms, the disease can also deeply affect young people's mental and social well-being, including strained family dynamics.

a) Loss of interest in activities

Participants often had to abandon hobbies and interests that once brought them joy and fulfilment due to the physical limitations imposed by TB. One participant shared how TB affected their ability to care for their fruit garden:

> This photo shows some fruits. I used to enjoy planting fruit trees, nurturing them by watering and caring for them. However, due to TB, I began to neglect my fruit trees, causing the fruits to dry up. It was disheartening for me because I have a deep love for fruits."
>
> **Young man on TB treatment (P7)**

Another participant shared how living with TB affected their ability to perform in sports:

> At our school we do sporting activities. I was the best football player. After being diagnosed with TB, whenever I played football, I experience shortness of breath and therefore could not run. So here in the picture I was admiring my friends playing football at school. I still want to play football, but I can't until now. This makes me worried. It's like I lost my chance to play football."
>
> **Adolescent boy completed TB treatment (P4)**

The loss of the ability to engage in these activities further contributes to the psychological burden of TB, as individuals may lose important sources of personal satisfaction and identity. This further reflects the broader impact of TB on the overall quality of life.

b) Sadness

The emotional burden of living with TB triggered feelings of sadness among many participants. This burden was exacerbated by the stigma and discrimination they faced, contributing to a pervasive sense of despair and hopelessness. For instance, one participant described the extreme emotional distress he suffered, stating:

> …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 (P8)**

Such experiences underscore the severe psychological impact of TB, where the intersection of illness and social rejection can lead to severe emotional distress and thoughts of self-harm. The sense of being ostracised by loved ones amplifies the emotional pain, further heightening the complexities of managing the disease.

c) Stigma and social isolation

Stigma and discrimination were pervasive issues in this study. Many participants faced negative reactions from their communities due to the fear and misinformation surrounding TB transmission, leading to social isolation and increased emotional distress. While many young individuals affected by TB reported experiencing stigma, young female adults specifically highlighted additional layers of discrimination within their communities. They were often subjected to assumptions linking their illness to promiscuity or HIV/AIDS, reflecting gender-based stigmatisation and the influence of social norms surrounding gender roles. One participant shared their experience of social exclusion:

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> This was the spot where we spent our break time at school. I used to meet all my friends here, and we'd chat together. However, when I started coughing frequently, my friends would run away, fearing I would spread my cough to them. Eventually, they told me to stay away from this area. During breaks, I could see them sitting there, but whenever I tried to join them, they would all run away. Now, whenever I pass by this place, I'm reminded of how my friends treated me."

Young man on TB treatment (P6)

Another participant described the change in social interactions after their diagnosis as stated below:

> Before I got sick with TB, my friends, relatives, and I would cook and eat together. However, after my TB diagnosis, I had to use separate cooking utensils and eat alone. This photo captures that change in my life."

Young man on TB treatment (P11)

These accounts reveal how rooted fears and misconceptions about TB can lead to exclusionary practices, isolating those affected from their networks. The experience of being treated differently, especially within one's own community, highlights the social divide that TB can create, which may fuel feelings of sadness and depression.

The participants described the numerous challenges they faced in accessing healthcare. Their narratives highlighted delays in diagnosis, which in some instances led to stigmatisation from the community, and the financial and emotional toll of prolonged illness. Some participants expressed how the community discriminated them as follows:

> The time I was sick, we went to different hospitals to seek help, but they could not find anything. People said maybe I was bewitched, so I should go to church for prayers. So, we have been moving here and there to seek help."

Young woman completed TB treatment (P2)

> I was diagnosed with TB whilst I was still attending school, and it caused me to worry constantly. My friends would leave the classroom, but I stayed behind, unaware of what was wrong with me. I visited multiple hospitals, spending a significant amount of money before finally discovering that I had TB. Since I didn't know what I was dealing with, I often sat alone, reading or doing other things, while my friends distanced themselves from me."

Young woman completed TB treatment (P5)

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> The time I was not sick, people were coming to buy from our shop. After being sick and people hearing that doctors couldn't find anything, they started speculating that I was being used for ritual to boost the shop. This made them not to buy from our shop."
>
> **Young woman completed TB treatment (P2)**

d) Violence

Some participants experienced violence and suffering not just from the disease itself but from the lack of empathy and understanding from people around them. This sentiment was expressed by both young people with TB and the caregivers. For instance, one participant recounted a particularly distressing experience with a religious instructor:

Another participant reflected on the harsh treatment they received while caring for a sick relative:

> When I became very sick, I was attending Madrassa. During that time, students who memorised the material but failed to recite it to the Sheikh were punished. Due to my illness and shortness of breath, I couldn't read as much, which he perceived as a failure. As a result, he would beat me and call me various names. I also struggled to memorise the Quran."
>
> **Adolescent boy completed treatment (P4)**

> This picture reminds me of the time I was taking care of the sick by giving him medication. He used to shout at me, saying not so kind words to me. When I recall such, I feel sorry and depressed as to why he shouted at me when was taking care of him."
>
> **Young man caregiver (P9)**

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3.4 Positive Experiences

TB has also been associated with positive experiences, particularly in relation to recovery following successful treatment completion, adoption of healthier lifestyles, and behavioural changes that reduce the risk of reinfection (37). In other settings, patients have reported appreciation for the care received at treatment centers, despite the persistence of certain misconceptions about the disease (37,38). Amidst the numerous challenges faced by young people associated with TB, positive experiences were pertaining to physical recovery, behaviour change, religion and coping mechanisms, and social support were highlighted. According to the young people, positive encounters not only improved their physical health but also provided a sense of hope and encouragement to others facing similar struggles.

a) Physical recovery

Recovery and positive changes brought moments of happiness and hope, emphasising the potential for improvement with proper treatment. One participant described their recovery journey:

> As you can see on the picture. I started taking TB treatment, 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 completed TB treatment (P5)**

These instances of improvement illustrate the transformative power of effective treatment and the importance of adherence to the prescribed regimen. The participant's ability to regain physical strength and resume activities they previously found challenging serves as a beacon of hope for others currently battling TB.

b) Behavioural Change

Behavioural changes emerged as key finding, with participants modifying their lifestyle habits and adhering more strictly to medical regimens. With the support of healthcare professionals, young individuals were able to modify harmful behaviors and demonstrate improved adherence to TB treatment. These changes were crucial for managing TB effectively and improving overall health outcomes. One young person living with TB reported a positive change in behaviour following counselling services that he received during TB treatment.

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> 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 (P12)

c) Religion and spirituality

In response to the multifaceted challenges posed by TB, participants adopted a range of coping mechanisms to navigate their daily lives. These strategies included seeking solace in religion and spirituality, relying on the support of friends and family, and finding personal resilience through various activities. These coping mechanisms played a crucial role in helping participants manage the physical, emotional, and social impacts of the disease. Religion and spirituality played a crucial role for many participants, providing comfort and strength during their struggle with TB. Some participant described how their faith helped them cope with the disease:

> Despite our family having been affected by TB, we didn't stop believing in God. We still go to church despite that the patient has difficulties in walking to church. So, we try to go with him."

Young man, caregiver (P9)

> The time I was taking care of the sick, I had time to read the Qur'an so that he should return to good health. I was encouraged to do good."

Young man, caregiver (P8)

> "While I suffer from TB, what makes me happy is when I read the bible and sometimes watching TV."

Young man on TB treatment (P10)

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d) Social support

The support of friends and relatives was another crucial mechanism that provided significant comfort to the participants. This support alleviated emotional distress and reinforced the importance of strong social support systems in managing the impacts of TB. Some participants shared how the support of friends and relatives helped them feel remembered and cared for:

> …My brother in-law encouraged me to still go to school despite being sick. He is the one who seeks school fees for me. Even though he is ill and it's difficult to find basic necessities at home, he still encourages me to work hard in school."

Young man, caregiver (P9)

> You can see this photo here. It depicts the period when my relative was ill, and the difficulties we faced in moving him. We received this wheelchair at the hospital to make it easier to transport him. Now, I am relieved that I no longer have to struggle to carry him and manage everything myself."

Young man, caregiver (P 9)

Young people reported deriving meaningful insights and positive experiences during their illness and caregiving roles. Guided by health professionals, they gained a greater understanding of medication adherence and healthy living practices essential for recovery. Religious beliefs and social support networks played a pivotal role in fostering emotional resilience and promoting healing. This reveals the critical importance of integrated healthcare support and the value of social and spiritual resources in the effective management and recovery from TB among young people.

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3.5. Young participants and stakeholders recommendations on management of TB and its effects on young people

While stakeholder engagement has demonstrated effectiveness in facilitating the sustainable and impactful implementation of interventions, its strategic integration within National TB Programmes (NTPs) in low-resource settings such as Malawi remains limited (39). Constrained resources and competing programmatic demands hinder comprehensive understanding and application of participatory approaches (39). The study's action-oriented workshop facilitated engagement and dialogue between young people and key stakeholders, including representatives from national, district, and community levels, health professionals, and media personnel to ensure that the challenges faced by young people affected with TB are sustainably addressed within NTPs and broader health and social systems. Participants engaged in an interactive discussion with stakeholders, raising a range of concerns including inadequate care during illness, TB-related misconceptions, lack of preventive resources, limited physiotherapy services, and long travel distances to treatment centres. They emphasised the need for youth-friendly TB services, support for employment and nutrition during treatment, and protection against mistreatment. Agreed recommendations are grounded in the key thematic areas identified during the study: Restoring physical health (see Theme 1); mitigating economic challenges (Theme 2); preventing emotional and social harm (Theme 3); and fostering positive experiences throughout the TB care journey (Theme 4).

a) Restoring physical health

Young participants stressed the importance of physiotherapy by emphasising on its importance including other rehabilitation services for the youth at the hospital. Highlighted were the concerns shared by young participants:

> Just to add. Physiotherapists are less in number. If possible, can we ask from seniors to add such doctors. Thanks"
>
> **Young man on TB treatment (P12)**

> But also, if there could be a gym at the hospital for exercising our bodies and many other things."
>
> **Young man on TB treatment (P10)**

Stakeholders viewed the idea of hospitals incorporating gyms, particularly for managing disease-related complications, as highly beneficial. Acknowledgement was given to the youth's concern regarding the limited number of physiotherapists in hospitals compared to nurses and doctors involved in diagnosing the disease.

> Physiotherapists are not available in health centres. In Malawi, trainings are provided in physiotherapy at different levels: certificate, diploma and degree. But we cannot compare to the numbers of nurses trained in a year, or doctors with degrees, diplomas. ... There are new guidelines of how to assist people affected with TB which have been established this year. In the guidelines, there are clear steps on how to assist people affected with TB to maintain health and wellbeing"
>
> **Stakeholder (SH2)**

One of the stakeholders stated that young people who had completed TB treatment but still felt weak were specially invited to attend physiotherapy sessions held at Bwaila Hospital every Tuesday and Thursday. Additionally, there was a WhatsApp group available for this group, where videos of physiotherapy exercises were shared for those facing transportation challenges. Participants who had completed TB treatment were encouraged to join this platform. It was advised to take physiotherapy equally serious as medication and to attend sessions regularly to regain strength. Participants were advised to commit to a three-month duration of physiotherapy to maintain their health.

The team at Bwaila Hospital agreed to meet and plan the schedule for physiotherapy sessions, particularly focusing on accommodating young people who were often in class during typical session times. However, it was difficult for health workers to arrive at the hospital earlier due to the distance from their homes and similarly challenging for them to leave late for the same reason.

Young people also recommended nutrition and dietary support alongside TB treatment, with one young participant specifically highlighting the importance of maintaining a nutritious diet during the discussion, as illustrated below:

> The drugs demand eating frequently. So, if possible, the hospital should help in terms of food. The patient should be assisted because those drugs have high strength. When taken without food, one can faint or even die. This is a threat to a person suffering from TB."
>
> **Adolescent boy completed treatment (P4)**

Stakeholders and participants noted that nutritious food was supplied only to persons with drug-resistant TB and malnourished children through the World Food Programme (WFP) at the district hospital. It was highlighted that hospitals lacked the capability to provide nutritious food to all patients, but efforts were ongoing to secure support from partners to address this issue.

> On the issue of nutrition, where people should be provided with healthy food to build their immune system, maybe you have heard of instances where some individuals have been provided with food. What is happening is, with the drug-resistant TB patients, at the very beginning, WFP was helping us with food for such patients. But recently, this programme is mostly targeting malnourished children. When it comes to adults, only drug-resistant patients are considered... its these people that government considered to provide nutritious food assistance."
>
> **Stakeholder (SH3)**

b) Mitigating economic challenges

In response to the young participants' request for skill-building and small business opportunities necessitated by school dropout due to TB, stakeholders highlighted the existence of institutions offering such support, as elaborated by one of the stakeholders:

> …There was also an issue of provision of loans for youths to do some work. In the near future, we will also have to push for that for those who have completed taking TB drugs."

Stakeholder (SH3)

> But as a country, we have NIF and other organisations that encourage the youth a lot. If we listen to the radio, on TV and other advisors. They formulate groups and provide information on business plans, farming and other things, and others mentioned that they love to do business... There is also TEVET, if the business papers are adequate, they also provide assistance so that your works do not stop because of sickness but are maintained…."

Stakeholder (SH3)

It was further acknowledged that additional support mechanisms exist, such as those offered by the MoGDSW. One such initiative was the Social Cash Transfer Programme, which targeted vulnerable populations and individuals living in extreme poverty by providing K150,000.00 to support small business development. Consequently, youth affected by TB would be eligible to benefit from this financial assistance.

> …at the Ministry of Gender, the department of social welfare, we have a programme called social cash transfer. This programme targets people who are in extreme poverty and vulnerable such as those who are lame, even those who have ever suffered from TB could have a chance of benefiting from this programme. Through this programme, people receive a total amount of K150,000.00. And as of now, these funds will also be shared in Lilongwe urban areas."

Stakeholder (SH1)

Access to TB services continues to pose a substantial challenge for many young individuals. Although Bwaila hospital is centrally situated in Lilongwe, the considerable distance from the homes of TB-affected youth, combined with socioeconomic hardship, made it particularly difficult for them to access care. The workshop highlighted the need for mobile clinics to bring TB services closer to the communities. One stakeholder explained the current strategies for improving last-mile drug distribution:

> What government is doing is to establish different areas closer to people where TB drugs were distributed."

Stakeholder (SH6)

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Initiatives such as mobile clinics promise to reduce the travel burden on patients, ensuring consistent access to medication and reducing the risk of treatment default. The focus on mobile clinics reflects a broader strategy to decentralise healthcare services, making them more accessible to those in remote areas and addressing one of the significant logistical challenges that hinder effective TB treatment.

c) Preventing emotional and social harm

Young participants emphasised on the challenges related to limited awareness of TB signs, symptoms, treatment options, and access to healthcare services. They equally voiced a strong need for targeted support and interventions. Several participants shared personal perspectives to illustrate these concerns:

> Okay, you were saying prevention, how can we prevent TB to avoid re-infection."
>
> **Young man on TB treatment (P10)**

> I would like to request for one thing. You see that photo of ashes towards the corner. This photo with ashes is mine. I cannot do my work without ash. Many people tell me I contracted TB from ash. I want to ask if possible, we should be provided with masks from the hospital to wear when working"
>
> **Young man on TB treatment (P6)**

> My views are, if we could have an opportunity to link with fellow Malawians in different ways to end the abuse for people like us affected with TB."
>
> **Adolescent girl completed TB treatment (P1)**

> ..If there could be ways on reviving our dreams which died because of being affected by TB. I believe that would be good."
>
> **Young man on TB treatment (P10)**

Upon reviewing the displayed photos, stakeholders highlighted the importance of raising awareness to reduce stigma, providing holistic TB care and enhancing accessibility for mental health support. The proposed actions included integrating mental health education into school curricula and community programmes, as well as establishing mental health clubs to offer training opportunities. A gap was identified in the under-reporting of abuse against TB patients and insufficient support systems. The proposed actions included strengthening reporting mechanisms and support services within government structures, as well as providing access to counselling and legal support for those facing discrimination

> We need to raise awareness to improve access to mental healthcare. So, the other solution is to integrate the mental health education to our school curriculums as well as community programmes…. we can also establish mental health clubs so that we provide trainings."
>
> **Stakeholder (SH1)**

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> I think many who are diagnosed with this disease or have suffered from it, experience abuse and all. I think there's a gap of under-reporting as well as a lack of support for people tortured and abused… we need to strengthen reporting and support mechanisms. We are also supposed to provide access to counselling and legal support service."
>
> **Stakeholder (SH1)**

Stakeholders noted that TB impacted the lives of young people and that many experienced discrimination, underscoring a lack of adequate information among the general population. As a result, raising public awareness was deemed essential. Stakeholders recommended awareness campaigns on TB transmission and prevention by the government and relevant organisations to reach a broad audience. Furthermore, radio stations were encouraged to develop and broadcast programmes focused on TB as part of these awareness efforts.

d) Promoting positive experiences: Young people's TB platform

It was observed that young people affected by TB lacked a platform to express their concerns, unlike those affected by HIV and AIDS. Therefore, stakeholders recognised the importance of supporting the creation of such a forum to ensure that young TB patients have a strong voice.

> I Just wanted to emphasise that as we are here, all young people, the major action point going forward is that the youth seated in here have no platform for which they can discuss issues concerning TB as youth. This is what I see, it's a very huge gap. HIV has a platform. People living with HIV have a network."
>
> **Stakeholder (SH9)**

e) Strengthening TB programmes: Research, database

The importance of research in addressing policy and interventions was emphasised by stakeholders. This came as a response to one of the young participants concern over government lacking interest in provision of TB programmes as stated below:

> You mentioned that the government wasn't interested in TB physiotherapy programmes back in the year, why was this the case?"
>
> **Young man on TB treatment (P10)**

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The stakeholders stated the main reason why government had not implemented as many TB programmes in the previous year was as a result of the need for evidence through research. One of the stakeholders emphasised the need for research as stated:

> Before government or any other organisation implements anything, there is need for evidence to implement the programmes."

Stakeholder (SH2)

This underscored the critical need for evidence-based decision-making and the adoption of globally validated policies and strategies. It also reflected the challenges associated with implementation hesitancy, particularly when programme execution is contingent upon donor funding, often resulting in delays in initiating or carrying out planned interventions.

Stakeholders discussed the need to establish of a centralised TB database accessible to all involved parties. A debate regarding whether this database should be accessible upon request was held, with some stakeholders questioning its appropriateness. However, a representative from the Quality Management Directorate (QMD) clarified that data was already accessible at the primary, zonal, and national levels. She explained that the information shared during dissemination meetings and TB Technical Working Group (TWG) sessions, which include a broad range of stakeholders as stated:

> Yes. The database is there at national level. Of course, it starts from the primary care level from the health centre to their office, to the district. And at district they have the zones through the central. But also the data is available in the DHIS2 system."

Stakeholder (SH7)

It was agreed that the MoGDSW would be included in the TB TWG meetings to enhance their understanding of the challenges faced by individuals affected by TB and to enable them to contribute informed perspectives toward supportive interventions. Furthermore, a consensus was reached for the QMD and the MoGDSW to collaborate on the development of a policy addressing TB and gender, with technical and financial support from partners such as FACT Malawi.

f) Action points

Action points were derived from the workshop with stakeholders assigning next steps to the responsible departments as follows:

Physical well-being

- Bwaila Hospital management team with support from stakeholders to facilitate training of health workers, including Health Surveillance Assistants (HSAs), to provide basic physiotherapy support to those affected by TB.
- Young people to practice simple exercises in their homes to regain strength.
- Young people who have completed TB treatment but still feel weak to attend physiotherapy sessions held at Bwaila Hospital every Tuesday and Thursday. Bwaila Hospital to ensure involvement of young people through TB department.
- Young people affected by TB to join WhatsApp group where videos of physiotherapy exercises are shared for those facing transportation challenges. Bwaila Hospital management team through TB department to spread awareness of the WhatsApp group to people affected with TB.

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- Bwaila Hospital team to meet and plan the schedule for physiotherapy sessions accommodating the young people.
- Young people to attend sessions for 3 months to regain body strength. Bwaila Hospital to spread awareness of effects of TB treatment and the importance of physiotherapy post-treatment.
- Young people to commit to preventive measures by seeking hospital care, avoiding overcrowding, procuring facemasks and acquiring prophylactic drugs.
- Hospital management to lobby for nutritious foods for TB patients in hospitals.
- Young people to commit to preventive measures by seeking hospital care, avoiding overcrowding, procuring facemasks and acquiring prophylactic drugs.
- Hospital management to lobby for nutritious foods for TB patients in hospitals.

Economic support

- MoGDSW to accommodate young people affected by TB in securing social cash transfer to maintain their businesses.

Emotional and social support

- Ministry of Health (MoH), MoGDSW and radio stations to be responsible for raising awareness to reduce stigma and enhance mental health accessibility.
- National Youth Council, MoH, MoGDSW through TB TWGs lobby for integrating mental health education into school curricula and community programmes, as well as establishing mental health clubs to offer training opportunities.
- Malawi government (MoH, MoGDSW), organisations, radio stations should conduct awareness campaigns on TB transmission and prevention to reach as many people as possible.
- Radio stations should develop programmes addressing TB as part of their awareness efforts.

Positive experience

- MoGDSW, NTLEP, stakeholders through TB TW to facilitated development of a platform for young people affected with TB by stakeholders to ensure their voice is heard.

Planning and strategy

- MoGDSW to be included in TB Technical Working Group (TWG) meetings.
- MoGDSW and MoH to meet and develop a policy over TB and gender effective for supporting people facing discrimination.
- MoH and MoGDSW to utilise monitoring hubs for tracking TB patients progress on health, work and many other issues faced.
- Stakeholders to use the TB TWG for addressing issues raised by young people affected by TB and present to the parliamentary committees.
- MoH, MoGDSW and stakeholders to engage the young people affected by TB over decisions towards their well-being in different forums such as the TB TWG, stakeholders' meetings, parliamentary committee sessions etc.
- The NYC and young people affected by TB to be engaged over issues raised and derive action points.
- AFIDEP and MLW to share the action workshop report with stakeholders to make sure that issues captured are followed.

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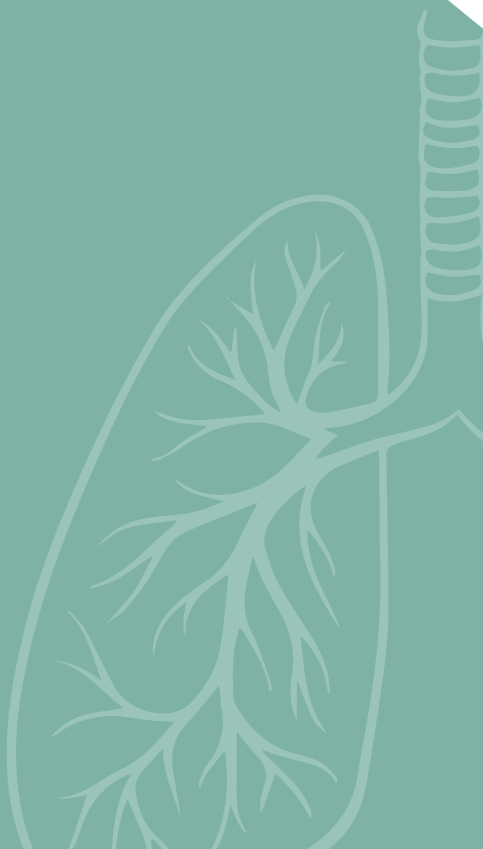
4.0
DISCUSSION



This study aligns with global and national TB strategies aimed at reducing TB incidence by 2030 (3,20) (Malawi Ministry of Health, 2023; World Health Organization, 2024a), drawing attention to the unique challenges faced by young people aged 15 to 24 who are affected by TB, a demographic often overlooked in TB programmes in research and interventions. Our findings indicate that young people encounter substantial challenges across multiple dimensions, including physical health complications, economic hardship, and psychosocial distress. Nonetheless, their experiences also revealed certain positive outcomes, reflecting resilience and adaptive coping mechanisms amidst adversity.

It was observed over the study that the Malawi NTLEP currently lacks disaggregated data specific to young people, particularly by age, sex, and gender. This is notable given that this demographic is critically important in both the transmission and vulnerability to tuberculosis (10,15). The present study is distinct in its focus on examining the roles of age, sex, and gender, while providing a platform for young people to articulate their specific concerns. In doing so, the study contributes to enhancing and informing NTLEP policies and strategies aimed at more effectively addressing the needs of young people in Malawi.

Young people with TB, expected to be physically fit and active at this stage of life, experienced weakness, pain, discomfort, and adverse effects from medication as significant challenges to their physical well-being. These issues were described as major impediments to their ability to carry out daily activities and routines effectively. These findings resonate with evidence indicating that TB adversely affects the human body, primarily manifesting with pulmonary dysfunction, fatigue, hemoptysis, and weight loss (40). Furthermore, individuals undergoing treatment for latent TB infection (LTBI) may continue to experience mild but persistent impacts on their health and overall well-being due to treatment related side effects (40). This underscores the physical health challenges experienced by individuals affected by TB. The World Health Organization's End TB Strategy, as presented at the United Nations High-Level Meeting on TB in 2018, reinforced the importance of implementing preventive measures to reduce the risk of TB infection (41). It is, however, particularly important to emphasise age specific research incorporating young adults to understand how their physical well-being is influenced by the developmental transition's characteristic of this life stage.

Despite age-specific health challenges related to TB, access to health care was challenging for young people. This oversight persists despite the critical developmental transition that characterises this age group, which necessitates tailored approaches to health care engagement and service delivery. Evidence from other settings underscores the heightened sensitivity and social mobility of adolescents and young adults, indicating that without targeted engagement and awareness, this population plays a significant role in TB transmission within communities (13,42). It was also essential to consider the influence of gender roles in the context of TB, as men and women often bear distinct social and familial responsibilities that may be disrupted by the illness (43–45). These disruptions can exacerbate societal discrimination and deepen the impact of the disease (45). The study deliberately incorporated an analysis of these gender-specific roles and expectations to ensure that the differential experiences and vulnerabilities of both men and women were adequately documented and understood.

Economic challenges among TB-affected young people affected their access to care, education, work and businesses. TB has highly been associated with socioeconomically disadvantaged groups (46,47) and commonly referred to as the disease of poverty. Malawi is significantly affected by poverty, with more than half of its population living below the national poverty threshold (48). Lilongwe, the capital city of Malawi, is characterised by densely populated suburban areas with substandard living conditions and limited access to essential services. The long distances to free government schools and hospitals, combined with the fast-paced urban lifestyle, could contribute to economic strain among young people affected by TB, potentially hindering their ability to pursue and sustain educational and health care progress due to the financial demands required to navigate these challenges.

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Social harm and discrimination present significant challenges for young people affected by TB, often manifesting as loss of interest, stigma, exclusion, depression, and emotional distress. These negative psychological effects are well documented in TB literature, highlighting the profound impact the disease can have on mental and emotional well-being in this age group (34,49–51). Although social harm and discrimination are well documented in the broader TB literature, specific information concerning young people remains limited. The Malawi NTLEP policy and strategic documents provide minimal attention to the unique challenges faced by this age group, particularly regarding social harm and the mechanisms in place to address it. It is critical that both global and national TB frameworks explicitly recognise young people as a vulnerable demographic, given their heightened susceptibility to stigma and discrimination, which may have long-term psychosocial consequences. As emphasised by stakeholders during the study's action meeting, there is an urgent need to incorporate young adults into policy and strategic planning to ensure their experiences and needs are adequately addressed.

The study findings revealed that, alongside numerous challenges as a result of being affected by TB, participants also experienced positive aspects of recovery, including behavioural transformation and meaningful social support. These positive experiences served as motivational drivers toward improved health outcomes. Behavioural changes among participants reflected both the initial psychological difficulties in accepting a TB diagnosis and the importance of supportive interventions such as counselling in facilitating critical shifts toward treatment adherence. The transition from denial and non-compliance to acceptance and commitment to care underscored the transformative potential of psychosocial support in enhancing disease management. Furthermore, participants highlighted the significance of emotional and material support from family and peers, noting that acts of kindness and solidarity not only alleviated emotional distress but also fostered a sense of inclusion and connectedness. These findings emphasise the crucial role of compassionate, community-based support systems in mitigating the psychosocial burden associated with TB and promoting sustained recovery among young people.

The photovoice methodology employed in the study demonstrated its significant value in facilitating meaningful engagement between young people and stakeholders. Through visual narratives, the method effectively illuminated the lived experiences of young individuals affected by TB, providing rich, contextually grounded insights revealing personal and systemic challenges. Photovoice method and evidence resonated with both young people and stakeholders. A study conducted in Mumbai demonstrated the effectiveness of the photovoice approach as a powerful tool for capturing and interpreting the lived experiences of women affected by TB with the methodology facilitating meaningful engagement, solidarity, and participatory dialogue, enabling the co-creation of context-specific interventions grounded in the personal narratives shared by participants (45). Young adults actively presented and articulated their concerns regarding the challenges they face while being affected by TB to stakeholders at national, district, and community levels. This engagement prompted dialogue among stakeholders, who emphasised the need to revisit existing policies and strategies to ensure the inclusion of young people and their specific needs. A study on person-centred and youth-oriented interventions to improve TB care for adolescents and young adults conducted in Zimbabwe highlighted the critical role of stakeholder engagement, as it enables the formulation of actionable recommendations that can be tracked and integrated into broader policy and strategy development platforms (52). Stakeholders recognised the importance of establishing dedicated platforms for young people affected by TB to express their perspectives. The discussions also underscored the critical role of collaborative efforts and data sharing in advancing TB research and informing evidence-based interventions. It is evident that young adults are largely excluded from most TB interventions (10,16). Enhancing stakeholder awareness of the necessity to include this demographic is essential, as it not only supports the health and well-being of young adults but also contributes to national productivity and socio-economic development.

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4.1 Strengths and Limitations

The photovoice methodology applied in this study provided unique insights into the experiences of young people affected with TB. One key benefit was its ability to amplify the voices of youth marginalised by TB, providing a platform for them to articulate their challenges, priorities, and aspirations in a participatory and empowering manner. Participants employed photographs and narratives to communicate complex issues in an accessible and impactful way which fostered greater understanding among stakeholders. The visual and narrative outputs of photovoice were effective in raising awareness and advocating for youth-friendly TB services, creating a compelling case for change. The collaborative nature of photovoice facilitated meaningful dialogue between young people and key stakeholders, such as healthcare providers and policymakers, and helped bridge the gap between service users and decision-makers. Workshops fostered the co-creation of solutions to the barriers faced by young people.

A primary limitation of the study was the absence of dedicated funding to support the implementation of the action points jointly developed by stakeholders and young participants. Additionally, participant attrition posed a challenge, as some of the initially sampled young individuals did not show up at the photovoice workshop. Due to group process, no additional participants could be recruited in their place.

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CONCLUSION

This study illuminates the complex and intersecting physical, economic, emotional and social challenges TB poses to young people in Lilongwe, Malawi, while demonstrating the value of photovoice as an empowering, participatory research method. The findings highlight systemic barriers such as limited access to care, financial hardship, insufficient rehabilitation services, and stigma, with distinct gendered impacts, young women facing disrupted domestic roles and stigma, and young men experiencing loss of provider identity and psychological distress.

Despite these adversities, participants exhibited resilience supported by treatment adherence, family and community involvement, and behavioural change. The study advocates comprehensive, youth-centred TB interventions that incorporate mental health care, physiotherapy, nutritional support, mobile service delivery, and economic empowerment initiatives. Photovoice effectively bridged the gap between young people and stakeholders, facilitating the co-creation of solutions and underscoring the importance of inclusive, holistic strategies in the TB response.

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