

Perspectives of TB survivors and policymakers on post-TB disability

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BACKGROUND: An international multistakeholder participatory workshop was hosted in the Gambia, West Africa, in November 2021.

OBJECTIVES: To explore the experiences, challenges and recommendations of workshop participants on health and wellbeing after TB treatment.

METHODS: An exploratory, descriptive, qualitative approach was used for data collection through facilitator-guided group discussions. Workshop participants included adolescent and adult TB survivors, and representatives of TB advocacy groups and the policy sector. Discussions were audio-recorded and transcribed verbatim, and the data were analysed using a deductive thematic approach.

RESULTS: Overall, 38 participants (22 women) from six West African countries participated in the workshop, comprising 33 TB survivors and advocacy group representatives and 5 participants from the policy sector. Although some TB survivors noted improved ability to carry out physical activities, others continued to experience detrimental effects on their family life, social interactions, physical health and ongoing stigma. Policymakers emphasised the lack of data and clear guidelines on post-TB disability.

CONCLUSIONS: Some TB survivors continue to suffer detrimental effects of the illness even after treatment completion. However, available data on post-TB disability is inadequate to support policy adoption. Therefore, there is an urgent need for increased advocacy, awareness and research to bridge knowledge gaps.

About 10.6 million people fell ill with TB in 2021, with sub-Saharan Africa accounting for nearly one-quarter of the total number of new TB cases.¹ Among the 30 countries considered by the WHO to have a high TB burden globally, 17 are in sub-Saharan Africa, with three countries (Liberia, Nigeria and Sierra Leone) from West Africa.¹

Recent reports by the WHO indicate that at least 85% of people who receive treatment for the first episode of TB disease achieve treatment success.^{2,3} Traditionally, the outcomes for people who are successfully treated for TB are classified as either 'cured' or 'treatment completed'.⁴ Although TB treatment success has resulted in more than 66 million lives saved between 2000 and 2020 globally,³ many TB survivors continue to experience medical and psychosocial challenges that often warrant repeated hospital visits.⁵

Published data suggest that adult pulmonary TB survivors have two- to four-fold higher odds of persistently abnormal lung function than people who never previously had TB.^{6–8} Other studies have documented the persistence of respiratory symptoms, and reduced health-related quality of life (HRQoL), despite successful completion of TB treatment in adults and children.^{9–13} There is also increasing evidence of adverse psychosocial morbidities and persistent socio-economic impairment among TB survivors.¹⁴

Despite the growing data on the long-term impact of TB on lung function and physical and psychosocial wellbeing, the care of TB patients currently ceases at the time of treatment completion.¹⁵ However, many TB survivors need continuous medical and psychosocial care beyond the completion of their anti-TB therapy, particularly children and adolescent TB survivors who still have a long life course ahead of them.^{13,15,16}

This issue is increasingly being recognised, and efforts to increase awareness of post-TB disability have begun. In 2019, the first International Post-TB Symposium was held in South Africa, bringing together TB survivors, clinicians and researchers to advocate for individuals suffering from post-TB complications and to identify existing gaps in knowledge.^{5,17} However, no participatory data are currently available from TB survivors or policymakers in West Africa in particular.

To begin advocacy initiatives toward increasing the awareness of post-TB lung health through active engagement with TB survivors and policymakers in West Africa, we organised an international multistakeholder participatory workshop in the Gambia in which we embedded a qualitative study.¹⁸ Our objective was to explore and document the lived experiences and challenges of adolescent and adult TB survivors, as well as advocacy groups beyond TB treatment. We also aimed to document the perspectives and recommendations of key policy sector representatives regarding post-TB disability.

METHODS

Study design, setting and participant selection

This was an exploratory, descriptive, qualitative study on post-TB disability that was conducted during an international multistakeholder participatory workshop on post-TB lung health in West Africa. The workshop took place in The Gambia from 17 to 19 November 2021.

Participants comprised adolescent and adult TB survivors, representatives of TB advocacy groups, as

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well as policy sector representatives from six West African countries (Benin, Burkina Faso, The Gambia, Ghana, Nigeria and Sierra Leone). Authors ON and TT purposively selected and invited the participants through our established collaborative partnerships in West Africa. All participants were given information about our intention to conduct the research at the time of invitation for the workshop. The list of TB advocacy and policy organisations that participated in the workshop is provided in Supplementary Data 1.

Data collection

Primary data collection in the study was by facilitator-guided group discussions.¹⁹ These were conducted using a semi-structured discussion guide (see Supplementary Data 2). Authors ON, EN, OO and PJ facilitated the group discussions in separate and quiet areas of the workshop venue. The workshop participants were divided into three groups: 1) adolescent TB survivors, 2) adult TB survivors and advocacy group representatives, who were further divided into two smaller groups, and 3) representatives of the policy sector. Each individual was assigned a unique identifier, which was used throughout the group discussions.

Topics explored included how persistent health problems affected family interaction, managing social interactions, physical activities, assessing healthcare support and strategies for coping with persistent health impairments due to TB. The researchers also asked probing questions during the group discussions to help clarify statements made by the participants. Generally, the probing questions used in this study were not predetermined and came from the need to seek clarity when required.

Interpreters in each group translated the conversations for non-English speaking participants. Questions were translated from English to the participant's preferred language (French, Wolof or Mandinka), and responses were back-translated into English. Each group comprised between five and 12 participants (excluding the facilitator and interpreter) with similar demographic characteristics, and three discussions were conducted per group over the course of the participatory workshop. Each group discussion lasted for 90 minutes. All group interactive sessions were recorded using an encrypted recorder.

Data analysis

Trained field assistants transcribed the recorded discussions. We used recordings and field notes to cross-check all transcripts, ensured that they were correctly translated to preserve the meaning of the participants' words and statements, and provided feedback to all field assistants.

We analysed our data using a deductive thematic approach.²⁰ The transcripts were read through, line by line, to identify key concepts. We then used these key concepts to develop a coding framework for data coding. The coding process involved reading the transcripts, linking and connecting texts to their representative key concepts. The key concepts were then organised into categories and sub-categories.

Ethical considerations

Ethical clearance was obtained from the Gambian Government/Medical Research Council Unit The Gambia at London School of Hygiene & Tropical Medicine Joint Ethics Committee, Banjul, The Gambia (Ref: 26573). Written informed consent was obtained from all study participants, including consent from parents/caregivers of the adolescents, and assent from the adolescents. Participants were given information about the study and the objectives, and taken through the informed consent process while registering for the workshop. Participation in the study was voluntary, and individuals could choose to attend the workshop without participating in the study. We used unique codes for each participant throughout the study to ensure data privacy and anonymity.

RESULTS

Sociodemographics of participants

Overall, 38 individuals representing different stakeholder groups from six West African countries attended the workshop, and all consented to participate in the qualitative study. The groups comprised 10 adolescents aged 13–20 years, 23 adult TB survivors and representatives of TB advocacy groups aged 21–60 years, and 5 participants from the policy sector (3 National TB Programme officers, 1 WHO staff and 1 representative of an international non-governmental organisation) (Table). Majority of the participants were female (22/38) and from the Gambia (28/38).

Themes, sub-themes and supporting quotes

Figure 1 shows the themes and sub-themes which emerged from the group discussions. From the groups with the TB survivors and advocacy group representatives, three emerging themes were 1) quality of life; 2) stigma; and 3) the need for psychosocial support (Figure 1A). The themes emerging from the group of policy sector representatives were 1) knowledge gap/inadequate data on post-TB disability to support policy adoption; 2) limited TB care package; and 3) recommendations (Figure 1B).

We present the findings from each theme and sub-theme along with supporting quotes from the participants to buttress the points made.

TB survivors and advocacy group representatives

Theme 1: Quality of life

Family life and work

All the adolescent TB survivors who participated in the discussions acknowledged that there was improvement in their general health status following TB treatment. However, the group discussions revealed that most of them reported disruptions in their relationships with family members because of their previous TB diagnosis:

... I was isolated even after I was cured to prevent further spread of the bug. I had a private room. (Code A002)

... everyone within the family started acting differently towards me. For example, I wasn't allowed to eat with

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TABLE Socio-demographic characteristics of workshop participants

Variables	Participants (n = 38)
Sex	
Female	22
Male	16
Country	
Benin	2
Burkina Faso	2
The Gambia	28
Ghana	2
Nigeria	2
Sierra Leone	2
Participating groups	
Adolescent TB survivors	10
Adult TB survivors and advocacy group representatives	23
Policy sector representatives	5

everyone. I also found out that we started fighting and getting into arguments. I now live with my uncle. (Code A001)

Similarly, the adult TB survivors acknowledged that their social participation patterns, family and work lives were negatively affected due to the illness. They emphasised the importance of family support during treatment and after treatment completion:

... when I got TB, I was the breadwinner in my family. It was difficult for me as the head of the family to fully function in my role. It was indeed a difficult time for me and my family, even after being cured. (Code AC001)

... I was laid off, with only 2 weeks' salary and hospital bills to pay ...It was a very dark time for me and my family, my wife and children had to struggle and suffer. (Code AC004)

The discussions also revealed the negative impact of TB on the work productivity of some of the adult TB survivors, with partici-

pants discussing the challenges they faced following completion of TB treatment compared to their life before contracting TB:

There is an assessment that is done for employees to assess their productivity and performance. Due to my struggles with TB, I wasn't able to meet up, and I was laid off. (Code AC004)

...you won't be able to work like you used to. (Code AC007)

Social participation

The adolescent survivors said that TB negatively impacted their social interactions with others in their neighbourhood during and after their treatment. For some of the adolescents, these experiences were associated with deleterious effects on their academics and the practice of their faith; however, one adolescent TB survivor reported a positive improvement in their academic performance.

I have lost interactions with my friends because they heard I had TB... I have improved, and I am working towards succeeding in my exams. (Code A001)

It has affected my prayer life; I find it difficult to observe all the five daily prayers. (Code A010)

After my treatment, I discovered I have regained the ability to focus in class and improve my grades. (Code A008)

The experience was similar among the adult TB survivors and advocacy group representatives. This group noted that they experienced reduced interaction with others in their neighbourhoods and communities due to their illness. For some participants, the experience remained the same even after treatment was completed.

...in fact, I stopped going to church out of fear of spreading the disease. (Code AC004)

...by the time I was cured, I had to stay back an extra year [in school] because of this illness. After my treatment, I went ahead to get two degrees. (Code AC008)

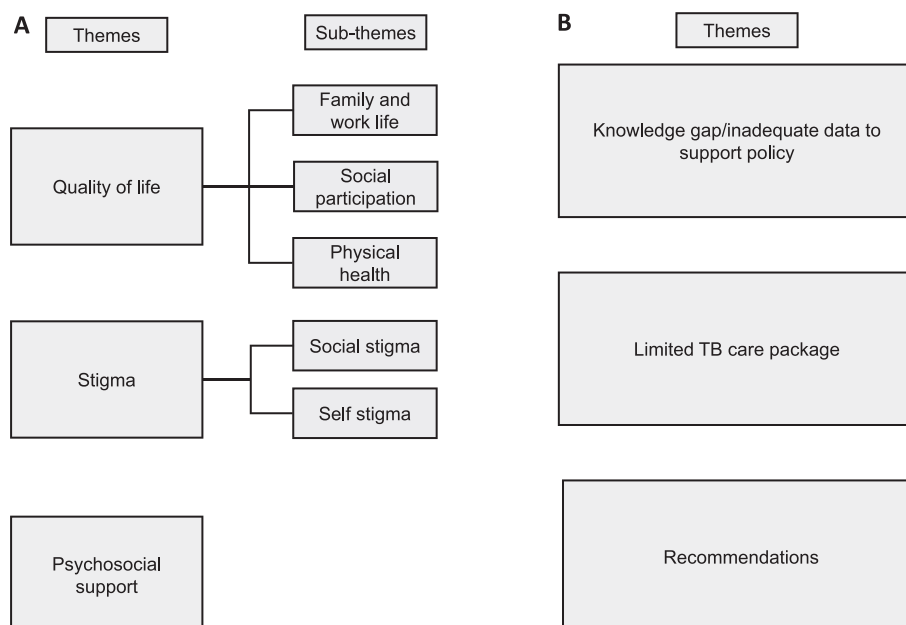


FIGURE 1: Key themes and sub-themes that emerged from the facilitator-guided group discussions with TB survivors and **A)** advocacy group representatives, and **B)** policy sector representatives.

Physical health

Several of the adolescents had high expectations and had hoped to resume their regular physical activities following completion of TB treatment. However, many said they are still experiencing persistent physical health challenges afterwards, including body pains and inability to perform regular physical activities.

Even after my treatment, I still feel pains in my body, sometimes I run a fever. After the sickness I noticed a large change in my abilities to do physical activities, I get tired easily. (Code A001)

I find myself getting tired easily. (Code A007)

I used to play football a lot before with my friends, but after I got ill, I found it difficult to keep up with the energy requirements of playing football, so I have stopped. (Code A003)

I used to do much physical exercise and work before TB, and after TB, I have resumed them. (Code A004)

Furthermore, although some of the adult TB survivors reported improvement in carrying out their physical activities following TB treatment, many expressed lingering and recurring health concerns similar to the adolescents, adding that there was still a need for supportive medical care following the completion of TB medication.

... the moment I was treated and cured, all the symptoms went. (Code AC003)

After TB treatment, I still produce sputum, and people start wondering whether I am still sick (Code AC021)

... [after completing TB treatment] when I was pregnant I was always feeling weak and even started coughing. The side effect of the TB is always there when I undergo stress. (Code AC020)

Theme 2: Stigma

Most adolescent survivors reported that they continued to experience discrimination, labelling and ill-treatment in their local communities, which led to social isolation in some instances.

I lost my best friend because of this sickness. She became scared of me and refused to be too close to me. (Code A006)

... when my co-workers found out, they started isolating me. (Code A002)

... when my father had TB, he kept it a secret from the rest of the family to avoid stigmatisation and discrimination from other members of the community and us... He went through the treatment without anyone of us knowing. (Code A010)

This perceived external stigma led many adolescents to hold onto negative beliefs about themselves even after they had finished their TB medication, thus further affecting their relationships with peers and social interactions.

None of my friends knew I had TB. I kept it a secret from them to avoid them feeling different about me. (Code A007)

I reduced going out to spend time with other people out of fear of stigma. (Code A010)

Many adult participants shared similar experiences of rejection, labelling and discrimination because of the perceived risk of transmission to other people, even after TB treatment.

Even after I got well, some of my friends still feel uncomfortable around me or even avoid me. (Code AC004)

... It was my younger brother that had TB, and I can tell first hand that the whole community stigmatised us. (Code AC014)

They said I took it from somewhere and brought it into the house, they said I used to stay out for a long time, so I have gone to get it. They said I got it from the ghetto. (Code AC002)

I reduced going out to spend time with other people out of fear of stigma and risk of transmitting the infection. (Code AC010)

Theme 3: Psychosocial support

Both groups emphasised the importance of psychosocial support from the community during and after TB treatment. Furthermore, they stressed the importance of awareness and proper sensitisation to achieve public acceptance. Parents, other family members and healthcare workers at TB treatment centres were mentioned as the ones who should provide continuous psychosocial support.

...mass education of the populace to debunk myths and misconceptions about TB... Changing people's orientation about TB to help stop discrimination and stigmatisation of TB patients. (Code A009)

...my mom is always trying to support me emotionally. (Code A002)

Moreover, adult TB survivors, who are now members of TB advocacy groups, felt that their experience could help others through their struggles. They did not want others to go through the same struggles they had experienced and were still experiencing.

The doctor that treated me told me about an advocacy group and asked me to join, that he believed my story would help others going through this struggle, and that is how I joined and became an advocate. (Code AC008)

Policy sector representatives

Discussions with policymakers revealed a significant gap in knowledge about health impairment following TB treatment in adults, adolescents and children. They expressed the need for data to determine risk factors for post-TB disability, the proportion of TB survivors who develop health challenges after treatment completion and for how long. There was an emphasis on the need for evidence to make a case for adopting post-TB lung health interventions on global policy agendas.

... If we look at the framework, there is nothing like post-TB, it is even new to me. Only research and evidence can tell us if these [problems] follow TB. (Code P004)

... there isn't even sufficient evidence for it to become a policy. (Code P002)

If there is evidence, people will spend on it. If it becomes a policy, the country will definitely find resources to implement it, and advocates would also find resources to pursue it. (Code P001)

Even if there is sufficient evidence for it to become a policy, it might not get to the surface because most people are looking at reducing numbers, not the long-term effect. (Code P002)

Discussions also highlighted the deficiencies of the current TB care package, which was perceived as not adequately addressing the patient's needs throughout the TB treatment process, let alone afterward.

... we do not care whether the person has eaten, what we want is that the person takes the drugs, these can result in toxic effects of the antibiotics. (Code P001)

... if you look at the central level that is at the level of the ministry, TB services are being stigmatised in the sense that if recruit-

ment is being done, the lowest care of people or staff at the facility are the ones that are recruited to give services to patients that are being affected by TB ...All that they do is recruit nurse attendants who are not that competent or qualified to care for people. (Code AC025)

The overwhelming recommendation from the policymakers for translating the post-TB agenda into policy was that there is a need for evidence to drive the discussions and advocacy for post-TB lung health:

... By producing clear evidence... [post-TB health] has to be assessed in terms of numbers, with representation from low and middle-income countries. The next thing is our intervention. The policy comes in guidelines, and the guidelines must be elaborate, detailed, and easy to do on a public health scale. (Code P002)

When the evidence is there, the policy drives some of these [interventions]. (Code P001)

DISCUSSION

In this study, we explored and documented the lived experiences of adolescent and adult TB survivors and advocacy group representatives, as well as the perspectives and recommendations of policymakers from six West African countries. Although TB survivors reported improvement in carrying out physical activities following treatment, some continue to experience deleterious effects on family life, social interactions, challenges in carrying out physical activities and ongoing stigma. Policymakers acknowledged that the available data on post-TB disability were inadequate to support policy adoption.

The adolescent and adult TB survivors in our study reported persistent and often disabling physical health challenges post-treatment, including continued respiratory symptoms probably due to residual lung damage. This finding is consistent with published reports suggesting chronic respiratory symptoms are often known to persist after TB treatment in adults and adolescents.^{10–13}

Published evidence has shown that the economic and social problems associated with TB illness may worsen the physical post-TB comorbidities and sequelae.²¹ Findings from our study support this assertion, with TB survivors reporting that their family, social and economic lives and livelihoods were adversely affected by the illness and its sequelae. A better understanding of the economic impact of TB disease beyond the end of TB treatment, and interventions to protect the livelihoods of TB survivors, should be integral components of TB control efforts.

As demonstrated in our study and confirmed by many others, TB is associated with stigma affecting TB survivors and their families, in addition to its physical consequences. Other studies have similarly reported that stigma associated with TB remains even after successful treatment when TB survivors are no longer infectious,²² and they are often silently isolated and avoided by the community members.²³ As such, TB survivors are often motivated to get involved in TB control activities such as treatment support and combating TB-related stigma.²⁴ Therefore, continuous capacity building and sensitisation within and outside the health sector with the aim of educating the community to reduce the TB-related stigma are essential.²²

It should be noted that the topic was not at all familiar to the policymakers, who highlighted the urgent need for more research to inform policy and guide decision-making for improving physical and psychosocial health, and quality of life after TB treatment.

This suggests that there is a need for the development of clear evidence-based guidelines for the management of respiratory symptoms and psychosocial sequelae of TB, as alluded to in other published studies.^{14,25} A positive step in this direction was the recent publication of clinical standards for post-TB lung disease by The Union.²⁶

The key strength of our study is the use of a participatory approach to gain an understanding of the lived experiences of TB survivors, including adolescents. However, our study also has clear limitations: we enrolled only a small group of individuals selected from existing collaborations by invitation. Therefore, our study may not reflect the experience of a broader population of TB survivors. Nevertheless, our findings have highlighted several critical implications for TB research, policy and programmes.

In conclusion, our study shows that some TB survivors continue to suffer detrimental effects of the illness on their family life, social interactions, physical health, and ongoing stigma. Furthermore, the currently available data on post-TB disability are inadequate to support policy adoption. These findings support an urgent need for increased advocacy, awareness, and research to provide the evidence base for developing robust guidelines for the care and support of TB survivors beyond the end of treatment. Further studies and interventions on health and wellbeing after TB treatment should put into consideration the peculiarities of the needs of adolescents, especially strategies to cope with body pains, inability to perform regular physical activities and the psychosocial challenges, as seen in the discussions from this study. Furthermore, we recommend further research to investigate the burden of physical, psychosocial and economic sequelae after completion of TB treatment, risk factors and determinants of post-TB disability for early identification of TB patients at risk of developing persistent health impairment after treatment, solutions to alleviate persistent symptoms amongst TB survivors, and interventions to cushion the economic impact of post-TB disability on TB-affected households and communities. These recommendations are in line with the conclusions of the first International Post-TB Symposium that called for increased advocacy and more research on post-TB lung health,²⁷ and they are potential action points for the second Post-TB Symposium that is planned for 2023.

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CONTEXTE : Un atelier participatif international multipartite a été organisé en Gambie, Afrique de l’Ouest, en novembre 2021.

OBJECTIFS : Analyser les expériences, les défis et les recommandations des participants à l’atelier en matière de santé et de bien-être après un traitement antituberculeux.

MÉTHODES : Une approche exploratoire, descriptive et qualitative a été utilisée pour le recueil des données par le biais de discussions de groupe encadrées par un animateur. Les participants à l’atelier étaient des adolescents et des adultes ayant survécu à une TB, ainsi que des représentants de groupes de plaidoyer de la TB et du secteur politique. Les discussions ont été enregistrées sur support audio et transcrites textuellement, et les données ont été analysées en utilisant une approche thématique déductive.

RÉSULTATS : Au total, 38 participants (22 femmes) de six pays d’Afrique de l’Ouest ont participé à l’atelier, dont 33 représentants de

groupes de plaidoyer ayant eux-mêmes survécu à une TB et 5 participants issus du secteur politique. Bien que certaines personnes ayant survécu à une TB aient constaté une amélioration de leur capacité à mener des activités physiques, d’autres ont continué à subir les effets néfastes sur leur vie familiale, leurs interactions sociales, leur santé physique et la stigmatisation permanente. Les responsables politiques ont souligné le manque de données et de directives claires sur le handicap post-TB.

CONCLUSIONS : Certaines personnes ayant survécu à une TB continuent de subir les effets néfastes de la maladie, et ce même après la fin du traitement. Cependant, les données disponibles sur le handicap post-TB sont insuffisantes pour soutenir l’adoption de politiques. Il est donc urgent de renforcer le plaidoyer, la sensibilisation et la recherche pour combler les lacunes en matière de connaissances.

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