Achieving universal social protection for people with tuberculosis

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As we mark World TB Day 2024, we take this opportunity to reflect on the 2023 UN General Assembly High-Level Meeting (HLM) on the fight against tuberculosis—a milestone in the commitment towards a more coordinated, comprehensive approach to end tuberculosis globally. The UN HLM declaration on the fight against tuberculosis includes a specific pledge that all people with tuberculosis should receive a social benefits package to mitigate financial hardship. However, it is not known how this specific pledge will be realised and through which concrete actions. The use of the term financial hardship instead of WHO's key End TB Strategy indicator of catastrophic costs might prove challenging for robust evaluation of both the socioeconomic impact of tuberculosis and the effectiveness of socioeconomic support strategies to mitigate this impact. Moreover, in contrast to the financial pledges made for biomedical interventions, there was an absence of explicit investment in social protection. Such investments are imperative to facilitate successful expansion of social protection to meet the needs of people with tuberculosis and their households. Successful expansion of social protection is also dependent on political commitment and protected budgets from relevant stakeholders, including across government ministries. These strategies will help to ensure that the commitments on social protection made in the UN HLM declaration are turned into tangible actions with measurable effects.

Introduction

Tuberculosis causes 4000 deaths every day globally, the highest among infectious diseases.[1] After the first UN High-Level Meeting (HLM) on tuberculosis in 2018,[2] initial progress towards ending tuberculosis was promising. However, in 2020, progress made was decimated by the COVID-19 pandemic.[3,4] In September, 2023, the second HLM on the fight against tuberculosis reiterated the crucial imperative of addressing this ongoing global health crisis and demonstrated a continued commitment to tackle the profound health, social, and economic repercussions for individuals, households, and communities affected by this disease.[5]

The political pledges agreed at the 2023 HLM culminated in a declaration, which embodied the collective global commitments required to effectively eliminate tuberculosis. Through these declarations and the collaborative efforts of nations, the international community is taking strides towards a more coordinated, comprehensive approach to combat this deadly and persistent infectious disease. However, despite the thorough political declaration, essential questions persist, especially questions related to pledges for social protection—which is generally defined as systems to reduce inequalities and intergenerational poverty by helping individuals and families cope with disease-related crises and shocks[6]—for people with tuberculosis and their households. These questions include how the pledges made will be realised and who will be held accountable if they are not realised.

A mismatch between rhetoric and investment related to social protection

Despite the long-standing evidence identifying social determinants as the key drivers of the tuberculosis epidemic and highlighting the crucial role of fighting poverty to end tuberculosis,[7–11] there is little emphasis on poverty alleviation and socioeconomic support in existing global tuberculosis care and prevention strategies. The declaration explicitly pledges to ensure that "100 percent of people with TB have access to a health and social benefits package so that they won't endure financial hardships because of their illness" by 2027.[5] However, no concerted effort for explicit investments to provide sufficient social protection was made at the HLM, in the declaration, or at related side events. Moreover, wording around mobilising "sufficient and sustainable financing for universal access" and aligning with "overall national health financing strategies towards achieving universal health coverage and social protection strategies",[5] although important, does not provide or suggest any meaningful steps to facilitate translation into concrete actions.

This lack of meaningful steps contrasts with the pledge and related well publicised funding announcements, underscoring the imperative to achieve sustainable financing of US$5 billion per year by 2027 to discover new tuberculosis vaccines, diagnostic tools, and medicines.[5] This mismatch indicates that, despite progress in acknowledging the importance of social protection, advocacy for investment still leans heavily towards biomedical rather than socioeconomic science and strategies. There is a substantial risk that under-investment in this area might mean that commitments to social protection remain rhetorical. Potential pathways to translate rhetoric into action could include, but are not limited to, a commitment to spending on national social protection platforms that exceeds a specific threshold of gross domestic product as well as a commitment to progressive taxation programmes and matched multisectoral funding schemes (including a public and

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private mix where appropriate) aimed at reducing health and social inequalities.

Beyond universal health coverage

The provision of social protection for individuals affected by tuberculosis must extend beyond the scope of universal health coverage (UHC). Numerous countries, including those with a high burden of tuberculosis, are strengthening their health-care financing and pooled insurance mechanisms to achieve universal access to free-of-charge quality health services, including free tuberculosis services, and alleviate the financial burdens associated with out-of-pocket health-care expenses, which can be financially catastrophic.[12–14]

However, the UHC agenda lacks explicit provisions for safeguarding individuals against adverse socioeconomic consequences arising from illness-related unemployment, income loss, or broader detrimental effects on livelihood. UHC focuses more on health-care access and provision and does not consider other crucial cost drivers, such as transportation, food, and accommodation costs spent by people with tuberculosis and their carers during their journey through diagnosis and care seeking and engagement. UHC is also not commonly designed to intervene on broader social determinants of health, such as income loss, unemployment, stigma, and discrimination related to tuberculosis disease.

Therefore, comprehensive and accessible social protection is indispensable for alleviating adverse socioeconomic consequences of tuberculosis. Social protection complements the role of UHC to improve access to health and social care in households affected by tuberculosis.[15] Moreover, the COVID-19 pandemic has exacerbated the socioeconomic impact on households affected by tuberculosis,[16,17] making the need for social protection even more severe and acute. We advocate for universal health and social coverage (UHSC), which places equal emphasis on the design, planning, implementation, and evaluation of social care systems and provisions as on health care. Among other necessary actions, the promotion of UHSC would require: integration of health and social care policies, governance, ministries, departments, and budgets; combined staffing and management across the health and social care sectors tailored towards people with poverty-related diseases (ie, social worker placement in tuberculosis clinics); and, with respect to tuberculosis, inclusion of ring-fenced resources for social protection interventions within the strategic plans of national tuberculosis programmes.

An absence of indicators to measure progress in social protection

Although the commitment expressed in the pledge is geared towards "strengthening financial and social protections for people affected by tuberculosis and alleviating the health and non-health related financial burden",[5] it lacks specificity by not explicitly using the 2015 WHO End TB Strategy's global tuberculosis indicator of catastrophic costs. Catastrophic costs are defined as tuberculosis-related out-of-pocket expenses and lost income exceeding 20% of the annual income of the household affected by tuberculosis.[18,19] Although briefly mentioned in the introduction of the UN HLM declaration,[5] the term catastrophic costs is notably absent throughout all aspects of the pledges, leaving a gap in specific standardised measurement against which to evaluate progress towards mitigating the socioeconomic impact of tuberculosis. The absence of the catastrophic costs indicator could be turned into an opportunity because it has a relatively narrow financial focus and does not incorporate wider dimensions of the sustainable livelihood framework, including human, physical, social, and natural capital assets.[20] Moreover, the current binary threshold of catastrophic costs is liable to neglect subtle gradations and nuances of the impacts of tuberculosis, in this case relating to financial hardship. For example, although households affected by tuberculosis who spend 19% of their annual household income are not defined as having experienced catastrophic costs, they are still likely to have substantial and long-lasting financial hardship.

Despite the shortcomings of the indicator, national tuberculosis patient cost surveys from more than 25 countries worldwide have amassed evidence that nearly half of households affected by tuberculosis globally currently experience catastrophic costs.[3] Therefore, it is essential that this measurable and explicit indicator of catastrophic costs is used to assess the global community's progress towards the WHO target of "No TB-affected families experiencing catastrophic costs due to TB by 2030"[21] within the context of the wider Sustainable Development Goals of poverty alleviation and hunger eradication. This measurement will also be essential to support assessment of the implementation and impact of WHO's upcoming global guidance on social protection for people with tuberculosis, which is scheduled for release in 2024.

Therefore, it is still not known how the UN HLM on tuberculosis political declaration will be turned into concrete action to achieve universal social protection for tuberculosis-affected households in the coming years.

The current landscape of social protection

Tuberculosis scientific, advocacy, and civil society communities must examine the current landscape of social protection based on the best available context-specific evidence. This step is essential to assess the extent to which this UN HLM declaration can convert commitments into actions.[21]

The current landscape of social protection for households affected by tuberculosis varies considerably among high tuberculosis burden countries, with some having established comprehensive programmes and others

having limited or non-existent provisions. These programmes often encompass a range of services and benefits. For example, financial support has been piloted or implemented in countries with a high burden of tuberculosis in the forms of conditional and unconditional cash transfers—ranging from an unconditional transfer of $8 in India to reimbursement transfer of $20 000 in China.[22] The components of such assistance, encompassing cash transfer programmes, health insurance schemes, and income support mechanisms targeting populations affected by tuberculosis are fundamental to achieving an effective social protection framework for tuberculosis, in addition to increasing the likelihood of becoming cured of tuberculosis.[23,24]

Provision of non-financial support is also essential.[25] Nutritional support, consisting of a core basic food parcel, is widely implemented by national tuberculosis programmes.[26] However, most food parcels delivered as part of interventional support or programmes are provided as one-offs at the beginning of tuberculosis treatment and cover only a small proportion of a household's nutritional consumption, sometimes only stretching to a few days. There has been also little evidence to guide on content, mode of delivery, and duration of nutritional support, which is important for national tuberculosis programmes and their partners to be able to optimise their related implementation and impact evaluation strategies.

Such nutritional support can improve food security and reduce undernutrition among households affected by tuberculosis. Considering that 15% of global tuberculosis cases are estimated to be attributable to undernutrition,[3,27] programmes to reduce undernutrition more broadly will have a much bigger impact on tuberculosis incidence and prevalence. The RATIONS Study in India showed that nutritional support for all members of households affected by tuberculosis (ie, both the person with tuberculosis and their household contacts) was associated with a 39% relative reduction in all forms of tuberculosis incidence and a 48% relative reduction in the rate of microbiologically confirmed pulmonary tuberculosis compared with control households, in which only the person with tuberculosis received nutritional support.[28] Reducing food insecurity and improving nutritional status in at-risk populations will also have broader health impacts, such as reduced stunting, improved schooling rates, and reduced incidence of other infectious diseases, especially among vulnerable children.[29]

One important but often overlooked consideration is that many people with tuberculosis and their households not only require economic or nutritional support but also require psychosocial support. Psychosocial support can enhance overall wellbeing and resilience, reduce tuberculosis-related stigma,[30] and improve mental health[31] among affected individuals and communities, all of which are highlighted by the UN HLM declaration on tuberculosis as important challenges to ending tuberculosis. However, once more, the pledges are not enough without the realisation of bold investments; clear and standardised definitions of measurable indicators; and integration of psychosocial support into routine tuberculosis, health, and social care services.

An additional necessary action is ensuring legal protection and legislative frameworks for people affected by tuberculosis, especially in relation to formal and informal occupational health. In particular, the informal workforce has a crucial role in many low-income and middle-income countries, including aiding in economic stability and resilience during crises by fostering real money circulation. Therefore, given the substantial workforce engaged in the informal sector globally, particularly in countries with a high tuberculosis burden, there is a pressing need for novel legislative approaches to effectively reach and protect this group. Those employed in the informal sector are frequently deprived of formal safeguarding policies, such as paid sick leave, making them more susceptible to financial hardships, loss of income, and barriers to accessing health-care services. To address this, occupational health legislation should adopt a more inclusive approach in line with UHSC and ensure that all citizens' rights are fulfilled and maintained.

Holistic and integrated social support

The existing evidence predominantly focuses on providing social support for people already affected by tuberculosis and their households, called tuberculosis-specific interventions.[22,23] For example, cash transfers can improve the socioeconomic and health outcomes of households affected by tuberculosis, including increasing treatment success, increasing preventive therapy uptake, and mitigating catastrophic costs.[32,33] This approach highlights the importance of considering social protection as a form of protection from tuberculosis and its consequences. Better generation, use, and application of evidence related to tuberculosis-specific support can facilitate understanding of successful interventions and identification of enablers to the provision and acceptance of support. In turn, this approach can pave the way to create and refine a more extensive, holistic, and integrated social support framework (figure). However, given the long-standing recognition of tuberculosis as a disease of poverty and the clear ecological associations of increasing national investment in social protection with decreasing tuberculosis incidence and mortality,[34] it is imperative to formulate strategic plans that not only include tuberculosis-specific interventions but also encompass broader tuberculosis-sensitive (ie, interventions that are targeted towards people at high risk of tuberculosis and can potentially affect tuberculosis care and prevention but are not solely for people affected by tuberculosis) and tuberculosis-inclusive interventions (interventions where having tuberculosis or being a family affected by

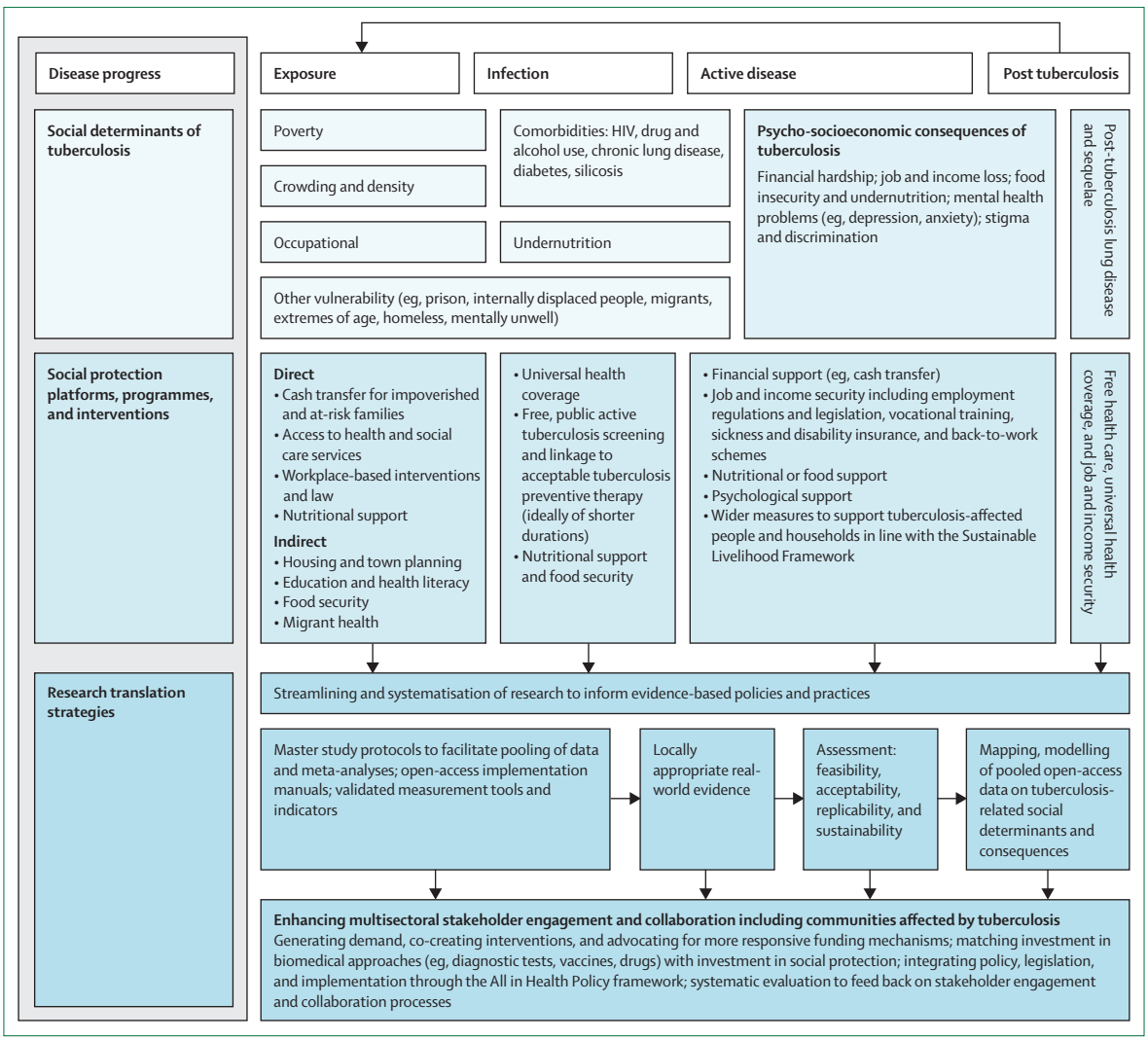

Figure: **Framework to enable achievement of universal social protection for people with tuberculosis**

tuberculosis is one of the inclusion criteria but not the only one).

This strategic shift aims to create a more inclusive and adaptable social support system that addresses the complex social determinants and consequences encountered across the spectrum of exposure, infection, subclinical disease, disease, and post-tuberculosis sequelae and disability. The scope of social protection should incorporate measures to address tuberculosis-related social determinants, which include, but are not limited to, poverty, overcrowding, unemployment, working environment, stigma, discrimination, undernutrition, and people living in vulnerable situations, such as refugees, individuals who are internally displaced and stateless, and individuals who are incarcerated.[35] Combating social determinants of tuberculosis is both pragmatic and plausible for implementation in many countries and will be a pivotal aspect for achieving sustainable progress in reducing tuberculosis incidence and improving tuberculosis treatment outcomes in the coming decades.[36,37] Moreover, expanding existing tuberculosis-sensitive social protection interventions is also recognised as a valid mechanism to ensure protection of populations affected by tuberculosis that can improve tuberculosis treatment outcomes.[38] Modelling evidence has shown that poverty elimination and scale-up of social protection in line with the Sustainable Development Goals would result in a reduction in tuberculosis incidence of 84·3% globally.[7,39] Additionally, an age and gender-responsive approach is required that incorporates and responds to the differential impact of tuberculosis on men, women, and children, and ensures a more effective, inclusive, and equitable tuberculosis response.[40,41]

The endeavour to enhance social protection for individuals with tuberculosis and their households necessarily incorporates multiple, complementary

strategies (figure). First, there is a need to streamline and systematise research efforts by producing master study protocols with a well defined core outcome set, creating open-access implementation manuals, and reaching consensus on the use of appropriately validated indicators and measurement tools. Protocols, manuals, and tools must be adaptable to local contexts and include assessment of feasibility, replicability, and sustainability. Second, addressing the social determinants and consequences of tuberculosis also necessitates evaluating the changing national, regional, and global trends in demographics, poverty, undernutrition, and social protection coverage to guide future policies. Moreover, tuberculosis-related social determinants exhibit inter-country and intra-country variation.[36] This evaluation can use pooled data, big data mapping, or modelling techniques to inform locally suitable planning and implementation strategies, as well as to forecast the burden of disease, estimate potential exacerbating sociopolitical factors and other factors, and predict and pre-empt funding requirements and thereby shape funding calls.[42]

All of these efforts require the fostering of multilateral cooperation and intersectoral synergies, including meaningful involvement of communities affected by tuberculosis, to extend access to health and social benefits packages through systematic strategic plans, yielding tangible and practical outcomes on the ground.[43] Therefore, although there might be core elements of social protection interventions that are relevant across settings, some aspects of intervention design and delivery will be highly context specific. It is the role of national governments, tuberculosis programmes, and researchers to translate global guidance and evidence to the local context, through assessment of their acceptability and replicability. This thorough process will ensure that any implemented forms of social protection promote equity across social, occupational, and environmental determinants, which, in turn, can support care and prevention and catalyse improvements in socioeconomic conditions.[44,45]

Multilateral cooperation and cross-sector synergy are also required to improve funding generation. Providing social protection might be perceived as high cost, challenging to comprehensively address, and constrained by limited government fiscal capacity. However, investing in social protection can return as good value for money as investing in averting tuberculosis deaths,[46] which can return an estimated $43 per dollar invested. The benefits of investing in social protection include the potential opportunity costs from a societal perspective, which, in turn, improve the employability and productivity of a country's future workforce and facilitate investments in other key sectors.[39] Given that evidence of the economic benefits of social protection is still sparse, rigorous economic evaluation is required alongside studies of social protection interventions and the outcomes measured in the economic evaluation need to extend beyond treatment outcomes but to encompass quality-adjusted life-years gained or disability-adjusted life-years averted. Such evidence presented in a clear and intuitive way could convince governments to invest more in social protection and ensure sufficient funding both from within and outside of the tuberculosis programme budget. Potential alternatives to ensure long-term funding support could include cofinancing from the private sector (including through public–private mix)[22] and finding innovative funding resources—eg, taxing unhealthy commercial products.[47] Ultimately, investment in social protection should be arranged and matched to complement the investment in drugs and vaccine discovery.

Conclusion

Successful enhancement of social protection for people with tuberculosis and their households depends on the political commitment from all tuberculosis-related stakeholders to ensure that adequate resources and funding are secured.[22] This entails complementary strategies to streamline and systematise research efforts, generate demands, co-create interventions, and advocate for more responsive funding, as well as to integrate cross-sectoral policy, practice, and legislation.

Contributors

AF did the conceptualisation, writing, and finalisation of the article. TH, NL, OH, and TW reviewed the conceptualisation, writing, and final editing.

Declaration of interests

We declare no competing interests.

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