The high-quality health system ‘revolution’: Re-imagining tuberculosis infection prevention and control

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ARTICLE INFO

Keywords:
Tuberculosis infection prevention and control
Person-centred care
Health system strengthening

ABSTRACT

The Lancet Commission on High-Quality Health Systems called for a ‘revolution’ in the quality of care provided in low- and middle-income countries. We argue that this provides a helpful framework to demonstrate how effective tuberculosis infection prevention and control (TB IPC) implementation should be linked with health system strengthening, moving it from the silo of the national TB programmes. Using this framework, we identify and discuss links between TB IPC implementation and patient safety, human resources for health, prioritising person-centred care, building trust in health systems and refining the tools used to measure TB IPC implementation.

Prioritising patient experience has been a recent addition to the definition of high-quality care. In high TB burden settings, the encounter with TB IPC measures may be a TB patient’s initial contact with the healthcare system and may cause feelings of stigmatisation. We advocate for re-imagining the way we implement TB IPC, by drawing on the principles of person-centred care through incorporating the experiences of people using healthcare services. Health workers who developed occupational TB also offer a unique perspective: they have both experienced TB IPC and have played a role in implementing it in their workplace. They can be powerful advocates for person-centred TB IPC implementation. Through framing TB IPC as part of health system strengthening and consciously including person-centred perspectives in TB IPC design, measurement and guidelines, we hope to influence future TB IPC research and practice.

1. Introduction

The Lancet Global Health Commission on High-Quality Health Systems (HQHS) has called for a ‘revolution’ in the quality of care provided in healthcare systems in low- and middle-income countries [1]. This call to define, measure and pursue healthcare quality has been taken forward by leaders in tuberculosis (TB) research and reiterated in the Lancet Commission on Tuberculosis report [2,3]. TB is particularly prevalent in countries with vulnerable health systems, and disproportionately affects vulnerable communities [4]. Similarly, the transmission of TB occurs in healthcare facilities with many other underlying health system weaknesses. These include facilities with staff shortages, long waiting times, uninvolved facility managers, lack of organisational safety culture, inadequate continuing education and training support and poor occupational health and safety practices. Given these constraints, TB infection prevention and control (IPC) implementation may be accorded a lower priority in facilities struggling to deliver basic services. However, we argue that focusing on TB IPC implementation in weak health systems might not only contribute to reducing transmission of TB in facilities but can also be an entry point for broader health system strengthening [5].

In this article we start by examining the evolution of approaches to TB IPC, then argue that TB IPC can embedded within components of a high-quality health system as identified in the Lancet Commission re-
2. Historical and current context of TB IPC guidelines

Following a series of hospital-based outbreaks of drug-resistant TB (DR-TB) in the United States, one of the first TB IPC guidelines to be used globally was in 1994 by the US Centers for Disease Control [6]. The World Health Organization (WHO) produced its first TB IPC guidelines in 1999 and focused it on healthcare facilities in resource limited settings [7]. These guidelines organised TB IPC interventions according to administrative controls, environmental controls and personal respiratory protection.

The 2019 WHO TB IPC guidelines have similar content to that of the 1999 guidelines. In the guidelines, TB prevention and control are defined as a combination of measures designed to minimise the risk of TB transmission within populations [8]. The update reiterates the limitations of the existing evidence base for most TB IPC sub-components. Proving the effectiveness of TB IPC interventions is challenging due to the infrequency of measurable outcomes like development of TB disease and potential confounders such as high rates of community transmission. The guidelines recommend that TB IPC should be implemented as a package, as the combination of interventions has consistently been shown to be associated with a reduction in the rates of latent TB infection in health workers, although it emphasises the hierarchy of intervention with administrative controls as the most effective [8]. In balancing the costs of TB IPC implementation and the current limited quality of evidence against the risk and impact of nosocomial transmission and occupational TB in health workers, the committee maintained conditional to strong recommendations for implementation of the established guidelines [8,9]. There is also emphasis on integrating TB IPC with broader IPC strategies within countries, thus drawing on an ‘interdisciplinary, multi-sectoral and multi-level’ approach to implementation.

3. TB infection prevention and control in the context of health systems strengthening

The Lancet Global Health Commission on HQHS set out to answer the question: ‘What should a high-quality health system look like in countries with resource constraints and competing health priorities that aspire to reach the Sustainable Development Goals?’ They developed a HQHS framework that identifies the foundations, processes of care and key outcomes of high-quality care. We used this framework to explore the links between TB IPC and health system strengthening, looking to locate TB IPC within the high-quality health system ‘revolution’ rather than as part of a vertical TB programme. (See Fig. 1).

This expands upon previous arguments made by Harries et al. about the potential that TB IPC initiatives have to link vertical disease-specific programmes with broader health systems strengthening efforts [5]. It also accords with the recommendation in the 2019 WHO TB IPC guidelines to link TB IPC with universal IPC efforts. Similarly, it incorporates the call to integrate TB IPC with occupational health and safety programmes [10,11].

We explore TB IPC as a patient safety initiative which is a process of care of a competent health system and as part of a comprehensive occupational health and safety programme aimed at promoting health worker well-being. Lastly, we look at how we can promote positive user experience in facilities where TB IPC is implemented, specifically as part of person-centred care. We reflect on how we can use a person-centred approach in developing guidelines and in the measurements we use for TB IPC.

3.1. Human resources for health

There is strong evidence that health workers are at increased risk of developing TB compared to the general population due to occupational exposure [12]. The rates of latent TB conversion and active TB disease in health workers have been used as a proxy to measure the effects of TB IPC implementation [9,13]. This indicator is reported in the WHO Global TB Report, but missing data from high burden countries yields a limited perspective [9].

Programmatically, there has been little integration of TB IPC and occupational health and safety programmes [14] despite joint International Labour Organisation and WHO guidelines promoting such integration [11]. The importance of worker’s compensation for health workers who develop occupational TB has also been neglected [14].

Health workers are affected by the nosocomial spread of TB in devastating ways – loss of health, of income, of physical abilities due to side effects of treatment, and in some cases also their health and their lives [13]. TB not only threatens the human right of health workers to a safe and healthy workplace [15] but also the health system’s ability to provide care when the health workforce falls ill [16]. There is a growing body of evidence on the relationship between patient safety and health worker burnout [17]. The well-being of overburdened health workers in high TB incidence settings is further threatened by an institutional culture that fails to prioritise TB IPC. We assert that TB IPC should form part of broader strategies to promote human resources for health [18], particularly in low-and middle-income countries where health workers are a scarce and valuable resource [1].

In some settings, TB IPC implementation may be incorrectly seen as a simple delegation to a member of staff, who may not even have received specific TB IPC training [19]. Consequently, poor IPC implementation, just as with poor quality care, may be incorrectly viewed as a failure by health workers at the individual level, attributable to deficits in their knowledge, motivation and behaviour [1]. It is important to acknowledge that health workers are part of teams within organisations that operate within a broader health system. An interplay between these factors will determine whether individual health workers
are likely to implement TB IPC. A renewed focus on the safety of health workers is an opportunity to create organisational support for TB IPC implementation, while affirming to health workers that they are valued as part of the health system.

3.2. Patient safety

“The very first requirement in a hospital is that it should do the sick no harm.” - Florence Nightingale, 1863 [20]. An outbreak of extensively drug-resistant TB (XDR-TB) in a rural hospital in South Africa demonstrated that person-to-person transmission was the major driver of drug-resistant TB, rather than acquired resistance through poor adherence [21]. It showed the critical importance of TB IPC for patient safety and preventing antimicrobial resistance.

Globally, there has been renewed focus on preventing healthcare associated infections as part of combating antimicrobial resistance [22,23]. TB infection control should be linked with such infection prevention strategies, both in preventing transmission of airborne infectious illnesses and developing skills for dealing with outbreaks [8,24].

TB IPC implementation research could similarly draw on work in the patient safety field. This could help to move away from a linear, cause-and-effect pipeline model, to viewing healthcare facilities as complex adaptive systems that function like an ecosystem, with many role players operating within a specific organisational culture [25]. Using a patient safety lens could also enable TB IPC to contribute to public trust in healthcare facilities. Building this trust is, in turn, important for linking people to care, currently identified as a major gap in TB care with the ‘missing millions’ campaign [2].

3.3. Using a person-centred approach to re-imagine TB IPC

The Lancet Commission on HQHS identified positive user experience as an important feature of high-quality care, drawing on evidence that indicates it is as important as patient safety and clinical effectiveness [26]. Person-centred has been defined as an approach that incorporates four key attributes: a shift from disease-orientated care to a holistic approach that focuses on the person and their context. It involves understanding the individual’s experience of illness. It is based on sharing power between health workers and patients and encourages informed decision making and self-determination [27,28].

If we want to reimagine TB IPC using a person-centred approach, we need to understand the experiences patients have in visiting a facility where TB infection control is being implemented and incorporate their perspectives and needs in its re-design. Similarly, health workers who have had occupational TB offer a unique perspective - they have experience of how TB IPC measures are implemented and what makes implementation difficult. They have also been on the “receiving” end of TB IPC as patients. In this article, two co-authors contribute their experiences of occupational TB as health workers and add personal reflections on how this relates to high-quality care. (Box 1 and 2)

3.3.1. Inviting patient perspectives on TB IPC

In high TB burden settings, the encounter with TB IPC measures could be a TB patient’s initial contact with the healthcare system. Even if TB IPC is implemented according to the guidelines, there is the risk of patients experiencing shame, stigmatisation and emotional isolation [29]. This compromise of patient dignity in the name of public health, can create an environment where persons with TB are disempowered. Militaristic terms like ‘TB suspects’, ‘defaulters’, the need for ‘surveillance’ and ‘cough officers’ suggest that preventing TB transmission is a conflict between people with TB and health workers, with the responsibility for achieving ‘control’ resting on health workers. The Stop TB Partnership’s guide against the use of stigmatising language [30] recommends a shift from using the term ‘controlling’ TB globally to using ‘integrated, patient-centred care and prevention’ as a central pillar of the WHO’s End TB strategy.

Box 1

How it feels to be the ‘infection risk’.

‘I think it is important for health workers to remember the patient in front of you with TB is having a new and frightening experience. When I was diagnosed with XDR-TB I was placed in an isolation room in the intensive care unit. I went from being a dietician to a patient and being free to bedridden in a matter of days. Some of the health workers and cleaning staff were scared of me and did not want to come close to me. They were even scared of objects that were close to me, like my linen or the cutlery I used when eating. The isolation room was lonely and depressing. I remember the day I was discharged from ICU to a new room, where my doctor moved my bed to the window so that I can see the trees outside. That small change, the bit of nature, made me feel hopeful. It made me believe that I could beat this disease. I’m grateful that the doctor initiated this and I think that shared positive person-centred care. Sensitising health workers to see the person behind the mask can play a big role in making TB IPC less stigmatising.’

-Ingrid Schoeman, dietician and XDR TB survivor

However, merely changing the wording we use to describe facility-based activities that may be stigmatising or discriminatory is insufficient. We need to map a patient’s journey through a healthcare facility and look at the impact of TB IPC implementation on their overall experience. In some facilities undergoing TB triage and testing may paradoxically lead to spending a longer time in facilities, as patients wait for TB test results. Patient counselling regarding the rationale for TB testing is often absent. Surgical masks, which patients being investigated for pulmonary TB are asked to wear, have been described as a public TB label that leads to shame [29].

We should explore these experiences with patients and seek ways in which they might be modified. This could include distributing masks to all patients visiting a healthcare facility or developing guidelines on how to explain the use of masks in healthcare facilities. We can think creatively about ways in which the appearance of masks can modify perceptions through redesign. These strategies should form part of the overall aim of sensitising health workers to the importance of person-centred TB care [Box 1].

3.3.2. Inviting perspectives from health workers who had occupational TB

Health workers who have had occupational TB are often hesitant to disclose this to their colleagues, due to the stigma associated with the disease [31]. Their reported experiences include delays in diagnosis, struggle to access treatment and compensation, and life-long physical and emotional sequelae [14,32]. However, health workers who have developed TB who decide to return to the clinical environment are faced with an enhanced realisation of the importance and difficulties of TB infection control implementation [Box 2]. Inviting health workers to share their experiences with occupational TB has been successfully combined with TB IPC training, changing the perception of risk of other health workers while providing the tools to create a safe working environment [33,34]. Although the responsibility lies in the first instance with managers of healthcare organisations to protect and support health workers, health workers should not underestimate their collective advocacy power. Health workers who have had occupational TB can play an important role in motivating for TB IPC implementation, both on a local facility-, national- and global-level [35].
Box 2

Occupational TB changed my perspective.

‘When I was diagnosed with TB, I was shocked. It was during my busy final year at medical school and everything came to a standstill. There were many difficulties, including being hospitalised with a drug induced liver injury. Having TB completely changed the way I looked at infection control in the hospital environment. I became very aware of the risks we were all exposed to and the need to take precautions. I always wore a mask when I was working in wards and areas of potential risk. But it was very hard. I was ignored by my seniors and ridiculed by my peers as the person who always, “unnecessarily” wore “that mask”. They simply did not see it as a priority. There was a general attitude that doctors are invincible. And as junior you take the lead from how your seniors are behaving. We need to pay attention to training students in TB infection control, and also look for good role models when they do their clinical training. We also need to promote an organisational culture where health workers are encouraged to look after their own health. Providing platforms where health workers who have had TB can share their stories is one way in which we can start this change.’

-Clio Pillay, medical doctor and TB survivor

3.3.3. Person centred TB IPC guidelines

Person-centred TB IPC might suggest tensions between health worker and patient needs or priorities. For example, when using drama techniques in a research exercise to act out TB IPC implementation, health workers expressed anxieties about ‘difficult patients’ as an obstacle to TB IPC [36]. However, the two should not be contradictory: health workers who feel safe and valued are more likely to be retained in the field, and also able to provide empathic, person-centred care [18]. Similarly, for patients there is intrinsic value in receiving a service that has a positive user experience, which influences intention to return for follow up visits, adherence to treatment, and, ultimately, trust in health systems [1,37]. A key message that should be part of TB IPC training and communication between health workers and patients is that TB IPC aims to ensure individual and communal safety in all health facilities.

The duration of infectiousness of a person with pulmonary TB on effective therapy is important for TB IPC, as this has implications for how long patient-focused TB IPC measures should be implemented in healthcare or congregate facilities once someone has started TB treatment. Country-based guidelines often state that for drug-sensitive TB, adequate treatment for two weeks or more is associated with non-infectiousness [38] although the evidence for this duration is not grounded in robust data [39]. Data using the human to guinea pig transmission model suggest that patients on effective therapy are less infectious to guinea pigs than those who are not receiving effective therapy and that these effects may be rapid (days rather than weeks) and precede smear conversion [40]. The 2019 WHO TB IPC guidelines omit recommendations on how long patient-focused TB IPC should be implemented, stating limited data as reason. We assert that although data are limited, this should not preclude having guidelines. The absence of guidance transfers this decision on individual health workers who are then expected to make decisions for each individual patient, which may be poorly founded. It also risks TB IPC efforts being focused on areas where they may have little impact, for example, patients with DR-TB on effective therapy who have had negative sputum cultures. It is disempowering for someone diagnosed with TB, as they do not have a reference for duration of infectiousness to use when interacting with health workers, employers, or family members. \( U = U \) is an example of an HIV campaign that focuses on empowering patients with knowledge about HIV transmission, emphasising that an Undetectable viral load equals Untransmittable HIV [41] This demonstrates the shift in power from health workers to patients that is a key part of person-centred care, and should be a future goal for TB IPC guideline translation and public health campaigns.

The 2019 WHO TB IPC guidelines primarily provide guidance for transmission in health facilities but mentions applicability to other high-risk congregate settings and the role of community health workers in facilitating early diagnosis [8]. Interventions for household settings were not addressed due to the lack of directly applicable data that could be systematically evaluated. Although it is mentioned that patients and family members providing care should receive clear guidance and indications on IPC, no recommendations are provided in the guidelines. Person-centred care requires consideration of the support that is needed to navigate each step of their TB care journey. This includes clear recommendations on duration of IPC implementation at healthcare facilities, home and about return to work, as well as helping patients to address the stigma associated with TB transmission.

3.4. Measuring what matters

The Lancet Global Health Commission on HQHS placed emphasis on developing measurement tools that ‘measure what matters’ to patients and health workers, is simple to use and provides real-time information [1]. Currently we have two broad strategies to measure TB IPC implementation: indicators that measure risk of current or recent exposure to TB, and indicators that measure infection status or disease as outcome. Process indicators such as time-to-diagnosis and time-to-treatment initiation are helpful to indicate whether a facility is able to minimise transmission risk through accelerating rapid access to treatment. This is encompassed in the FAST strategy, which entails Find cases Actively by cough surveillance and rapid molecular sputum testing, Separate safely, and Treat effectively [42]. Periodic evaluation tools, including the WHO TB IPC checklist [43], cover all of the components of TB IPC implementation, and provide an overall view of gaps in implementation which can be re-evaluated in subsequent reviews. Continuous evaluation tools like carbon dioxide monitoring use proxy measures to assess ventilation [44]. Levels above a certain target could trigger a response from managers to intervene and improve conditions.

Outcome indicators can be quantified by the rate of latent TB conversion in health workers, measured with tuberculin skin tests (TST) or Interferon-Gamma Release Assay (IGRA) tests, which should be performed at the start of a health worker’s employment in a given facility and then serially repeated. These tests present different challenges, notably TST confounding by Bacillus Calmette–Guérin vaccination and unexplained IGRA reversions [45]. Although not a proxy for recent infection, the rate of occupational TB disease in health workers is necessary information for action to protect health workers and patients [14]. In high incidence TB settings where infection may be community acquired, special effort is needed to acquire information on occupational risk given the impracticability of laboratory matching of MTB strains [46]. TB in health workers should be recorded to allow an epidemiological analysis of group risk and trends, and outbreak analysis of specific risk settings where indicated.

Currently, there is a gap in our measurement toolbox for a strategy that captures patient and health worker experience. This gap could be closed through qualitative evaluation of patient perceptions of TB IPC implementation, although people could be hesitant to criticise care they receive. Another option would be to include participant observation techniques, where TB IPC implementation is observed over a longer period of time. Standardised patients (also called ‘mystery patients’) have been used to evaluate quality of TB care in many high TB burden countries [47]. Actors are trained to present with symptoms of TB, which is then used to compare diagnostic investigations and management plans across different facilities, in different countries. While the experiences of actors would differ to those seeking care for illness, this technique offers a way to incorporate patient experience in IPC measurement. We could consider using standardised patient facility visits to measure TB IPC, combining process measures (such as queue time),
with periodic evaluation tools (like the use of masks by patients, respirators by staff, and subjective reports of air quality) with reflections on overall experience of utilising care, including potentially stigmatising experiences.

4. Mapping the path towards re-imagining TB IPC

Re-imagining TB IPC using a person-centred approach can be a helpful tool when developing implementation strategies for national TB IPC policies (Fig. 2). The process could involve inviting health workers and patients to contribute to facility-specific implementation strategies as has been done in Romania [48]. Research methodologies that embrace this approach include human centred design and participatory action research.

5. Conclusions

The neglect of TB IPC remains an important gap in the provision of high-quality care in high TB burden countries. While there are limitations in our understanding of the effectiveness of different components of the TB IPC package, there is consensus about the risks faced by health workers and patients in facilities. There is an opportunity to shift TB IPC from the silo of national TB programmes and embed it within health systems strengthening efforts. We have used components of the Lancet Commission on HQHS framework to explore those links. This includes viewing TB IPC as part of patient safety initiatives, including those focused more broadly on general IPC and combating antimicrobial resistance. TB IPC should also be seen as a component of a comprehensive occupational health approach to promoting the well-being of health workers as part of the foundation of a strong health system.

The HQHS framework emphasises the importance of prioritising health user experience as component of high-quality care. We argue that this requires making person-centred care an essential part of re-imagining TB IPC implementation. This will only be achieved if we invite patients and health workers who have been affected by TB to contribute their perspectives. We need to keep the experiences of those seeking care for TB at the core when developing TB IPC guidelines and implementation strategies. This will enable us to create safe and compassionate healthcare environments that provide high quality care.

References
