



What quality of care means to tuberculosis survivors

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ABSTRACT

Quality of care for patients of TB suffers in India as well as in other countries, because the commonly accepted definitions of high quality care, rarely goes beyond correct diagnosis, treatment and adherence. The problem with the existing definitions and metrics of quality care is that they leave out patients, and when high quality care is defined without patients' perspectives, their needs and expectations are not addressed. This paper, based on a workshop held by TB survivors, attempts to examine the current state of quality of care extended to patients of TB, and to improve the scope of this care for the affected individuals, by the government, the healthcare system, and the society. The aim of the workshop and this paper is to arrive at a comprehensive, inclusive, and most importantly, a patient-centric definition of what quality of care looks like – to them.

1. Introduction

What quality of care looks like, depends on who is defining it. Healthcare must follow evidence-based guidelines, pose minimal risks and minimal delays for service users, and must be delivered equitably, regardless of factors like race, gender, geography, and socioeconomic status. It calls for healthcare that is people-centric, and takes into account the preferences and aspirations of individual service users and their communities [1].

However, analysis of user narratives reveals actual quality of care suffers in India as well as in other countries, because the commonly accepted definitions of high quality care, rarely goes beyond correct diagnosis, treatment and adherence. This is based on extensive interviews and documentation of cases of TB affected individuals by the SATB team and reflect quality of care challenges across urban rural geographies, regional and gender variations as also socio-economic variations. The problem with all these definitions and metrics is that they leave out patients, and when high quality care is defined without patients' perspectives, their needs and expectations are not addressed. This is particularly true in India where these definitions are often developed by international agencies and experts and become the basis of discussions for quality.

When speaking of healthcare, it is a given that the patient is the consumer – then why is it that healthcare services do not include the perspective of the patients? This represents an ethical, systemic but also epistemological contradiction where affected communities lack the agency either to shape, own or negotiate quality metrics for them.

Patients understand high quality care better than anyone else.

Foregrounding their experiences and perspectives puts patients back at the centre of care, which is only logical but also ethical since they experience healthcare first hand. In order for all stakeholders within the health system to understand and know what patients need, Survivors Against TB – a patient-led movement to strengthen India's fight against TB – convened a meeting with TB survivors to identify challenges and solutions to quality care, asking a simple question: *As patients, what do you need?*

2. Methodology

Through a comprehensive workshop held in Mumbai, we used a 360-degree approach to look at how quality care can be defined and implemented in a people-centric manner in both public and private sectors. The objective of conducting a workshop was to essentially employ generative learning, narrative and textual analysis so as to evolve a patient led definition of quality, make the existing definitions of quality of care in TB, more inclusive and sensitive and define key metrics to measure quality as defined by patients.

The workshop included 20 TB survivors, a healthcare provider and community workers, to evolve what high quality care means from the point of view of patients.

A bottom-up, participatory research [2] method was applied, wherein patients/survivors of TB, and community workers, were familiarized with each other and the context – this was done by having a focus group discussion [3] where all the participants were given the opportunity to substantiate where they came from and what influenced their experience and perception of quality of care as a TB-affected

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individual, or TB health professional in India. Focus group discussion is frequently used as a qualitative approach to gain an in-depth understanding of social issues. The method aims to obtain data from a purposely selected group of individuals rather than from a statistically representative sample of a broader population.

Verbal as well as non-verbal observations and interactions were duly noted down as field notes through the process of the workshop. Key socio-economic nuances such as gender, class, caste, etc. were taken into consideration while analysing responses as well as the final data.

We performed a content analysis of the interactions, field notes and other verbal and non-verbal interactions. Content analysis is a research tool used to determine the presence of certain words, themes, or concepts within some given qualitative data (i.e. text). Using content analysis, researchers can quantify and analyse the presence, meanings and relationships of such certain words, themes, or concepts.

The idea was to evolve a more comprehensive and thoughtful definition of quality of care, and this was what emerged.

2.1. What does quality care mean to patients?

Based on the focus group discussion, content analysis of participant responses, a definition was evolved through consensus. Participants defined high quality care for TB-affected patients meant care which is affordable, easily available and accessible – to begin with; care which is delivered efficiently in settings that are convenient and comfortable for patients, and provided in a dignified, empathetic and stigma-free manner.

TB-affected individuals stated that ideally, high quality care would be rooted in patients' economic, social and cultural realities, and would respond to patients' needs, including the need to address stigma and other mental health issues, while respecting their dignity and privacy.

Keeping these broad expectations in mind, we have found the following indicators of high quality care for TB patients:

High Quality Care is available, accessible and free. If a healthcare facility offers free tests or treatment but is located miles away, without convenient and affordable transportation, it is neither free nor high quality's affected in individuals and their families experience hardships in procuring drugs, availing healthcare facilities, and paying for long-drawn treatment [4]. This was included as the role of family and caregivers, and they were seen as critical to facilitating access. If the quality of care is only high in terms of its effectiveness, and not so much with respect to its affordability, availability or accessibility, then that is not care to begin with.

High Quality Care is evidence based and best in class, involving access to the best diagnostics and drugs, and a transparent drug supply chain. Patients and survivors of TB demanded that they receive point-of-care accurate diagnostics that adhere to the relevant WHO guidelines [5], and necessitate drug-susceptibility testing. Patients must have access to the best quality medicines, regardless of whether they seek care in the public or the private sector. In other words, both sectors should offer equitable and fair access, pricing, and quality of drugs to all patients. An argument made by survivors about the need to include this in quality metrics is to ensure the best technologies and most suitable regimens where governments and private may use sub-optimal technologies or toxic drug regimens.

High Quality Care is efficient. A rather ignored aspect of quality care, is efficient timely and flexible care; TB affected individuals are also workers and often the only breadwinners in their homes. Efficiency may seem relatively simple though here it should also be viewed as the right of the consumer. A broader content analysis throws multiple issues from economic support to affordability and related poverty and debt. To that end, healthcare facilities should be open according to patients' work schedules, so as to not impede their employment chances. Tests must be available promptly, so that patients are not forced to continue taking medicines just because of delays in test results. More

importantly, efficiency should be a core value in the conceptualisation and delivery of care.

High Quality Care must be transparent, and provide patients with information about their disease and the treatment. Respect for patients' autonomy is a cornerstone of high quality care. As patients, they deserve to know what their diagnosis means – what kind of TB they have and what drugs they are given, or not given, and why. TB survivors recounted their difficult experiences of having to spend a fortune on their treatment, a major part of which was unforeseen. So they demand that patients must be made aware of what the hidden costs of their treatment will be – care without this information is neither free nor transparent. They also need to know all the possible side-effects they can expect, and how they can manage them [6]. Patients should be provided with information as and when they ask for it, in easily accessible or visual formats, in their local languages. They need this to make informed, well-considered decisions about their health care.

Finally, every affected individual must have the freedom to choose where they seek care – they need to know what options they have for their treatment and their drugs, and how they choose to pay for and access them. Based on content analysis we may conclude that this specifically refers the lack of patient agency and choice between the public and private sectors particularly in India.

High Quality Care must address the mental health of patients. Over the course of the workshop, it was discovered that most patients, regardless of their socio-economic or medical differences, had at some point of their treatment, felt like their mental health was ignored, disregarded or often treatment caused these issues [7]. Treatment providers need to be alert to side-effects that impact mental health of the TB patient, along with the psychological and emotional toll that the disease and treatment can have on them. Proper counselling and mental health support must be made mandatory across all sectors – public or private as part of TB care [8].

High Quality Care must protect the patients' privacy. A patient's TB status should never be revealed to others, including other patients at healthcare facilities. Treatment providers ought to be mindful of how they may be inadvertently violating the privacy of their patients. Divulging a patient's TB status not only exposes them to unnecessary stigma and discrimination, but is also likely to create unwanted panic in the community. With an increase in online health information systems, protecting the health data of patients is critical [9].

High Quality Care is care with dignity. As a patient, one needs to feel reassured and respected during treatment. During the workshop, an overwhelming majority of patients claimed that they felt discouraged or dissuaded from asking their healthcare providers legitimate questions related to their treatment. This was based on extensive content analysis and recurring use of phrases. Patients must be made to feel comfortable asking their doctors questions and voicing their concerns, not just in general, but also about taboo topics like sex and menstruation. This was cited as a particular challenge by female members of the group. Healthcare settings need to be conducive to patients with diseases like TB, that are generally stigmatized, and these patients must be treated with respect and dignity by health workers. Care with dignity means care that is free of stigma. Patients cannot be stigmatized by the very people who are supposed to be caring for them, especially doctors and healthcare workers.

Other associated issues: An important aspect highlighted was the lack of agency or ability to give feedback to modify or improve the current paradigms of care and its associated behavioral practices. Another important issue was the lack of indigenous paradigms of quality –referring to most discussions dominated by international expert and agencies. The insufficient focus on punitive action for poor quality care, especially inadequate clinical practice, open discrimination and

2.2. So how can we achieve high quality of care?

While this is by no means a comprehensive set of solutions to achieve high quality care, here are suggestions developed by TB survivors themselves on what India can do to achieve high quality TB care for everyone.

Create new and more flexible forms of service delivery, increased private sector engagement in TB management and care, and more flexible timings to ensure improved access in the public sector.

Governments must invest in high quality diagnostics and powerful stakeholders must actively work on ensuring the availability of important drugs to avoid stock-outs –in both public and private sector.

More robust research and investment should go into drug development, so that patients can get newer, cheaper, and safer drugs, with shorter courses, and make them physically, socially, and financially accessible to the affected individuals.

Critically examine and address specific challenges that children affected by TB face, and then develop child friendly medicines and ensure their availability across India, in both private and public sector.

Create mandatory skill-building for the affected community and survivors, and continuous education program and refresher training using ICT for all health personnel in the public and private sectors on TB, on dealing with patients, their families, information on services available and necessary training on diagnostic and treatment guidelines, mental health, and stigma. Here, skill building is referring to reskilling for those unable to go back to work they were doing especially manual labour in the informal sector. An important aspect that is germane to high-quality care though has remained largely neglected in foundational work on quality. Every single member of the healthcare community must be aware of these fundamental aspects of disease and treatment, without which they cannot deliver high quality care to patients who need it most.

Build peer and mentor support networks to help provide patients with care that informs and educates them; here, patients will have access to a community that listens to them, has had similar experiences and can therefore act as each other's support system and sounding board, in addition to extending logistical or medical help based on their own personal experience. While the Indian government has begun initial efforts in this regard they remain unclear and need a proper community directed strategic focus for them.

These networks must be funded, formalized, strengthened and integrated with the rest of the healthcare system.

Create patient education and information programs in local languages which are rolled out as soon as a patient seeks diagnosis and care. This will allow them to be informed about what's to come, and they will not be forced to rely on someone else to understand their own disease and its treatment.

Expand and strengthen the 24 × 7 toll-free helpline that will actually provide patients with help and information. Texting options should be made available so that the helpline is accessible to individuals with hearing impairments as well.

The wider community will also need to be sensitized through information sessions at workplaces, schools, social and cultural gatherings, and targeted marketing on social media. In the absence of support from one's own community, patients may feel further isolated from the rest of the world, thus aggravating the stigma and mental health condition and making it harder for them to recover from the disease and its attendant problems.

Provide for legal punitive action against discrimination against TB patients in workplaces, families, healthcare settings and in communities.

Build the capacity of healthcare providers to provide realistic care that addresses issues of class, caste, gender especially marginalized gender identities. This remains a broader issue across the health system one that has been neglected up till now. Patients' social and economic identities often intermingle with their health, and the treatment that is

then offered to them. Therefore it is crucial that healthcare professionals be aware of these nuances while dealing with patients from different socioeconomic backgrounds.

Create systems of feedback and information collection for government and private doctors, so as to ensure long-term accountability and continuous improvement, referring to the lack of agency or ability to give feedback to modify or improve the current paradigms of care and its associated behavioral practices.

These systems should be people-centric, and include patient interviews and reviews of doctors, for the reference and safety of other patients to protect their interests.

Ensure legal provision for paid leave and job assurances for TB patients; this should be a part of all workplace policies, public or private. While it is relatively unclear the form this can take as its both law and institutional practices-workplace policies were a clear pathway as was a non-discrimination policy.

For the huge percentage of Indians working in the informal sector, create economic support programs and provisions for skill-building, so that they can gain an income while undergoing treatment, as well as after the treatment is completed.

Create expanded mental health counselling services that are available and accessible to TB patients throughout the course of their treatment, to eliminate self-stigma and help with depression and other mental health issues that the patients may face or be predisposed to. Also train all healthcare staff in basic mental health awareness screening and stigma reduction so that they can support patients appropriately.

Ensure that TB helpline responders receive training in mental health issues, and the helpline is connected to peer support groups and suicide help lines.

Create robust systems that safeguard privacy in the public and private sectors. Ensure legal repercussions for privacy violations to deter healthcare providers from divulging personal information of patients.

Finally, never forget – the TB patient is the most important stakeholder in the fight against TB.

3. Conclusion

Discussions, definitions and metrics of quality, clearly need strong patient and community led inputs. A lack of such participative and sufficiently inclusive efforts would, from the perspective of patients, in quality definitions and programs that are neither owned, nor beneficial. In a more pragmatic and implementation sense, a lack of patient led definitions would result in creating programs that are top down and have an insufficient understanding of patient needs and ground realities.

This, in the long-term, would create poor quality care, and exacerbate the health system and its consumers. It can also limit the autonomy of communities to intervene and engage with the health system and other key stakeholders. This together with increased investment in such programs would increase inequality and inequity.

A renewed discussion on high quality care led by survivors, patients and affected communities, presents a clear window of opportunity to redress power imbalances, improve quality of care and create a people focussed paradigm of high quality care that is currently missing in both the public and private sectors. This could be leveraged effectively by national programs in high burden countries like India as spring board to recasting approaches to TB care and addressing the epidemic in a more comprehensive, people—focussed and community centric way. For this, to happen, the conversation must be inclusive and also equal-paradigms that have remained missing in earlier conversations on TB care.

Ethical statement

Hereby, I, Chapal Mehra, consciously assure that for the manuscript WHAT QUALITY CARE MEANS TO US: SURVIVORS SPEAK, the following is fulfilled:

(1) This material is the authors' own original work, which has not been previously published elsewhere.

(2) The paper is not currently being considered for publication elsewhere.

(3) The paper reflects the authors' own research and analysis in a truthful and complete manner.

(4) The paper properly credits the meaningful contributions of co-authors and co-researchers.

(5) The results are appropriately placed in the context of prior and existing research.

(6) All sources used are properly disclosed (correct citation). Literally copying of text must be indicated as such by using quotation marks and giving proper reference.

(7) All authors have been personally and actively involved in substantial work leading to the paper, and will take public responsibility for its content.

Declaration of Competing Interest

None

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