In the eye of the multiple beholders: Qualitative research perspectives on studying and encouraging quality of TB care in India

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ABSTRACT

This paper outlines insights qualitative research brings to the study of quality of care. It advocates understanding care as sequential, interpersonal action aimed at improving health and documenting the networks in which care occurs. It assesses the strengths and weakness of contemporary quantitative and qualitative approaches to examining quality of care for tuberculosis (TB) before outlining three qualitative research programs aimed at understanding quality of TB in India. Three case studies focus on the diagnosis level in the cascade of TB care and use qualitative research to examine the clinical use of pharmaceuticals as diagnostics, the development of diagnostic tests, and the role of care providers in the utilization of diagnostic services. They show that 1) care must be understood as part of relationships over time, 2) the presence or absence of technologies does not always imply their expected use in care, 3) physicians' provision of care is often inflected by their perceptions of patient desires, and 4) effective care is not always perfectly aligned with global health priorities. Qualitative methods with a networked perspective on care provide novel findings that can and have been used when developing quality of care improvement interventions for TB.

1. Introduction

Qualitative research is one approach to addressing quality of care for tuberculosis (TB). A substantial body of qualitative and ethnographic research, including work we (AM, NE, AD) have led, views quality of TB care as a networked phenomenon [1,2]. These inquiries define care as interpersonal action aimed at improving or regaining health and wellbeing. Care, as repeated interpersonal action, occurs within a network of people—such as physicians, patients, pharmacists, laboratory technicians, families, and nurses—, places—such as clinics, households, and hospitals—, and things—such as technologies, money, health systems, and pharmaceuticals. Hence to meaningfully document care and interpret its quality, we must study the network of factors at play in a given care action – in our case TB – and from multiple perspectives.

In our work, we examine the form and quality of TB care as a function of the network within which it occurs. We argue that analyzing linkages and multiple interactions between networked elements of care to understand how they inform care provision is essential for

understanding and improving quality of TB care. A networked approach also recognizes that quality of care is dependent on context and changes according to illness and outcomes. In TB, a networked approach allows us to document and draw on quality expectations from unique localized care networks and from global public health. Insights on diverse drivers and assessments of quality of care inside and outside health facilities provides important data for developing quality of care metrics and interventions that can integrate local and international expectations of care.

A networked approach is different from many existing studies of quality of care which measure quality by assessing possible epidemiological and public health effects of care or it's correspondence to international standards. These studies, often quantitative, utilize scales to assess a particular action's adherence or non-adherence to national and international standards like the Hippocratic oath or the US's Institute of Medicines' six aims for health care: Safe, Effective, Patient-centered, Timely, Efficient, and Equitable [3–5]. Other studies, many of which engage TB quality of care, create checklists to record the absence or presence of material objects deemed essential for quality [6,7], analyze

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stepwise models of successful or unsuccessful care cascades [8–10], or observe practices such as referral or prescription for possible effects on epidemic trends and individual health [11–14]. Quality is assessed on the basis of single interactions between a physician and patient rather than a relationship over several visits. Other methods rely on patient pathways and satisfaction surveys to document clinical action as a measure of quality [15–19]. Based on recollections of experienced care and care in sequence, these studies privilege efficient care for its effects on health outcomes like transmission or adherence. However, they struggle to capture care in real time, and often neglect to report on the contexts that could help interpret patient satisfaction or dissatisfaction.

Qualitative researchers by contrast seek to understand and describe care as a social phenomenon and interpret its effect on individuals. Rarely is care framed in terms of high or low quality in the aggregate [20–27]. Care processes are often described from the perspectives of engaged actors such as doctors, families, and patients to avoid imposing normative standards on quality assessments, foreground the complexity of care as social and moral action, and learn how global health interventions can affect caregiving at the front-line [28–34]. This approach has been used to study programmatic interventions for TB and relatedly HIV's effects on social relations between disease, care providers and patients [35–38]. For example, qualitative researchers have studied the effects of direct observation of treatment on patients' lives and described changes in care resulting from the DOTS strategy [35,39–41]. A second body of qualitative research concerning the 'knowledge, attitudes, and practices' or *KAP studies* of TB healthcare workers and patients relies on the idea that care is shaped by individuals' reported beliefs and attitudes [42–47]. These KAP studies probe contextual factors to a lesser extent. A networked approach avoids reducing quality of care through a single indicator, episode, or system of evaluating quality, as many quantitative studies do. Additionally, it moves the qualitative framework beyond focus on single interactions and individual behaviors to investigate how broader, but mutable, contextual factors shape quality, including the very definition of quality as well as its intended and inadvertent impacts.

In this article, we combine our own original research projects to outline a qualitative, networked approach to quality of care. It helps us move beyond KAP frameworks to understand contexts, pathways and processes of care, and develop multivariate tools to study and improve quality of care. By considering the multiple factors that affect quality across sequential caring actions and from multiple perspectives, a networked method illuminates the dynamism that is implicit within care, and qualitative research's struggle to locate clinical care in a public health's quality of care discussion. Finally, a networked qualitative approach identifies the ways in which context affects care, particularly when working in settings associated with less-than-optimal outcomes for patients and public health.

Using qualitative methods such as in-depth and/or serial interviews, observations, focus groups, patient narratives of care, mapping networks, and policy analysis, we investigate dynamic TB care processes. We engage values used by multiple actors to interpret care as they traverse tasks like diagnosis, treatment, palliation, adherence, or rehabilitation. One can use these methods in multiple entry points throughout the cascade of TB care for indicators of quality, but here we focus on diagnosis and diagnostic processes.

2. Qualitative research on quality of TB care in India

Clinicians and public health researchers argue that tuberculosis care in India is highly idiosyncratic, of variegated quality, and often diverges from global standards [48]. Studies of the private sector, where just under 50% of patients access care, reveal a staggering diversity of care practices [49–54]. Though few published analyses of quality of care in the public sector exist, patient pathways indicate that public sector TB care may vary across clinics, cities, and states [15–17,55]. Attention to quality of care is essential in India where drug resistance is a persistent

problem [56–58] and pharmaceuticals, though rarely anti-TB drugs [13], are often dispensed without a prescription [59–62]. Interventions designed to address quality of care in India thus require flexible, dynamic solutions that can address the problem from multiple angles.

Our three cases, all based in India, engage TB diagnosis as care from different qualitative perspectives. McDowell uses medical anthropology to describe how physicians diagnose TB in urban private-sector clinics. Engel uses a science and technology studies (STS) perspective to analyze the production and use of diagnostic tools. Daftary uses an implementation science approach to understand how extra-clinical actors such as pharmacists can be partners to improve diagnosis. In each case, a networked approach helps to identify important levers for improving quality of care.

2.1. Quality of care viewed from medical anthropology and the clinic

Most medical anthropologists study clinics and hospitals to observe care [28,29,63–66]. They consider the effects of patient and physician communication about disease and the ways relationships affect care [64]. They also examine how physicians learn about and respond to disease [63,67]. Though anthropologists once understood factors related to quality of care as 'cultural,' contemporary work shows that care is influenced more strongly by economic, political, and infrastructural contexts than cultural practices or beliefs [68,69].

As part of a broader research team, McDowell conducted ethnography of TB care in Mumbai by observing clinical interactions and interviewing clinicians and patients to describe clinical care practices that combine diagnosis and treatment [70,71]. He observed 3000 clinical interactions and interviewed 300 general practitioners and patients. He documented the progression of care from first visit to TB diagnosis and treatment. He paid particular attention to the signs and symptoms that prompted physicians to ask for a diagnostic test or begin empirical TB treatment. With this real-time approach, he and colleagues compared physicians' clinical action and their self-reported behavior and found divergences in the characteristic of 'the know-do gap [72].' In practice, physicians did not implement the best practices they reported to know. McDowell and colleagues sought to understand this divergence in context and found that physicians rely on low cost pharmaceuticals as diagnostic tools and privilege symptom relief above diagnostic certainty in their assessment of quality of care.

By tracing the network of physicians, pharmaceuticals, laboratories, patients, and finance that made up medical care in the city, this approach reveals that most patients left the clinic without a clear diagnosis and very few demanded one. Instead, patients received small sachets of medicines to consume until their next visit and perhaps a prescription. On follow-up visits, physicians assessed changes in clinical signs to gauge the medicine's effects. Physicians adjusted their regimen based on physiological and etiological responses to pharmaceuticals until the patient's health improved or it became clear that the health issue would require testing. They ordered a diagnostic test only after passing through these steps, without observable improvements in the patient's health, or in the context of clear pathology like crepitation. They most often ordered complete blood counts, erythrocyte sedimentation rates, or chest x-rays. This majority of physicians observed shared this multiple-visit pattern of care-before-testing. On further interviews and analysis, McDowell's research found that non-standard practices in the context of several weeks of cough were related to the very low cost of generic pharmaceuticals, patients' prioritization of symptomatic relief over diagnostic certainty, and ambiguity of cough as a sentinel TB symptom in urban slums.

In this case ethnography was able to outline a set of considerations shared across a community that could be engaged at the collective level. It revealed important information about time and process that quantitative research rarely captures. Care was a process with several steps or layers rather than a single 'snap shot' event. The subsequent analysis does not identify a single cause of non-standard quality but

rather presents a way to understand quality that privileges a community-wide approach and situates clinical behavior in context, and from which a palette of interventions may be developed.

2.2. Quality of care viewed from science and technology studies

Tests can support provider-patient relationships and contribute to quality of care. A diagnostic test conducted at the doorstep can support community health workers in convincing patients to accompany them to the public clinic and instill trust in the healthcare system. Yet, if done inconsistently, the same test can damage care relationships [73]. In each case, the interaction between the imagined use of a clinical technology and the care setting makes for unexpected patterns of quality that could be studied by focusing on the production and use of diagnostics as technologies.

Science and technology studies scholars highlight the multiple actors, objects and steps that must be involved and coordinated to make technologies work. Even a seemingly simple technology like the Pap smear includes more than just the testing kit, swab and brush. The kit includes all the people, bodies, things, infrastructures, places and activities that produce a Pap smear result [74]. Such a networked technology-in-practice perspective has implications for how quality of care is produced and analyzed. It highlights that medical practice, and therefore its quality, is always a combination of very different elements (bodies, samples, professionals, research designs, patients, hospital or clinic organization, equipment, materials, reagents, conversations, questions, etc.) [75].

Secondly, STS scholars identify co-constructions of imagined designers and users during innovations' design and use [76]. Designers anticipate future users' interests, motives, skills and behavior, and build these ideas into the material aspects of the technology [77]. As a result, technologies contain an anticipated mode of use and anticipated type of user which influence what form and quality of care is possible. Over time, such anticipations or 'inscriptions' are stabilized, tools become entrenched in routine practice, and their use is not problematized [78]. While imagined users, inscribed in this way into innovations, guide human-machine interactions [77], real users also shape technology by attaching different meanings [79] or changing and manipulating the technology in daily practices [80,81]. That means diagnostic tests do not exist independent of health systems and practitioners, but are a central part of and transformed through their application within a network of actors and objects [82–89].

Engel mobilized these STS perspectives in her study of technology and diagnostic practices across different points of care. Her team's work helped to explain why tests are unlikely to be used in the ways developers envisioned and examined ensuing differences in quality of care. Mapping the processes and challenges of diagnosing major infectious diseases at point of care (POC) across different healthcare settings in India, her team showed how the majority of diagnostics at POC (including TB tests and tests intended to be rapid) were not being made to work within one patient encounter. The majority of (rapid) tests were conducted in overburdened laboratories, not at the bedside or consultation space. Even if test turn-around times were just a few hours or minutes, patients were told to return for test results and further management the following day, a practice that increased chances of loss to follow-up. The scarcity of human resources, material equipment and money available to providers and patients, combined with complicated referral pathways and strained relationships between patients and providers meant that, in trying to mitigate patient costs, providers more easily prescribed treatment rather than diagnostics. The resulting care favored empirical treatment over treatment guided by diagnostic test results [54,73].

In this case, technology was not used as intended and influenced how care was given. An STS perspective showed that to improve quality of care the availability of rapid and easy-to-use POC diagnostics was insufficient. Instead, existing relationships, infrastructure, networks,

and resulting practices as well as the undesired or unexpected consequences of introducing such technologies must equally be taken into account. Though frequently presented and researched separately in global health, diagnostic technologies interact with, are molded by, and shape health system issues, and can produce altered constructions of quality.

2.3. Quality of care viewed from implementing interventions

Implementation science (IS) is a common framework guiding public health interventions. Social, behavioral, economical and operational factors are considered key determinants of intervention uptake and adoption. Related research uncovers 'real-world' bottlenecks to incorporating evidence-based knowledge and strategies into routine healthcare practices [90,91]. As qualitative researchers also study people's behaviors and practices in their 'real world' setting [92], qualitative inquiry fits well within IS projects by bridging gaps between intervention efficacy and impact and helping improve quality of care under an intervention [92].

Working with pharmacists in urban Patna, Daftary's team [93] adopted an IS framework to analyze the impact of a referral intervention among private pharmacies, from whom people commonly seek medical advice. Indeed, pharmacists are the preferred provider amongst people disinclined to wait in queue or pay to see a doctor [94]. Pharmacists, however, are known to sell over-the-counter (OTC) medicines to people who could benefit from immediate referral for a test or consultation [13]. The intervention team trained one hundred and five pharmacists to triage and directly refer persons with TB symptoms for a TB screening test. Referred patients would bypass OTC drugs or an initial doctor consultation, and access a consultation only after completing the test. Daftary's team hoped that quality of TB care would improve due to increased efficiency gained when removing one step from patients' diagnostic pathway.

In the preparatory phase, the researchers conducted a situation analysis observing retail pharmacies and interviewing doctors, patients, and other actors affected by the planned intervention. They identified three considerations which challenged early conceptualizations of good quality care [95]. First, persons approaching pharmacies for medical advice were assumed to benefit from referral to a testing laboratory and go directly thereafter to a doctor. However, it became apparent that this process would disrupt people's expectations for a resolution during their initial pharmacy encounter and jeopardize longstanding relationships between pharmacists and patients. Enforcing off-site referrals before pharmacists had an opportunity to provide symptom relief through the sale of an OTC medicine was thus not entirely feasible. In response, the interveners re-conceptualized good quality of care as practices that allowed providers to balance decisions to refer patients away from their own practice in ways that nurtured patient expectations. Even so, sales of unnecessary medicines, especially antibiotics needed to be curtailed. Negotiating between intervener and pharmacist priorities, the team eventually gained pharmacists' buy-in by advertising the referral as an item they could 'sell' to patients. Though the tests were free of charge to patients, pharmacists 'dispensed' a voucher to reflect that a test had been ordered. This dispensing of a service maintained patient-pharmacist trust and satisfied the demand of those who expected to leave the encounter with a tangible product in hand.

Second, it was assumed that people referred for a TB test would visit a doctor immediately after test completion. Here too, deep-set patient and provider expectations outweighed efficient practices. Using interviews and observations, Daftary's team learned that it was critical for patients to return to the initial referring provider to share their test result before considering a subsequent consultation. Patients and pharmacists valued exchanging information and stoking relationships through constant check-ins prioritized this above any public health mandate to accelerate the diagnostic pathway. Accommodating this existing networked care process in the intervention likely promoted

referral uptake and completion amongst participating pharmacists and patients which, as part of a subsequent impact evaluation, were found to be 81% and 86% respectively [93].

Finally, open-ended inquiry revealed that tedious monitoring and evaluation processes discouraged providers from participating. Referring patients was simple, but documenting it in line with a research protocol was onerous. In response, Daftary's team invited pharmacists to design instruments that could improve acceptability. Nonetheless, even these simpler forms were cumbersome, and many busy pharmacists opted to provide patients with undocumented verbal referrals.

These considerations improved acceptability and uptake of the intervention model. Efficiency, understood to denote good quality by traditional global health metrics, was found to be detrimental to attentive, personalized and affective care that was a closer marker of high quality from the perspectives of intervention implementers and users. Using the qualitative results produced by an IS model, the resulting intervention model catered to the norms, behaviors and expectations of key actors. It more aptly responded to local notions of good quality care.

3. Discussion

The cases studies and the qualitative networked approach we advocate reveal four important points about the study of quality of TB care: 1) Care must be understood as part of relationships over time, 2) The presence or absence of technologies does not always imply their expected use in care, 3) Physicians' provision of care is often inflected by their perceptions of patient desires, and 4) Effective care is not always perfectly aligned with global health priorities.

Our approach points out that quality is produced over time rather than in a single action. The clinical diagnosis case engages quality of care as the sum of actions from first visit to completed treatment. The POC case extends the drivers of quality of care even earlier to the development of a technology and its use. Finally, the pharmacy case shows that quality of care can begin outside the clinic and relate to events in illness episodes preceding it. These cases show that it is necessary to consider quality of care as a process. Our qualitative networked research approach allows this by attending to a whole cascade of steps, by analyzing linkages and multiple interactions between networked elements and actors of care inside and outside the clinic that shape the patterns through which care emerges and by capturing a dynamic view of care through iterative data collection and analysis.

Second, the cases suggest that quality of care needs to be studied through the use rather than mere presence of clinical or technical objects. The presence of a rapid test did not necessarily speed up diagnosis. A surplus of incomplete referral slips at a pharmacy did not necessarily mean that pharmacists were not referring patients or improving quality of care. In each case a focus on what people actually do in a care setting by observing their work and asking questions about the ways they give care helps shed new light on what objects might mean for quality of care.

Third, care is a negotiation between caregivers' priorities and knowledge and patients' needs and desires. Each case shows how caregivers negotiate effective medical practice and their patient's expectations, budgets, and desires to achieve quality. In the clinic and pharmacy cases caregivers went through a complicated process of providing care and meeting patients' expectations of quality of care, often providing care that their patients considered as high quality but did not match international standards. Caregivers with access to POC tests had to balance the health system workload, patient desires to leave the clinic and return to their normal life, and technology producers' ideas that a test's speed would speed up diagnosis. Attending to the negotiation between caregiver and patient is important to assess quality. Qualitative research's insistence on actors' perspectives allows it to account for multiple values in caregiving and how values are

negotiated. Qualitative work also considers key interpersonal aspects of quality of care like listening, meeting patient expectations, and adjusting for context in ways that quantitative studies find difficult.

Finally, our approach shows that global public health's standards of quality of care are important but may not always align with good clinical practice. Each case suggests that assessing quality of diagnostic care retrospectively, when researchers know the diagnosis, misses the complexity of determining what quality of care might look like before diagnosis. Clinicians and pharmacists had to work toward a TB diagnosis while most often seeing patients who sick with self-limiting or other bacterial illness. They take the likelihood of TB into account before ordering a test, despite its recommendation by global standards. This led to inefficiency, diagnostic delay, and transmission when the patient had active TB, but in other cases avoided unnecessary procedures, another indicator of quality care. For instance, physicians assessed the additional stress put on the health system and patient when asking patients to wait for a rapid test that might or might not be run immediately. Qualitative research with a networked approach at core allows for the uncertainty of diagnostic and other care because it frequently observes care in action, and situates itself in the know-do gap rather than on one side of it. This can help avoid the pitfalls of assuming knowledge or attitudes necessarily affect behavior.

Our networked approach to care has some limitations. It is often time consuming and requires multiple investigation and analytic exercises. It can be affected by self-reporting bias and the Hawthorne effect as observation may affect the kinds of care given. Its commitment to studying care in context and mapping networks also makes the creation of global level comparability difficult. These obstacles, however, can be overcome by using qualitative methods alongside quantitative ones and creating collectives like ours.

4. Conclusion

Together the three cases show that quality of care, both in terms of form and degree of excellence, is not reducible to a single factor or individual. They suggest that quality of TB care improvement work that aims to put patient experience at the center of TB care and intervention cannot rely solely on measures by efficiency, technical excellence, or speed. Instead they should consider a networked approach to understand quality of care in context. Our disciplinary diversity means that we use different analytics and methods to understand care, but in each case the networked and uncertain nature of quality of care reveals itself. Moreover, qualitative results can be used to interpret patient pathways, studies of diagnostic or treatment delay, or standardized patient results. In light of these benefits we propose interdisciplinary intervention teams include social scientists from conceptualization and that quantitative studies of quality of care too will benefit from a consultation with social science colleagues.

Declaration of Competing Interest

We wish to confirm that there are no known conflicts of interest associated with this publication and there has been no significant financial support for this work that could have influenced its outcome.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.jctube.2019.100111.

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