No more business as usual: A case for qualitative approaches in the fight against TB

Setting the stage

Decades of efforts to mitigate the global burden of tuberculosis (TB) have led to it rematerialising in even more burdensome and troubling multidrug-resistant (MDR) strains. Traditional approaches to TB control across the globe, and in South Africa (SA) specifically, reflect decades of biomedical research focused primarily on clinical surveillance and the reduction of new infections.[1-3] Reduction of disease through a health-system process, where detection, treatment and cure become the work of clinical staff and hospitals, are only optimal under social conditions where screening, seeking care, follow-up and adherence to treatment are consistent with norms in communities. What if community behaviours vary based on geography, language and culture? How would standardised clinical practices address the various differences across groups?

Given the challenges associated with the current surveillance and control mechanisms to arrest TB, not to mention MDR-TB, across SA, the emphasis on clinical-based approaches is neither sufficient nor appropriate for capturing the sociocultural aspects of TB-related illness.[4-6] Health services researchers who have learned from medical anthropologists and sociologists have adopted qualitative community-based approaches to address these very real gaps in sociocultural understanding. The following editorial calls attention (Table 1) to four characteristics of community-based qualitative approaches that may effectively challenge the 'business as usual' approaches to TB control, and guide more appropriate and relevant TB intervention design.

Today's consensus is that despite decades of research, intervention and spending, the global TB epidemic is still a social disease. TB continues to attack vulnerable communities across the globe. Bacteria thrive in areas where people live in close proximity. They hide in the spaces where people live and spend most of their time – eating and sleeping, visiting with family and chatting with friends. While the health costs of the disease are easy to quantify, the social costs often go unnoticed. There are reams of data about the unremitting impact of TB, MDR-TB, and extensively drug-resistant (XDR) TB in the developing world, as well as in rural, more isolated parts of the globe. Money from USAID as part of the Stop TB Partnership has been spent to further methods of delivering better services (mainly medicines) to individuals in these communities, and yet reports suggest that these efforts remain grossly underfunded. Leaders at high political and ministerial levels have raised their collective voices for interventions to end the growing TB burden.

This public commitment to change is readily available to global health professionals, and can be found in the report published by the Stop TB Partnership called 'Paradigm Shift'. This report outlines in detail how current research and funding practices must be redefined and repositioned to support three main pillars to seeing the end of TB: (i) integrated patient-centred care and prevention; (ii) bold policies and supportive systems; and (iii) intensified research and innovation.[7] There are myriad examples of how researchers have contributed to the reduction of global TB, not to mention

Table 1. Four characteristics of community-based qualitative approaches to improving TB treatment and services				
Characteristic	Approach method	Purpose	Relevance	Key takeaway
Person-centred	Elicitation interviews; cognitive interviews	Contextualises collection and validation of data within lived experiences of individuals in communities.	Consistent with 1st pillar of End TB Strategy;[7] ensures external validity wof findings	Transfers setting of evidence from lab to community
Participatory	Community-based participatory research; stakeholder analysis	Levels power hierarchies by emphasising shared goals and responsibilities for research and implementation of new services; engages diverse stakeholders	Meets demand of 3rd pillar of End TB Strategy[7] to promote innovative and rapid intervention designs	Engages groups in the codesign of innovative context-driven strategies
Preference-based	Implementation science; shared decision-making	Provides communities with most up-to-date evidence to foster informed conversations with the intention of finding optimal service and treatment solutions	Feasibility and acceptability of interventions are necessary for sustainability; sustainability is only possible if strategies match community preferences (needs and wants)	Any intervention designed in the absence of evidence and community choice risks failure
Persistent	Applied ethnography	Formal commitment between researchers and communities that emphasises co-leadership	Addresses 2nd pillar of End TB Strategy[7] to ensure bold strategies and commitment to communities; research designed with purposes of application and improving outcomes has sustainability as main feature	Bold action requires ambition and commitment to communities

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the fact that much of this work has led to innovative approaches and potentially novel pharmaceuticals to reinforce prevention measures, but despite these relatively impressive effects, those who perform health services research in infectious diseases know that we are still losing the battle with TB in the form of multi-drug resistance.

The global plan to end TB led by the Stop TB Partnership[7] follows the ambitious 90-90-90 programme, where in theory, 90% of people with TB are reached, 90% of key populations where need is greatest are screened, and there is a 90% success rate in treatment.[4] This partnership readily acknowledges a need to change the 'business-as-usual' practice, calling instead for patient-centred prevention, bold supporting policies and intensified research and innovation. In SA, while ambitious, it is possible that this programme reinforces the same old approach that has included screening, treating and follow-up, as described in traditional approaches that collect incidence and prevalence data on TB. The reality is that while many across SA recognise the need for novel approaches, the questions of method and approach are limited by strict patterns consistent with clinical outcomes-based approaches, and are in dire need of modification.

Qualitative approaches offer new insights into relevant challenges posed by current gaps in TB control. Arguably, the scope of qualitative methods and their relevance towards optimising approaches to fighting TB are best characterised by four features: they are person-centred, participatory and preference-based, and require perseverance. While other approaches eschew bias for parsimony, objectivism and clear comparative controls, qualitative methods look at the social world as messy and fully of diverse, subjective and naturally unfamiliar phenomena. The lived experiences of individuals, in how they form groups, come together in networks to support or defend each other, relate to one another and are impacted and impact their environment are just a few of the related areas of inquiry appropriate for qualitative methods. By design, the methods permit the use and analysis of diverse forms of data, and embrace multiple modes of data collection. Qualitative, community-based methods are flexible, as well as specifically useful to the right context. Social scientists from disciplines such as anthropology and sociology have adopted and expertly applied these methods in ways that have led to deep insights into human behaviour, not to mention the worlds of communication and medicine. Ironically, the strengths inherent to qualitative methods are also the characteristics criticised by the most strident positivists.

Person-centred
Qualitative community-based approaches are by design embedded in the communities in which they are applied. In order for TB research to be impactful, before description, it must first be dedicated to understanding the cultural and behavioural aspects of how people with TB, and those who are at highest risk of acquiring TB, actually live. In medical sociology, the phrase 'lived experience' is used to define those attributes of human behavior that encapsulate the social world of people in their day-to-day lives. Author Ursula K Le Guin once said that 'all knowledge is local,' which is critical to this argument about the necessity of finding methods that are

person-centred. Individual knowledge is often constructed in space and environment. These concepts are naturally a part of one's community, and where one lives, and was born and raised. Determining which aspects of TB are most locally relevant, and how the bacteria spread in communities requires intimate knowledge of local habits, customs and structures.

Collecting this type of data, which requires local knowledge, is the purpose of qualitative methods, and in particular the focus of elicitation interviews and cognitive interviews. These types of interviews require the investigator to be versed in multiple skills in community engagement and interviewing. Whether collecting data independently or in teams, the skills necessary for doing person-centred work require an ability to train others, approach research more locally, and analyse data with community partners. This kind of approach runs counter to many objectivist approaches to data collection, yet underscores one of the fundamental strengths of qualitative inquiry – the understanding that all knowledge is local.

Participatory
To achieve person-centred approaches, the researcher must put aside professional constraints associated with hierarchies, and abandon so-called rigorous objectivism, to embrace the natural phenomenon of partnership. Participatory methods, historically associated with anthropology, see their modern origins in Paulo Freire's codesigned educational methods.[8] These approaches have also been highlighted in more contemporary epistemologies, where researchers and communities collaborate to develop more effective interventions for education, health promotion and public health.[9,10] The principles of community-based research, or community-based participatory research, have also been successfully applied in SA in HIV prevention and treatment.[11] What participatory methods offer, beyond the idea of partnership with communities, is the multi-stakeholder approach to developing research questions, and to data collection. By partnering with stakeholders in the community and beyond, researchers can incorporate multi-level, multi-perspective data that can uniquely inform service delivery.[12,13]

Preference-based
The importance of offering choices in treatment and modes of receiving treatment is often overlooked and misunderstood as reflecting an uneducated point of view. As mentioned already, if we work from the premises that all knowledge is local, and that a person-centred approach is ethically appropriate, then we must acknowledge that individual choice matters. People living in diverse communities see the world differently, and most likely have independent experiences that uniquely characterise their social worlds. If we further recognise that our job as health professionals is to educate as well as treat, then we must agree on some level that providing communities with evidence permits the examination of choice.[14,15] One might only have to look at the availability of treatment for TB. Whether an individual receives TB medicine through a directly observed treatment, short-course (DOTS) or community health-worker model, the data support both approaches. How can we as health professionals determine the optimal approach for

receiving treatment if we don't provide individuals with the choice to decide which option they prefer, given the evidence?

Persistent

In a world of medicine and clinical science where hypothesis testing, counts and percentages, objective principles of measurement and minimising error and limiting bias hold sway, qualitative methods face a tough path towards relevancy. Yet I argue (Table 1) that it is indeed this unique role in the science of medicine where a qualitative method, ethnography in this case, offers deeper insight into some of the most challenging of questions that perplex the most accurate process and outcome measures. Ethnography is widely accepted as one of the most appropriate qualitative methods for capturing the unique cultural and situational characteristics of illness.[16,17] Illness, the common marker of human physical distress, has been defined by and subject to specific cultural and social orientations. Ethnography in general, and applied ethnography specifically, is well-positioned to explore sociocultural issues related to TB treatment and care delivery.[18,19] TB is by nature a social disease, and as others have pointed out, requires a specific methodological skill set to properly understand it. TB's impact has been widely experienced by the poor, rural and unseen. In more ways than one, applied ethnography, framed by stakeholder engagement, participant observation and collaborative approaches to data collection, holds the most promise for supporting the development of long-term treatment approaches to mitigate the TB burden.[20]

Conclusion

New approaches to TB research that are patient-centred, participatory, preference-based and persistent offer the most robust set of methodologies to change current 'business-as-usual' paradigms in health services research on TB control. The history of TB is a timeless story characterised by frustration, forced labor and migration, fear and filth. For decades, large investments have been made in mitigating the progression of the illness, and while some methods have seen improvements in incidence, the rise of multi-drug resistant strains has caused many to question these traditional approaches. The time is now for business as usual to stop. Those who are most likely to acquire TB, and be unable to fight against its effects, are people who are already unhealthy and malnourished, and who live in close proximity to one another. This is a perfect recipe for disaster in rural areas of the world, where resources are limited and traditional methods of care delivery have a history of ineffective implementation. The methods described here in brief offer some insight into qualitative approaches that might capture more relevant data to shape more applicable and useful TB interventions in the future.

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