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Role of acceptability barriers in delayed diagnosis of Tuberculosis: Literature review from high burden countries

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ABSTRACT

Purpose: Direct transmission of mutated tuberculosis (TB) strains is among major contributors to the worldwide epidemic of Drug-Resistant Tuberculosis. Expanding access to TB-services and decreasing diagnostic delays are acknowledged as potential solutions. We aimed to summarize evidence about links between health care acceptability barriers and TB diagnostic delays. Scoping and systematic review approaches were combined to determine the depth/breadth of the literature, identify gaps, and synthesize findings.

Methods: Electronic data-bases, key journals, other relevant electronic sources, and references of relevant articles were selected as potential sources through a preliminary search and expertsí advice. Titles and abstracts of 4046 initial records and 1796 references were screened against preliminarily developed and post-hoc inclusion/exclusion criteria. Author, year of publication, study location, study aims, overview of methods, study population, *intervention* type, outcomes measures and results of each included paper were extracted. Methodological quality of studies was assessed. Narrative synthesis of the study results was conducted through the thematic analysis approach.

Results: Patients' negative expectations, doubts about quality of services/medications and burden of stigma, as well as providers' discriminative attitudes towards patients' characteristics (age, gender, ethnicity) were reported as major barriers. Scarcity and unequal distribution of the literature and lack of attention to all potential acceptability barriers were found as major gaps in the current research.

Conclusion: Overall, study findings indicate the significance of acceptability barriers' role in TB diagnostic delays. Emerging character of the field is demonstrated. Recommendations about further research directions are outlined.

Contents

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1. Background

Due to its high epidemiological and financial burden, tuberculosis (TB) has been announced as a global emergency by the World Health Organization (WHO) in 1993 and is the second-leading cause of death from a single infectious agent, after the human immunodeficiency virus (HIV) (World Health Organization, 2013a).

Problem of drug-resistance, along with TB-HIV co-infection, is among main contributors to the current resurgence of TB epidemics. Multidrug-/extensively drug-resistant (MDR/XDR) TB cases, have significantly lower cure rates (40%) compared to drug susceptible cases (95%) (World Health Organization, 2013a). Available evidence indicates that M/XDR-TB has to be considered a predominantly man-made phenomenon, since human activities (e.g. improper treatment) are the main contributors to the development of the TB-bacteria resistance and the poor administration of M/XDR-TB problem promotes direct transmissions of resistant strains (Lambregts-van Weezenbeek and Veen, 1995; World Health Organization, 2008; Ye et al., 1997). Concentration of over 95% of TB-cases/deaths in low and middle-income countries (World Health Organization, 2013b), where suboptimal socioeconomic and demographic environment, coupled with the lack of preventing, diagnostic and treating facilities, create favorable conditions for the spread of disease (World Health Organization, 2013a), demonstrates transition from "treatment-generated to transmission-generated MDR-TB" (Andrews et al., 2008; Suen et al., 2014).

Diagnostic delays (duration of time from onset of symptoms (such as cough, unintentional weight loss, fatigue, fever, night sweats, chills, loss of appetite (World Health Organization)) to the final diagnosis) play a significant role in exacerbating this trend. Research has revealed associations between postponed diagnosis and increased risk of TB transmission (Cheng et al., 2013; Golub et al., 2006). An untreated TB patient is estimated to infect an average of 10 personal contacts within a year and up to 20 – during the natural course of disease (World Health Organization, 2006a).

Barriers to access to TB diagnostic services are, on the other end, discussed among factors, contributing to diagnostic delays (Gele et al., 2010; Lin et al., 2008; Long et al., 2008; Murray et al., 2013; World Health Organization, 2013a). To address the problem, WHO and Stop TB Partnership strongly emphasize the need of improving access to TB services and incorporate this as an objective in the global TB-policies (World Health Organization, 2011, 2006b; World Health Organization et al., 2014). The complexity of access as a concept, however, impedes adequate attention to all of its dimensions, hence limits success in addressing access-related and consequent problems.

Early literature abounds with examples of narrow definitions of access, either from supply (access as physical/spatial availability of services (Freeborn and Greenlick, 1973; Guagliardo, 2004; Mooney, 1983; Perry and Gesler, 2000; Rosero-Bixby, 2004)) or from demand perspective only (access as an issue of financial affordability (Falkingham, 2004; Jutting, 2001)). Interpretations of access in terms of its measurement (e.g. access as total cost of service utilization etc.) can also be found in the literature (Finkelstein, 2001; Goddard and Smith, 2001; Penchansky and Thomas, 1981; Vilhjalmsson, 2005). Understanding of access as a complex concept was firstly proposed in 1970–80s (Aday and Andersen, 1974; Penchansky and Thomas, 1981). Access was described as the 'degree of fit' between clients and the health system in five key areas: Availability (volume and type of services), Accessibility (geographic location), accommodation (organizational aspects), affordability (financial access), and acceptability (patients and providers attitudes to, expectations from and perceptions about each other) (Penchansky and Thomas, 1981). Along somewhat similar lines, McIntyre et al. (2009) conceptualized framework of access to health care (HC) as "the interaction (or degree of fit) between health care systems and individuals, households, and communities", uniting physical (availability), financial (affordability), and social/cultural (acceptability) dimensions, and measured in degree of "empowerment of individual to use health care" (McIntyre et al., 2009).

Adopting the framework of McIntyre et al. (2009), we define social access (acceptability) as degree of fit between expectations, attitudes and beliefs of both, health service providers and patients with respect to each other (McIntyre et al., 2009). Parties' attitudes towards provider characteristics (race, ethnicity, age, gender, language etc.), expectations about being treated respectfully with minimum burden stigma, and beliefs about efficiency of care process, drugs etc. may influence their ability to use health services when needed. The same aspects on provider's side, if not matching to those of individuals, may become barriers for patients in the future (McIntyre et al., 2009).

Acceptability barriers are frequently confused and interchangeably used with barriers to health seeking behavior. However, according to the most recent understanding of the issue, two constructs – access to care and health seeking, are disassociated from each other (Evans et al., 2013; McIntyre et al., 2009). McIntyre et al. distinguish between the access to care and actual utilization of services, stating that empowerment of an individual to use services (access) may be exercised or not by the individual (health seeking behavior), based on circumstances, independent from degree of empowerment; hence access cannot be measured by actual use of services and the barriers to health seeking behavior may be different from barriers to access the services (McIntyre et al., 2009). Addressing the same issue, WHO defines acceptability (social access), capturing "people's willingness to seek services. Acceptability is low when patients perceive services to be ineffective or when social and cultural factors such as age, sex, ethnicity, language or religion of the health provider discourage them from seeking services" (Evans et al., 2013).

Based on the above provided understanding of WHO and the adopted framework of access in this study, health seeking behavior is understood as the action of service utilization, hence not as