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Review

Tuberculosis stigma as a social determinant of health: a systematic mapping review of research in low incidence countries

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SUMMARY

Tuberculosis (TB)-related stigma is an important social determinant of health. Research generally highlights how stigma can have a considerable impact on individuals and communities, including delays in seeking health care and adherence to treatment. There is scant research into the assessment of TB-related stigma in low incidence countries. This study aimed to systematically map out the research into stigma. A particular emphasis was placed on the methods employed to measure stigma, the conceptual frameworks used to understand stigma, and whether structural factors were theorized. Twenty-two studies were identified; the majority adopted a qualitative approach and aimed to assess knowledge, attitudes, and beliefs about TB. Few studies included stigma as a substantive topic. Only one study aimed to reduce stigma. A number of studies suggested that TB control measures and representations of migrants in the media reporting of TB were implicated in the production of stigma. The paucity of conceptual models and theories about how the social and structural determinants intersect with stigma was apparent. Future interventions to reduce stigma, and measurements of effectiveness, would benefit from a stronger theoretical underpinning in relation to TB stigma and the intersection between the social and structural determinants of health.

1. Introduction

1.1. TB in low incidence countries

Q4 Tuberculosis (TB) is a major global public health problem affecting lower and middle income countries.[1,2] TB continues to present a significant challenge in 33 low incidence countries (defined as ≤100 cases per million), which would include most of Western Europe, the USA, Canada, Australia, and New Zealand. Cases of TB are over-represented in socially and economically marginalized populations in low incidence, high income countries and, in particular, in migrant communities.[1] More than 50% of TB cases in low incidence countries occur amongst people born outside of those countries; in some cases this figure increases to 90%.[1] Migration from countries of high to low disease burden is unlikely to decrease.

In the UK in 2013, 70% of TB cases came from the 40% most economically deprived areas and 44% of TB cases did not have employment.[3] In low incidence countries, TB is concentrated in groups often defined as hard-to-reach, or underserved, and is characterized by complex health and social risks,[4] for example homelessness, imprisonment, high rates of alcohol and substance misuse, HIV, a recent history of migration from countries with a high disease burden, and lack of entitlement to welfare. All of these factors can impact on access to health care and treatment outcomes and present particular challenges for services that may lack the necessary resources to outreach a service to vulnerable communities.

In response to these unique challenges, in 2014 the World Health Organization (WHO), in collaboration with the European Respiratory Society (ERS),[5] developed a framework of eight priority actions for the elimination of TB in countries with low incidence (or approaching low incidence): ensuring political commitment, addressing the needs of vulnerable and hard-to-reach groups and migrants (which includes actions to mitigate stigma), targeted screening for both active and latent disease in high-risk groups,

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improving case management, supporting global TB prevention efforts, care and control, action on drug-resistant TB, and investment in research.[5] The framework clearly outlines the challenge of decreasing TB incidence from >1000 cases per million population to <100 cases per million by 2035. Out of the 33 countries, all but six have experienced an average rate of decline of approximately 3% over a 12-year period. However future projections suggest that no low incidence country will manage to eliminate TB by 2035 and only one country would manage to eliminate TB by 2050. The authors conclude that: "the task of reaching TB elimination in the coming decades may thus seem daunting, even in countries with the lowest incidence in the world"[1] (page 4).

In the last decade, we have witnessed a sea change in policy and rhetoric underpinning TB care from one focused on a curative model to one that, additionally, aims to tackle the social determinants of disease that render people vulnerable to TB and impact on their ability to sustain a course of treatment.[6,7] The social determinants of health (SDH) include the range of social, political, economic, and environmental factors that determine the health status of populations and hence risk of TB and treatment outcomes. Despite the evidence that wealth inequalities are an important predictor of TB rates in low incidence countries,[8,9] some argue that the social determinants of TB are overlooked given the dominance of biomedical approaches,[10] which still emphasize case detection, case management, and screening and surveillance, particularly of migrant communities in TB control efforts. TB policy may therefore reflect concerns about 'border control and health securitization'.[11,12] The situation in low incidence countries, therefore, is symptomatic of a global response to TB focused on technical and biomedical solutions and the general failure of global TB control efforts to address the underlying causes of TB.

1.2. Stigma as a social determinant of health

Stigma is a social determinant of health,[13] found to be a major barrier to accessing health care (hence resulting in diagnostic delay) and the ability to manage illness and complete treatment.[14–16] Conceptualizations of stigma are most often borrowed from Goffman (1963), who defined stigma as "an attribute that is deeply discrediting" (page 3), which 'spoils' a person's social identity or sense of self. Goffman distinguished between people who are 'discredited', whose stigma is visibly apparent or 'known about', and the 'discreditable', those whose stigma is only occasionally apparent as in the case of epilepsy.[17] Scambler differentiated between 'felt' stigma, or the fear of prejudice perceived by individuals, and 'enacted' stigma, an overt act of prejudice.[18] He posited that felt stigma was ultimately more socially and emotionally disruptive than enacted stigma because of the psychological work (covering) an individual has to do to keep the stigma hidden from others; for example: secrecy, avoidance, and withdrawal from relationships,[19,20] resulting in loneliness and social isolation, or in some cases, engaging in risky behavior.[21,22] Goffman used the term 'courtesy stigma' to describe the way stigma extends to others by virtue of their association with the stigmatized individual.

Others have differentiated between (1) internalized[23] or self-stigma[24] (believing negative public stereotypes and translating those negative perceptions to oneself), as exemplified in people with HIV,[25] mental illness,[26,27] and other concealable illnesses, (2) anticipated stigma[28] (fear of experiencing the negative effects of stigmatization, akin to felt stigma), and (3) experienced stigma[23,28] (discrimination, akin to enacted stigma).

Courtwright and Turner suggest stigmatization is different from discrimination, as the former has more to do with shame, while the latter involves exclusion.[29] Here stigmatization is seen as "a complex process involving institutions, communities, and inter- and intrapersonal attitudes" (page 34). However, Deacon argues that stigma and discrimination, although related, are distinct entities, and calls for greater clarity on the relationship between the two, suggesting that stigma suffers from "conceptual inflation" and "lack of analytical clarity".[16]

These dimensions of stigma are not exhaustive or mutually exclusive when it comes to understanding stigma in relation to a social disease such as TB. Rather, they are inextricably linked to an individual's social positioning.[30–32] The prevalence of double or multiple stigmas is recorded among individuals affected by overlapping illnesses and social statuses. For example, multiple stigmas are documented along the lines of mental illness and race,[33] mental illness and old age,[31] and mental illness and cancer.[34] Multiple stigmas are also identified among HIV-positive persons in the context of their minority ethnic status, race, sexual orientation,[32,35] and/or gender.[36] Studies with HIV patients show that multiple stigmas result in a greater social burden of illness, for which reason they may delay accessing medical attention and suffer worse adherence to prescribed treatments.[32,33,35,36] In high HIV prevalence settings, TB is labelled as a marker for HIV, leading to distinct forms of double stigma that render stigmas associated with HIV to be transferred to those living with TB, and reinforce the stigmatization of HIV.[30]

Contemporary scholars such as Link and Phelan[32,37] and Parker and Aggleton,[38] suggest that the negative labelling of particular traits is socially created and used as a tool to assert dominance over people who are already marginalized within society on the basis of extant social inequalities (location), such as those related to race, class, religion, or gender. These later conceptualizations of stigma resonate with the social determinants of TB,[39,40] and allow for stigma to be conceived of as a socially constructed phenomenon rather than an individualistic issue. Whether it be internalized, felt, or enacted, the construction of stigma is inevitably social.

Technologies used to control TB, diagnostics, drugs, and guidelines have also been implicated in this social construction of stigma and can further reinforce stigma and stigmatizing practices. Innovations and technologies intersect with the setting they are introduced into and at times have unintended consequences; for instance HIV rapid tests that, due to their rapidity and ease of use, allow private doctors in India to test for HIV without the patient's knowledge, further reinforcing the existing stigma that prevents patients agreeing to HIV testing.[41] Similarly, patient treatment cards that identify patients as HIV- or TB-positive through their colour, physical spaces that identify HIV patients,[42] or directly observed therapy (DOTS) treatment schedules that expect patients to attend a TB clinic in their community daily, can reinforce existing stigma. This suggests that TB control policies and research need to critically examine how to address the social determinants of TB, including the aspects of TB control that allow, perpetuate, or generate stigmatizing practices.

These different definitions and understandings are important because, as Deacon[16] (page 419) states: "Theories provide frameworks or models within which researchers can develop better research and intervention strategies". For if we cannot define stigma and understand how it operates, how can we measure stigma and devise strategies for reducing it?

Generally, more research into interventions for reducing HIV stigma has been conducted and reviewed in systematic and global reviews[43–45] than research into TB stigma reduction strategies, for which the first systematic review in the field is currently underway.[46] Research into TB-related stigma has predominantly taken place in high incidence countries and, arguably, the evidence base is less well developed in low burden countries. For example, in one qualitative review of the stigma of TB, only four out of 30 studies were from the USA and conducted before 2006; the

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remainder came from high incidence countries.[19] Another review reported on 99 studies globally: the majority were conducted in Asia and the Pacific Islands (33%), or were multiregional (17%) or from Africa and the Middle East (28%). North America comprised 9%, with Latin/South America 8% and Europe/Russia 8%.[29] However, results were synthesized and not differentiated according to context or TB disease burden. Chang and Cataldo conducted a systematic review of global cultural variations in knowledge, attitudes, and health responses to TB stigma, where out of 83 studies, two were from the UK and eight were from the USA.[47]

Given stigma is increasingly associated with health inequalities, the aim of this review is to contribute to debates about stigma as a social determinant of health and, in particular, ways in which stigma is defined and measured, including any tools and interventions that are effective in reducing stigma.[48] It was with this in mind that it was aimed to conduct a systematic mapping review of research into TB-related stigma in low incidence countries to map out recent research (the last 10 years), the main characteristics, and identify any gaps.

2. Methods

A systematic mapping review of the literature was conducted to identify research into TB stigma and associated interventions to mitigate the impact of TB stigma.[49] Mapping reviews aim to map out and categorize research on a given topic with a view to identifying evidence gaps and commission further reviews or research as required. Mapping reviews do not appraise research for quality, but rather describe and categorize the existing evidence base.[49] Additionally, in this review, it was aimed to explore: (a) whether stigma was the main focus of the research, (b) the theoretical underpinnings of the concept of stigma used in studies and whether this was based on individual-level explanations or factored in broader social determinants, as well as how stigma was defined, operationalized, and measured.

2.1. Inclusion and exclusion criteria

All articles from a low incidence country, defined as ≤100 cases per million, were included. However, because low incidence has also been defined as ≤20 cases per 100 000, and in order to enhance the scope of the review, countries that were defined as low incidence using the broader definition were included to incorporate countries approaching low incidence, in line with the action framework. Table 1 highlights all the countries as a result of the more inclusive definition. Studies were also included if they reported on primary research, including both qualitative and quantitative studies or mixed methods; the focus was active or latent TB infection (LTBI); interventions aimed to reduce stigma; they aimed to explore or measure stigma including knowledge, attitudes, beliefs, or experiences about TB, or health-seeking practices or adherence. Only studies published in peer-reviewed journals were included. The search was limited to articles published between January 1, 2006 and January 1, 2016.

Articles were excluded if they were not written in the English language, published in the grey literature, an opinion piece, a conference abstract or dissertation, or a systematic review.

2.2. Keyword strategy

A keyword strategy was developed based on previous work involving the lead author and an information scientist.[50] Search terms included medical subject heading (MeSH) or other associated terms for TB and stigma. Two other researchers reviewed the strategy (see Appendix A for an example). Additional articles were obtained through further searches.

Table 1
TB in low incidence countries; estimated rate per 100 000 population (2014)

High income countries[a]	TB rate[b]
Australia	6.4
Andorra	9.2
Antigua and Barbuda	7.6
Austria	7.8
Bahamas	12
Barbados	0.91
Belgium	9
Bermuda	0
British Virgin Islands	1.7
Canada	5.2
Cayman Islands	7
Chile	16
Cyprus	5.3
Czech Republic	4.6
Denmark	7.1
Finland	5.6
France	8.7
Germany	6.2
Greece	4.8
Hungary	12
Iceland	3.3
Ireland	7.4
Israel	5.8
Italy	6
Jamaica	4.7
Luxembourg	6.6
Malta	12
Monaco	2.2
Netherlands	5.8
New Zealand	7.4
Norway	8.1
Puerto Rico	1.4
San Marino	1.6
Slovakia	6.7
Slovenia	7.7
Sweden	7.5
Switzerland	6.3
Trinidad and Tobago	22
Turks and Caicos Islands	10
United Arab Emirates	1.6
United Kingdom	12
United States Virgin Islands	-
USA	3.1
Upper middle income countries[a]	
Albania	19
American Samoa	7
Costa Rica	11
Cuba	9.4
Dominica	0.71
Grenada	1.3
Jordan	5.5
Lebanon	16
Libyan Arab	40
Lower middle income countries[a]	
Samoa	19
West Bank and Gaza Strip	5.8
Income no classification[a]	
Cook Islands	12
Jamahiriya	-
Montserrat	0
Netherland Antilles	-
Saints Kitts and Nevis	7.2
Saint Lucia	9.1

[a] World Bank list of economies (July 2016).
[b] Global Tuberculosis Report 2015. Key TB indicators for individual countries and territories, WHO regions and the world. http://www.who.int/tb/publications/global_report/gtbr15_annex04.pdf?ua=1.

2.3. Databases

The following databases were searched: Centre for Reviews and Dissemination, CINAHL, Cochrane Central Register of Controlled

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Trials, Cochrane Database of Systematic Reviews, MEDLINE, PsychInfo, Embase, ERIC, SocINDEX, Social Policy & Practice, Global Health.

2.4. Data extraction

The review and data extraction were informed by a critical health psychology perspective (CHPP), which understands health and illness behaviour within social, political, and cultural contexts that not only influence health and illness, but systems of health and social care.[51,52] This approach also takes cognizance of the SDH. The resulting framework was developed and studies coded according to the year, country, sample characteristics, methods, whether a definition of stigma was provided and the conceptual framework used, whether it was an intervention study, how stigma was measured, whether the focus included other diseases/co-morbidities, e.g., HIV–TB stigma, and outcomes. The studies were further coded according to the thematic content. All abstracts were searched and where it was unclear whether the article should be included, the full article was read. All articles were reviewed independently by two researchers (G.M.C., A.I.) and the lead researcher reviewed all articles.

3. Results

The abstracts of 204 citations were identified from the search and an additional 14 from other sources (including seven articles obtained when the search was re-run to include the names of additional low incidence countries in line with the inclusive definition). Fifty-three duplicates were removed leaving 165 abstracts, and 134 of these were excluded. Of the remaining 31 articles, nine were excluded at full review, leaving 22 studies in total. Figure 1 provides the reasons for the exclusions.

3.1. Which low incidence country has conducted research into TB with relevance to stigma?

Twenty-two studies were included in the review. The majority of studies (n = 10) were conducted in Canada/USA, followed by the UK (n = 7), Europe (n = 2), and Australia/New Zealand (n = 3). There was only one intervention study (health education), which was conducted in Australia (Sheikh and MacIntyre[53]), although TB was not the main focus and neither was stigma. There were no studies from lower/middle income countries represented in this review. Table 2 characterizes the studies in more detail.

3.2. Which type of community was the focus of the research?

Most of the research studies focused on migrant communities,[54] including communities from broadly Spanish-speaking South American and Caribbean countries,[55–58] Sub-Saharan African refugees,[53] migrants or refugees from Somalia or Ethiopia,[59–61] Chinese migrants,[62] African communities/migrants,[63] homeless populations,[58,64,65] migrant and refugee learners,[66] and a mixed population of migrants;[67,68] one study was performed in an indigenous community – the Inuit.[69] Only one study surveyed the views of the general population in the USA.[34,70] Three textual studies aimed to analyse how migrants were represented in the media in relation to reports about TB.[11,71,72] The focus on different migrant communities reflects patterns of migration in different

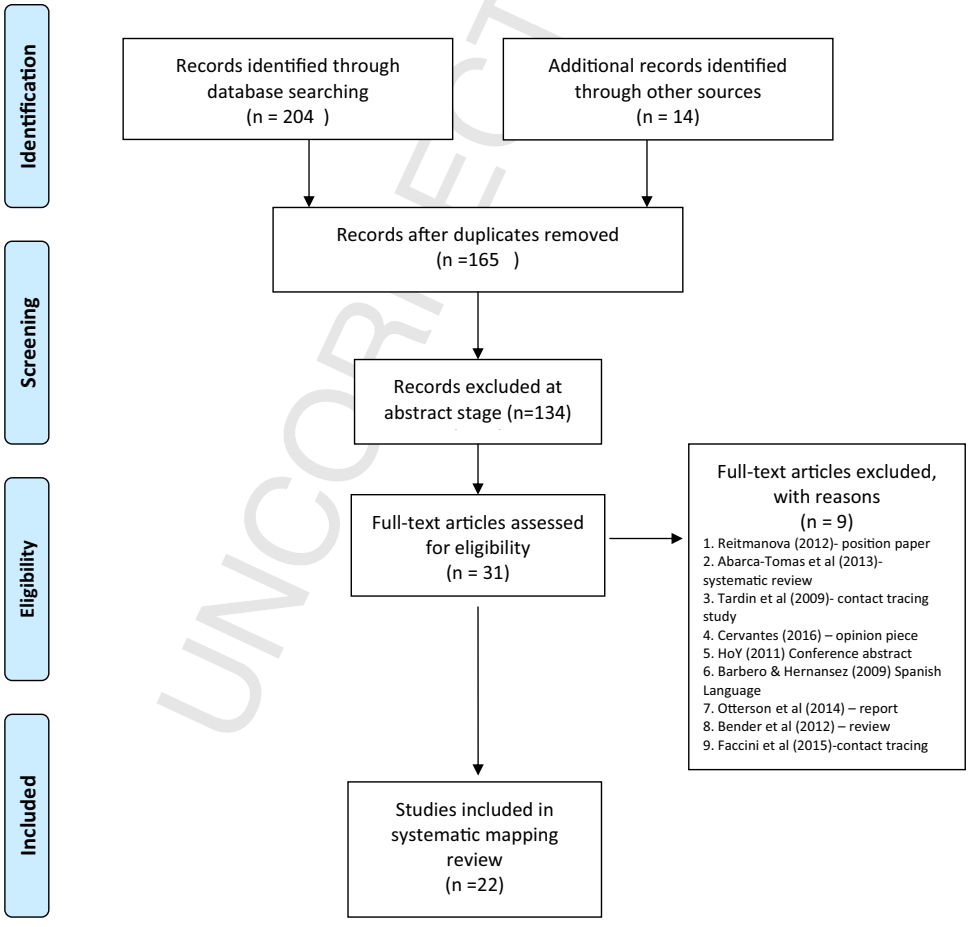

Figure 1. Flow diagram.

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Table 2
Included studies

No.	Country	Authors	Methods	Participants and other details	Conceptual framework	Selected findings
1	USA/Canada	Colson et al., 2014 [54]	Population-based cross-sectional survey; structured interviews administered face-to-face	1475 participants; born outside USA/Canada	K-A-B	Improved health education for people born outside UK Measures to reduce stigma needed
2	Australia	Sheikh and MacIntyre, 2009 [53]	Intervention study; structured questionnaire developed in focus groups administered face-to-face	34 Sub-Saharan African refugees and 12 non-African refugee parents	K-A-B	Targeted promotion to refugee parents is effective in changing K-A-B about infectious diseases
3	USA	Lurie et al., 2012 [55]	Qualitative research	5 bilingual focus groups including Mexican, Puerto Rican, Venezuelan, Ecuadoran, Haitian American, and indigenous persons from Latin America; interviews with agency leaders and staff	K-A-B	Local agencies can serve as informed liaisons to improve the health of newly arrived immigrants Stigmatized through public health emphasis on elevated risk
4	USA	Wieland et al., 2012[66]	Community-based participatory research	10 focus groups; 83 people in total; immigrant and refugee learners and staff in an adult education centre	Health belief model	Perception of TB included secrecy, shame, fear and isolation Adult education centres with large immigrant and refugee populations are good venues for TB prevention
5	Australia	Horner, 2015 [71]	Qualitative research; critical textual analysis; interviews; analysis of print media	19 migrants with TB in Canada, HCP	Discourse theory	Need to prioritize settlement support and health care rather than disease through migrant screening, which reinforces stigma
6	Canada	Gao et al., 2015 [62]	Qualitative research; mixed methods cross-sectional patient survey, focus group	912 survey respondents and 2 focus groups; Chinese immigrants	K-A-B	Need to raise awareness of LTBI and reduce LTBI-related stigma Cost of treatment a significant barrier
7	Canada	Reitmanova and Gustafson, 2012 [11]	Qualitative research; textual analysis of print media	273 news articles, editorial and letters analysis; of how are migrants represented in media	Discourse theory	TB control policies focus on screening and surveillance Media racializes and represents migrants as a health threat
8	New Zealand	Lawrence et al., 2008 [72]	Qualitative research, newspaper reports as a case study; textual analysis	120 media representations of TB	Discourse theory	Media fails to report on links between the SDH and TB Migrants stigmatized Attention to the cultural and political context needed when reporting TB
9	USA/Haiti	Coreil et al., 2010 [56]	Mixed method, cultural epidemiology and ethnography using EMIC	182 in-depth interviews and 12 focus group Haitians living in South Florida; Haitians residing in Leogane Commune, Haiti	Structural forces in the production of TB-related stigma perceived and anticipated stigma	Discussions of findings focused on the social production of perceived and anticipated stigma as influenced by politics, economics, institutional polices and health service delivery structures Findings demonstrate value of transnational framework
10	USA	Joseph et al., 2008 [57]	Ethnographic research	50 interviews with Mexican-born persons living in Atlanta/Denver in the USA	Socio-cultural aspects of TB reflected in stigma scale	Concern about stigma varied, depending on TB status Anticipated stigma by those with no history of TB was greater than the actual stigma reported by people who had TB disease
11	UK	Nnoaham et al., 2006 [63]	Qualitative interview study	16 people self-identified as African living in the UK attending a clinic for TB treatment, London, UK	Enacted or felt stigma using Kleinman's explanatory model of illness	Despite reports of felt stigma, denial reduced with good coping strategies Reports of good adherence suggest stigma can be mitigated
12	USA	West et al., 2008 [58]	Qualitative research, focus groups	11 focus groups; 52 participants; Spanish-speaking immigrants, homeless shelter residents, and persons attending a drug/alcohol rehabilitation centre	K-A-B	Participants projecting disease onto other social groups perceived as less desirable is also evidence of stigma
13	UK	Gerrish et al., 2013 [60]	A focused ethnography with individual interviews	14 Somali refugees who had received treatment for TB in the UK; 18 health care practitioners	Socio-cultural aspects of TB	Although patients reported felt and enacted stigma, they reported good adherence to treatment

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Table 2 (*Continued*)

No.	Country	Authors	Methods	Participants and other details	Conceptual framework	Selected findings
14	UK	Craig and Zumla, 2015 [64]	Qualitative interview study	7/17 participants were African migrants; the majority were homeless and had complex medical and social needs, including drug and alcohol use or immigration issues	Social context of adherence; critical health, psychology/ SDH	Reported on an example of felt stigma TB used as an excuse to shun and evict a person because of dislike Others reported social distancing, sympathy, indifference and acceptance
15	UK	Brewin et al., 2006 [67]	Qualitative interview study	53 adult immigrants	None reported	Stigma not mentioned Acceptability of screening high in migrant communities, seen as a socially responsible activity The view of screening unfairly targeted at migrants not supported
16	Norway	Sagbakken et al., 2010 [74]	Qualitative interview study	22 patients from Somalia and Ethiopia; the duration of stay in Norway varied from 6 months to 16 years	None reported	Stigma not mentioned, but there was a suggestion that perceived negative attitudes of health care staff toward migrants could result in delay
17	UK	Gerrish et al., 2012 [59]	A focused ethnography, interviews, and focus group	48 individual interviews; 8 focus groups, involving 56 people; community leaders from Somali organizations; members of the wider Somali community and patients who were receiving or had recently completed TB treatment	Socio-cultural meanings	Authors developed model of stigma based on beliefs, attitudes, experiences of anticipated or actual stigma/felt and enacted are also used strategies employed to avoid stigma
18	USA	Marks et al., 2008 [70]	National health interview survey	190 350 unweighted and 209 560 379 weighted respondents; civilian, non-institutionalized household residents from 2000 to 2005	K-A-B	Poor knowledge of TB transmission and curability in general population Experience of shame more likely in marginalized groups
19	UK	Seedat et al., 2014 [68]	Qualitative interview study	20 interviews with community leaders representing new migrants groups	None reported	Screening acceptable Barriers include disease-related stigma in communities and perceptions that services are non migrant friendly – not accessible to migrants
20	Sweden	Kulane et al., 2010 [61]	Qualitative research	5 focus groups with 34 adult women and men from the Somali community living in Stockholm	None reported	Use of interpreters a concern if they came from the community Contact tracing associated with a fear of deportation
21	UK	Craig et al., 2014 [65]	Qualitative interview study	7/17 were African migrants; the majority were homeless and had complex medical and social needs, including drug or alcohol use or immigration issues	Critical health psychology/SDH	Fear of drug withdrawal in PWID – major barrier to health seeking Stigma not reported as people did not associate symptoms with TB
22	Canada	Møller, 2010 [69]	Qualitative ethnographic research, interviews/ observations	29 Inuit; 7 interviews of health care professionals	None reported	Participants discussed illness experiences in the context of oppression, prejudice, and racism Examples of discrimination within and outside the health care system impacted on the experiences of TB

Q28 K-A-B, knowledge, attitudes, beliefs; TB, tuberculosis; HCP, health care professionals; LTBI, latent TB infection; SDH, social determinants of health; EMIC, ; PWID, people who inject drugs.

countries. Three studies involved community leaders and their views on how TB and stigma were perceived within their own communities.[55,59,68]

3.3. What research methods were used?

The majority of studies (18/22) could best be described as qualitative, involving interviews and/or focus groups; three of these 18 studies adopted a textual analysis of print media and five adopted an ethnographic approach. Two out of the total 22 studies involved population-based surveys and there was one mixed methods study involving a patient survey and focus group. Two studies involved a comparator group. Coreil et al. compared the views of Haitian migrants living in Florida with Haitians residing in Haiti.[56] Sheik and MacIntyre compared 34 Sub-Saharan African refugee parents with 12 non-African refugee parents.[53]

3.4. Was stigma the main focus for the research?

Few studies set out to research TB-related stigma as the main focus,[56,60,63] and only one study featured the word 'stigma' in the title.[56] Rather stigma emerged in many studies about knowledge, attitudes, and beliefs (K-A-B) about TB, or studies on the socio-cultural understandings or experiences of affected communities. This is not surprising given that qualitative research aims to allow themes to emerge from the data. Other studies included questions on stigma in relation to the broader aims of capturing knowledge and beliefs about TB or infectious diseases more generally.

Two studies focused on a range of infectious diseases in addition to TB, including a study that aimed to raise awareness of infectious diseases in refugee communities[53] and an interview study with community leaders exploring the acceptability of screening for infectious diseases in recent migrants.[68] In the latter study, although screening was reported to be acceptable, 'disease-related stigma' was found to be a barrier. The study by Brewin et al. also focused on the acceptability of TB screening in migrant populations in the UK, but did not anticipate or report stigma in the findings.[67] Rather, screening was reported as a socially responsible activity with a high degree of acceptability in migrant communities. Craig and colleagues suggested that stigma was not reported as a barrier to accessing health care, as patients with complex health and social needs generally did not attribute their symptoms to TB, rather they normalized their symptoms in the context of their everyday lives.[65] Only one study focused on LTBI in Canada; the authors argued for greater awareness of LTBI and measures to reduce LTBI-related stigma in Chinese migrant communities.[62]

3.5. How was stigma measured?

Where studies set out to explore TB-related stigma, the majority used structured questions to determine attitudes and beliefs about TB and hence stigma (see Table 3). Colson et al., in a cross-sectional study ascertaining the attitudes and beliefs of people diagnosed with TB and born outside the USA/Canada, used structured questionnaires administered in face-to-face interviews.[54] Of the 14 attitudinal items, three questions were designed to measure stigma, including differential treatment by others, concern about others knowing a person's TB status, being found out, and concerns about deportation. A further question on disclosure was included under group norms, rather than stigma, but could be used as a proxy for stigma. West et al. used a standardized list of questions to guide focus group discussions and asked participants what they thought about people with TB.[58] Sheik and MacIntyre piloted a questionnaire to evaluate a change in attitudes, knowledge, and health beliefs before and after an educational intervention in a structured questionnaire administered face-to-face and asked the participants if they would be ashamed if a family member had TB or whether TB was caused by sin.[53] Marks and colleagues, in a national health survey in the USA that included seven questions on TB, one of which addressed stigma, asked whether the respondent, or family members, would feel shame and embarrassment if diagnosed with TB.[70] In the study by Coreil et al., the researchers adapted a semi-structured instrument to include a stigma scale with 22 core items for the Haitian sample and 24 for the Florida sample.[56] The scale explored internal perceptions and emotions (2 items), disclosure (6 items), external perceptions (4 items), external actions (6 items), and courtesy stigma (3 items), as well as two items that related specifically to Haitian identity as migrants in Florida, and thereby attempted to capture the intersection of TB stigma with migrant identity. The internal consistency of the scale was reported to be good (Cronbach's alpha >0.80)

Table 3
Range of questions/scales used in the studies to measure stigma

Colson et al., 2014 [54]
Stigma
Do people who know that you have TB treat you differently?
Are you concerned that others may find out that you have TB?
When you went for TB treatment, were you afraid you might be sent back to the country you came from?
Group norms
Have you told people close to you that you have TB?
Marks et al., 2008 [70]
If you or a member of your family were diagnosed with TB, would you feel ashamed or embarrassed?
Sheik and MacIntyre, 2009 [53]
Would not be ashamed if family member had TB
Sins can cause TB
West et al., 2008 [58]
What would you think about a person with TB?
Coreil et al., 2010 [56]
Internal perceptions and emotions
e.g., Would Jean think less of himself because he has TB?
Disclosure
e.g., Do you think Jean would discuss this problem with family members/close friends/neighbours?
External perceptions
e.g., Would people assume he [Jean] has HIV?
External actions
e.g., Do you think people might avoid Jean because of his actions?
Courtesy stigma
e.g., Would contact with Jean have bad effects on others around him even after he is treated?
Haitian identity
e.g., Is it more embarrassing for Jean to have TB because he is Haitian than it would be for other people in Florida?

3.6. Conceptual frameworks

As there were few studies that aimed to research stigma, the range of conceptual models theorizing stigma was limited. The study by Coreil et al. drew on perceived and anticipated stigma;[56] Nnoaham et al. drew on felt and enacted stigma.[63] Coreil focused on the social production of perceived and anticipated stigma informed by the political and economic context, institutional policies, and health service delivery structures. Disease-related stigma and community stigma were also reported.[68]

Two studies drew on the concepts of felt and enacted stigma to illustrate their findings.[59,64] Gerrish et al. devised a model on the meaning and consequences of TB, including ways in which historical contexts, cultural norms, and individual experiences influence ideas about the causes, transmission, and treatment of TB, which then influenced attitudes and translated into anticipated stigma (felt stigma – fear of discrimination, a sense of shame and lack of self-worth) or enacted stigma (experience of discrimination, social isolation, and social exclusion leading to feelings of low self-esteem and risk of depression, with the resulting coping strategies of withdrawal, concealment, or open/partial disclosure).[59]

Excluding the three research studies that analysed textual print media, seven of 19 studies adopted a K-A-B approach to TB/infectious diseases (see Table 1), including one study that was explicitly premised on the health belief model (HBM) as a lens to understand the views of participants.[66] Four studies drew on the socio-cultural meanings participants ascribed to TB, three studies explicitly adopted a structural/social determinants approach, and four studies did not report the use of a conceptual framework. One study related the experiences of indigenous people to a history of colonialism.[69]

The predominance of the K-A-B studies is not surprising given the dominance of social cognition models (most commonly referred to as the health belief model, HBM) in the literature on health-seeking practices. The HBM was initially developed to

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understand the reasons for the failure of a free, preventative TB screening programme in the USA in the 1950s.[73] Social cognition models posit a (linear and possibly incremental) relationship between knowledge, beliefs, and access to health care, but have been criticized for their rational actor approach, which overstates individual agency.[39] The role of structures including the wider socio-economic and programmatic barriers are therefore often under-theorized within these models. In the main, K-A-B studies recommend increasing awareness of disease through an education-through-information approach levelled at the individual or community. Additionally some K-A-B studies also acknowledge programmatic barriers, for example, the cost of treatment.[62]

3.7. Stigma and programmatic barriers

A number of studies brought into relief the programmatic barriers to health-seeking practices and illness management. Craig and Zumla, for example, reported on the zero tolerance policies of a hospital on the use of drugs and alcohol as a barrier to accessing care.[64] The perception that methadone was under-prescribed for those patients who used drugs, and the subsequent fear of experiencing withdrawal syndrome, was also a concern. Studies on TB and infectious disease screening, including HIV, have reported high levels of acceptability amongst migrant communities,[67] but choice of place of screening was considered crucial and some screening facilities were not viewed as accessible or migrant-friendly.[68] Fear of deportation as a result of contact tracing has also been reported in a Swedish study involving the Somali community.[61] One study in Norway suggested that health care delay may be due to the negative attitudes of staff. Contact tracing was associated with the threat of deportation, and the use of interpreters was of concern if they came from the same community.[74] These studies suggest that stigma per se may not be a barrier to accessing health care, but rather policies that can be discriminatory and service delivery models that are not patient-centred and that may also reinforce stigma. Interventions at the programmatic level would be needed in these examples.

3.8. Stigma and structural determinants

There were studies that analysed the wider structural causes of stigma; for example, the study by Coreil et al. demonstrated the intersection of stigma, discrimination, and identity as a migrant in a sample of Haitians in Florida compared with non-migrant Haitians in Haiti.[56] The study highlighted how TB policies, such as detention, intersected with the marginalized status of Haitians living in the USA and their migrant identity in ways that were specific to the USA context compared with non-migrant Haitians living in Haiti. In one study of the Inuit community, participants discussed their experiences of TB in the context of colonialism, oppression, prejudice, and racism.[69] They recounted examples of inhumane treatment historically in relation to TB control polices. Examples of discrimination within and outside of the health care sector therefore impacted on their experiences of TB. The author concluded that decolonizing measures were necessary to address the high incidence of TB.

The three studies with a focus on textual analyses of print media and newspaper articles used discourse theory to explore representations of TB and migrants in Australia,[71] Canada,[11] and New Zealand. The authors argue that media reporting serves to stigmatize migrant communities by racializing TB and constructing migrants as the health threat; the focus on migrant screening and surveillance also serves to reinforce stigma by suggesting the locus of the problem resides within migrants, and not the social determinants of disease.

Marks et al. identified poor knowledge of TB transmission and curability among a representative sample of the general population in the USA, suggesting a lack of awareness is not solely an issue for those communities most affected.[70] A small percentage (2%) reported feeling ashamed or embarrassed if they had a family member with TB, and this relationship increased if the respondent was homeless or a prisoner (2.2-times as likely), or born outside the USA (1.5-times as likely). Similar patterns were found with ethnic status (black) and education (low), reflecting the intersection between stigma and social positioning, particularly amongst marginalized groups, but in general the intersection of the SDH was under-theorized. These complex intersections present challenges for stigma reduction interventions in terms of how they can be tailored to specific groups and contexts.

4. Discussion

Stigma research in low incidence countries is mainly conducted in migrant populations because these groups are over-represented in the TB statistics and comprise the majority of communities affected by TB. A number of studies included interviews with community leaders who represented the views of those communities. Although valued as an important source of expertise within those studies, this does raise issues about who represents the voices of communities and which sectors of the community are included or excluded in these accounts. Few studies in this review addressed stigma as a substantive topic, rather stigma emerged as a theme within studies that aimed to explore knowledge, beliefs, and health-seeking practices more generally. This contrasts with research in the HIV field,[75] where the evidence base is more extensive.

There was only one study that reported on LTBI and LTBI-related stigma, although it was unclear whether LTBI stigma was qualitatively different to TB stigma.[62] No studies focused on the relationship between HIV and TB stigma and no studies focused on stigma in relation to drug-resistant TB. This may be because the number of people who experience HIV–TB co-infection or drug-resistant disease is relatively small in low incidence countries compared to high disease burden contexts. The difficulty of accessing the views of these groups and indeed the impact of stigma and willingness to participate in research may also be reasons. Research in high disease burden countries suggests patients with multidrug-resistant and extensively drug-resistant TB may experience particular forms of stigmatization on account of their incurable and contagious state.[76] No research focused on TB-related stigma in health care workers and no studies attended to gender as a social determinant.

Both quantitative and qualitative research was used and only one study reported on the use of a validated stigma scale to measure stigma.[56] The dearth of intervention studies is worthy of comment. Courtwright and Turner, in their systematic review of the global TB literature, similarly concluded that interventions to reduce TB stigma and analyses of how they impact on diagnostic delay and treatment adherence are few.[29] Yet no studies have investigated whether and how TB stigma reduction impacts on TB morbidity and mortality.[29,43,46] While some interventions, such as TB clubs, have been reported to decrease stigma and improve adherence, other interventions involving an educational component have not.[29]

Moreover intervention studies would clearly benefit from a stronger theoretical underpinning in relation to the social determinants. K-A-B studies, which assume improving knowledge will result in health-seeking, premised on an information-through-education model, fail to take into account the structural barriers that impact on health-seeking practices and ways in which social positioning intersect with racism and discrimination for example.

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Avoidance of health care may be less to do with stigma than fear of discrimination based on other factors. The difficulty for any intervention study will be to identify, theorize, and take action on those very structural factors. Lessons may be learned from the HIV field, where socio-ecological models have been applied routinely to interventions to tackle the multiple drivers of stigma in people with HIV.[43,77,78] Attention and action on HIV stigma have also stemmed from the creation of a distinct, indeed exceptional, HIV community as a result of the more acute levels of discrimination experienced by those affected in the early stages of the global epidemic. The very forces that suppressed the rights of people with HIV led to mass movements of global resistance, world over, to quell systematic actions on the parts of individuals, systems, and governments, that could compound their stigmatization.[79,80] This is in sharp contrast to responses for TB, where collective efforts to empower communities most affected by TB have struggled to gather commensurate momentum.

In line with other research, TB control programmes and practices were reported to (inadvertently) contribute to, or cause, stigma. In one systematic review of qualitative research on TB in migrant populations, the authors reported that TB-related stigma has been prominent because of the assumed impact on TB screening and treatments "rather than a consequence of these programmes" (page 9).[81] Authors have cautioned about the way TB is represented in research or the popular press as a disease of migrants or "foreign born and hence the outsiders" and a "non-native threat"[82] (page 129). This raises ethical issues about the way communities are represented in research and in TB control programmes.[83–85]

Few studies embraced a SDH framework to render legible the experiences of participants and there was a tendency to homogenize experiences of a diverse range of migrants, rather than theorize difference according to social positioning (e.g., gender). Despite a global consensus on the relevance of the social determinants of TB and the relevance and recognition of a SDH framework across many research disciplines, including the global policy world, they are often not effectively translated into policy and action. This is partly because SDH, such as stigma, tend to be conceptualized as mere individual barriers to health interventions rather than structural factors (as evidenced by the number of studies conceptualizing TB stigma within an individualistic K-A-B framework), and partly because of the limited understanding of the exact relationship between SDH and health (as evidenced by the overall limited number of comprehensive in-depth case studies of stigma). Effective policy and action, taking into account stigma as a SDH, thus requires extensive and in-depth case studies to allow a careful and comprehensive understanding of the different elements and how they interact at local, national, and global levels.[48]

4.1. Questions and challenges for future research

Given TB predominantly affects migrant communities or newcomers in low incidence countries, further research into effective strategies for reducing TB stigma in migrant and other populations within a SDH framework is warranted. Although lessons may be learned from evidence based on findings in low and middle income countries, these will need to be translated and adapted to local country contexts. More research is needed to determine differences in experience, both within and between migrant communities and in relation to LTBI and active disease, but also how people's experiences are influenced by the wider social and structural determinants.

A structural approach to the causes of stigma inevitably raises more complex theorizations of the intersections between stigma, other stigmatizing illnesses (HIV, hepatitis), stigmatized identities (sex worker, drug user), and social positioning (e.g., migrant, gender). There are gaps in this regard in low incidence countries. The difficulty of measuring the effectiveness of TB stigma reduction strategies that take into account the complex ways in which these social determinants intersect should not be underestimated,[86] particularly in marginalized communities. Chang and Cataldo argue that cultural variations need to be factored into interventions aimed at reducing stigma and improving treatment adherence, which, given the diversity of communities affected, presents its own challenges.[47] Møller cautions that culturally appropriate health care may be difficult to deliver to indigenous communities, not least because of the colonial models of health professional education (page 42).[69] Indeed we might ask how different identities and social positioning interact with the very interventions to tackle stigma and the implications for engagement with such interventions.

The need to translate measures and tools into the various community languages, given migrant populations are not homogeneous, will also present cost and logistical challenges.[65] For example in London, UK, approximately 22% of people do not speak English as their first language, and in some London boroughs, over 100 different languages are spoken, a pattern common in many major cities, suggesting a role for bilingual researchers. Process evaluations and sophisticated qualitative methods, including ethnographic approaches and case studies, will be needed to inform the development of future interventions and to measure outcomes, in addition to providing rich contextual detail to better understand how complex interventions work.[87] Finally the major challenge for TB programmes and researchers will be how to research and report on the experiences of vulnerable communities in ways that do not reinforce stigma. This is particularly difficult when interventions, and hence research, are targeted at affected communities in low incidence countries rather than the general population.

4.2. Conclusions

There is scant research into the assessment of TB stigma in TB in low incidence settings. As stated by Macq et al. "It is striking to see that stigma is at the center of global strategies to fight AIDS and it is so little present in the international priorities of TB control" (page 351).[75]

Priority action 7 of the WHO and ERS framework for the elimination of TB in low incidence countries recognizes the need to invest in research and new tools.[5] There is ample evidence to suggest that TB is represented and experienced as a stigmatizing disease by many different communities in low burden settings, either due to illness or particular practices of TB control measures. There is much less research on how the social determinants intersect with stigma and interventions to reduce stigma, including what such interventions should look like and how reductions in stigma can be measured. The framework may provide a driver for such research. Finally approaching stigma as a problem requiring a technical fix by the health sector, without addressing the inequities that place communities at risk of disease and poor health outcomes, within and between countries, will have little impact without accompanying global political solutions.[88]

4.3. Limitations

It is possible that some research was missed, as not all articles were read in full if stigma was not mentioned in the abstract or if the abstract did not indicate the study was relevant for full article review. Given much research focused on knowledge, attitudes, and beliefs, in which stigma emerges as a theme rather than an extant

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focus, this only adds to the contention that, unlike HIV stigma, TB stigma is rarely researched as a topic in its own right in low burden countries, despite being an important SDH. This may reflect the dominance of biomedical research. Some studies were not included because they fell outside the period of study for the review (i.e., before 2006). However given that the populations affected by TB, TB as a disease, and stigma are dynamic, social phenomena with manifestations contingent upon time, place, space, social positioning, and geo-political factors, experiences and solutions derived from research more than 10 years ago may need to be reappraised in the contemporary situation, including their relevance to low burden settings. The research studies were not appraised for quality; some have argued that mapping research studies without addressing quality may be of limited value. However the aim was to map the nature of research into TB stigma (including stigma reduction interventions) in low incidence countries and the conceptual frameworks adopted, to provide a better understanding of how stigma operates and intersects with other social statuses or positioning. Few studies set out to address these aims and therefore achieved this 'gold standard' in this review.

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Appendix A

Example of search terms used in relation to stigma in CINHAL

("Stigma") OR (MH "Stereotyping") OR (MH "Social Attitudes") OR (MH "Social Norms") OR (MH "Social Behavior") OR (MH "Social Identity") OR (MH "Social Conformity") OR (MH "Social Inclusion") OR (MH "Social Isolation") OR (MH "Social Alienation") OR (MH "Social Participation") OR (MH "Social Values") OR (MH "Vulnerability")
AB discriminat* OR AB prejudice* OR AB "social determinants" N3 health OR AB "social* exclus*" OR AB marginali#* OR AB soci* N3 reject* OR AB scapegoat*
AB stigma OR AB stereotyp* OR AB "social attitudes" OR AB "social norms" OR AB "social behavio#r" OR AB "social identit*" OR AB "social conformity" OR AB "social* inclusi*" OR AB "social* isolat*" OR AB "social alienat*" OR AB "social participation" OR AB "social values"
(MH "Social Determinants of Health") OR (MH "Health Status Disparities")
(MH "Prejudice") OR (MH "Scapegoating") OR (MH "Social Conformity") OR (MH "Social Desirability")
(MH "Social Norms") OR (MH "Social Isolation") OR (MH "Social Alienation")
(MH "Social Stigma") OR (MH "Stereotyping") OR (MH "Social Marginalization") OR (MH "Social Isolation") OR (MH "Social Discrimination")

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