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Evidence-based interventions to reduce tuberculosis stigma: a systematic review

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SUMMARY

SETTING: While substantial progress is being made in tuberculosis (TB) control, the success of public health efforts is hampered by pervasive stigma.

OBJECTIVE: To perform a systematic literature review to assess the effectiveness of interventions aimed at reducing TB stigma in patients, health care workers, care givers and the general community.

DESIGN: Studies were eligible for inclusion if they evaluated interventions aimed at reducing TB stigma and were published between 1950 and 2015. We searched eight databases (PubMed, Cochrane Library, Ovid, Embase, PsycInfo, Sociological Abstracts, Cumulative Index to Nursing and Allied Health Literature, World Health Organization Latin American and Caribbean Health Sciences Literature), and complemented the searches by using the snowball strategy and by reviewing relevant grey literature.

RESULTS: Only seven studies were identified as providing quantitative ($n = 4$) or qualitative ($n = 3$) evidence of effectiveness in reducing TB stigma. Quality assessment of the studies was poor. Knowledge-shaping and attitude-changing interventions aimed at the public, patients and their families were effective in reducing anticipated stigma. Home visits and support groups were effective in reducing both anticipated and internalised stigma.

CONCLUSION: There is a dearth of reliable information on the effectiveness of TB stigma-reduction interventions. Knowledge-shaping, attitude-changing and patient-support interventions can be effective in reducing TB stigma, but more rigorous evaluations are needed.

KEY WORDS: evaluation; TB; discrimination

ALTHOUGH TUBERCULOSIS (TB) is curable and preventable, it remains a significant public health problem. With 1.8 million TB deaths in 2015, TB remains one of the leading causes of death worldwide.[1,2] The stigma faced by people with TB is a major cause of the delay or failure to seek treatment, as well as poor adherence to treatment.[3–7] Stigma is thus a major barrier to eliminating TB. Moreover, the social relationships of people with TB are often negatively affected by community members and care givers, who may be reluctant to socialise or be associated with them.[3,4] Negative stereotypes have connected TB with concepts such as immorality, poverty, frailty, hedonism, effeminacy and self-destruction.[3,5] As stigma negatively impacts the physical and social consequences of TB, there is a need to reduce it effectively.[6]

Through a systematic literature review, we aim to assess the effectiveness of interventions aimed at reducing TB stigma in patients, health care workers (HCWs), care givers and the general community.

METHODS

By applying the Cochrane Search Strategy, we conducted a systematic and comprehensive literature review to identify and assess the effectiveness of evaluated interventions aimed at reducing TB stigma.[8] As different types of stigma have different outcomes and effects, three types were conceptualised to aid this synthesis: anticipated, internalised and enacted stigma.[7]

'Anticipated stigma' refers to the imagining of the prejudices, discrimination and negative attitudes that a person would experience if he/she was to have a 'tainted identity'. 'Internalised stigma' is the degree to which someone is believed to possess the negative traits assumed to be associated with the stigmatised characteristic. 'Enacted stigma' refers to the lived

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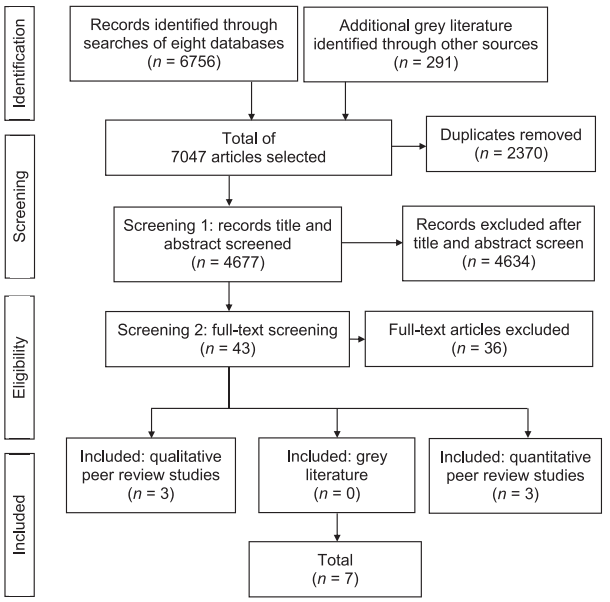

Figure PRISMA flowchart. PRISMA = Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

experiences of mistreatment and discrimination.[9] We used terminology from different behaviour-change methods to describe and synthesise the interventions.

Eight databases (PubMed, Cochrane Library, Ovid, Embase, PsycInfo, Sociological Abstracts, Cumulative Index to Nursing and Allied Health Literature, World Health Organization [WHO] Latin American and Caribbean Health Sciences Literature) were searched for peer-reviewed literature published between 1950 and 2015 in English, Spanish, Portuguese, German, Dutch and French. 'Grey literature' was obtained from the WHO database, the Stop TB partnership internet website, the US Centers for Disease Control and Prevention TB resource database, KNCV Tuberculosis Foundation archives, and abstracts from the International Union Against Tuberculosis and Lung Disease's annual World Conference on Lung Health between 2008 and 2015. The reference lists of relevant articles were searched to find additional studies. As qualitative studies are often not found using conventional search methods,[10] the 'snowball strategy' and citation tracking were also applied.

Selection criteria

Included study types were randomised controlled trials, quasi-experimental studies with longitudinal or cross-sectional designs, qualitative, and mixed-methods studies.[11] Studies focused on three types of participants: 1) the general public, 2) people with TB, and 3) care givers, including HCWs.

Search strategy and screening

To perform a thorough search, a wide range of search terms was included: Title: tubercul* or 'lung tuberculosis' or 'pulmonary consumption' or 'consumption, pulmonary' or 'TB' AND Title: stigma* or discrimin* or barrier* or attitud* or discredit* or self-efficacy or 'self-concept' or discrimina* or inequ* or prejudic* or stereotyp* or 'social percept*' or 'social isolat*' or 'social inclus*' or disclos* or 'patient-centered' or shame or perspect* or percept* or 'patient satisfact*' or depress* or quality or fear or inter-personal or psychosocial or default or adher* or psycholog* or self-harm or identity or emotion* or communicat* or 'social suppor*' or 'patient suppor*' or culture*. Titles and abstracts in the abstract books from the Union Conference on TB and Lung Disease were screened for the term 'stigma'.

Three reviewers (NS, LR and MN) screened (in parallel) potentially eligible studies for original research in which the title, abstract or key words suggested the evaluation of reduction of TB stigma. In the second eligibility screening, the full texts of selected studies were reviewed by two reviewers (NS and CM) using standardised eligibility criteria. Discrepancies were solved by consensus. Reasons for excluding potentially eligible studies were listed, and the full papers of the selected articles were read by two researchers (NS and CM) to extract information (for coding scheme, see Appendix Tables A.1–A.3) (Figure).*

Assessment of study quality

Three authors (NS, CM and EW) independently assessed the quality of the selected studies using the Downs and Black scale,[12] which can be used to assess the evidence of both randomised controlled trials and quasi-experimental studies, even if the studies lack a control group.[13] For qualitative individual studies, we applied the guidelines created by Spencer et al., as recommended by the Cochrane group,[8,14] and each assessment question was awarded 0–3 points.

RESULTS

Seven articles published between 1999 and 2015 in peer-reviewed journals were retained in the review. Three originated from Central and South America,[15–17] two from Africa[4,18] and two from Asia.[19,20] Most interventions had stigma reduction as one of several main aims: three studies also aimed to increase knowledge about TB,[18–20] two also aimed to improve TB treatment adherence[4,16] and one also aimed to improve knowledge about leprosy and TB (Table 1).[19]

Methodology and stigma types

Of the seven studies, five targeted anticipated stigma,

* The appendix is available in the online version of this article, at http://www.ingentaconnect.com/content/iuatld/ijtld/2017/00000021/a00111s1/art00013

two internalised stigma, but no studies focused on enacted stigma. Chalco et al. mentioned the ostracising of TB patients by household members, but did not provide examples of how it might have been affected by the intervention[16] (see Appendix Table A.4). Of the studies targeting anticipated stigma, two were quasi-experimental before-and-after studies without a control group,[18,20] one had a retrospective case-control design, with cases and controls selected from different regions,[19] and one was a qualitative study using focus groups and in-depth interviews with participants of 'TB clubs', where people with TB meet, share experiences and take responsibility for each other's treatment process.[4] Of the two studies aimed at reducing internalised stigma, one was a qualitative study using participant observation and focus groups,[15] and the other used a quantitative quasi-experimental design.[17] One ethnographic study was based on both anticipated and internalised stigma using structured observations and focus groups.[16]

Interventions to reduce stigma

Overall, two of the seven interventions aimed to reduce TB stigma focused on the general community,[18,19] four focused on TB patients, including two on multidrug-resistant TB (MDR-TB) patients[4,15–17] and one on HCWs, including community workers.[20] The effect of the intervention was measured in TB patients ($n = 268$, 7 TB clubs and 42 focus-group sessions, including one study that evaluated MDR-TB patients),[4,15,17] in HCWs ($n = 1266$)[16,20] and in the general community ($n = 352$).[18,19]

To clarify the nature of how the interventions might work and thus improve and facilitate the accuracy of future replication, the review identified behaviour-change methods, i.e., 'the observable and replicable component designed to change behaviour inherent to the interventions'.[21] Several types of interventions were evaluated in the studies included (see Table 1 for a more detailed description of interventions). Of the five interventions aimed at reducing anticipated stigma,[4,16,18–20] most used attitude-changing or knowledge-shaping components. These components educated the general population, family members and/or TB patients about TB while also projecting positive images of TB patients.[16,18–20]

Balogun et al. used an interactive approach to knowledge shaping: community workers were trained to spread information about TB in the community.[18] Croft and Croft used mass media dissemination tools such as loudspeakers, large film screenings and flipcharts.[19] Wu et al. evaluated an attitude- and knowledge-shaping training course for HCWs. Chalco et al. also evaluated attitude-changing interactions of nurses with the general community and families of people with MDR-TB, to empower the latter to be more self-sufficient.[16] Demissie et al. evaluated an intervention using TB clubs (see above).[4]

Two of the studies aimed at reducing internalised stigma identified community nurses as important agents.[15,16] Acha et al., for example, studied the impact of nurse-led psychosocial patient support groups, celebrations, excursions and family workshops for MDR-TB patients.[15] Macq et al. evaluated an intervention with TB clubs and patient-centred home visits by HCWs.[17]

Measurements and results

All but one study concluded that their intervention had reduced stigma.[18] Because different outcome measurements were used, it was not possible to compare the strengths of the effects between studies or to summarise the impact of stigma-reduction interventions. To measure the effect of the intervention on stigmatising attitudes towards people with TB, several outcome measures were used (Table 1).

Wu et al. used a validated (Cronbach's α 0.7) eight-item scale adapted from the Attribution Questionnaire (AQS8) for mental illness.[20] The intervention slightly reduced anticipated stigma in public HCWs, but not in facility-based DOTS workers. Croft and Croft measured attitudes toward TB in the general population using four questions. They found that the information campaign effectively improved attitudes towards people with TB on all the questions that they used to measure stigma.[19] Using qualitative methods, Demissie et al. established that participation in TB clubs led to increased understanding of TB, a reduction in social and financial isolation, and increased adherence to treatment.[4] Chalco et al. reported qualitative evidence for improved attitudes and reduced fear towards MDR-TB patients among family members and the general community after home visits by community nurses.[16] Using a validated 10-item scale (Cronbach's α 0.7),[17] Macq et al. observed improvements in internalised stigma in the intervention group after 2 months. Acha et al. and Chalco et al. identified that support groups and community nurses led to the reduction of internalised stigma and improved treatment adherence in MDR-TB patients, respectively.[15,16] In contrast, based on results of two questions ('stays away from people with TB' and 'fears people with TB'), Balogun et al. reported that stigmatising attitudes among the general community increased after community volunteers disseminated TB knowledge (Table 1).[18]

Quality assessment

We found a general lack of quality in the TB stigma-intervention studies. As there are no established quality criteria, we calculated the percentages of the total possible score to give an indication of quality (Table 2). Scores ranged from 7 to 11 on the Downs and Black Scale (out of a maximum of 27). For

Table 1 Study and intervention characteristics, stigma types and results from seven studies

First author, year, reference	Country	Study population	Outcome	Sample
Acha, 2007[15]	Peru	MDR-TB patients	Reduction in internalised stigma in MDR-TB patients	42 support group sessions
Balogun, 2015[18]	Nigeria	General community	Reduction in anticipated stigma in the general community	252
Chalco, 2006[16]	Peru	Nurses	Reduction in internalised stigma in MDR-TB patients	7
Croft, 1999[19]	Bangladesh	General community	Reduction in anticipated stigma in the general community	100
Demissie, 2003[4]	Ethiopia	TB patients	Reduction in anticipated stigma in the TB patients and the general community	11 TB clubs
Macq, 2008[17]	Nicaragua	TB patients	Reduction in internalised and anticipated stigma in TB patients	268
Wu, 2009[20]	Taiwan	HCWs	Reduction in anticipated stigma in HCWs	1259

* $P < 0.05$.
† $P < 0.01$.
MDR-TB = multidrug-resistant TB; NA = not applicable; TB = tuberculosis; HCW = health care worker.

qualitative studies, the score ranged from 26 to 35 based on the framework of Spencer et al. (out of a maximum of 53) (see Appendix Tables A.5–A.7, Table 2).

DISCUSSION

The results of this first systematic review of TB stigma interventions showed a lack of reliable information on evidence-based interventions for anticipated and internalised stigma, and no evidence-based intervention for enacted stigma. Of the seven studies included, most (5/7) evaluated an intervention to reduce anticipated stigma, and almost all (6/7) showed a reduction in TB stigma. However, one study reported that the training of community volunteers resulted in increased stigma towards people with TB, but this was based on responses to two questions: 'stays away from people with TB' and 'fears people with TB'. The authors suggest that the observed negative effects may have been due to poorly trained community volunteers who might have perpetuated stigmatising attitudes or due to the fear in response to learning that TB is transmitted by air.[18] Stigma interventions therefore need carefully crafted messaging and design as well as trained messengers. As one of the seven described interventions had a negative outcome of increased stigma, it is important to avoid publication bias and ensure that all evaluations—even those that are unsuccessful interventions—are published.[22]

While the strength of this review is its comprehensiveness, several limitations must be noted. First, the shortage of interventions evaluated using a scientific approach and the use of different outcome measures made the comparison and summary of effect sizes impossible. For future evaluations, attention should be paid well in advance to how stigma is measured, preferably using validated and

Table 1 *(continued)*

Intervention type/s	Study design	Measurement unit	Results
Psychosocial support groups: intervention comprised four components—support groups, recreational excursions, symbolic celebrations and family workshops	Qualitative	NA	The support groups were effective against the negative social impact faced by MDR-TB patients
Awareness raising by community volunteers. Community volunteers organised health talks in markets, churches and mosques targeting households and different occupational groups, and one-on-one discussions with other community members. They also delivered educational pamphlets door-to-door and posters on every street to aid the health talks, and held a rally to create awareness	Quasi-experimental	2 items	Stays away from people with TB: pre-intervention 13.5%, post-intervention 34.9%* Fears people with TB: pre-intervention 0.8%, post-intervention 6.7%*
Community nursing: nurses visited the homes of patients to better understand the patient, the patient's family and the patient's environment. Information was used to adjust treatment to patient needs, including factors that can facilitate or hinder treatment. Communication with patient's family to reduce stigma	Qualitative	NA	Support from nurses reduced the internal stigma of MDR-TB patients
Health education programme: included a day/night mass information programme run from a jeep using flipcharts, a bullhorn loudspeaker and two locally developed slide series showing simple stories about TB sufferers who receive successful treatment. The slide series was shown five times in evening sessions over 2 years, with an audience of several hundred each time. In addition, in 1995 all schools were visited and given information	Case control	4 items	Stigma was significantly lower in the intervention group for all four items
TB clubs: each club had regular weekly meetings conducted in places such as churches, mosques, market places or other venues for social events to support each other in adhering to treatment and to share information about the course of the disease and possible drug side effects. Patients failing to make satisfactory progress or suffering from side effects were reported to the health centre	Qualitative	NA	The intervention with TB clubs had improved the societal attitudes toward TB patients and increased confidence and reduced fear of disclosure in TB patients
TB clubs, home visits: group of TB patients benefitted from a patient-centred intervention package, including at least TB clubs and home visits, and a control group in rural Nicaragua. Increased power-sharing between health personnel and TB patients (i.e., giving more power to the patient in the health care provider-patient interaction)	Quasi-experimental	Validated 10 item scale: range 10–50 (higher is more stigma)	After 2 months: control group 33.1, intervention group 27.4† Difference between 2 months and 15 days: control group 1.5, intervention group 4.3*
Educational workshops: health care workers attended a training course which included knowledge about destigmatisation and human rights of TB patients	Quasi-experimental	Validated 8-item scale: range 8–40 (higher is more stigma)	*t*-tests: public HCWs pre-intervention 36.83, post-intervention 35.69* DOTS workers pre-intervention 36.91, post-intervention 36.15

standardised instruments to enable meta-analysis (for example, those used by Courtwright and Turner, Macq et al., Wouters et al. and Açikel and Pakyüz[23–26]). Second, as for all systematic reviews, the quality of this review was determined in part by the quality of the original studies. Quality assessments revealed major flaws in the methodology and reporting of most studies. Future research should pay greater attention to using a sound evaluation design to ensure reliable evidence. Third, most studies assessed at least two intervention components and measured multiple outcomes.[4,15,16,18–20] This approach made attribution of the effect of the different components on the outcomes difficult. This was particularly the case if different outcomes were interconnected, such as stigma and treatment adherence. Researchers should define the order of the outcomes and the change mechanism of the intervention. Evidence of interventions to reduce the stigma attached to infection by the human immunodeficiency virus has also stressed the importance of targeting not only one but several levels where the mechanisms of stigma work in combined interventions.[27]

Table 2 Quality assessment scores using different assessment tools

Author, year, reference	Assessment tool	Quality assessment score
Balogun, 2015[18]	Downs and Black	11/27
Croft, 1999[19]	Downs and Black	7/27
Macq, 2008[17]	Downs and Black	11/27
Wu, 2009[20]	Downs and Black	9/27
Acha, 2007[15]	Spencer et al.	35/54
Chalco, 2006[16]	Spencer et al.	26/54
Demissie, 2003[4]	Spencer et al.	34/54

CONCLUSION

Despite the importance of stigma reduction to achieve the goal of TB elimination, few stigma-reduction interventions have been rigorously evaluated, and

none of the interventions showing positive effects have been replicated. Based on the existing body of evidence and our quality assessment, support groups such as TB clubs, combined with a conscious focus on improving attitudes in the general community, showed promising results in reducing both internalised and anticipated stigma.[4,15,17] There may also be synergies in simultaneously engaging a range of populations, such as TB patients, their families, and HCWs, in multivalent stigma interventions.[15,16,28]

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APPENDIX

Inclusion criteria

Table A.1 First eligibility screen

Variable	Explanation	Answer categories
study_id	Individual study ID	
reviewer	Review author name	
title	Title	
type	Type of literature	Article, report, website
source	How was the study found?	Electronic database, citation, manual search, website
language	Is the language English, Spanish, Portuguese, German, Dutch or French?	English, Spanish, Portuguese, German, Dutch, French, other
tb_stigma	Does the study address TB stigma?	Yes, no
intervention	Does the study contain an intervention aimed at reducing TB stigma?	Yes, no
included	Does the study fit all the inclusion criteria?	Yes, no, unclear
comments	Review authors' comments	

TB = tuberculosis.

Table A.2 Second eligiblity screen

Variable	Explanation	Answer categories
study_id	Individual study ID (can start with different number for each author extracting data)	
reviewer	Review author name	
title	Title	
authors	Author/s	
participants	Is the study population the general community, TB patients or care givers?	General community, TB patient, care giver, other
method	Is the method for the intervention assessment experimental, quasi-experimental, qualitative, mixed methods or a review study?	RCT/CRCT (control for intragroup variance), quasi-experimental (method for controlling bias/matching), mixed methods, qualitative, review study, other
included	Does the study fit all the inclusion criteria?	Yes, no, unclear
exclusion_reason	What was the reason for exclusion?	
comments	Review authors' comments	

TB = tuberculosis; RCT = randomised controlled trial; CRCT = cluster RCT.

Table A.3 Data abstraction

Variable	Explanation	Answer categories
study_id	Individual study ID	
report_id	Report ID	
reviewer	Review author name	
title	Title	
authors	Author/s	
year	Year of publication	
citcon	Citation and contact details	
type	Type of literature	Article, report, website
source		Electronic database, citation, manual search, website
language	Is the language English, Spanish, Portuguese, German, Dutch or French?	English, Spanish, Portuguese, German, Dutch, French
Intervention		
Intervention purpose	Is the study outcome to improve stigma-related attitudes among the general community, improve self-concept for people with TB, and improve the behaviours of care givers?	General attitudes, self-concept, improve care givers
participants1	Is the study population the general community, TB patients or care givers?	General community, TB patient, care giver
stigma_participant1	Is this population assumed to be stigmatising or being stigmatised?	Stigmatising, stigmatised
stigma_type1	What type of stigma is the target for this population?	Anticipated, internalised, enacted
age1	What age were the participants?	
number1	Total number of this group of participants	
participants2	Does the study have a second population type?	General community, TB patient, care giver
stigma_participant2	Is this population assumed to be stigmatising or being stigmatised?	Stigmatising, stigmatised
stigma_type2	What type of stigma is the target for this population?	Anticipated, internalised, enacted
age2	What age were the participants?	
number2	Total number of this group of participants	
participants3	Does the study have a third population type?	General community, TB patient, care giver
stigma_participant3	Is this population assumed to be stigmatising or being stigmatised?	Stigmatising, stigmatised
stigma_type3	What type of stigma is the target for this population?	Anticipated, internalised, enacted
age3	What age were the participants?	
number3	Total number of this group of participants	
intervention_type	What type of intervention?	Information campaign, skill building, counselling, contact/interaction
specific_intervention	Describe the intervention	
HIV	Was the study targeting both HIV and TB stigma?	HIV/TB, only TB
Methods		
study_design	RCT/CRCT (with query control for intragroup variance)/ quasi-experimental (method for controlling bias/ matching), mixed methods, qualitative, review study	Experimental (with query control for intragroup variance), quasi-experimental (method for controlling bias/matching), mixed methods, qualitative, review study, other
mixed_type	In the mixed-methods study, was the outcome of interest in the quantitative or qualitative module (or both)?	Quantitative, qualitative, both
quant_type	What type of quantitative study?	RCT, CRTC, longitudinal, cross-sectional
qual_type	What type of qualitative study?	Phenomenology, ground theory, ethnography, action research, descriptive study
review_type	What type of review study?	Descriptive, meta study
duration	Total study duration (months)	
Outcomes		
anticipated_outcome	Outcome definition anticipated stigma	
internal_outcome	Outcome definition internalised stigma	
enacted_outcome	Outcome definition enacted stigma	
unit_ anticipated	Unit of measurement, anticipated stigma	
unit_ internal	Unit of measurement, internalised stigma	
unit_ enacted	Unit of measurement, enacted stigma	
scale_range	For scales: upper and lower limits, and whether high or low score is good	
scale_valid	For scales: if validated	Yes, no
Result		
Anticipated stigma (a)		
n_group_a	Number of participants allocated to each intervention group	
n_a	Sample size	
missing_a	Missing participants	
result_summary_a	Summary data for each intervention group (e.g., 2×2 table for dichotomous data; means and standard deviations for continuous data, summarising matrix or other from qualitative data)	

Table A.3 *(continued)*

Variable	Explanation	Answer categories
effect_a	Estimate of the effect with confidence interval; *P* value. Increase/decrease in stigma for qualitative reviews	
Internalised stigma (i)		
n_group_i	Number of participants allocated to each intervention group	
n_i	Sample size	
missing_i	Missing participants	
result_summary_i	Summary data for each intervention group (e.g., 2×2 table for dichotomous data; means and standard deviations for continuous data, summarising matrix or other from qualitative data)	
effect_i	Estimate of the effect with confidence interval; *P* value. Increase/decrease in stigma for qualitative reviews	
Enacted stigma (e)		
n_group_e	Number of participants allocated to each intervention group	
n_e	Sample size	
missing_e	Missing participants	
result_summary_e	Summary data for each intervention group (e.g., 2×2 table for dichotomous data; means and standard deviations for continuous data, summarizing matrix or other from qualitative data)	
effect_i	Estimate of the effect with confidence interval; *P* value. Increase/decrease in stigma for qualitative reviews	
Miscellaneous		
funding_source	Funding source	
references	References to other relevant studies	
correspondence	Correspondence required	
comments_author	Comments by the review authors	

TB = tuberculosis; HIV = human immunodeficiency virus; RCT = randomised controlled trial; CRCT = cluster RCT.

Table A.4 Excluded studies describing a TB stigma-reducing intervention but no intervention outcome effect, or not fulfilling the methodological criteria

First author, year, reference	Country	Population in which to reduce stigma and type of stigma	Intervention
Chalco, 2006[1]	Peru	Enacted stigma in families of TB patients	Community nurses talked to family members about TB to create understanding for the ill family member and end ostracising behaviour
Dick, 2004[2]	South Africa	Enacted stigma in HCWs towards TB patients	Education programme focusing on patient-centred care: visualised stories describing the hardship, stigma and difficulties of having TB. This exercise provoked lively discussion on the psychosocial aspects of case management in the clinical context
Karels, 2014[3]	The Netherlands	Anticipated stigma in a Somali population in the Netherlands	A TB awareness-raising programme involving the Somalian community. After the programme, it was easier to talk openly about TB within the population
Liefhooge, 1999[4]	Pakistan	Internalised stigma in TB patients	Informational and motivational counselling to improve TB patient's self-efficacy
Machmud, 2015[5]	Indonesia	Anticipated stigma in elementary school children	Knowledge building: colouring book competition to learn about TB, incorporating a committee of government officials
Mohammed, 2015[6]	Pakistan	Internalised stigma in TB patients, anticipated stigma in the general community	Patient empowerment and awareness raising using Photovoice, a participatory qualitative action research methodology to help TB patients document their story through photography. Resulted in an exhibition for the general public
Moya, 2015[7]	Mexico	Internalised stigma in people with TB	*Nuestra Casa*, a portable house was built where stories of TB patients were told and displayed for the general public, said to have an empowering effect on TB patients
Unmask Stigma, 2015[8]	South Africa	Internalised and anticipated stigma among HCWs	An international awareness and education initiative aimed to unmask and expose the true character or hidden truth about a set of negative (and often unfair) beliefs about a particular circumstance, quality or person surrounding TB

TB = tuberculosis; HCW = health care worker.

Table A.5 Downs and Black checklist for non-randomised studies

	Answers: yes, no, unable to determine	Author, year, reference			
		Balogun, 2015[18]	Wu, 2009[20]	Macq, 2008[17]	Croft, 1999[19]
1	Is the hypothesis/aim/objective of the study clearly described? Must be explicit Yes/No	Yes	Yes	Yes	Yes
2	Are the main outcomes to be measured clearly described in the Introduction or Methods section? If the main outcomes are first mentioned in the Results section, the question should be answered 'no'. ALL primary outcomes should be described for 'yes'	Yes	Yes	Yes	Yes
3	Are the characteristics of the participants included in the study clearly described? In cohort studies and trials, inclusion and/or exclusion criteria should be given. In case-control studies, a case-definition and the source for controls should be given. Single case studies must state the source of patients	Yes	Yes	Yes	Yes
4	Are the interventions of interest clearly described? Treatments and placebo (where relevant) that are to be compared should be clearly described	Yes	Yes	Yes	Yes
5	Are the distributions of principal confounders in each group of subjects to be compared clearly described? A list of principal confounders is provided. Yes = age, severity	Yes	Yes	Yes	Yes
6	Are the main findings of the study clearly described? Simple outcome data (including denominators and numerators) should be reported for all major findings so that the reader can check the major analyses and conclusions	Yes	No	Yes	Yes
7	Does the study provide estimates of the random variability in the data for the main outcomes? In non-normally distributed data, the interquartile range of results should be reported. In normally distributed data the standard error, standard deviation or confidence intervals should be reported	No	No	No	No
8	Have all important adverse events that may be a consequence of the intervention been reported? This should be answered 'yes' if the study demonstrates that there was a comprehensive attempt to measure adverse events (complications but not an increase in pain)	No	No	No	No
9	Have the characteristics of patients lost to follow-up been described? If not explicit = no. Retrospective – if not described = unable to determine; if not explicit re: numbers agreeing to participate = no. Needs to be >85%	Unable to determine	No	No	Unable to determine
10	Have actual probability values been reported (e.g., 0.035 rather than <0.05) for the main outcomes except where the probability value is <0.001?	Yes	Yes	Yes	No
11	Were the subjects asked to participate in the study representative of the entire population from which they were recruited? The study must identify the source population for patients and describe how the patients were selected	Yes	Unable to determine	Yes	No
12	Were those subjects who were prepared to participate representative of the entire population from which they were recruited? The proportion of those participants invited to participate and who agreed should be stated	No	Unable to determine	Unable to determine	Unable to determine
13	Were the staff, places and facilities where the participants were treated representative of the treatment that the majority of patients receive? For the question to be answered 'yes', the study should demonstrate that the intervention was representative of that in use in the source population. Must state type of hospital and country for 'yes'	Yes	Unable to determine	Unable to determine	Unable to determine
14	Was an attempt made to blind study subjects to the intervention they have received? For studies where the patients would have no way of knowing which intervention they received, this should be answered 'yes'. Retrospective, single group = no; unable to determine if >1 group and blinding not explicitly stated	No	No	No	No
15	Was an attempt made to blind those measuring the main outcomes of the intervention? Must be explicit	No	No	No	No
16	If any of the results of the study were based on 'data dredging', was this made clear? Any analyses that had not been planned at the outset of the study should be clearly indicated. Retrospective = no; prospective = yes	Unable to determine	Unable to determine	Unable to determine	Unable to determine
17	In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls? Where follow-up was the same for all study patients the answer should be 'yes'. Studies where differences in follow-up are ignored should be answered 'no'. Acceptable range 1-year follow-up = 1 month each way; 2-year follow-up = 2 months; 3-year follow-up = 3 months...10-year follow up = 10 months	Unable to determine	Unable to determine	No	No

Table A.5 *(continued)*

	Answers: yes, no, unable to determine	Author, year, reference			
		Balogun, 2015[18]	Wu, 2009[20]	Macq, 2008[17]	Croft, 1999[19]
18	Were the statistical tests used to assess the main outcomes appropriate? The statistical techniques used must be appropriate to the data. If no tests were performed, but would have been appropriate to do = no	Yes	Yes	Unable to determine	No
19	Was adherence to the intervention/s reliable? Where there was non-adherence to the allocated treatment or where there was contamination of one group, the question should be answered 'no'. Surgical studies will be 'yes' unless the procedure was not completed	Unable to determine	Unable to determine	Unable to determine	Unable to determine
2°	Were the main outcome measures used accurate (valid and reliable)? Where outcome measures are clearly described, which refer to other work or that demonstrates the outcome measures are accurate = yes. ALL primary outcomes valid and reliable for 'yes'	Unable to determine	Yes	Yes	Unable to determine
21	Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population? Patients for all comparison groups should be selected from the same hospital. The question should be answered 'unable to determine' for cohort and case-control studies where there is no information concerning the source of patients	Unable to determine	Unable to determine	No	No
22	Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same time? For a study which does not specify the time period over which patients were recruited, the question should be answered as 'unable to determine'. Surgical studies must be <10 years for 'yes', if >10 years then 'no'	Unable to determine	Unable to determine	Yes	Yes
23	Were study subjects randomised to intervention groups? Studies which state that subjects were randomised should be answered 'yes', except where method of randomisation would not ensure random allocation	Unable to determine	Unable to determine	No	No
24	Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable? All non-randomised studies should be answered 'no'. If assignment was concealed from patients but not from staff, it should be answered 'no'	Unable to determine	Unable to determine	No	Unable to determine
25	Was there adequate adjustment for confounding in the analyses from which the main findings were drawn? In non-randomised studies, if the effect of the main confounders was not investigated or no adjustment was made in the final analyses the question should be answered 'no'. If no significant difference between groups shown, then 'yes'	Unable to determine	Yes	Yes	No
26	Were losses of patients to follow-up taken into account? If the numbers of patients lost to follow-up are not reported = unable to determine	Unable to determine	No	No	Unable to determine
27	Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance <5%. Sample sizes have been calculated to detect a difference of x% and y%.	Yes	Unable to determine	Unable to determine	Unable to determine
	Score (number of 'Yes' answers)	11	9	11	7

Table A.6 Qualitative framework used by Spencer et al.*

1	How credible are the findings?
2	How has knowledge/understanding been extended by the research?
3	How well does the evaluation address its original aims and purpose?
4	Scope for drawing wider inference—how well is this explained?
5	How clear is the basis of the evaluative appraisal?
6	How defendable is the research design?
7	How well defended is the sample design/target selection of cases/document?
8	Sample composition/case inclusion—how well is the eventual coverage described?
9	How well was the data collection carried out?
10	How well has the approach to, and the formulation of, the analysis been conveyed?
11	Contexts of data sources—how well are they portrayed?
12	How well has the diversity of perspective and content been explored?
13	How well has detail, depth and complexity (i.e., richness) of the data been conveyed?
14	How clear are the links between data, interpretation and conclusions, i.e., how well can the route to any conclusions be seen?
15	How clear and coherent is the reporting?
16	How clear are the assumptions/theoretical perspectives/values the have shaped the form and output of the evaluation?
17	What evidence is there to attention of ethical issues?
18	How adequately has the research process been documented?

* Based on reference 9.

Table A.7 Spencer et al. framework scores*

	Chalco, 2006[16]	Score	Acha, 2007[15]	Score	Demissie, 2003[4]	Score
1	Moderate confidence	2	Moderate confidence	2	Moderate confidence	2
2	Low confidence	1	Moderate confidence	2	Moderate confidence	2
3	Moderate confidence	2	Moderate confidence	2	High confidence	3
4	Moderate confidence	2	Low confidence	1	Moderate confidence	2
5	Low confidence	1	Low confidence	1	Low confidence	1
6	High confidence	3	High confidence	3	High confidence	3
7	Low confidence	1	Moderate confidence	2	Moderate confidence	2
8	Very low confidence	0	Moderate confidence	2	Low confidence	1
9	Moderate confidence	2	High confidence	3	Moderate confidence	2
10	Moderate confidence	2	Moderate confidence	2	Low confidence	1
11	Low confidence	1	Moderate confidence	2	Moderate confidence	2
12	Low confidence	1	Moderate confidence	2	Low confidence	1
13	Low confidence	1	Moderate confidence	2	Moderate confidence	2
14	Moderate confidence	2	High confidence	3	High confidence	3
15	Moderate confidence	2	High confidence	3	Moderate confidence	2
16	Low confidence	1	Low confidence	1	Moderate confidence	2
17	Moderate confidence	2	Very low confidence	0	Low confidence	1
18	Very low confidence	0	Moderate confidence	2	Moderate confidence	2
		26		35		34

* Based on reference 9.

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RÉSUMÉ

CONTEXTE : Bien qu'il y ait des progrès substantiels en matière de lutte contre la tuberculose (TB), le succès des efforts de santé publique est entravé par une stigmatisation généralisée.

OBJECTIF : Réaliser une revue systématique de la littérature afin d'évaluer l'efficacité des interventions visant à réduire la stigmatisation liée à la TB parmi les patients, le personnel de santé, les aidants et la communauté dans son ensemble.

SCHÉMA : Les études ont été éligibles pour leur inclusion si elles avaient évalué des interventions visant à réduire la stigmatisation liée à la TB et si elles avaient été publiées entre 1950 et 2015. Nous avons fait des recherches dans huit bases de données (PubMed, Cochrane Library, Ovid, Embase, PsycInfo, Sociological Abstracts, Cumulative Index to Nursing and Allied Health Literature et World Health Organization Latin American and Caribbean Health Sciences Literature) et complété les recherches en utilisant la stratégie de la boule de neige et en revoyant la littérature grise pertinente.

RÉSULTATS : Seules sept études ont été identifiées car elles ont mis en évidence des preuves quantitatives ($n = 4$) ou qualitatives ($n = 3$) de leur efficacité en matière de réduction de la stigmatisation liée à la TB. L'évaluation de la qualité des études a été médiocre. Les interventions de modification des connaissances et de changement d'attitude destinées au public, aux patients et à leurs familles ont été efficaces en termes de réduction de la stigmatisation anticipée. Les visites à domicile et les groupes de soutien ont été efficaces en réduisant à la fois la stigmatisation anticipée et internalisée.

CONCLUSION : Il y a une pénurie d'informations fiables relatives à l'efficacité des interventions de réduction de la stigmatisation liée à la TB. Les interventions de modification des connaissances, de changement d'attitude et de soutien au patient peuvent être efficaces en réduisant la stigmatisation liée à la TB, mais des évaluations plus rigoureuses sont nécessaires.

RESUMEN

MARCO DE REFERENCIA: Pese a los progresos considerables alcanzados en el control de la tuberculosis (TB), la ubicuidad de la estigmatización obstaculiza los esfuerzos de salud pública.

OBJETIVO: Llevar a cabo una revisión sistemática de las publicaciones científicas con el objeto de evaluar la eficacia real de las intervenciones encaminadas a disminuir la estigmatización asociada con la TB en los pacientes, los profesionales de salud, los cuidadores y la comunidad en general.

MÉTODO: Se consideraron idóneos los estudios que evaluaban intervenciones cuyo objeto era disminuir la estigmatización generada por la TB, publicados entre 1950 y 2015. La búsqueda se llevó a cabo en ocho bases de datos (PubMed, Cochrane Library, Ovid, Embase, PsycInfo, Sociological Abstracts, el Cumulative Index to Nursing and Allied Health Literature and el Latin American and Caribbean Health Sciences Literature de la Organización Mundial de la Salud) y se complementó mediante la estrategia en bola de nieve y un análisis de la literatura gris pertinente.

RESULTADOS: Se encontraron solo siete estudios, los cuales comunicaban pruebas de eficacia real cuantitativa ($n = 4$) o cualitativa ($n = 3$) en materia de reducción de la estigmatización asociada con la TB. La evaluación de la calidad de los estudios era deficiente. Las intervenciones de adecuación de los conocimientos y modificación de las actitudes dirigidas al público, los pacientes y a sus familias fueron eficaces para disminuir la estigmatización. Las visitas domiciliarias y los grupos de apoyo lograron reducir los estigmas anticipados y también los estigmas internalizados.

CONCLUSIÓN: Se confirmó la carencia de información fiable con relación a la eficacia práctica de las intervenciones encaminadas a disminuir la estigmatización asociada con la TB. Las intervenciones de adecuación de los conocimientos, modificación de las actitudes y apoyo a los pacientes pueden ser eficaces con este fin, pero es necesario realizar evaluaciones más rigurosas.