Original Article

Evaluating patient education resources for supporting treatment decisions in latent tuberculosis infection

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Abstract

Objective: People with latent tuberculosis infection (LTBI) are required to make complex treatment decisions, which require an understanding of personal risk and associated benefits. However, many people with LTBI in the United Kingdom are at risk of low health literacy and can also experience language barriers, which can affect decision making. Patient education resources can support understanding but must meet the needs of the target population. The aim of this study was to evaluate the accessibility, readability and content of LTBI patient education resources.

Design: Review and descriptive analysis of online LTBI patient education resources.

Setting: UK-based online patient education resources.

Method: We searched UK public health and charitable organisations for online LTBI patient education resources. Resources were evaluated in terms of accessibility (availability of translated versions); readability (Flesch–Kincaid Reading Ease [FKE], Flesch–Kincaid Grade Level [FKG] and Simplified Measure of Gobbledygook [SMOG]), theoretical content (Extended Common-Sense Model) and principles of shared decision making.

Results: Seventeen out of 60 articles identified in the search met the prespecified criteria for inclusion. Translated materials were available for 7 of them. The overall mean $\pm$ *SD* readability scores and corresponding reading ages were FKE 63.51 $\pm$ 8.81 (13–15 years), FKG 9.14 $\pm$ 8.95 (13–15 years) and SMOG 8.27 $\pm$ 1.51 (13–14 years). No resources met Health Education England recommended readability levels for health-related information. Dimensions of cognitive representations of illness and treatment most commonly addressed included treatment control, cause and identity (symptom and label); no resources addressed emotional identity.

Conclusion: Current and future LTBI patient education resources would benefit from greater consideration of the needs of non-English language speakers, readability and theoretical content to improve patient illness experience and support informed treatment decision making.

Keywords

Common-Sense Model, latent tuberculosis infection, patient education, readability, treatment decisions

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Introduction

Newly identified cases of tuberculosis (TB) are rapidly falling in England (Public Health England, 2018). However, TB continues to disproportionately affect some people, with the non-UK-born population representing 72.2% of all TB cases notified (Public Health England, 2018). The majority of active TB cases in the United Kingdom result from the reactivation of latent tuberculosis infection (LTBI) (Zenner et al., 2017). As such, the Collaborative Tuberculosis Strategy has aimed to 'ensure the delivery of a quality assured local programme of new entrant LTBI screening, focused on areas of high TB incidence' (Public Health England, 2015). The World Health Organisation (WHO) recommends an individual-level approach to LTBI screening and treatment in low-incidence countries such as the United Kingdom (Lönnroth et al., 2015). This means that any intention to screen for LTBI is an intention to treat a positive diagnosis, based on the decision that the benefits of treatment should outweigh any risks (Campbell et al., 2019).

Shared decision making is a key long-term priority of the National Health Service (NHS) (NHS England and NHS Improvement, 2019). National guidelines for the management of LTBI recommend that the risks and potential benefits of each treatment regimen should be explained clearly, and a suitable regimen selected in discussion with the patient should they accept preventive treatment (National Institute for Health and Care Excellence, 2016b). However, discussions with people about LTBI are often challenging. While there are individual benefits to accepting treatment such as reducing personal risk of TB disease, the concept of latency is complex. Given that the individual is asymptomatic, poses no current risk of infection to others and may not progress to active TB (Dobler et al., 2018), a 'common-sense rationale' in which the patient is able to make a link between LTBI and treatment may be unclear. Similarly, such consultations do not occur in isolation of the patient's personal, social and environmental context, as each patient brings pre-existing beliefs about the illness and treatment (Horne et al., 2013). Addressing misconceptions about illness and treatment, as well as communicating both the risks and benefits of preventive treatment is essential to enable the patient to make an informed choice. At the core of shared decision making is the patient and health care professional relationship, wherein patients should be supported to explore their preferences and make decisions (Elwyn et al., 2012).

Psychological theory can be used to better support informed choice, taking into consideration the potential harms and benefits of medicines as well as a range of intrinsic and extrinsic factors that influence treatment decisions (Horne, 2017). The Common-Sense Model of Self-Regulation (CSM) is a widely used theoretical framework that describes how people use 'common-sense' to generate representations of health threats and subsequent coping strategies (Leventhal et al., 2016). The CSM depicts five core domains of cognitive illness representation – identity (symptoms and label), timeline (extent to which an illness is perceived as acute or chronic), cause (perceived cause of illness), consequence (extent to which illness is perceived to negatively affect life) and control (extent to which illness is expected to be responsive to treatment) – which are processed in parallel to emotional representations (emotional response to illness). When the coping procedure (strategies used to manage threat) includes a decision about treatment, it is recommended to use the extended CSM (Horne, 2003). This model sees treatment perceptions as linked to illness representations, with an individual not only having to decide if the threat warrants treatment, but whether the treatment is appropriate (Horne, 2003). The extended CSM encapsulates the Necessity-Concerns Framework (NCF), which provides a theoretical basis for understanding how patients make decisions about treatment, outlining two categories: (1) perceptions of personal need for treatment and (2) concerns about a range of potential adverse consequences (Horne et al., 2013).

Another factor which may impact on shared decision making is patient health literacy, defined as the 'cognitive and social skills which determine the motivation and ability of individuals to gain

access to, understand and use information in ways which promote and maintain good health' (Nutbeam, 1998: 357). A recent report highlighted how the diversification of cultural backgrounds and health profiles within the European Union presents unique challenges in terms of how to reduce systemic inequalities in health care delivery (Matlin et al., 2018). Poor health literacy, language barriers, and different cultural or religious beliefs are associated with lower medication adherence in people with LTBI (Butcher et al., 2013). Ensuring suitable levels of readability and accessibility of patient materials in different languages may be a first step to reducing these inequalities (Kalengayi et al., 2012).

Against this background, the aim of this study was to evaluate how LTBI patient resources in the United Kingdom support understanding and informed choices about treatment. Specifically, we investigated the accessibility and readability of the resources; and evaluated the content in terms of its potential for encouraging and supporting shared decision making and understanding of LTBI and treatment as mapped to the extended CSM.

Methods

Data collection

We conducted a rapid review of online UK-based patient education resources. Searches were performed on targeted specialist public health websites including the NHS (https://www.nhs.uk/), gov. uk (https://www.gov.uk/), the National Institute for Health Care Excellence (https://www.nice.org. uk/) and Google (www.google.com) between November and January 2020. Websites were searched using variations of the term LTBI, pages were then navigated by clicking on relevant links related to diagnosis, patient information and treatment. Where a search function was not available, we manually searched the website and relevant links to identify resources.

Selection criteria

Searches identified relatively few resources (materials designed to support patient education) that were LTBI specific as indicated by title. Flow of data through the different phases of the study is shown in Figure 1. Resources were screened initially by title, with any potentially relevant resources selected for full review against the inclusion/exclusion criteria. During the screening process, we expanded our criteria to include patient resources that targeted either TB or LTBI, so long as the resource included relevant information specific to LTBI.

Inclusion criteria

- Provides specific information about LTBI treatment
- Aimed at patients or the public
- Published by a UK organisation
- Available to view, download or stream online
- Available in the English language

Exclusion criteria

- Focused only on active TB disease
- Focused only on LTBI in children
- Aimed at supporting health care professionals, or those working with people with LTBI only, as opposed to patients
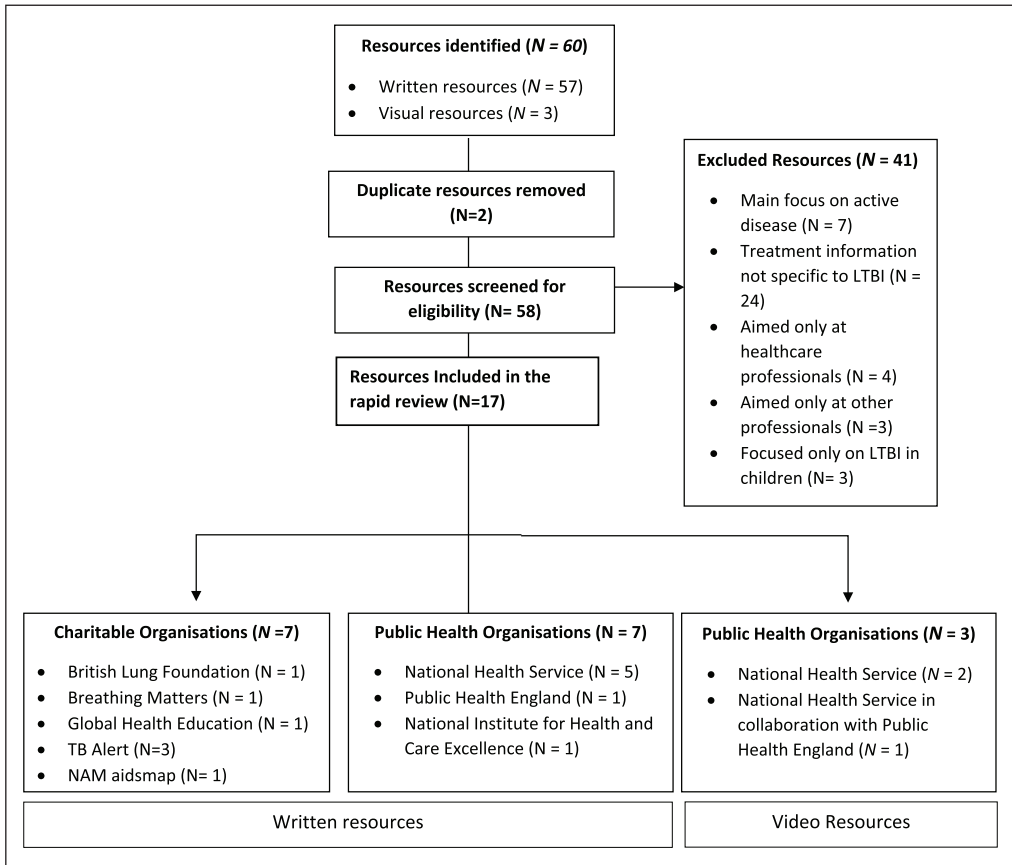
Figure 1. Flow of data through the different phases of the study.

Content analysis of patient education resources

Patient accessibility. We assessed the accessibility of resources, both in terms of format (e.g. streamed, viewed online or downloaded) and the availability (or otherwise) of translated resources for non-English speakers.

Readability. Readability was assessed using a free online readability test tool (https://www.webfx. com/tools/read-able/). The main text from each written resource was imported directly into the tool. Health Education England (HEE) recommends that patient resources be written at a level suitable for comprehension by an average 11-year-old. Mean $\pm$ *SD* readability scores were calculated for the Flesch–Kincaid Reading Ease (FKE), Flesch–Kincaid Grade Level (FKG) and Simplified Measure of Gobbledygook (SMOG) as recommended by HEE (2018). Scores can be converted into UK reading ages – see Supplementary Material 1.

Theoretical content. We developed a coding framework to assess the following theoretical principles: cognitive and emotional representations of illness (identity, timeline, cause, consequences, control/cure [subcategories personal control and treatment control] and emotion) as specified in the CSM (Leventhal et al., 2016) and treatment perceptions (necessity beliefs and treatment concerns)

as specified in the NCF (extended CSM) (Horne, 2003) (Table 1). Domains were discussed in terms of definition and relevance to LTBI. Communication was included as an additional domain to assess the extent to which resources encouraged discussion with health care professionals, an important component of shared decision making. An initial classification-coding table was developed based on published definitions for each domain. Key criteria for each domain, along with the classification system were iteratively refined using a constant comparison approach following familiarisation and indexing of the resources. We developed a three-level coding system (fully addressed, somewhat addressed and failed to address) to demonstrate sensitivity regarding the extent to which each resource addressed each of the theoretical domains.

Content analysis. Data analysis was guided by the principles of a deductive content analysis (Elo and Kyngäs, 2008) in which resources were coded against the predefined theoretical framework (Table 1). The authors A.L.C., T.S. and A.S.K.J. individually coded the resources; codes were combined and any inconsistences resolved through discussion.

Readability data were analysed using SPSS (version 26) and are presented as means ± *SD*.

Results

Our search identified 60 resources of which 17 resources met the inclusion criteria (Table 2). The publication dates of included resources ranged from 2007 to 2020. Of the included resources, nine were LTBI specific and eight focused on TB disease but included relevant LTBI information.

Format and accessibility

Table 2 details the accessibility of the resources. Patient resources were available in various formats including leaflets, booklets, websites, guidelines and video animations. All resources were accessible online. Alternative formats for increased accessibility were available for three resources, including the addition of subtitles (animation video), larger text or versions compatible with assistive technology. Translated materials were reported as available for seven resources, but only three translations were available for immediate viewing. For the remaining resources, access to translated materials were either only available on request (e.g. by contacting a request telephone line or health care professional), were not easily located on the site or unavailable due to a broken hyperlink.

Readability Statistics

Of the included resources, 14 were in a written format and evaluated for readability. The remaining 3 resources were video animations. The overall mean ± *SD* readability scores and corresponding reading ages were FKE 63.51 ± 8.81 (13–15 years), FKG 9.14 ± 8.95 (13–15 years) and SMOG 8.27 ± 1.51 (13–14 years). None of the resources met HEE recommendations for readability across all three tests. The resource with the lowest reading age score was a leaflet authored by Public Health England: FKE 74.10 (reading age 12–13 years), FKG 6.20 (reading age 11–12 years), SMOG 6.50 (reading age 11–13 years).

Theoretical content analysis

Coding criteria and domain glossary are shown in Table 1, and a summary of the number of resources adequately addressing each theoretical construct of interest is shown in Table 3. A further

Table 1. Theoretical domain classification criteria.

Domain	Fully addressed	Somewhat addressed	Not addressed
Identity: names or labels the condition and perceptions of symptoms/condition.	Resource names LTBI, states explicitly that there are no symptoms and that it is not infectious.	Resource names LTBI, *but inadequately describes or fails to describe the lack of symptoms* (e.g. person does not feel unwell), or misses either symptom or transmission information.	Resources names LTBI *but fails to address symptoms and transmission.* Resources that do not state LTBI should have been excluded at an earlier stage.[a]
Timeline: perceived and measured rates of illness onset, duration and decline. Optional criteria – resources might also state an approximation of risk, e.g. 1 in 10 during lifetime.[a]	Addresses the unknown timeline to disease progression *and* states that LTBI can be persistent.	Addresses the unknown timeline to disease progression or that LTBI can be persistent.	Fails to adequately address the unknown timeline to disease progression *and that* LTBI can be persistent.
Consequences: experienced and anticipated physical, cognitive and social disruptions.	Addresses both the potential physical (e.g. progression to active disease) *and* social consequences (e.g. passing TB on to others) associated with a diagnosis of LTBI.	Addresses only the potential physical consequences or the social consequences of LTBI, e.g. risk disease progression without treatment.	Fails to address any potential consequences associated with a diagnosis of LTBI.
Causal: beliefs about the cause of illness, e.g. biological, emotional, environmental and psychological.	Resource states that LTBI/TB is caused by breathing in bacteria; and describes the three different immune responses, e.g. (1) body clears bacteria, (2) body supresses bacteria (LTBI) or (3) active disease occurs.	Resource only states that LTBI/TB is airborne, but does not explicitly state that it is has to be breathed in. Alternatively, states that TB bacteria is breathed in, but does not explain the difference in immune responses.	Fails to address what causes TB or LTBI.
Emotional Identity: level to which negative emotions might be felt because of the illness.	Addresses potential negative emotions of LTBI.	Resource alludes to a negative emotional response but does not link this to LTBI.	Fails to address any emotional response.

(Continued)

Table 1. (Continued)

Domain	Fully addressed	Somewhat addressed	Not addressed
Personal control: level to which a person has control over a condition.	Resource states that a person has no control over disease progression.	Resource alludes to reduced control in some way by suggesting people who might be more at risk of progression, e.g. those with weakened immune systems.	Resource fails to address personal control at all.
Treatment control: level to which a condition can be controlled or cured by treatment.	Resource states that LTBI is treatable and provides information about the types of medicines and treatment regimen.	Resource states that LTBI is treatable but provides no additional information.	Resource fails to address the fact that LTBI can be treated, e.g. focuses only on screening and diagnosis.
Treatment necessity: beliefs about the necessity of LTBI treatment to achieve a goal that is important to the patient.	Resource explains the condition and how treatment will influence this, as well as the importance of treatment to help a person reach a goal that is important to them.	Resource explains the illness and how treatment will influence this but does not link it to potential goals, e.g. reducing risk of TB becoming active.	Resource fails to explain the condition and how treatment will influence this.
Treatment concerns: beliefs related to treatment concerns that might include side effects	Resource provides information that targets specific concerns about taking treatment, including side effects.	Resource alludes to possible concerns about medication but does not address these adequately.	Resource fails to address medication concerns, simply listing side effects is not enough.
Communication: encouragement to engage in continued discussion about treatment with health care professional.	Resource recommends the patient communicate further with a health care professional for support about their treatment. Advice to report side effects was not sufficient.[a]	Resource only recommends non-specific communication (e.g. contact doctor if you have questions) or only provides direction not encouragement (e.g. tell your doctor if you experience these side effects).	Resource fails to address the need for further health care professional involvement with care or treatment.

LTBI: latent tuberculosis infection; TB: tuberculosis.
[a]Optional criteria on risk presentation was collected for interest but did not add to the classification scoring protocol.

Table 2. Description of LTBI resources (*N* = 17) and level of accessibility.

Material	Purpose	Accessibility
Webpage (TB Alert, 2016)	To provide an essential guide to LTBI	Website has a built-in function where the patient can translate materials to the following languages: Arabic, Bengali, Gujarati, Hindi, Punjabi, Somali, Urdu
Leaflet (TB Alert et al., 2016)	To provide information about treatment for LTBI	Patient advised to ask their doctor or nurse about local translation and interpreting services. Print friendly versions of the documents are available online in the following languages: Arabic, Bengali, English, Farsi, Gujarati, Hindi, Nepali, Pashto, Punjabi, Somali, Tamil and Urdu. Found only when searching further reading section.
Leaflet (TB Alert et al., 2018)	To provide information about LTBI in general.	No
Leaflet (Public Health England and NHS England, 2015)	To provide information about LTBI testing and treatment for patients. Leaflet also designed to help GPs and nurses talk about TB with their patients.	Yes – readily available in Arabic, Bengali, Farsi, Gujarati, Hindi, Nepalese, Pashto, Punjabi, Somali, Tamil and Urdu Option to request an accessible format via email for use with assistive technology.
Webpage (NHS, 2019)	To provide an overview of TB.	No
Webpage (Global Health Education TB Facts.org, 2020)	To provide facts about TB.	No
Webpage (British Lung Foundation, 2017)	To provide information for people to learn about the symptoms and treatment of TB and how to prevent infection.	No
Video animation (NHS Birmingham and Solihull Clinical Commissioning Group, 2018)	To provide information about LTBI and encourage testing	No

(Continued)

Table 2. (Continued)

Material	Purpose	Accessibility
Factsheet (NHS Direct Wales, 2007)	To provide facts about TB	Not readily available
		States that electronic versions of the leaflet (along with translated materials) can be found at www.wales.go.uk/immunisation – faulty link
Leaflet (Harrogate and District NHS Foundation Trust, 2016)	To provide information about new entrant screening and LTBI	Not readily available
		Patient advised to email or telephone (contact provided) for information in a more accessible format or alternative language.
Webpage (Breathing Matters, 2020)	To provide a brief overview of TB.	No
Leaflet (NHS Southwark Clinical Commissioning Group [CCG], 2017)	To provide information about LTBI and testing	Not readily available
		Participant advised to contact NHS Southwark CCG if requiring the leaflet in other language or format.
Webpage (NHS Inform, 2019)	To provide an overview of TB including symptoms, cause, diagnosis and treatment.	No
Guidance Document(National Institute for Health and Care Excellence [NICE], 2016a)	To provide information explaining the advice about TB that is set out in NICE guidance.	No
Webpage (Nam aidsmap, 2017)	To provide an overview of TB, with a focus on people living with HIV who have a low CD4 count.	No
Video animation (NHS Leicester City Clinical Commissioning Group, 2017)	To provide information about LTBI.	No
Video animation (Public Health England et al., 2018)	To provide information about LTBI.	Yes – readily available for download in Arabic, Bengali, Gujarati, Punjabi, Somali and Urdu.
		Available with and without subtitles.

TB: tuberculosis; LTBI: latent tuberculosis infection.

Table 3. Summary of theoretical domains addressed by the included patient education resources (*N* = 17).

Domain	Fully addressed n (%)	Somewhat addressed n (%)	Not addressed n (%)
Identity	8 (47)	6 (35)	3 (18)
Timeline	0 (0)	14 (82)	3 (18)
Consequences	1 (6)	13 (76)	3 (18)
Causal identity	8 (47)	5 (29)	4 (24)
Emotional Identity	0 (0)	1 (6)	16 (94)
Personal control	2 (12)	11 (65)	4 (24)
Treatment control	11 (65)	6 (35)	0 (0)
Treatment necessity	4 (24)	9 (53)	4 (24)
Treatment concerns	1 (6)	6 (35)	10 (59)
Communication	3 (18)	5 (29)	9 (53)

breakdown of the individual resources mapped to the theoretical domains is contained in Online Supplemental Material.

Illness perceptions

All resources named LTBI. However, identity was fully addressed by only 47% of resources. Resources that did not fully address the identity domain tended to provide vague statements related to the asymptomatic nature of the condition, such as 'LTBI does not make you feel unwell'.

The majority (65%) of resources fully addressed treatment control by providing information about the curability of LTBI and additional information about treatment type and duration. In contrast, only 12% of resources fully addressed personal control by explicitly stating that there is no way of knowing whose infection will progress from LTBI to active TB.

Causal identity was fully addressed by 47% of resources. Resources failing to address this domain often stated that TB was airborne but did not explicitly state that TB bacteria are inhaled or describe the different immune responses following exposure to TB bacteria. No resources addressed causal misconceptions commonly held by certain TB patient groups, for example, 'TB is a family curse or sign of witchcraft'.

One resource fully addressed consequences, stating both the physical (e.g. disease progression) and social (e.g. risk of transmission to friends and family) consequences of not treating LTBI. While most resources addressed the physical consequences, social issues were not addressed beyond the future risk of transmission. Missing concepts included the impact of LTBI diagnosis on social identity or social relations, and experience of stigma.

No resources fully addressed timeline. The majority (82%) referred to the unknown duration of disease progression, yet failed to acknowledge that LTBI can be persistent. Eleven patient resources provided absolute risk estimates for disease progression (optional criterion within the timeline domain) using numerical event rates (e.g. 1 in 10 or 10% chance of disease progression.).

No resources adequately addressed emotional identity, which refers to the extent to which an illness promotes a negative emotional reaction (Hagger et al., 2003). One resource alluded to negative emotions generally, and some resources provided links to support, but these were not specific to addressing negative emotions resulting from LTBI or treatment.

Treatment perceptions

Treatment necessity was only addressed fully by 24% of resources. Resources often failed to link the problem and the treatment. For example, many resources simply stated that treatment can prevent progression to active TB (benefit of treatment), but did not include a common-sense rationale for how treatment might work to help the patient achieve a health goal that is important to them. Only one resource fully addressed treatment concerns, by making reference to common patient concerns throughout the resource such as 'I don't feel ill so why should I take treatment for latent TB?' This same resource also provided a common-sense rationale for treatment necessity (TB and Alert, 2016c).

Communication

Communication was addressed by 18% of resources. Most failed to address communication with a health care professional at all or only identified the need for contact in relation to the experience of side effects. No resources facilitated shared decision making by addressing both illness and treatment perceptions and encouraging communication with a health care professional.

Discussion

This study aimed to evaluate the accessibility, readability and content of online UK LTBI patient education resources. Searches yielded a modest number of patient resources ($N=17$), with the majority of these focusing predominately on active TB disease.

All included written resources scored higher than the recommended reading level for patient information, as advised by HEE (2018). This is problematic as non-UK-born individuals disproportionately bear the burden of TB in the United Kingdom (Pareek et al., 2016), may have limited English language proficiency and an increased vulnerability to poor health literacy (Ward et al., 2019). Furthermore, only three resources were readily available in other languages. Translated resources available only on request can add an extra barrier to asserting candidacy (eligibility for medical attention/intervention jointly negotiated between individual and health care system) among the UK migrant population (Potter, 2018). This potentially limits patients' ability to make informed treatment choices, thus widening the gap for health inequality within the United Kingdom (Salway et al., 2020).

The majority of resources were in written format, but there may be more optimal formats for delivering patient education. The review identified three video animations whereby written or spoken information were supported by graphics. One video animation had high accessibility, being readily available for streaming and download in a number of languages, but the primary focus was LTBI screening (Public Health England et al., 2018). Animations have been shown to improve TB knowledge among low literacy populations (Reeves et al., 2020), suggesting animation as an effective channel of delivery for improving patient knowledge and supporting informed treatment decisions.

Theory-based materials (in the form of the application of a set of concepts and/or standards with specification of how phenomena relate to each other, applied to the development of interventions such as patient education resources) can enhance knowledge and facilitate informed choice about treatment (Bishop et al., 2019; Davis et al., 2015). However, this review highlighted a lack of theoretical content in LTBI patient education resources. No identified resource fully addressed all the theoretical domains in the extended CSM and the additional domain of communication. A website page by the leading UK TB charity, TB Alert, had the most

theoretically based content (fully addressing 6 out of 10 domains) (TB and Alert, 2016c); however, it failed to address emotional identity.

A recent mixed-methods cross-sectional study of 108 people with LTBI conducted in Sweden, showed emotional concerns (anxiety and depression) to be prevalent among 27.7% of the sample (Shedrawy et al., 2019). Qualitative work described how lack of clarity about the disease, the future and risk to others had a negative impact on participants' mental health (Shedrawy et al., 2019). This highlights the importance of acknowledging emotional identity and treatment concerns in LTBI patient education resources, and the need for signposting to appropriate supportive services.

Identified patient education resources also commonly neglected certain illness perceptions such as treatment concerns and timeline, despite the likely influence of these beliefs on treatment decision making. A recent study found that ~30% of patients declined participation in a ran- domised international trial of new LTBI treatment regimens, due to beliefs about LTBI (e.g. no perceived risk of active TB) or treatment perceptions (e.g. negative impact on health) (Hedges et al., 2019). Addressing treatment perceptions may help to support informed treatment decisions; however, only one resource addressed treatment concerns. Listing side effects is not enough to alleviate patient concerns, and may exacerbate anxiety or leave patients with outstanding ques- tions, particularly in the absence of information to weigh up concerns against treatment benefit (Wells and Kaptchuk, 2012).

The majority of resources described the unknown timeline of progression to active TB but failed to indicate that LTBI can be persistent with (albeit to a lesser extent) or without treatment. This is important to communicate, as many younger patients may only have experience of treating acute or self-limiting conditions. Communicating the risk of progression to active TB is further compli- cated by the differing risk profiles observed across groups (e.g. contacts and migrants) (Abubakar et al., 2018) and the inability of current diagnostic tests to confirm viable dormant TB bacteria and accurately predict progression (Lalvani et al., 2019). Despite this, the majority of resources included generalised risk statements (e.g. 1 in 10 people with LTBI will progress to active TB), which may lead patients to form inaccurate representations around their own risk. Newly devel- oped tools such as the Periskope.TB (http://periskope.org/tb-risk-predictor/), which take into con- sideration individual demographics and medical characteristics, may help to communicate personal risk to patients (Gupta et al., 2020). However, further research is required to understand how per- sonalised risk estimates influence treatment decisions.

Similarly, the majority of resources inadequately addressed personal control. Previous qualita- tive work has demonstrated patient beliefs about the use of exercise and nutrition to manage their risk of developing active TB (Gao et al., 2015). Misconceptions concerning personal control can influence perceptions of risk and treatment necessity, affecting the ability to make informed treat- ment decisions. Personal control needs to be communicated accurately to patients with the limits pointed out. For example, if resources promote the benefits of a healthy lifestyle, they should also clearly state that this is not a substitute for LTBI treatment.

Patient education resources can support patients to make informed choices about their health. However, the difficulties and extent to which this can be achieved within the boundaries of pub- lic health agendas and screening programmes to eliminate TB in low-incidence settings should be acknowledged. Systematic programmes offer personal and public health benefits for some, but may disadvantage others through treatment that is potentially harmful, may be of no personal benefit, and which has negative health and social consequences (Degeling et al., 2017; Scandurra et al., 2020). In particular, anticipated or experienced stigma may have a negative influence on the uptake of screening and treatment but was not addressed by the included patient education resources.

The extended CSM is a useful model for addressing commonly asked questions about illness and treatment and can be used to inform future LTBI patient education resources. Similarly, including the views of people with lived experience of LTBI and relevant stakeholders can help to ensure resources are acceptable and sensitive to the priorities and values of the target community (Yardley et al., 2015).

This study analysed online LTBI patient education resources from UK-based organisations. Our search was restricted to Internet-based resources and more local materials may have been missed. Furthermore, while readability tests are useful in gauging how a patient might understand text, they offer little insight into how a patient might engage with a resource, which may be affected by the use of headings, imagery, tables, tone and ease of access.

Conclusion

Our searches found a modest number of UK LTBI patient resources, none of which fully addressed patient perceptions of LTBI and treatment, and promoted shared decision making. The quality of resources identified was variable in terms of accessibility, readability and theoretical content. All written resources failed to meet HEE reading age recommendations for patient materials, and only three were readily available in other languages. This is particularly worrying given the NHS and UK government priority to address health inequalities in UK multi-ethnic and migrant populations (Salway et al., 2020). Video animations may be a promising channel for health information delivery to groups with low literacy or limited English. Further research is now required to develop and test the acceptability and effectiveness of theory-based patient resources to support informed treatment decisions in LTBI.

Declaration of conflicting interests

Funding

Ethical approval and consent to participate

Given the nature of the study and the fact that all the resources analysed are publicly available, ethical approval was not required for this investigation.

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Supplemental material

Supplemental material for this article is available online.

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