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# The meaning and consequences of tuberculosis among Somali people in the United Kingdom

Kate Gerrish, Andrew Naisby & Mubarak Ismail

## The meaning and consequences of tuberculosis among Somali people in the United Kingdom

### Abstract

**Aim.** To ascertain the socio-cultural meaning and consequences of tuberculosis among people of Somali origin living in the UK.

**Background.** In countries where treatment has not been readily available, tuberculosis has become highly stigmatized. Research in Somalia has documented the stigma and social isolation associated with tuberculosis which acts as a powerful deterrent to sufferers acknowledging their illness. The Somali community in the UK is diverse and dynamic: little is known about how tuberculosis is understood, or how stigma is articulated and experienced post-migration.

**Design.** A focused ethnography was undertaken.

**Method.** A total of 48 individual interviews were undertaken in 2008–2009 with community leaders, Somali community members and tuberculosis patients to explore the social meaning of tuberculosis and perceived consequences of the disease. Eight focus groups were undertaken involving 56 participants. Vignettes concerning tuberculosis were used to prompt discussion of community norms and socio-cultural constructions of tuberculosis. Data were analysed using the 'Framework' approach.

**Findings.** Most participants were familiar with tuberculosis, its characteristics and treatment. However, many participants held misconceptions about how the disease spread and its prognosis. Tuberculosis was perceived as a stigmatizing disease. Somalis with tuberculosis were considered likely to experience felt and enacted stigma with fear of discrimination in the form of social isolation influencing the extent to which people with tuberculosis disclosed their condition.

**Conclusion.** Nurses should understand the socio-cultural meaning and consequences of tuberculosis for Somalis to educate the community through public health initiatives and support patients and their families.

**Keywords:** health beliefs, nurses, nursing, socio-cultural, Somali, stigma, tuberculosis

## Introduction

Tuberculosis (TB) is a serious but treatable communicable disease. A third of the world's population are infected with TB and around nine million people develop active TB annually (World Health Organization 2010). Alongside other European countries, TB incidence in the UK has increased by 25% over the last decade [Health Protection Agency (HPA) 2010] with 8587 new cases of TB reported in 2010, a rate of 14.9 per 100,000 population (HPA 2011). Major differences exist geographically with the main burden of the disease concentrated in large cities. The majority of cases occur in persons born outside the UK (73%), many of whom are from South Asia (57%) and sub-Saharan Africa (27%) (HPA 2011).

Early presentation, timely diagnosis, concordance with treatment and effective contact tracing are essential to curbing the spread of TB. However, knowledge of, and attitudes towards TB among at risk populations influence the success of endeavours to improve TB control. Health beliefs and health-seeking behaviours vary among ethnic groups. If nurses are to fulfil their role in the prevention and management of TB (Ghebrehiwet 2006), they need to understand the meaning that TB may hold for members of particular ethnic groups and the consequences that may result.

## Background

In countries where treatment has not been readily available, TB has become highly stigmatized with discrimination shown towards sufferers (Dodor et al. 2008). The community norms and inter and intra-personal attitudes that lead to stigmatization of TB can hinder its control (Courtwright & Turner 2010). According to Link and Phelan (2001) stigma arises when a person is identified by a label that sets the person apart and prevailing cultural beliefs link the person to undesirable stereotypes that result in loss of status and discrimination. An individual who possesses the adverse attributes may perceive themselves to be stigmatized and as a result may feel unworthy or guilty. This in turn may lead to a lack of self-worth, self-isolation and avoidance behaviour (Kelly 1999). Someone who possesses the adverse attributes may also experience social stigmatization whereby others discriminate against them (Albrecht et al. 1982). This may then lead the individual to feel shunned and to experience guilt and shame (Heatherton et al. 2000).

The effects of stigma and discrimination associated with TB in developing countries are well documented (e.g. Liefoghe et al. 1995, Ogden et al. 1999, Baral et al. 2007, Armijos et al. 2008). People with TB often isolate themselves

to avoid infecting others or may hide the fact that they have TB to minimize the risk of being shunned (Baral et al. 2007). Moreover, patients may experience social isolation in the family where they are required to eat and sleep separately and also outside the family where the person may be avoided by friends (Baral et al. 2007). Stigma and the associated discrimination have important implications for TB control. Concern about being identified as someone with TB can make it harder for people who suspect that they have TB to seek care. Delays in diagnosis and treatment mean that people remain infectious for longer and are more likely to transmit the disease to others (Mohamed et al. 2011). They may also be less likely to identify contacts for screening for fear of social repercussions. This can lead to subsequent cases of TB that could have been prevented.

Migrants from countries where TB is highly stigmatized are likely to continue to share many of the cultural norms and attitudes towards TB prevalent in their country of origin (Johnson 2006). In Somalia, research has documented the extreme stigma and social isolation associated with TB which acts as a powerful deterrent to sufferers acknowledging their illness (Kwan-Gett 1998). In the UK Shetty et al. (2004) identified that Somalis in London, varied in their level of understanding of TB and attitudes towards the disease, although the study did not look at stigma.

The UK Somali community is diverse and dynamic: little is known about how understandings of TB are developed and communicated, or the ways in which stigma is articulated and experienced. In recognizing that TB is not just a medical disease to be treated with antibiotic therapy but an entity with historical and cultural roots, it is important to develop insight into the socio-cultural understandings of TB to develop culturally appropriate services (Houston et al. 2002, Gibson et al. 2005).

## Aim

To ascertain the socio-cultural meaning and consequences of TB among people of Somali origin living in the UK.

## Methods

### Design

A focused ethnographic approach was used. According to Knoblauch (2005) focused ethnography provides the opportunity to study specific issues in a single culture or social situation among a limited number of people within a specified period of time. By exploring a specific research question (in this case the meaning and consequences of TB for people of

Somali origin) only those elements of knowledge relevant to understanding the practices involved are highlighted.

The research team included a Somali researcher and four Somali community researchers were appointed to assist with community interviews. All Somali researchers were fluent in Somali and English and received training in ethnographic data collection and analysis and in TB.

## Participants

Participants were recruited from the Somali community in Sheffield, a city with one of the largest (estimated 10,000) and longest established Somali populations in the UK. The population comprised people with varied histories of migration including economic migrants from the 1930s, refugees from the civil war in the 1990s, recent migrants from Somalia through family reunions and European Somalis who migrated mainly from the Netherlands and Scandinavia.

Purposive sampling was used to recruit the following participants (Table 1):

- Ten community leaders from Somali organizations. Initial participants were identified by the Somali researcher who was part of the local Somali community and subsequently by snowball sampling.
- Eighty members of the wider Somali community. Participants were recruited through Somali researcher/community researchers' social networks to reflect diversity in age, gender, history of migration and socio-economic background.
- Fourteen patients who were receiving or had recently completed treatment for TB. In accordance with ethical requirements, patients were recruited by a TB specialist nurse who was involved in their care.

The different groups of participants enabled a broad range of perspectives to be accessed. The size of the respective samples was determined to enable data saturation, with the exception of TB patients, where the sample comprised all

people with a recent history of TB who were well enough and agreed to participate.

## Data collection

Data were collected during 2008–2009 and comprised four phases:

- In-depth interviews with community leaders from Somali organizations focused on developing an understanding of the Somali community, to include history of migration, family/social networks, health beliefs and behaviours associated with TB.
- Semi-structured interviews with members of the wider Somali community explored personal knowledge and attitudes towards TB and related health-seeking behaviours and participants' perspectives of community cultural norms.
- Semi-structured interviews with TB patients sought to capture participants' experiences of TB, including strategies adopted to 'manage' their condition, the roles of family and friends and factors influencing their response to the disease.
- Focus group discussions, based on vignettes developed from earlier interviews enabled a more detailed discussion of health beliefs associated with TB. Focus groups were undertaken with four groups of men and four groups of women. Focus groups varied in size from four to nine participants. Two vignettes that provided a scenario relating to TB in the Somali community were used to prompt discussion relating to community norms and socio-cultural constructions of TB.

Interviews and focus groups were undertaken in the preferred language of participants. Participants were able to choose to be interviewed by a male or female researcher. Focus groups were facilitated by researchers of the same gender as participants.

## Ethical considerations

Ethical approval was obtained from an NHS Research Ethics Committee and research governance approval obtained from participating NHS organizations. The research design respected and responded to the multiple sensitivities surrounding the study. The research team were aware that Somali participants may have particular concerns about the confidentiality of data and their anonymity as research participants. It was recognized that the social stigma associated with TB and its treatment could lead to participants being stigmatized by taking part in the study.

Every effort was made during recruitment to explain to participants the ethical standards to which the research team

Table 1 Research participants.

Participants	Gender		Data collection method	Anonymous code for quotes
	Male	Female		
Community leaders	5	5	In-depth interviews	CL
Somali community members	10	14	Semi-structured interviews	SCM
	28	28	Focus group discussions	FG
TB patients	9	5	In-depth interviews	P

would adhere and how confidentiality of information and anonymity of participants would be ensured. On the advice of Somali community leaders, no personal biographical information, other than gender, was collected as formal data from participants to reassure them of their anonymity. However, information on participants' backgrounds was used to ensure diversity in the characteristics of participants recruited as outlined above.

### Data analysis

Focus groups and individual interviews were audio recorded with participants' permission and subsequently transcribed. Interviews/focus groups conducted in Somali were translated into English prior to analysis. Data analysis drew on the principles of the 'Framework' approach to qualitative analysis (Ritchie et al. 2003) which involved five stages:

- Members of the research team familiarized themselves with the data by reading the transcripts several times.
- A thematic framework for coding the data was developed based on the interview agendas and issues arising from initial scrutiny of the transcripts.
- Individual transcripts were coded by applying the thematic framework.
- The coded data were subsequently organized into major themes.
- Data from each phase were analysed separately and then brought together to form a composite analysis. The relationships between different themes were mapped by analysing the data set as a whole.

### Rigour

Triangulation of data from interviews and focus groups and from different groups of participants was used to check for consistencies and divergent perspectives across the data set. All researchers were involved in analysis. Initial analysis undertaken by one researcher was checked by a second researcher to ensure consistency in coding and to safeguard against selectivity in the use of data. A reflexive approach was adopted throughout whereby researchers examined their role in the research process and the assumptions that influenced their interpretation of data. The multi-ethnic composition of the research team assisted in validating the cultural interpretations placed on the data.

### Results

The meaning that TB held for participants was shaped by their knowledge and beliefs about the disease which influ-

enced the extent to which it was stigmatized. Perceived stigma carried anticipated and actual consequences for individuals and the wider Somali community. Different strategies used by people who contracted TB to address the stigmatization were identified.

### Knowledge and beliefs about TB

Knowledge of TB varied among participants. Community leaders generally demonstrated a biomedical understanding of causes, transmission, symptoms, treatment and prognosis. By contrast the wider Somali population held various beliefs about the nature of TB and how infection spread. Whereas Somalis attributed illness including TB to the will of Allah, participants did not perceive contracting TB as divine retribution for some demeanour. Rather, they offered biomedical, behavioural, psycho-social and material explanations.

Some participants identified TB as an airborne disease whereby people became infected by 'breathing in the germ' and once infected, they could pass it on to others. Whereas this explanation reflected a biomedical understanding, other views about TB were prevalent. Many Somalis thought TB was an inherited disease that could affect several generations and although treatable it could not be eradicated completely:

There is inherited TB, it will stay with you forever, your grandfather had it, then your father, then you. (SCM 3)

Some participants suggested a causal link between TB and other diseases, seeing it as a complication that might arise from respiratory illnesses such as influenza:

It starts with flu and then gets worse and becomes a chest infection. If the infection is not treated, it will change to TB. (SCM 9)

Others proposed a link between TB and poor socio-economic circumstances, or that it was attributable to lifestyle. Enclosed spaces, such as khat houses (Khat – the leaves of the shrub *Catha edulis* which are chewed like tobacco or used to make tea, it has the effect of a euphoric stimulant) where men socialized in close proximity were identified as places where people might be at greater risk:

People get TB because of hunger, living rough, not being healthy, from the environment. Somali men chew khat, even if they are hungry, they don't eat, they don't sleep for 2–3 days and that combined causes TB. (CL 8)

The view that TB could be spread through sharing eating utensils with someone with TB was widespread. Even if utensils were cleaned thoroughly, some people believed that the risk of cross infection remained.

Psycho-social factors also provided an explanation for succumbing to TB:

I was a business lady, buying and selling in a village (in Somaliland) before the civil war. When the war started we lost everything. All our assets had been looted. I think that the worry and stress caused my TB. (P5)

It was apparent that many beliefs about TB existed among Somalis and although some contrasted with biomedical understandings, they were not mutually exclusive. Even Somalis who had received treatment for TB in the UK and had been provided with biomedical explanations by health-care professionals simultaneously believed that there were other reasons why they had contracted TB. In particular, hereditary explanations appeared embedded in the cultural beliefs of people who had contracted TB.

Many Somalis identified clinical features of pulmonary TB: a persistent cough, weight loss, fever and haemoptysis were seen to characterize the disease. However, there was little awareness of non-pulmonary forms of TB. Most participants knew that TB could be treated with a lengthy course of antibiotic therapy and people generally made a good recovery if they completed treatment. However, there was a prevalent belief that the disease may not be fully cured even after treatment. This was linked to the belief that TB was hereditary and therefore could not be eradicated:

I've taken tablets, it was a long time, 6 months. They tell me I'm cured, but I think it may come back. It's in my family. (P2)

Whereas people who had contracted TB or had a relative with the disease were generally knowledgeable about its course once treatment commenced, knowledge varied among the community at large. There was little understanding among the general Somali population of the length of time a patient who commenced treatment remained infectious. Several participants believed that patients remained infective throughout treatment and possibly beyond and that precautionary measures should be instigated to reduce the spread of the disease:

Somali people think that anyone who has TB is infectious until he dies. (SCM19)

Even if someone says he's cured of TB, I still think I can get the disease from them. I won't use the same cup, I may get TB. (SCM11)

#### Attitudes towards TB

Somali participants' frequently referred to the social stigma associated with TB in Somalia when explaining contemporary attitudes towards the disease in the UK. Before treatment

was available in Somalia, TB brought 'shame on a family' and social isolation for the person concerned, which could be extended to the whole family:

When I was in Somalia people used to stay away from anyone who had TB, they used to isolate him and warn people not get close to him or eat with him. People even used to say 'that person has TB so nobody talk to him'. Anyone who has TB will be (socially) isolated, not only him, but his family will be stigmatized. (SCM 20)

Attitudes towards TB were explored from two perspectives: interviewees' personal attitudes towards TB and their perceptions of how TB was viewed in the Somali community at large. Personal attitudes expressed by individuals often differed from their perception of the beliefs and attitudes about TB held by the wider community. The prevailing view was that TB remained stigmatized in the community with potentially important consequences.

Individuals who contracted TB were perceived to experience a loss of self-worth and a sense of shame:

Somali people have stigma (about TB), they feel disgrace to admit that they have TB. They feel ashamed if they have it. (SCM18)

People with TB were considered likely to experience discrimination, most frequently manifest as social isolation. In a community where socializing with family and friends was integral to everyday life, being excluded was felt keenly:

Anyone who has TB, as soon he tells someone, that person will keep a distance because they think they'll get it from him. People will start saying 'he has TB, stay away from him'. They will isolate him. (FG8)

No one will eat with him or eat from the same plate, no one will like to sit next to someone with TB. (FG2)

A belief that TB could not be fully cured also meant that friends may be reluctant to resume normal social interactions because of fear that they might contract TB:

Even when he's had treatment for TB, when he coughs they think he has TB again. They're fearful, they'll keep away. (FG1)

Concern was expressed about the impact that TB had on employment opportunities: it was thought that people with TB may encounter difficulties continuing in employment or securing new employment. In addition, as TB was considered hereditary, it could affect marriage prospects:

TB affects different aspect of your life, even your marriage. You won't be able to marry a woman because you have TB in your family. (FG5)

Fear of discrimination was seen to lead individuals with TB to instigate measures to minimize the impact of discrimination.



One strategy was for people with TB to isolate themselves and withdraw from social interactions outside their immediate family, thereby reducing the distress caused by experiencing discrimination. Alternatively, they chose to conceal their illness:

People don't tell anyone that they have TB. He thinks people will call him names and verbally abuse him, even his best friends will cut him off and stop seeing him. That's why people are scared to tell others. (FG3)

Several participants justified the secrecy on the basis of the detrimental psychological effect it would have on the stigmatized individual:

People are only human. When they feel they are going to be treated like this, they will hide the disease. If they experience stigma, it might affect them mentally. If you're isolated and everyone keeps a distance from you because you have TB, then you get depressed. (CL8)

Despite remarkable consistency in participants' accounts of the attitudes towards TB held by the Somali community at large, several individuals held personal views that differed from community norms:

TB is seen as taboo illness, but it shouldn't be. It's not a bad disease. It can be cured with treatment. We shouldn't be afraid of it. (SCM18)

Participants with personal experience of TB varied in their response to the disease. Whereas some were accepting of the diagnosis, for others self-stigma and fear of discrimination were real concerns:

I was very shocked. People are scared of TB because they think they'll die and they can pass it to their children. When I found out that I had TB, I was very upset because Somali people think TB is very bad and anyone who hides it will suffer a lot and if you tell them about it, they'll stay away. (P8)

Although the general community view was that people diagnosed with TB would be reticent about making their diagnosis known, TB patients who were participants indicated that their actual experiences had been less stigmatizing than those reflected in their perceptions of community norms. There was little evidence that people with TB isolated themselves. Although most participants had been reticent about making their illness widely known in the community, they had shared it with family and close friends and subsequently had received their support:

Truly speaking, my family and friends are very understanding so they didn't panic or anything like that. (P5)

It was rarer to share the diagnosis outside of immediate family and close friends because of fears of perceived stigma

and the possible isolation that could ensue. One patient who was very open about his diagnosis reported some hostile reaction and others experienced a cooling of relations and distancing from some friends, even loneliness, as a result of sharing their illness:

When I said I had TB he was shocked, he stopped eating with us. (P14)

But hostility was often tempered when friends realized that the patient was acting responsibly in taking medication:

The man who shared the house with me had reservations when he found out I had TB and there were others who were shocked, but when they knew that I was taking my medication, they treated me ok. (P2)

A few participants had been very open about their illness, seemingly motivated by the importance of contact tracing:

I didn't hide it from anyone. I told all my friends I had TB and asked them to check themselves. A close friend of mine, we spent a lot of time together, I told him that he needs to be checked. I asked the nurse to send an appointment for him and another family who live nearby. (P1)

Several participants indicated that, once they disclosed their illness to others, they discovered individuals who had TB in the past. Opening up about TB sanctioned others to share their own experiences:

After we'd been treated, people started telling us about other people we know who had TB. Some people told us that they had TB in the past and been treated. (P10)

The variation between individual attitudes and experiences and community norms was attributed to variability in people's understanding of biomedical explanations of the disease. Once members of the community at large became more aware of the transmission, treatment and prognosis of TB, then it was anticipated that the associated stigma would diminish further. Indeed, several community leaders commented that in their view attitudes were changing:

People's attitudes are starting to change. TB is no longer seen with the same stigma. As people become more educated about TB, they aren't so afraid. They'll talk more about it. We're moving in the right direction, but it's a slow process. (CL6)

## Discussion

Several factors shaped the socio-cultural understanding of TB for Somali participants and the perceived consequences of contracting the disease. These included the historical context

of the disease, cultural norms and personal beliefs and individual experiences of TB. Although attitudes were changing, TB was perceived to be stigmatized and different strategies were employed to ‘manage’ discrimination arising from the stigma.

There is a lack of research examining socio-cultural understandings of TB among Somalis, in particular following migration to high income countries. This study sheds new light on the complexity of health beliefs and behaviours associated with TB among Somalis post-migration. In drawing together the findings from the current study, Figure 1 presents a framework which depicts the linkages between the meaning and consequences of TB for Somalis. This may be helpful to nurses in understanding the complex relationship between knowledge, attitudes and behaviours of Somali TB patients both in the UK and other countries which have notable Somali populations such as Scandinavia, North America and Australia. The potential transferability of the framework to other migrant communities in the UK and elsewhere is supported by evidence from studies of TB among communities originating from countries where TB is prevalent. These are drawn out in the discussion that follows. However, additional research is required to validate its wider applicability.

The observation that Somalis generally had a good biomedical knowledge of TB is supported by a small scale study of Somalis living in London (Shetty et al. 2004). However, the current study goes further by providing greater insight of how knowledge is shaped by cultural norms and individual experiences of Somalis. Although most participants knew that TB could be treated with good effect, there

was considerable doubt that the disease could be cured completely. Participants generally understood that TB was contagious but held various views about its transmission. The widespread belief among Somalis that TB could be spread by fomites, such as eating utensils, has been identified among other ethnic groups, both in the UK (Johnson 2006, Marais 2007) and in countries where TB is prevalent (for example Liefoghe et al. 1995, Houston et al. 2002, Baral et al. 2007, Armijos et al. 2008). Likewise, the belief that TB is an hereditary disease is shared by some other migrant communities in the UK and other high income countries (Farah et al. 2005, Gibson et al. 2005, Marais 2007).

The observation that Somali TB patients who were provided with biomedical explanations of the disease still held misconceptions about its transmission is not reflected in other studies of TB among Somalis. It suggests that deeply held views are hard to challenge, especially if reinforced by community norms and most probably contribute to sustaining the perceived stigma associated with the disease. This highlights the need for nurses to engage in on-going dialogue with patients about their understanding of TB to challenge misconceptions which may influence how patients respond to the disease.

In analysing stigma associated with mental illness, Scambler (1998) draws a distinction between felt and enacted stigma. Felt stigma refers to the fear of discrimination whereas enacted stigma refers to the actual experience of discrimination. The findings from the current study of TB give evidence of these two forms of stigma in relation to a different disease with a particular ethnic group and identify strategies people use to manage stigma. Cultural norms led many participants to

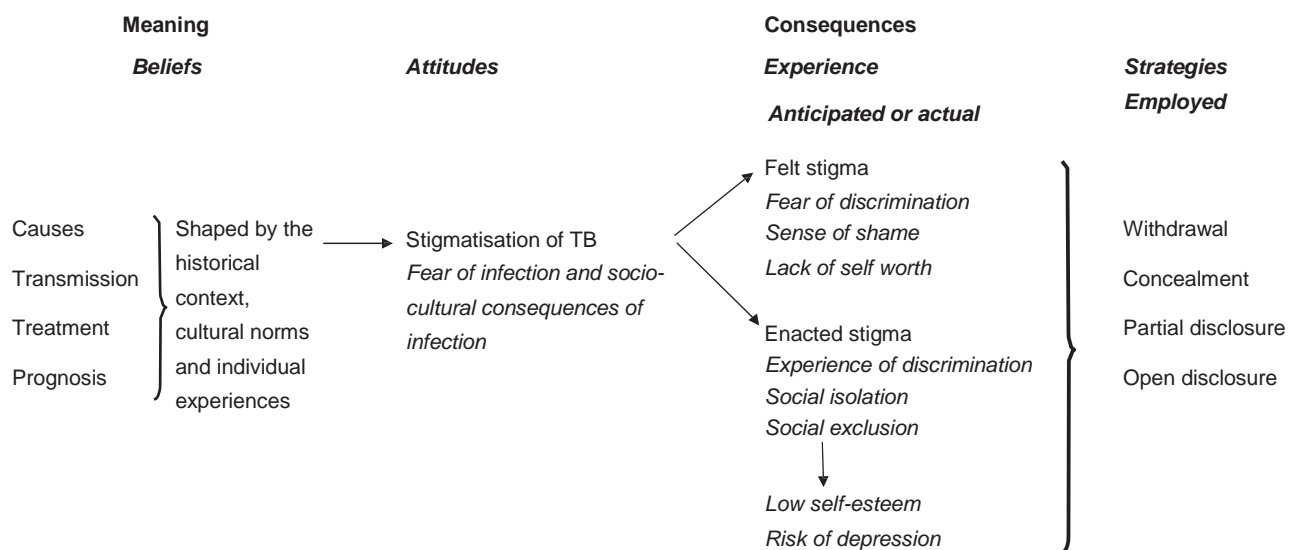


Figure 1 Meaning and consequences of TB for people of Somali origin in the UK.



### What is already known about this topic

- In countries where treatment has not been readily available, tuberculosis has become highly stigmatized with discrimination shown towards sufferers: community norms and inter-personal attitudes that lead to stigmatization can hinder the control of the disease.
- Migrants from countries where tuberculosis is highly stigmatized are likely to continue to share many of the cultural norms and attitudes towards tuberculosis prevalent in their country of origin.
- In Somalia tuberculosis has been associated with extreme stigma resulting in social isolation, however, little is known about the meaning and consequences of the disease for people of Somali origin living in the UK.

### What this paper adds

- Although most Somalis were familiar with tuberculosis, its characteristics and treatment, many held misconceptions about how the disease is spread and its prognosis.
- Tuberculosis was seen to result in both felt and enacted stigma with fear of discrimination in the form of social isolation influencing the extent to which people suffering from tuberculosis might disclose their condition.
- Individual attitudes towards tuberculosis were less stigmatizing than perceptions of community norms about the disease.

### Implications for practice and/or policy

- Nurses are well placed to educate through public health initiatives but to do so effectively they require insight into the socio-cultural understandings of tuberculosis held by Somali people.
- In recognizing the diversity of beliefs that may exist among Somali people, nurses need to gain insight into how individual patients view tuberculosis as part of the assessment process.
- Nurses need to be sensitive to the different strategies (ranging from withdrawal and concealment through partial to open disclosure) that tuberculosis patients may use to manage both felt and enacted stigma to give culturally appropriate care.

perceive that Somali people would experience felt stigma in that they would feel ashamed of contracting the disease and as a result may choose to withdraw or conceal their condition

from others because of the fear of being shunned. It was also suggested that Somali people who openly disclosed that they had TB may experience enacted stigma in terms of social isolation and consequently may elect not to share their diagnosis (concealment) with others, or disclose it only to close family (partial disclosure).

The findings from the current study have identified how beliefs and behaviours associated with TB are shaped by cultural norms and individual attitudes which may be at variance with each other. It was evident that individual attitudes towards TB were less stigmatizing than participants' perceptions of community norms. Despite reports that stigma associated with TB was diminishing, it could still be a potent force. There was a generally held view among Somalis that people would be circumspect about sharing their diagnosis with others due to possible negative consequences. Nurses need to be sensitive to the strategies (ranging from withdrawal and concealment through partial to open disclosure) that TB patients may use to manage felt and enacted stigma as this has implications for the support of individual patients and for contact tracing others who may be at risk of contracting TB.

It is difficult to judge whether people's expressed preference to conceal TB from the community at large is justified on the basis of concern about stigmatization and discrimination. Few TB participants had spoken openly about their disease among their wider social networks. However, for those who had shared their diagnosis more widely, there was little evidence of direct discrimination.

The findings from this study highlight the need to increase an understanding of TB among Somalis. Nurses are well placed to educate through public health initiatives and by supporting TB patients and their families. However, it will require strategies which challenge deeply held community norms about how the disease is spread, the long term prognosis and negative attitudes. The discrepancy between community norms of negative responses to TB and the reality of patients who found family and close friends to be largely supportive provides a potential avenue for actions to reduce the perceived stigmatization of TB.

The use of community link workers supported by health-care professionals is one model shown to be effective in managing TB (Craig et al. 2007). However, evidence of the effectiveness of stigma-reduction strategies is not strong. Whereas there is some evidence of effective strategies aimed at individual and community level, additional research is needed on interventions targeted at empowering people affected by TB to contribute to the development and implementation of strategies to reduce stigma (Heijnders & Der Meij 2006).

## Limitations

This study sought to gain insight into how TB was understood by a Somali community in the UK. The inclusion of community leaders, wider community members and TB patients meant that a broad range of perspectives and personal experiences of TB could be captured. The use of interviews and focus groups created the opportunity to uncover variance between individual attitudes and cultural norms. Although the study was undertaken in one location, the extensive social networks that participants reported with Somalis living in the UK and Scandinavia suggest that the findings may be transferable. Whereas community researchers facilitated access to a broad range of participants the sampling strategy which relied on social networks, and snowball sampling may mean that the views are not representative of the wider Somali community. Likewise, the experiences of TB patients who had been included as participants in the study may not be representative of Somali TB patients more broadly.

## Conclusion

This study has provided new insights into the socio-cultural meaning and consequences of TB for people of Somali origin living in the UK. TB is understood by Somalis to be more than an infectious disease: it carries social and psychological consequences due to deeply embedded cultural norms and inter and intra-personal attitudes which can lead to stigmatization. Such insights are important for nursing to develop culturally appropriate strategies for the prevention and management of TB.

In recognizing diverse beliefs that may exist among Somalis, nurses need to gain an understanding of how individual patients view TB as part of the assessment process. The consequences of felt and enacted stigma associated with TB means that nurses will need to build a trusting relationship with patients if they are to provide culturally sensitive care. However, additional research is required to develop an evidence-base supporting strategies that nurses might employ to reduce the stigmatization of TB.

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## Conflict of interest

No conflict of interest has been declared by the authors.

## Author contributions

All authors meet at least one of the following criteria (recommended by the ICMJE: [http://www.icmje.org/ethical\\_1author.html](http://www.icmje.org/ethical_1author.html)) and have agreed on the final version:

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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