

**Experiences of the diagnosis and management of tuberculosis: a focused ethnography of Somali patients and healthcare professionals in the UK**

KATE, Gerrish, NAISBY, Andrew and ISMAIL, Mubarak <<http://orcid.org/0000-0001-6601-9781>>

Available from Sheffield Hallam University Research Archive (SHURA) at:

<http://shura.shu.ac.uk/6798/>

---

This document is the author deposited version. You are advised to consult the publisher's version if you wish to cite from it.

**Published version**

KATE, Gerrish, NAISBY, Andrew and ISMAIL, Mubarak (2013). Experiences of the diagnosis and management of tuberculosis: a focused ethnography of Somali patients and healthcare professionals in the UK. *Journal of advanced nursing*, 69 (10), 2285-2294.

---

**Copyright and re-use policy**

See <http://shura.shu.ac.uk/information.html>

# **Experiences of the diagnosis and management of tuberculosis: a focused ethnography of Somali patients and healthcare professionals in the UK**

Kate Gerrish, Andrew Naisby & Mubarak Ismail

Experiences of the diagnosis and management of tuberculosis: a focused ethnography of Somali patients and healthcare professionals in the UK.

## **Abstract**

### **Aim.**

To explore experiences of the diagnosis and management of tuberculosis from the perspective of Somali patients and healthcare professionals involved in their care.

**Background.** The Somali population has the third highest incidence of tuberculosis occurring in persons born outside the UK. Tuberculosis is a disease with sociocultural as well as physical consequences. Nurses should understand how the disease is experienced by people from different ethnic backgrounds to implement strategies for prevention and management of tuberculosis.

**Design.** A focused ethnography.

### **Method.**

Individual interviews with 14 Somali patients and 18 healthcare professionals with experience of providing care to Somalis were undertaken in 2008–2009. Interviews explored the patient experience from onset of symptoms to completion of treatment. Data were analysed using Framework approach.

### **Findings.**

Despite presenting in primary care early, patients experienced diagnostic delays due to low clinical suspicion of tuberculosis among general practitioners. Although patients reported felt and enacted stigma, it did not adversely affect concordance with treatment. Patients were reticent about sharing their diagnosis among wider networks due to perceived stigma. Psychological support from families and specialist nurses was valued highly. Healthcare professionals perceived that stigmatization of tuberculosis was diminishing among Somalis leading to improved management of tuberculosis. Patients and healthcare professionals raised concerns about the longer term physical and psychosocial implications of tuberculosis once treatment was completed.

### **Conclusion.**

Nurses have a role in promoting early presentation, timely diagnosis, and treatment adherence through supporting Somali patients and raising awareness of the disease among primary care practitioners.

**Keywords:** diagnosis, nurses/nursing, sociocultural, treatment, tuberculosis

## **Introduction**

Although over 90% of cases of tuberculosis (TB) occur in low- and middle-income countries (Munro et al. 2007), a global resurgence of TB has affected high-income countries including the UK. The incidence of TB in the UK shows a similar pattern to other European countries, with 25% increase in the past decade (Health Protection Agency 2010). There are notable differences in the incidence of TB among the UK population with 73% of cases occurring in persons born outside the UK: the third largest group are people born in Somalia (Health Protection Agency 2011).

Nurses have a key role in the prevention and management of TB (Ghebrehiwet 2006). In recognizing that TB is a disease with sociocultural as well as physical consequences (Gerrish et al. 2012) nurses need to understand how the disease is experienced by people from different ethnic backgrounds. The current study explores how TB is experienced from onset of symptoms to completion of treatment by people of Somali origin in the UK. Such insights are valuable in helping nurses contribute to reducing the global impact of TB.

## **Background**

Studies have identified that patient and healthcare system delays in TB diagnosis and treatment are associated with increased morbidity and mortality (Sherman et al. 1999, Yilmaz et al. 2001, Metcalf et al. 2007). Diagnostic delays arising from patients' reluctance to seek medical advice are greatest in communities where TB is highly stigmatized and leads to social isolation of TB sufferers. Several studies have identified the stigmatization of TB in low-income countries, such as Somalia, which is attributed to lack of knowledge about the disease and deeply embedded sociocultural attitudes and beliefs (Baral et al. 2007, Armijos et al. 2008). Less is known about the experiences of people who migrate from low-income countries where TB is stigmatized to high-income countries. In a study related to the current one, Gerrish et al. (2012) identified that although stigmatization remains a concern, attitudes towards TB are changing as knowledge about the disease increases: a view supported by others (Gibson et al. 2005, Van der Oest et al. 2005, Marais 2007, Sagbakken et al. 2010). However, misconceptions about TB may influence how UK Somalis engage with healthcare services leading up to diagnosis and during treatment.

In low-income countries, poor adherence to treatment is associated with the financial costs of treatment, practical community support (Munro et al. 2007). Although less evident in high-income countries, migrants experience health-care system delays to the timely diagnosis and treatment of TB (O'Mara et al. 2010). Healthcare systems vary across high-income countries. In countries where patients are required to pay for health care, cost may be a deterrent (Van der Oest et al. 2005). However, this has not been the case in the UK, where health care is free at the point of delivery (O'Mara et al. 2010).

In the UK, the management of TB is supervised by specialists in the field; however, most patients present in primary care. Although limited, there is evidence to suggest that access to healthcare services and inadequate service provision, together with language and cultural differences, pose significant barriers for migrants from low-income countries (O'Mara et al. 2010).

Clearly, the timely diagnosis and successful management of TB are influenced by several factors, which interact with each other. These include sociocultural factors, especially

stigmatization and sociocultural norms, structural factors such as poverty, and social deprivation, accessibility and responsiveness of healthcare services, as well as personal factors such knowledge and attitudes and beliefs about TB, and the availability of family and community support (O'Mara et al. 2010).

Little is known about how UK Somalis with TB experience their illness and their interactions with healthcare services leading up to diagnosis and during treatment. This article presents selected findings from an ethnographic study of sociocultural factors influencing TB prevention, diagnosis, and treatment among the Somali community. The earlier paper (Gerrish et al. 2012) reported on sociocultural understandings of TB amongst the Somali community at large. In contrast, this article focuses on the experiences of Somali patients with TB and healthcare professionals. As most TB among migrants from countries where the disease is prevalent typically occur several years after settlement in the UK due to activation of latent TB (Moore et al. 2009), this study focuses on established migrants rather than on new migrants/asylum seekers.

## **The study**

### **Aim**

To explore experiences of the diagnosis and management of tuberculosis from the perspective of Somali patients living in the UK and healthcare professionals involved in their care.

### **Design**

A focused ethnographic approach involving individual interviews with Somali TB patients and healthcare professionals was employed. Unlike traditional ethnography which requires prolonged periods of data collection in the field, focused ethnography examines specific issues in a single social situation among a limited number of people within a defined period of time (Knoblauch 2005). As in the current study, data collection may be restricted to interviewing participants on one occasion (Pollitt et al. 1990). The research team included a Somali researcher who was a member of the local Somali community and fluent in Somali and English.

### **Setting**

The study was undertaken in Sheffield, a city with a large and established Somali population. It included European Somalis who migrated recently from northern Europe; refugees following the civil war in the 1990s and early economic migrants who settled in the 1930s.

### **Participants**

A purposive sample of 14 Somalis who had received treatment for TB in the UK took part. In accordance with ethical requirements, participants were recruited by a TB specialist nurse involved in their care. All participants had been granted asylum and secured refugee status. The sample size was sufficient to enable data saturation to be achieved (Procter et al. 2010).

A purposive sample of 18 healthcare practitioners with experience of caring for Somali TB patients was recruited. The sample included general practitioners (GPs), TB physicians, TB specialist nurses, community/hospital nurses, specialist healthcare practitioners working with

migrant communities, and Somali health workers. The sample size allowed perspectives from different health professionals to be captured, while at the same time enabling data saturation (Mays & Pope 2000).

### **Data collection**

Data collection was undertaken during 2008–2009. Individual in-depth interviews with Somali TB patients explored their experiences of TB leading up to diagnosis and the subsequent management of their condition. Interviews were undertaken in the preferred language of the participants, in the patients' home, and lasted between 30–90 minutes.

Individual in-depth interviews undertaken with healthcare professionals explored participants' experiences of caring for Somali TB patients from initial presentation, through diagnosis to completion of treatment and their perceptions of factors influencing how Somali patients responded to their illness. Interviews were undertaken in the workplace and lasted between 30–60 minutes.

### **Ethical considerations**

Ethical approval was obtained from an NHS Research Ethics Committee and research governance approval obtained from participating NHS organizations. Written informed consent was obtained from all participants.

Due to stigma associated with TB, it was recognized that Somali patients may have particular concerns regarding confidentiality of data and anonymity as research participants. During recruitment, participants were provided with a full explanation of how these issues would be addressed. Following advice from Somali community leaders, limited personal biographical information was collected from participants to reassure them of their anonymity.

### **Data analysis**

Interviews were audio-recorded and subsequently transcribed. Interviews conducted in Somali were translated into English prior to analysis. Data analysis drew on the 'framework' approach to qualitative analysis (Ritchie et al. 2003). First, the research team familiarized themselves with the data by reading transcripts several times. An initial thematic coding framework, based on interview topics, was developed and refined following preliminary analysis of the first few transcripts. The revised thematic framework was subsequently used to code transcripts and coded data were organized into themes. Data from patient and healthcare professional interviews were analysed separately and then integrated to form a composite analysis. Finally, the relationships between different themes were mapped by analysing the data set as a whole.

### **Rigour**

Several strategies were employed to ensure rigour in data analysis. The multi-ethnic composition of the research team enhanced the validity of cultural interpretations of data. The team employed a reflexive approach when examining assumptions that influenced interpretations placed on the data. The analysis undertaken by one researcher was verified by another team member by checking that coding was consistent and that data were not being used selectively.

Data from patients and healthcare professionals were triangulated to check for consistencies and divergent perspectives across the whole data set. An audit trail was maintained throughout the study.

## **Results**

### **The sample**

Of the 9 male and 5 female patients, 12 were still completing treatment. Ten patients had been diagnosed with pulmonary TB and the remaining patients had forms of non-pulmonary TB. Patients had been resident in the UK from 3 to 51 years (median 10 years) with the majority (n = 10) having resided in the UK for between 6 and 10 years. Three patients had migrated to the Netherlands from Somalia and subsequently settled in the UK. All patients had managed their treatment regime with support from TB specialist nurses, but had not engaged with the Directly Observed Treatment Short course (DOTS). The sample of healthcare professionals comprised three TB physicians, five GPs, two TB specialist nurses, three community/hospital nurses, three Somali health workers, and two specialist community health practitioners who worked with minority ethnic communities, including Somalis.

### **Experiences leading up to diagnosis**

All patients found the time leading up to diagnosis distressing. Concern about symptoms and uncertainty about diagnosis caused considerable anxiety. Although some patients experienced symptoms associated with pulmonary TB, others had more diffuse symptoms, which were not readily attributable to TB:

I was very tired, I was resting a lot, losing energy, I couldn't understand what was happening. I'd been very active. Day after day I was feeling weaker. (Patient 7)

The psychological impact of illness prior to diagnosis was felt keenly. Several patients felt 'anxious', 'stressed', and 'powerless' and this was intensified the longer it took to confirm a diagnosis. The social impact of their illness over a prolonged period of time was notable. Patients found it hard to maintain social networks. Two patients were unable to continue in employment and loss of income as well as status was distressing.

All patients presented in general practice shortly after initially feeling unwell and a few were diagnosed relatively quickly:

In two months I see myself losing weight and my temperature was going up, I wasn't sleeping well, coughing, coughing. I went to GP. They sent me for chest x-ray and tests and found I had TB. (Patient 14)

However, most patients expressed frustration at the time it took from first visiting their GP to a diagnosis of TB being confirmed. They reported visiting their GP repeatedly and being prescribed analgesia and/or antibiotics, which had not alleviated their symptoms:

For two years I had problems, I went to GP. I was very worried. Every time I went they told me I was stressed. I had pain in my chest, they prescribed something but it did no good. (Patient 10)

Several patients felt that their concerns had not been treated seriously: they lacked trust in their GP and felt 'let down by the system'. Some GPs were perceived to have been slow

to refer patients to hospital when symptoms persisted. By way of illustration, one patient outlined the distressing, convoluted process leading to diagnosis:

I told the GP I am feeling very sick. The GP prescribed pain-killers and told me nothing's wrong with me. But tablets didn't help. I went back to the GP and asked them to take blood samples. They took blood samples and told me to come back in seven days. They said nothing's wrong with your results so keep taking pain-killers, which I did. The situation continued, I kept going back to the GP, every time I get different tablets. I ask them to refer me to hospital but they refuse. Several months later they check me and see that I had high temperature and told me that my blood result shows there's infection but they don't know what is the infection. (Patient 6)

This patient's illness continued for several months before referral to TB services and a diagnosis was confirmed. In the absence of a diagnosis the patient became more anxious:

The GP said 'we don't know what's wrong with you'. This made me suspicious. I thought I might have a serious illness and they don't want to tell me. It's difficult to believe that with all these tests and doctors around nobody knows anything about my illness. Every time they take an X-ray it comes out nothing, they take it again and it's nothing. At last the GP referred me to the specialist. All that time I was suffering and nobody could do anything about my problem.

TB specialist practitioners acknowledged that diagnosing TB could be challenging when patients presented with atypical symptoms and this made it difficult for GPs to make a provisional diagnosis and refer appropriately: a situation also recognized by GPs:

It can be hard to diagnose TB. Patients can present with vague symptoms, it may be difficult for them to explain what's wrong and it's harder when there are communication difficulties and different cultural perspectives. (GP 2)

### **Moreover:**

If a practice has a significant number of patients who are migrants, or at high risk of contracting TB, GPs generally tend to be 'on the ball' in identifying TB as a possible diagnosis. However, it's much harder for GPs who might see very few, if indeed any, cases of TB in a year. (TB physician 2)

Language barriers compounded the difficulty of gaining an accurate account of a patient's symptoms. Only one GP employed a Somali speaking health worker. Others had no ready access to interpreting services, although interpreters could be arranged in advance. Most patients who were not fluent in English relied on relatives to translate, even though it compromised confidentiality and GPs voiced concern about the accuracy of interpretation.

Specialist TB practitioners identified instances where patients could have been referred earlier. However, overall, there was a sense that GPs were becoming more aware of TB as a possible diagnosis:

There's been a shift among GPs, they do seem to be thinking about TB and referring patients on to us. (TB physician 1)

Whereas all patients reported seeking medical advice soon after the onset of symptoms, healthcare professionals perceived that some other patients delayed seeking help because of stigma associated with TB, fear of social isolation, and loss of standing in the community. Moreover, late presentation was perceived to be associated with the use of khat:

Some men who've been unwell for a long time are heavy users of khat. I can understand their reluctance. Heavy use of khat is like heavy use of any drug, it's escapist. Also if they're found to have TB they're going to lose their entire social life because who wants you to go to the Marfesh if you have TB, so they'd be ostracised. (TB nurse)

## **Response to diagnosis**

Patients varied in their response to a diagnosis of TB. Many were relieved that after being unwell for some time, they finally knew what was wrong and that their illness could be treated:

I was happy because I'd been feeling ill for a long time. Every time they did tests they tell me 'we don't know what is your illness'. When the doctor told me it was TB, I was relieved because only known illnesses can be treated. (Patient 9)

However, for a minority of patients, the diagnosis caused psychological distress because of potential social consequences:

I was very shocked. People are scared of TB because they think they'll die and they can pass it to their families and children. 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. (Patient 8)

All patients had made known their diagnosis to immediate family, but several had been reticent about sharing the information more widely because of the perceived stigma associated with TB and fear of social isolation.

Although healthcare professionals were aware of stigma associated with TB among Somalis, they perceived that this was diminishing:

A few years ago TB was a taboo subject that nobody in the Somali community talked about and if you thought that somebody had TB, if you said that to them, they were horrified. My impression now is that patients would rather know so I think there's been a change. People come asking 'could I have TB?' whereas we were the ones thinking of it before. (GP 1)

However, occasionally, healthcare professionals encountered patients who were reluctant to accept the diagnosis and this presented challenges in terms of contact tracing and concordance with treatment.

## **Experiences of treatment**

All patients had completed or were in the process of completing treatment and felt confident that they would recover. The complex medication regimen was arduous. The benefit of support from close family in promoting treatment concordance was stressed by patients and health-care practitioners.

TB healthcare practitioners sought to present a positive view of treatment and prognosis. In their experience, most Somali patients accepted the diagnosis, adhered to treatment, and had a positive outcome. It was acknowledged that completing a 6-month course of medication was difficult for many patients irrespective of their ethnic background. However, the social and economic circumstances of some Somalis created additional difficulties:

My sense over the years has been that it's rare for people not to complete treatment even if they've not wanted anybody else to know they have TB. I suspect the reasons why people don't complete treatment are to do with chaotic things in their lives. There may be all kinds of social difficulties that make it difficult for them to seek



treatment. (TB physician 3)

The support of TB specialist nurses and Somali health workers was highly valued by patients and healthcare professionals. In addition to supporting patients and their families through the treatment regime, specialist nurses acted as a conduit for patients accessing other health and welfare services.

## **Living with tuberculosis**

After initial treatment, most patients began to feel better and gradually resumed normal life. Many were well supported by family and close friends. The experiences of patients who had disclosed their diagnosis to their wider social network varied. Some received considerable support, which had been valued highly in helping them manage the disease. However, many patients encountered a degree of social isolation, which caused psychological distress. A minority of patients experienced loneliness as friends withdrew from social interactions. The social stigma that these patients experienced was attributed to a lack of understanding of TB in the wider Somali community; in particular, a false belief that it could be spread by sharing eating utensils. Other patients reported that their initial experience of social isolation reduced once they made known that they were responding well to treatment. In addition to the sociocultural consequences of the disease, some patients experienced economic hardship. One patient, who was particularly ill, had been made homeless and despite support from TB specialist nurses, managing his disease proved difficult due to inadequate temporary accommodation, poor nutritional intake, and lack of social support. Those who had given up work due to illness lacked confidence to look for employment because of how the disease might be viewed by employers and colleagues.

The longer term consequences of the disease were keenly felt. Participants who had completed treatment recounted how it took some considerable time before they felt better:

I was very ill. It is everything to get back to normal life, to feel fit and strong. It took three years to get back to normal, to find a job. (Patient 11)

Although patients believed that they could make a good recovery, several were concerned that they could not be cured completely: a view linked to a belief that TB was hereditary.

I have taken the tablets, they tell me I am cured, but the TB, I think it may come back. It's in my family. (Patient 4)

This caused anxiety as they believed distressing symptoms might return and carry implications for social relationships.

Family and friends may be reluctant to resume normal social interactions because of fear that they might contract TB. Indeed, despite TB specialist practitioners emphasizing that they provided patients with biomedical explanations of the aetiology, treatment, and prognosis, many patients expressed deeply rooted, yet inaccurate, sociocultural beliefs about TB.

Healthcare professionals also alluded to difficulties in the longer term recovery of patients:

We don't know what happens to people once they are no longer engaging with the TB services. Some still have a long road to full recovery, if indeed they recover completely. (TB physician 1)

We've a young Somali lady who completed treatment three years ago. She had TB affecting the spine and has difficulty with mobility. She feels quite depressed; she's concerned that she won't marry because of the stigma of TB. We really know very little about the longer term physical and psychological effects of TB. (GP 2)

## **Discussion**

The findings from this study shed light on Somali TB patients' experiences from onset of symptoms, through diagnosis, treatment, and living with the disease in the UK. Most research examining the experiences of TB patients has been conducted in low-income countries where TB is more prevalent, or focused on recent migrants to high-income countries. By contrast, this study provides new insights into how established Somali migrants in a high-income country manage TB and interact with primary care and specialist services.

Tuberculosis among migrants generally arises from activation of latent TB several years after settlement in the UK or contracting the disease postmigration (Moore et al.

2009): this was reflected by participants in the current study. An understanding of how established migrants engage with healthcare services is therefore essential to shaping strategies for the prevention and management of TB.

There is a paucity of research examining how stigmatization of TB may influence established migrants' engagement with TB services. A related paper (Gerrish et al. 2012) examining stigmatization of TB among established Somali migrants in the UK identified that following migration TB remained stigmatized among the community at large. The disease was perceived to result in both felt and enacted stigma with fear of discrimination in the form of social isolation seen to influence the extent to which people

suffering from TB might engage with healthcare services and disclose their condition to others, thereby affecting contact tracing. The stigmatization of TB therefore carried potential implications for the prevention, diagnosis and management of the disease. Although individual attitudes towards TB were found to be less stigmatizing than perceptions of community norms, the extent to which stigmatization might influence how patients engaged with TB services was not clear. The current paper builds on these findings to provide new insights into the experiences of TB patients from an established migrant community where the disease remains stigmatized.

Although research indicates that people living in low-income countries where TB is highly stigmatized, including Somalia, may delay in seeking medical assistance due to fear (Liefoghe et al. 1995, Mohamed et al. 2011), patients in the current study sought medical assistance soon after symptoms appeared. Similar readiness to access health care is reported in studies of established Somali and other migrant communities in high-income countries such as Canada (Gibson et al. 2005) and Norway (Sagbakken et al.

2010), suggesting that stigmatization is not a deterrent at an individual level. One of the few studies of TB among UK Somalis (Marais 2007) identified a lack of awareness about service availability among recent migrants which influenced access, but the current study suggests that this does not appear to be the case with established Somali migrants.

An interesting finding from the current study is the delay in diagnosing TB due to its atypical presentation and low clinical suspicion among GPs. Whereas these factors may act as barriers to effective diagnosis of TB more generally (Metcalf et al. 2007), this study identified that the situation can be compounded where there may be poor clinician–patient communication due to language barriers and/or cultural misunderstandings. As diagnostic delays can result in worse outcomes for patients and expose others to the risk of infection by hindering contact tracing (Sherman et al. 1999, Yilmaz et al. 2001), further research examining the challenges of achieving timely diagnosis of TB among Somalis and other migrant communities with high rates of TB is warranted. This is particularly important bearing in mind that people with TB born outside the UK are more likely than those born in the UK to have non-pulmonary TB, which can be difficult to diagnose (Kruijshaar & Abubakar 2009).

Raised awareness and early diagnosis are seen as the most important contribution of primary care to TB control (Griffiths & Martineau 2007). Recently published guidance on managing TB among hard-to-reach groups, including at-risk migrant populations (National Institute for Health & Clinical Excellence 2012), identifies the need for ongoing education of healthcare professions, which should include sociocultural influences. TB specialist nurses are well placed to raise awareness among GPs of how different forms of TB might present as well as sociocultural understandings of TB among different minority ethnic groups.

There were high levels of concordance with treatment among Somali patients in the current study with no evidence of DOTS needing to be implemented. This finding contrasts with concerns about poor adherence to treatment regimens among recent migrants to the UK from sub-Saharan Africa (O'Mara et al. 2010). These differences may be because asylum seekers/recent migrants have limited access to health care, whereas the current study considered established migrants who readily accessed primary care and specialist services. These observations are important insofar as they identify a need to target strategies for effective TB control differentially. Existing research indicates that strategies to diagnose and manage TB among Somali asylum seekers/new migrants should focus on access to healthcare services and concordance with treatment (National Institute for Health & Clinical

Excellence 2012). In contrast, the findings from the current study prioritize the need to raise awareness of TB among established Somali communities and ensure timely referral of patients by GPs to specialist services when TB is suspected.

To date, no studies have compared the stigmatization of TB among recent and established migrants and how the beliefs of new migrants may influence their uptake of services. However, reports suggest that asylum seekers may be reluctant to seek medical care in case it adversely affects their application for refugee status (Race for Health & TB Alert 2010).

Relief once diagnosis was confirmed and overall confidence in specialist TB practitioners were key factors supporting patients' concordance with treatment. Ongoing support from specialist TB nurses working in the community was valued highly by patients and was seen by physicians to promote adherence. Nnoaham et al.'s (2006) study of African immigrants in the UK, likewise found that personalized care from specialist nurses could improve adherence to treatment.

Support from family members has been identified as an important factor in achieving concordance with TB treatment among people from sub-Saharan Africa living in Norway (Sagbakken et al. 2010). The support of family and close friends was valued highly by patients in the current study. Interestingly, although some experienced both felt

#### **What is already known about this topic**

- There are notable differences in the incidence of tuberculosis in the UK with nearly three quarters of cases occurring in persons born overseas: the third largest group are people born in Somalia.
- Cases of tuberculosis among migrants from countries where the disease is prevalent typically occur several years after they have settled in the UK due to activation of latent tuberculosis.
- In low-income countries such as Somalia, diagnostic delays and poor adherence to treatment are associated with stigmatization, the financial costs of treatment, practical difficulties in accessing health care, and lack of family support. Little is known about the experiences of Somali migrants with tuberculosis living in the UK.

#### **What this paper adds**

- Insight into diagnostic delays for Somali patients presenting with tuberculosis in primary care due to lack of awareness and low clinical suspicion among general practitioners.
- Experiences of felt and enacted stigma did not adversely affect treatment concordance, suggesting that patients drew on personal resources to overcome the potential impact of stigmatization on the management of tuberculosis.
- Identification of longer term physical and psychosocial implications of tuberculosis once treatment has been completed.

#### **Implications for practice and/or policy**

- Nurses have a key role in raising awareness of tuberculosis among Somali communities and primary care practitioners to promote early presentation and timely diagnosis.
- Tuberculosis specialist nursing services are important in supporting patient adherence to medication and in providing psychosocial support to patients and their families.
- Sociocultural and economic implications of tuberculosis need to be considered alongside the physical consequences of the disease.

and enacted stigma, it did not adversely affect treatment concordance. This suggests that although stigmatization remains an issue in the Somali community, patients were able to draw on personal resources to overcome the impact of felt and enacted stigma in managing TB. Nevertheless, patients experienced enacted stigma among some of their wider associates: the psychological distress that this may cause among a community where social networks are culturally important (Kwan-Gett 1998), should not be underestimated. Moreover, family members may need support as they take on the added physical, psychological, and social burden of caring for a relative with TB. To date, there is a lack of research that examines the support needs of family carers.

Several patients experienced significant social and economic hardship leading up to diagnosis and, in some instances, extending beyond completion of treatment. These experiences are reflected in the socioeconomic disadvantage experienced by many minority ethnic communities in the UK (Marmot 2010) and highlight the need for strategies targeted at TB to address the wider manifestations of socio-economic inequalities in addition to sociocultural considerations.

Research examining the longer term impact of TB in communities where the disease is stigmatized is lacking. The findings from this study suggest that recovery following treatment can be slow and patients may continue to experience felt and/or enacted stigma for some time. There is clearly a need to consider how primary care nurses and physicians can support ex-TB patients to reduce the psychological and in some cases the longer-term physical burden of the disease.

### **Limitations of the study**

This study sought to gain insight into how TB was experienced by established Somali migrants living in the UK. The inclusion of TB patients and healthcare professionals involved in their care meant that a broad range of perspectives and personal experiences of TB were captured.

The sample was restricted to one geographical area: it is recognized that the experiences of patients who participated in the study may not be representative of Somali TB patients living in the UK more generally. Nevertheless, the study location had one of the largest established Somali populations in the UK, which gives confidence to the potential transferability of findings.

The requirement of the ethics committee to recruit patients via a nurse involved in their care inevitably influenced who was approached to take part. We acknowledge that the findings could have been strengthened had we been able to access Somali people with TB who were less engaged in healthcare services.

## **Conclusion**

This study has provided new insights into how TB is experienced by established migrants of Somali origin in the UK. Although felt and enacted stigma associated with TB did not prevent patients accessing primary care and complying with treatment, the psychological impact of stigma, together with the socioeconomic consequences of TB, should not be underestimated and may extend beyond completion of treatment. Nurses need to understand how TB is experienced by Somalis to promote early presentation, timely diagnosis, and treatment adherence through supporting Somali patients and raising awareness of the disease among primary care practitioners.

## **Funding**

This research was funded by the Sheffield Health and Social Care Research Consortium England. Grant number ZB63. Dissemination of the findings to Somali communities has been supported by funding from NIHR CLAHRC South Yorkshire.

## **Conflict of interest**

There are no declared conflicts of interest.

## **Author contributions**

All authors have agreed on the final version and 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))]:

- 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.

## **References**

- Armijos R.X., Weigel M.M., Qinchu M. & Ulloa B. (2008) The meaning and consequences of tuberculosis for an at-risk urban group in Ecuador. *Pan American Journal of Public Health* 23(3), 188–197.
- Baral S.C., Karki D.K. & Newell J.N. (2007) Causes of stigma and discrimination associated with tuberculosis in Nepal: a qualitative study. *BMC Public Health* 7, 211. doi:10.1186/1471-2458-7-211.
- Gerrish K., Naisby A. & Ismail I. (2012) The meaning and consequences of tuberculosis among Somali people in the United Kingdom. *Journal of Advanced Nursing* 68, 2654–2663.
- Ghebrehiwet T. (2006) Nurses at the forefront of tuberculosis prevention, care and treatment. *International Nursing Review* 54 (3), 239–240.
- Gibson N., Cave A., Doering D., Ortiz L. & Harms P. (2005) Socio-cultural factors influencing prevention and treatment of tuberculosis in immigrant and Aboriginal communities in Canada. *Social Science and Medicine* 61, 931–42.
- Griffiths C. & Martineau A. (2007) The new tuberculosis: raised awareness of tuberculosis is vital to general practice. *British Journal of General Practice* 57, 94–95.

- Health Protection Agency (2010) Tuberculosis Update March 2010. Retrieved from [http://www.hpa.org.uk/web/HPAwebFile/HPAweb\\_C/1267551047404](http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1267551047404) on 13 February 2013.
- Health Protection Agency (2011) Tuberculosis Update. Heath Protection Agency, March. Retrieved from [http://www.hpa.org.uk/web/HPAwebFile/HPAweb\\_C/1296683847254](http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1296683847254) on 13 February 2013.
- Knoblauch H. (2005) Focused ethnography. *Forum Qualitative Social Research* 6,3. Retrieved from <http://www.qualitative-research.net/index.php/fqs/article/view/20/44> on 13 February 2013.
- Kruijshaar M.E. & Abubakar I. (2009) Increase in extrapulmonary tuberculosis in England and Wales 1999–2006. *Thorax* 64(12), 1090–5.
- Kwan-Gett T.S. (1998) Somali Tuberculosis Cultural Profile. Retrieved from <http://ethnomed.org/clinical/tuberculosis/somali-tb-cultural-profile> on 13 February 2013.
- Liefoghe R., Michiels N., Habib S., Moran M.B. & De Muynck A. (1995) Perception and social consequences of tuberculosis: a focus group study of tuberculosis patients in Sialkot, Pakistan. *Social Science and Medicine* 41(12), 1685–1692.
- Marais F. (2007) Towards Improvement of Tuberculosis Control and Participatory Research. A Multi-Method Community-Based Participatory Research Study of TB in Migrant African Communities in the Borough of Westminster, London. Imperial College London, London.
- Marmot M. (2010) Fair Society, Healthy Lives: The Marmot Review: Strategic Review of Health Inequalities in England Post- 2010. University College London, London.
- Mays N. & Pope C. (2000) Assessing quality in qualitative research. *British Medical Journal* 320, 50–52.
- Metcalfe E., Davies J., Wood F. & Butler C. (2007) Unwrapping the diagnosis of tuberculosis in primary care: a qualitative study. *British Journal of General Practice* 57, 116–122.
- Mohamed E.Y., Abdalla S.M., Abdelgardia M.A., Elsayed A., Khamis A.A. & Abdelbadea A. (2011) Stigma among tuberculosis patients in Gezira State, Sudan. *Sudanese Journal of Public Health* 6(1), 22–26.
- Moore J., Crofts J., Anderson L., Bradshaw L., Kruijshaar M. & Abubakar I. (2009) Tuberculosis in the UK: Annual Report on Tuberculosis in the UK 2009. Health Protection Agency, London.
- Munro S., Lewin S., Smith H., Engel M., Fretheim A. & Volmink J. (2007) Patient adherence to tuberculosis treatment: a systematic review of qualitative research. *PLOS Medicine* 4(7), e238, doi: 10.1371/journal.pmed.0040238. Retrieved from <http://www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.0040238> on 13 February 2013.
- National Institute for Health and Clinical Excellence (2012) Identifying and Managing Tuberculosis Among Hard- to-Reach Groups. NICE Public Health Guidance 37. NICE, Manchester.
- Nnoaham K.E., Pool R., Bothamley G. & Grant A.D. (2006) Perceptions and experiences of tuberculosis among African patients attending a tuberculosis clinic in London. *The International Journal of Tuberculosis and Lung Disease* 10(9), 1013–1017.
- O'Mara A., Marrero-Guillamón I., Jamal F., Lehmann A., Cooper C. & Lorencet T. (2010) Tuberculosis Evidence Review 1: Review of Barriers and Facilitators. National Institute for Health and Clinical Excellence (NICE) Matrix Knowledge Group, NICE, London.
- Pollitt C., Harrison S., Hunter D. & Marnoch G. (1990) No hiding place: on the discomforts of researching the contemporary policy process. *Journal of Social Policy* 19(2), 169–190.
- Procter S., Allan T. & Lacey A. (2010) Sampling. In *The Research Process in Nursing* (Gerrish

- K. & Lacey A., eds), Wiley- Blackwell, Oxford, pp. 142–152.
- Race for Health & TB Alert (2010) Race Against Tuberculosis: An Agenda for Action. Race for Health & TB Alert, London. Retrieved from <http://www.thetruthabouttb.org/sites/default/files/resources/RfH%20TB%20Alert%20Report%20WEB.pdf> on 13 February 2013.
- Ritchie J., Spencer L. & O'Connor W. (2003) Carrying out qualitative analysis. In *Qualitative Research Practice: A Guide for Social Science Students and Researchers* (Ritchie J. & Lewis J., eds), Sage, London, pp. 219–262.
- Sagbakken M., Bjune G.A. & Frich J. (2010) Experiences of being diagnosed with tuberculosis among immigrants in Norway: factors associated with diagnostic delay: a qualitative study. *Scandinavian Journal of Public Health* 38, 283–290.
- Sherman I.F., Fujiwara P.I., Cook S.V., Bazerman L.B. & Frieden T.R. (1999) Patient and health care system delays in the diagnosis and treatment of tuberculosis. *International Journal of Tuberculosis Lung Disease* 3, 1088–1095.
- Van der Oest C., Chenhall R., Hood D. & Kelly P. (2005) Talking about TB: multicultural diversity and tuberculosis services in Waikato, New Zealand. *Journal of the New Zealand Medical Association* 118(1216), 1–12.
- Yilmaz A., Boga S., Sulu E., Durucu M., Yilmaz D., Baran A. & Poluman A. (2001) Delays in the diagnosis and treatment of hospitalised patients with smear positive pulmonary tuberculosis. *Respiratory Medicine* 95(10), 802–805.