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A qualitative study exploring awareness and attitudes towards tuberculosis in migrant populations in a Metropolitan District Council in the North of England

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Abstract

Background

The majority of tuberculosis (TB) cases in the UK occur among people born in high-burden countries (73%), and are concentrated in large urban centres. This study explores migrants' attitudes and beliefs toward TB in an English District where the incidence is higher than the UK average.

Methods

Community engagement workers ran 26 focus groups using a standardised questionnaire. Purposeful sampling was used to obtain a cross-section of migrant communities. The summary reports were analysed using thematic analysis.

Results

Most groups did not see TB as a current issue in their community and associated it either with the past or with their country of birth. It appeared to be rarely discussed in their communities and generally not noted as being associated with stigma.

Conclusions

This study revealed a change in social attitudes to TB in migrant groups to those reported in previous literature. Stigma had considerably less effect than expected. However, the evidence revealed that these high-risk groups made the erroneous assumption that, by moving to a low incidence country, they were no longer at risk of the disease. TB services need to respond by revising the information that they provide to take into account the risk perception of these populations.

Introduction

Tuberculosis (TB) remains a global health challenge.[1] Although globally the number of new cases of active TB has declined in the past decade due to improved treatment, case management, case detection and contact tracing, it is still a major contributor to morbidity and mortality.[1] In 2012 alone, an estimated 8.6 million people developed TB and 1.3 million died from the disease.[1]

Most cases of TB occur in South-East Asia (29%), Africa (27%) and the Western Pacific region (18%).[1] In Europe, North America, and Australasia the disease disproportionally affects foreign-born populations from Africa, Asia and Latin America where TB infection rates are much higher.[2] For example, in the UK 73% of cases occurred among people born in high-burden countries.[3] Among the non-UK born, the highest rates of TB were in Pakistani, Indian and Black-African ethnic groups (286, 220 and 170 per 100,000 respectively) compared to the national incidence rate of 12.3 cases per 100,000.[3] Reactivation of latent TB is believed to account for two thirds of cases in the non British-born UK population.[4]

A systematic review of TB in migrant communities in low incidence countries included migrants from Central America, Pacific Islands and South East and South Asia and Africa.

Tomas et al found there was poor knowledge of TB. Although some respondents did have some understanding on how the infection was acquired it was also erroneously attributed to factors such as excessive labour, irresponsible lifestyle, genetic inheritance, poisoning, pneumonia, and climate.[2]

The review examined the reasons for engaging with healthcare. These were varied and included: a desire to receive a negative result to avoid stigma, gaining the right to stay legally in a country until treatment completion, confirmation of disease status and the desire to protect family members from the disease. The barriers to accessing health services and treatment included: lack of knowledge or familiarity with the local language, illiteracy, fear of a painful test, social consequences of a positive result and the cost and logistical issues of getting to a treatment centre. Different migrant groups have their own cultural and contextual influences which make the issue much more complex than it might, at first, appear.

This study addresses the paucity of research evidence on the social determinants, attitudes and beliefs regarding TB in migrant groups in the UK.[5] It aims to deepen our understanding by identifying the attitudes and beliefs on tuberculosis in the migrant groups in one English district.

Methods

Setting

This study was undertaken in Kirklees, an urban district in the north of England with a long industrial history. It has an ethnically diverse population.[6] 10% of the Kirklees population was born outside the UK, which is higher than the UK average of 13.3%; 21% of the population described themselves as non-white in the last Census.[6,7,8] The largest migrant group is from Pakistan, followed by Poland.[7] The incidence of TB in Kirklees is 17.3 per 100,000 compared to 12.0 per 100,000 in England, (2013-15), which is one of the highest rates outside London.[9] Over half the cases of TB in Kirklees occur in the Pakistani population.[10]

Approach

This study was commissioned by the local authority as part of a wider TB health needs assessment to inform the commissioning of TB services locally. A qualitative approach was chosen in order to explore the attitudes and beliefs towards TB in migrant groups. This approach has previously been shown to be an effective method for elucidating views on health needs in ethnic minority subgroups of African and African Caribbean communities.[11] A rapid approach was used with the resources available, involving council employees already working with migrant groups to garner the views of a wide range of community members using structured group interviews.

Sampling methodology

A mixture of sampling methods was adopted to ensure that a broad range of migrant groups (both first and second generation) and age groups were engaged. Whilst second generation migrants are technically not migrants it was felt that they should be included as they often associate with the migrant community and, from a practical point of view, it was difficult for the community engagement workers (CEWs) to separate these groups. The CEWs, who are employed by the local authority, used their local knowledge to purposively identify and approach pre-existing natural groups in the community. In addition, snowball sampling was used to identify other relevant ethnic minority groups to survey. Groups that had already been interviewed helped the community engagement workers to invite other community groups to participate. The key inclusion criteria used was that the group would predominantly consist of adult individuals who were first or second generation migrants. These included both UK and non-UK born ethnic minority persons.

The structured group interviews

CEWs led the structured group interviews and took contemporaneous handwritten notes which they typed up for analysis by the authors. CEWs were used as they were known to the community groups and had already built up rapport and trust. They were briefed prior to carrying out the structured group interview, and were given a standardised questionnaire devised by the authors. This consisted of a series of open questions to explore public awareness and opinions of TB and related services. Prior to the group interviews, participants were informed by CEWs that participation was wholly voluntary, not remunerated and there would be no adverse consequences for not participating.

Twenty–six focus group discussions were carried out between 26th November and 23rd December 2013. The group interviews were conducted in familiar community settings. These included community centres, schools, children's centres, mosques, shops and Sikh temples. There were 221 participants, varying in age from early to late adulthood (Table 1). The size of the groups ranged from 2-26 participants. Men and women took part from a variety of ethnic groups. The majority of participants were of Indian or Pakistani ethnicity.

Analysis

The summaries of the structured group interviews were analysed by three of the authors separately for key themes which were coded using an open coding system. The authors then collated and jointly discussed the themes identified. Any discordant themes were discussed until reaching a consensus. Most of the transcripts raised similar themes suggesting thematic saturation was achieved.

Results

Forty-five themes were identified which were grouped into nine categories and four higher categories (figure 1):

- Risk perception
- Social repercussions of TB
- Service perception
- Health seeking behaviour

Varying opinions were often expressed in the group discussions, both within and between groups. Excerpts from the group discussions are shown in figure 2.

Risk Perception

All the groups were aware of TB and most were aware of someone who had suffered from the disease, in some cases close family members, although no-one admitted to having had the disease themselves. A repeated theme revealed in the focus groups was the perception that participants were not personally at risk of TB. Many felt that it was no longer an issue or a common problem in their community as *"it is an old disease that isn't around anymore"*. A few groups thought TB was brought into the country by recent migrants and holidaymakers. A common perception, reported in several groups, was that TB was a disease that affected others and not themselves. Some groups incorrectly thought that the BCG (Bacillus Calmette–Guérin) immunisation offered them complete protection from the disease.

Although all groups were aware of TB, the level of knowledge of the disease and associated risk factors was variable. Risk factors correctly identified in the groups included poor living conditions, having a chronic health condition, having a weakened immune system, being old or young, poverty and smoking. Some groups correctly stated that TB is infectious although there was not a common understanding of its mode of transmission. Some correctly identified it as a respiratory illness, transmitted through coughing and sneezing and one group recognised that it can also be acquired by drinking infected milk. There were common misconceptions such as the view that TB is transmitted through sharing crockery and drinks, eating infected meat, or through saliva. There was also some confusion about transmission from animals, particularly around the links with TB in badgers. One group thought it was hereditary whilst another believed that the *"illness can be eliminated by eating healthily and regular worship"*.

Although not asked directly about symptoms of the disease, many volunteered symptoms of pulmonary disease. However, there was a lack of awareness of the manifestation of extra-pulmonary TB disease. There was general knowledge that TB was treatable, which was another reason, cited by some groups, for the lack of concern.

Social repercussions of TB

Unexpectedly, many groups reported that there was no longer a stigma attached to TB and that it was no longer a taboo subject. However, this was not a universal finding. From the information collected, it is not clear whether these views were influenced by the generation, ethnic group, age, sex, level of education or socioeconomic group. Some groups attributed this absence of stigma to a lack of disease awareness as it was not seen as a relevant concern. They felt that stigma was more apparent in the past or in their home country. A few groups felt there was still some stigma. One group reported that the main issue was a fear of social isolation, particularly in their home country. Another mentioned that people do not talk about TB and that it *"is kept quiet within the family"*.

Service issues

Little was reported on service experience, and it is not clear from the comments that were received whether they were based on supposition or experience. Some groups did identify issues such as language barriers, fear of treatment, fear of isolation if infectious, cultural sensitivity and lack of TB awareness by general practitioners. Some thought that part of the problem was not the service itself but people not seeking medical advice early enough. Most of the suggestions for service improvements concentrated on the need for more community awareness, raised particularly through community-based organisations. This included the use of leaflets, posters, local media including radio, newspapers and TV stations and local engagement through community organisations. Other service improvement ideas included using a mobile health bus, making information available in other languages and offering bilingual support, having annual health checks, using mosques to get health messages across, using drop-in centres and better signposting to services.

Health seeking behaviours

Most of the groups mentioned that they would seek medical help if they thought they had TB. When asked about who they would go to for help and advice, many groups reported that they would primarily seek medical attention from their GP. Others mentioned seeking a hospital doctor or attending the Accident and Emergency department. The use of alternative therapies to treat TB was not reported. Most groups also mentioned using a range of other sources of health information such as the internet, family and friends, but the GP was generally the first port of call. One group reported seeking religious guidance or adhering to religious practice as a means to protecting their health, but this was in conjunction with medical intervention. As none reported having suffered from TB in the past, it is not known whether they were speaking from experience.

Discussion

Main findings of the study

The key finding from this study was the low perception of personal risk of TB among the migrant groups who participated. Although most knew of someone who had suffered from TB, a common belief was that TB was a problem that affected others. TB was seen as an uncommon disease, a problem of the past or a problem in their home country. With a few exceptions, stigma was not reported to be an issue. Unfortunately the data was not sufficiently detailed to allow exploration of this by migrant ethnicity, age, sex or length of time in the UK. Although there was universal awareness of TB, the accuracy and level of knowledge was variable. The mode of transmission was not always understood, with some believing that TB could be caught from contaminated objects or is hereditary. These misconceptions about transmission have been reported elsewhere.[2 ,15]

What is already known on this topic

Tomas et al[2] reported a false sense of protection amongst migrants who believed they had left the hazardous situation behind in their home country. The knowledge and attitudes towards TB in migrant populations were variable and largely built on experience of TB in their home country or through family and friends. Similar misconceptions of risk have been found in individuals with current or historic TB infection in Pakistan[12] as well as amongst migrants in the UK.[13] It is likely, therefore, that misconceptions and the lack of knowledge of TB in migrant groups reflect similar misconceptions in their countries of origin.

It is known that stigma results in people with the disease becoming socially isolated and consequently influences the extent to which they disclose their status to others.[12,14] High levels of stigma have been reported to persist in migrant communities.[15] The most common reason for this is the perceived risk of transmission of the disease from the affected individuals to others in the community. A systematic review of global attitudes to TB by Chang and Cataldo found cultural variation in the role that stigma played in TB. They found that stigma was commonly found in migrant groups from high HIV prevalence areas such as sub-Saharan Africa who associated TB with HIV.[18] This association was not mentioned in the groups in this study who came from lower HIV prevalence areas.

What this study adds

Whilst many of the beliefs and attitudes reported in this study reinforce previous findings, it also exposes inaccuracies in the assumptions about the major barriers to TB treatment within migrant groups. It reveals that the low perception of personal risk of TB in migrant populations in the UK may be a more important determinant affecting health behaviour and access to services than the “traditional” factors such as stigma, taboo, language barriers, fear of immigration authorities and cost of treatment. Indeed, many of the groups surveyed no longer felt that there was a stigma attached to TB. This finding is in contrast to some of the other qualitative studies which have shown that a high level of stigma persists in some migrant groups.[2]

The participants in this study were mainly from South Asia. Further research is needed to explore how impressions of stigma vary amongst migrant populations and the reasons for these variations. No participants admitted to having TB so there is uncertainty as to whether continued stigma has resulted in a lack of disclosure. The participants referred to felt stigma (i.e. “internalised sense of shame and immobilising anticipation of enacted stigma”) rather than enacted stigma (“discrimination by others on groups of being ‘imperfect’”).[17] Whilst the term “stigma” was often absent from discussions, other disclosures from the groups suggested that it could still have repercussions. For example, it was not clear why it was reported that some people did not seek medical advice early enough and whether this was a result of stigma, a lack of education or an aversion to the use of medical services.

Another important discovery is the low perception of personal risk of TB in migrant populations in the UK. It is particularly challenging to address this with seemingly well individuals who believe they are no longer at risk. TB practitioners must be fully aware of this to ensure that TB services provide appropriate health advice and education to enable individuals to gain a more realistic view of their personal risk. This is particularly pertinent at a time when new entrant latent TB infection screening is being rolled out in higher incidence areas of England.

Limitations of the study

This study focused primarily on South Asian migrants (both first and second generation) in the Kirklees area. However, it became clear that the attitudes and beliefs of migrants towards TB are influenced by many other determinants including age, sex, cultural background, religion, duration of stay in host country, socio-economic groups, and educational attainment.[2,18] It was not possible to separate the different views by many of these factors as this information was not recorded. There is also considerable heterogeneity within the South Asian ethnic group. Consequently, the findings may not be generalisable to all South Asian communities in the UK.

Whilst we sought to survey a representative sample of the migrant population in this district, it was not possible to ascertain if participants were truly representative. The survey did not establish whether participants had suffered from TB. Perception of TB is likely to be influenced by the degree to which individuals have been exposed to it. That said, we believe the survey used a fair sample of the communities due to the large number of groups and individuals surveyed, and the involvement of local CEWs.

We were aware that the use of local CEWs could be a source of bias as they were employed by the local authority. Some individuals, seeing them as authority figures, may have chosen not to engage in the group discussions or may have given answers that they thought would be viewed favourably. We sought to mitigate this by ensuring that CEWs engaged with community groups where they already had established a trusting relationship.

Conclusions

The finding that the stigma surrounding TB is less than expected in migrant groups highlights the importance for local health commissioners to carry out regular health needs assessments of these groups. Further efforts should be made to gain a fuller understanding of the extent and impact of stigma within these communities, as well as exploring means of destigmatising the disease.

The level of knowledge and attitudes towards TB, held by migrant populations, are likely to be culturally specific and dependent on how long the migrants have lived in the country as well as other factors. Risk perception amongst participants was lower than expected and this needs to be taken into account when developing new entrant latent TB programmes targeting these groups. Services formulated on incorrect assumptions will fail to tackle the real social drivers of the disease in migrant communities. It is vital, therefore, that service providers are properly informed of the prevailing attitudes and misconceptions in the communities that they serve and that they ensure that their literature and educational services address these issues.

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References

1. WHO. Global Tuberculosis Report 2013

2. Tomás B A, Pell C, Cavanillas A B, Solvas J G, Pool R, Roura M. Tuberculosis in Migrant Populations. A systematic review of the qualitative literature. *PLoS online*. 2013 December 2013 ,Volume 8, Issue 12, e82440

3. Public Health England. Tuberculosis in the UK 2014 Report. September 2014

4. Public Health England. Tuberculosis in the UK 2013 Report. August 2013

5. Offer C, Lee A and Humphreys C. Tuberculosis in South Asian communities in the UK: a systematic review of the literature. *J Public Health* 2015 Published online

6. ONS. Mid-2012 Population Estimates: Components of Population change for England and Wales, estimated resident population Date Published: 26 June 2013. http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-310118 (Date last accessed 17.6.14)

7. Yorkshire Migration. Kirklees Local Migration Profile November 2013

8. ONS Statistical Bulletin. Population of the UK by Country of Birth and Nationality: 2015. 26 August 2016.

9. PHE TB Strategy Monitoring Indicators Available at URL: https://fingertips.phe.org.uk/profile/tb-monitoring (Date last accessed 8.5.17)

10. Cooper D and Okereke E. Tuberculosis Health Needs Assessment and Service Review for Kirklees and Wakefield. West Yorkshire Health Protection Unit. Health Protection Agency 2012

11. Okereke E, Archibong U, Chiemeka M, Baxter C E, Davis S. Participatory approaches to assessing the health needs of African and African-Caribbean communities. *Diversity in Health and Social Care* 2007; 4:287-307.

12. Khan JA, Irfan M, Zaki A, Beg M, Rizvi N. Knowledge, Attitude and Misconceptions regarding Tuberculosis in Pakistani Patients. *Journal of Pakistan Medical Association*. May, 2006.

13. Karim F, Chowdhury A.M.R, Islam A and Weiss MG. Stigma, Gender, and their Impact on Patients with Tuberculosis in Rural Bangladesh. *Anthropology and Medicine*. Vol 14 No. 2 August 2007, pp139-151

14. Gerrish K, Naisby A, Mubarak I. Knowledge of TB within the Somali Community. Nursing Times, 2013 109: 20, 22-23;

15. Brewin P, Jones A, Kelly M, McDonald M, Beasley E, Sturdy P, Bothamley G. Is screening for tuberculosis acceptable to immigrants? A qualitative study. *J Public Health.* Vol 28 No. 3 July 2006. pp 253-260

16. Courtwright A and Turner A N. Tuberculosis and Stigmatization: Pathways and Interventions. *Public Health Reports.* 2010 Supplement 4. Volume 125

17. Scambler G. Review Article Health-related stigma *Sociology of Health & Illness* Vol 31 No 3 2009, 441-455

18. Chang SH and Cataldo JK. A systematic review of global and cultural variations in knowledge, attitudes and health responses to tuberculosis stigma. *Int J Tuberc Lung Dis* 18(2):168-173.

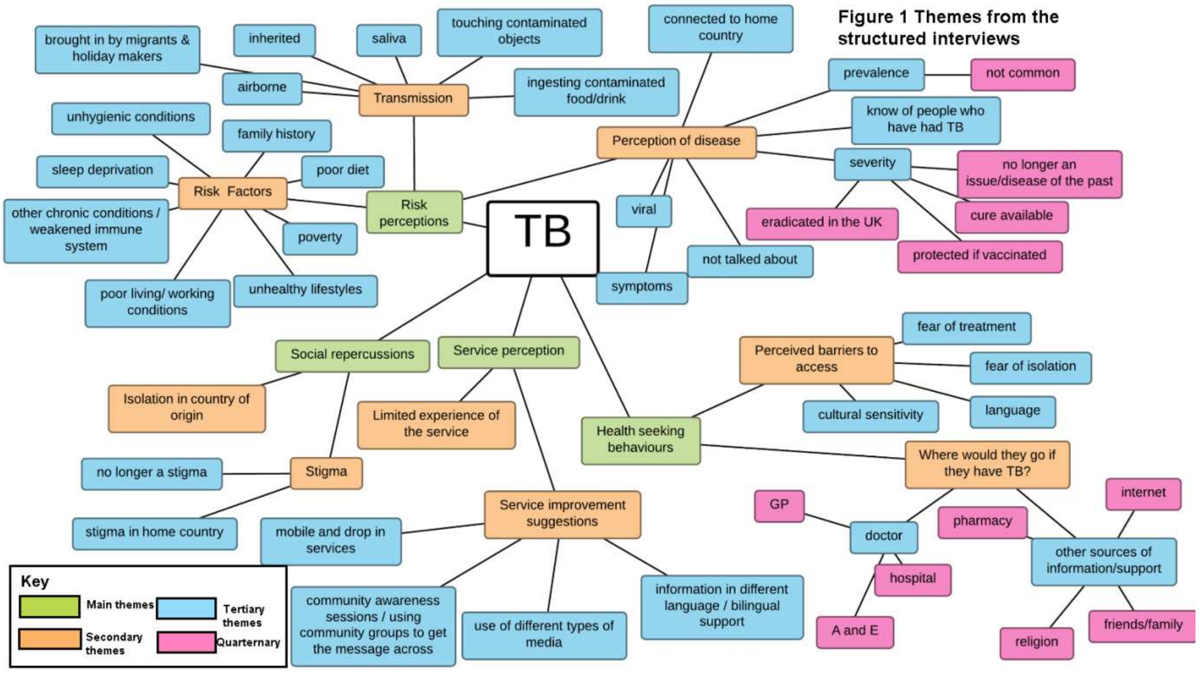

Figure 1 Themes from the structured interviews

Table 1 Demographic characteristics of the focus groups

Characteristics		**Number of focus groups**
Sex	Male	11
	Female	10
	Male and Female	4
	Not recorded	1
Ethnicity	South Asian	20
	European	1
	Central Asia	1
	South Asian and European	2
	South Asian and African Caribbean	1
	No recorded	1
Size of focus group	2-10	19
	11-20	5
	21-30	2

Figure 2. Views expressed in the focus groups

Risk perception	***I think people generally associated it [TB] coming from India or Pakistan and bringing it back from those countries – that's the perception rightly or wrongly anyway.*** **Female, African Caribbean, Group 20** ***People are aware of TB in community. In the past seemed to be a taboo subject as there wasn't a cure for it, now we know there is medication to help with illness.*** **Female, Pakistani, Group 3** ***There might have been a stigma in the 1970s perhaps seeing people with TB as being from poor backgrounds, the uneducated, living a low standard of living – but not now.*** **Male, Indian, Group 10** ***When you're healthy you don't think about these diseases.*** **Male, Indian, Group 21**
Social repercussions	*We don't think that TB is an illness that has stigma attached to it anymore, that culture has far gone, we know it is treatable condition and we know families and people in contact of TB are tested and screened.* **Female, Pakistani, Group 2** *Yes [there is a stigma] for some people because people [have] to [be] isolated when they contracted TB.* **South Asian, Group 4** *Yes because it is infectious people don't understand what it is and*

	don't know how to deal with it. **Female, South Asian, Group 5** *Yes I think there is a stigma as people would be scared to admit they have it thinking no one would visit them. No one admits they have it.* **Male, Indian, Group 21**
Service issues	*The real concern is many times people visit their doctor and the root of the problem is not looked at and if someone had TB this could go undetected.* **Female, Pakistani, Group 15** *It's no good sticking a leaflet through their door and expecting them to go to a health centre. They need to be explained to and need that face to face contact, which should be provided by trusted local groups and organisations….* **Male, South Asian, Group 13** *TB services are brilliant if someone has the disease, but that's only because he or she has approached health services on their own, but what's missing is education around TB, there is absolutely no information widely available that we have come across.* **Female, South Asian , Group 1**
Health seeking behaviours	*We would visit a doctor, or the hospital if really bad, you might even look things up on the internet.* **Male, South Asian, Group 10** *We believe that Allah helps us through these conditions and by being close to our religion the illness can be eliminated by eating healthy and regular worship; we don't always follow this however.* **Female, Pakistani, Group 2** *We believe that some things in the Quran can help with minor problems but at the end of the day we need professional help if it's*

available.

Female, Pakistani, Group 2