

Systems of support for foreign-born TB patients and their family members

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SETTING: Adverse social determinants of health for people who are foreign-born are key drivers of TB-related disparity, particularly in low-incidence countries. Patients diagnosed with infectious TB and their family members must confront psychosocial challenges which may deepen pre-existing health inequities. However, little is known about patient and family members' perspective on these experiences.

OBJECTIVE: To explore the infectious TB experience of patients and family members who are foreign-born.

DESIGN: This study formed one component of an ecologically framed, qualitative case study conducted in Calgary, AB, Canada. Data were collected using semi-structured interviews, chart review and field notes, and analysed thematically.

RESULTS: Eight families were represented in the sample comprised of six patients and 13 family members. Many patients and family members experienced high levels of fear and stress for months following the patient's diagnosis. Isolation was pervasive and multifaceted for both patients and family members. Intra-family support was critical for managing during early stages when the situation was most challenging. Support from outside the family was not prominent and attempts to obtain support from government programmes for paid sick leave and health insurance were mostly unsuccessful.

CONCLUSION: Patients and family members who are foreign-born experience multidimensional isolation as a result of TB stigma, language barriers and poor access to government programmes. TB programmes cannot meet family needs alone and systems of support should be created through collaboration with government institutions, and organisations serving ethnocultural communities.

In 2018, United Nations (UN) member states endorsed a landmark commitment to reduce global TB incidence and improve supports for patients, families and impacted communities.¹ Local strategies are key to fulfilling this commitment because of the wide variation seen in TB epidemiology and socio-economic conditions between regions.² In Canada, people who are foreign-born are diagnosed with TB at a rate nearly 30 times higher than people who are Canadian-born, non-Indigenous.³ Poverty, unhealthy work environments and poor access to healthcare for people who are foreign-born are key drivers of disparity in TB incidence.⁴⁻⁶ Being diagnosed with TB often exacerbates pre-existing social vulnerabilities, thereby undermining the likelihood of full recovery.^{4,7,8} Patients diag-

nosed with advanced infectious TB are among the most physically and socially affected. Patients with advanced infectious TB have a high burden of bacteria in the lungs (indicated by smear-positive sputum status), leading to significant symptoms, prolonged rehabilitation and isolation to protect public health.⁹ Isolation, damaging to wellbeing on its own, often leads to economic losses and increases exposure to stigma.^{10,11}

Families are complex, interconnected systems, and illness in one member has far-reaching effects on overall family function.¹² In addition to the fear and stress faced by families experiencing non-communicable illness, family members experiencing infectious TB, must also contend with the physical threat to their health posed by the disease. Very little is known about the family experience of infectious TB, particularly in low-incidence settings. Researchers working in high-incidence settings have shown that social stigma¹³ and financial losses¹⁴ can devastate the entire household. However, we are not aware of any study that has previously explored interconnected family experience in a low-incidence setting with prominent cultural and linguistic barriers. Therefore, the purpose of this article is to explore the infectious TB experience of patients and family members who are foreign-born.

SETTING

Data presented in this paper were obtained as part of a multi-phase, ecologically framed, qualitative case study.^{15,16} The overall aim of the case study was to generate recommendations for improving the infectious TB experience of foreign-born patients and family members through education and counselling. Information on other components of the case study is available elsewhere (Bedingfield N, et al. Tuberculosis health care workers' perspectives on education and counseling for patients and family members who are foreign-born 2021 ; unpublished).¹⁷

The research took place at the Calgary Tuberculosis Clinic, which is the sole provider of outpatient TB services for approximately 1.4 million people residing in the city and surrounding zone.¹⁸ In 2019, 93% of the 124 people diagnosed with active TB in Calgary were born outside of Canada (Alberta Tuberculosis Program, 2020, Case Report - 2019, unpublished). Care for families experiencing infectious TB in Calgary is based on national guidelines and provided free of charge for those with government health insurance.¹⁹ Patients diagnosed with advanced infectious TB are initiated

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KEY WORDS

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on treatment as soon as possible and are required to isolate at home for approximately 3 weeks, if medically stable. TB health care providers in Calgary do not recommend patients who receive this diagnosis isolate from other household members, wear a mask at home or engage in extra household cleaning, as these practices do not reduce transmission of this exclusively airborne disease.⁹ Other household members are screened for active TB and offered testing and treatment for latent TB infection (LTBI), an asymptomatic, non-communicable condition, if needed. Family members are rarely infectious and are not routinely asked to isolate. Household contacts under the age of 5 years are prioritised for assessment and treatment because of their high risk for progression to advanced TB disease.²⁰

METHODS

Eligibility, sampling, and recruitment

After receiving approval from Alberta Health Services and the University of Calgary Health Ethics Review Board (REB# 19-0366), the first author (NB) reviewed approximately 25 patient electronic medical files, noting age, diagnosis, date of diagnosis, country of birth and number of household contacts to determine eligibility and direct sampling. Eligible patients were aged ≥ 18 years, born outside of Canada, had at least one household contact and were diagnosed with advanced infectious TB, as evidenced by one or more smear-positive sputum samples, in the preceding 3–9 months. Maximum variation sampling principles were applied in an effort to include patients of different ages, countries of birth, family roles and family sizes. Patients were introduced to the study by clinic staff. If patients indicated interest, staff forwarded contact information to NB who phoned to further explain the study and arrange an interview. Eligible family members were aged ≥ 18 years and identified by staff or family as a household contact and family member of an eligible patient. Family members were introduced to the study by the patient or clinic staff. In the same fashion as patients, interested family members were then contacted by NB to further explain the study and arrange an interview.

Data collection

Patients were interviewed individually. When more than one family member participated, family members were offered a choice between individual interviews, or a family group interview. Fifteen individual and two small group in-person interviews were conducted between November 2019 and mid-February 2020 at a location chosen by the participant which was home in most cases. Follow-up interviews were conducted in March and April 2020 by phone with three participants. Interviews were conducted by NB who is a Canadian-born, Caucasian PhD candidate, a TB nurse, and experienced cross-cultural qualitative researcher. Participants provided written informed consent prior to their interview. The consent process was conducted in the language of the participant's choice and included an introduction to NB and her professional background. The research team, collectively possessing expertise in TB, qualitative methods and cross-cultural research, developed the semi-structured interview guide collaboratively. The guide was directed at two topics: participants' experience of infectious TB, and participants' feedback on the infectious TB education and counselling process. Only data pertaining to participant experience are included here. The interview guide was revised iteratively based on incoming data. Interviews ranged between 15 and 80 min in length.

Probing and confirmatory questions were used liberally to reduce misinterpretation related to linguistic and cultural dissonance. Ten participants were interviewed with the assistance of certified, professional language interpreters who had signed confidentiality agreements. All interviews were audio recorded and a transcript of the English dialogue was produced by a trained transcriptionist. Language interpretation was verified with the assistance of bilingual research assistants (either professional interpreters or volunteer bilingual university students) not involved in the original interview. NB met in person with the research assistant for verification sessions and non-English portions of audio were played for the assistant who provided interpretation. The oral interpretation was then compared to the English transcript to ensure equivalent meaning. Verification results were satisfactory; in some cases, details, such as mode of transportation, numbers of medication and specific cultural references, which were excessively summarised during the live interpretation, were added from the audio recording. NB recorded field notes containing process observations, non-verbal communication and debriefing with interpreters (if present) as soon as possible after each interview and verification session.

Analysis

Data were analysed following the steps of inductive thematic analysis as outlined by Braun and Clark.²¹ Familiarisation with the text was completed by listening to the interview while reviewing the transcript. Next, individual data segments were labelled with one or more codes. Codes were then reviewed and refined using comparative techniques. Data pertaining to the topic of this manuscript were extracted and codes progressively collated until two separate, but interrelated dimensions of experience were produced. An audit trail of the analysis process was recorded in NVivo software (QSR International v.12, Doncaster, VIC, Australia) and on paper records. The research team met regularly to review ongoing analysis and data collection. During language verification sessions, NB also reviewed evolving interpretations with bilingual research assistants to add cultural context and reduce cross-cultural misinterpretation.

RESULTS

Six patients diagnosed with advanced infectious TB and 13 family members were interviewed. Tables 1 and 2 provide additional sociodemographic details. Taken together, 8 families (5 intergenerational, 3 nuclear) were represented among the 19 participants, who were born in Africa, South Asia and East Asia. Four participants had high school diplomas, 12 had some post-secondary education and three had graduate credentials. Participants described close connections to their countries of birth, which they maintained via travel and frequent communication with overseas fam-

TABLE 1 Patient demographic information

	<i>n</i>
Total, <i>n</i>	6
Age, years, median (range)	58 (29–70)
Sex	
Female	2
Male	4
Time in Canada at TB diagnosis, years, median (range)	1.1 (0.25–29)
Family role	
Parent	2
Grandparent	4

TABLE 2 Family member demographic information

	<i>n</i>
Total	13
Age, years, median (range)	35 (22–72)
Sex	
Female	9
Male	4
Time in Canada at TB diagnosis, years, median (range)	10 (0.25–19)
Family role relative to patient	
Adult child	4
Spouse	4
Adult grandchild	4
Sister	1

ily members. Eight participants had lived in Canada for less than 2 years.

Results were organised into two dimensions. ‘Psychosocial impact’ was comprised of the social, emotional and financial ramifications of the experience. ‘Managing with infectious TB’ was comprised of participants’ individual and collective efforts to overcome adversity.

Psychosocial impact

Participants described feeling afraid when they learned of the TB diagnosis. However, fear of TB transmission, particularly the consequences for young children in the home, was more common than fear of dying. Participants with deeper knowledge about the curability of TB, gained through schooling, previous family illness or health care employment, were less distressed. Having access to Canadian health care, widely perceived as high quality and free, was comforting to participants. The first several weeks following TB diagnosis was described by many as stressful and confusing, with high levels of uncertainty.

The patient’s TB diagnosis resulted in multiple simultaneous demands on the family. Patients’ level of activity both inside and outside the home was severely reduced for 3 weeks or longer due to home isolation requirements, weakness caused by disease or personal choice. Family members not only had to cover the patient’s usual responsibilities, but also care for the patient, and arrange medical care for themselves and other family members. Ensuring toddlers took prophylactic medication was an especially difficult task that fell to women. One mother described this task as follows:

It was just so stressful, there were moments when I would throw a tantrum myself because she wouldn’t take it (*the medication*) and me throwing tantrums would get her to have more tantrums. ... we had fights every night.

Patients and family members alike described isolating themselves from others in different ways. Out of care and concern for loved ones, patients wore masks at home or avoided touching grandchildren. Family members changed their sleeping and eating arrangements to increase distance from the patient. One grandson described changes this way: “We were just afraid that the (*younger*) kids would pick up the bacteria, right? ... We had to isolate her (*my grandmother*) in her room”. Family members who had been cleared of active TB also reduced contact outside the home in an attempt to protect others. This family member gave an example from his community:

Consciously, I tried not to visit people... I had a neighbour that just gave birth to a baby, so normally I would go there like every

day when I’m back from work to say “Hello! How is the baby doing?” and everything like that.... (*but*) I avoided them.

When it came to disclosing the family’s TB experience to outsiders, participants had varying levels of concern and took different approaches. Five participants said they were very reluctant to talk about TB outside of the family and another five reported sharing this information freely. The remaining participants described taking a position somewhere in the middle, carefully weighing the ease of hiding TB, the relevance of the information to the recipient and the risk of stigmatisation. One family member described how her family opted for partial truth-telling to avoid TB stigma:

...we just told them that she was sick, (*that*) she had like a fever and cough and stuff because honestly, no one in the house was comfortable telling. It’s just you know, kind of a cultural thing.

Another patient described his approach which was more open, I was not worried to tell other people that I have TB, yes because I believe that most of them (*friends/neighbours*), they are knowledgeable. Once I’m cured, I’m cured.

Participants often referred to negative attitudes towards people with TB which were common in their home countries. One family member described how people with TB were isolated,

I saw, in my country, I saw some people have that (*TB*). That’s why I am so scared. They so skinny and they always... ah eh, ah eh (*coughing sound*). Yeah and in my country, everybody stays away from (*those*) people.

However, two participants also said that the widespread availability of treatment in their home country had reduced the social exclusion of patients.

Family members also experienced isolation. Two family members described staying home from a community event, although they knew they were not infectious. They believed that others at the event, aware of the patient’s diagnosis, would assume they were also infectious and feel afraid. One family member described his view on the social consequences for families:

I think that most of the people who get information that a family ... has a patient of TB, the person feels a negative sense about that family... (*people will not go to that family because they believe*) they may also catch the TB germs.

Although participants were not specifically asked about interventions to reduce TB stigma, three participants volunteered their thoughts. They explained that multilingual family doctors could play an important role in sharing accurate information about TB because community members had a high level of trust in physicians who spoke their language and shared their culture. One family member, speaking via an interpreter, offered her suggestion,

...(*if there were*) posters out with the information at the Vietnamese family doctor or any family doctor for Vietnamese people... they read, they understand more the detail, and then they’re not scary about if people are infected from TB.

Participants described a negative impact on their employment or finances, although the degree of impact varied widely. Patients were forced to miss work because of home isolation, generalised weakness and the need to attend medical appointments. Family members missed work because of caregiving responsibilities, fear

of TB transmission and attending medical appointments. One patient indicated she lost her job because of frequent absences for medical appointments. Another patient visiting Canada without health insurance was extremely worried about how his family, already stretched financially, would pay his medical bills, which had accumulated to several thousand dollars. A family of four experienced food and housing insecurity because the father and sole earner went without income for 30 days when he was first diagnosed. He described the situation this way:

Because that time, it was my wife, she's not working because she was taking care of children, so she was staying at home. The one that is working is me. So I was not working. Plus our work(*place*) is ... no benefits so... this is a problem... you have rent, you have grocery... you have a lot of things to do ... expenses.

Managing with infectious tuberculosis

Participants described managing the strain of the experience through strong intrafamilial support, which took the form of emotional reassurance, financial aid, caregiving, arranging transportation and language interpretation for medical appointments. Emotional support also came from close family members overseas. Intergenerational and financially secure families coped more easily. These comments from a granddaughter with a large family, and a wife with a small family, illustrate the difference in available resources:

It was usually me (*who went*) with (*my grandma to appointments*) ... I would translate ... (*it wasn't hard for us to go with her*), because we have a lot of family members, fortunately, so if it's not me, then my sister or my brothers. There was always someone.

Yeah, she said it was very difficult, because her husband was in hospital and (*her child*) was admitted for one week to the Children's Hospital. For her it was too much because her sister was in ... Africa and she's the only one here dealing with this whole thing. (*via interpreter*)

It was not common for participants to receive help from outside the family. Only three participants mentioned employers, friends and neighbours who offered food, child care, or kind words. Four families had requested government support to manage with TB. Services requested were for immigration visas, public health insurance, paid sick leave, and subsidised housing. Representatives from all four families who had requested support stated that interactions with government agencies were confusing and frustrating. Three of the four families eventually abandoned their requests without receiving any assistance. Participants who abandoned their requests conveyed that they did not meet eligibility criteria, were challenged by limited English proficiency to learn about the application process or were fed up with long delays. One patient, very weakened by TB, described her frustration as follows:

My dad is in... (*Africa*) and I really needed emotional support then because ... my husband's job was very demanding at that time, and like, he was juggling ... I applied for a visa for my dad to visit, ... I didn't get that support. ... I have young kids... I needed somebody to look after me, or maybe somebody that could stay to look after my kids ... it's not everybody that comes in that has that support, (*or has that*) ... immediate access (*for their families*) to come into Canada.

Although the strain of the experience had greatly subsided by 3–9 months after the patient's diagnosis, participants' strain continued as treatments were ongoing, lost employment had not been regained, bills were unpaid and concerns about social exclusion persisted.

DISCUSSION

Participants in this study managed the fear, stress and isolation posed by infectious TB through strong support within the family. Few received assistance from the wider community, and those who attempted to access government supports were largely unsuccessful. For some families, isolation and stress related to TB disease (e.g., fear of transmission or lost employment) intersected with isolation and stress related to being foreign-born (e.g., employment lacking in paid sick leave, linguistic barriers to accessing government support). Families in this situation verged on crisis as they endured months of extreme stress with little to no outside assistance.

Addressing stigma through community partnerships

With one exception, participants (and interpreters) in this study did not use the word stigma when describing their experiences with TB. Nevertheless, features of stigma were evident. TB stigma is poorly understood, and experts have called for more qualitative research to clarify the drivers, outcomes and types of TB stigma.²² Stigmatising experiences are often categorised as anticipated, enacted, internalised and secondary.^{22, 23} Participants in this study experienced anticipated stigma – or fear of devaluation – when they chose not to disclose to others that they had been diagnosed with TB. Participants withheld this information because they believed others lacked TB knowledge and would fear its lethality and infectiousness. In withholding this information, participants protected themselves from stigma but also reduced opportunities to receive support from outside the family. Internalised stigma – or negative self-perception – was evident when patients stopped touching family members and family members unnecessarily avoided friends and neighbours. Participants often overestimated the risk posed by their bodies and segregated themselves above and beyond public health recommendations in order to protect others. Enacted stigma – or overt exclusion – could be seen in the converse experience when family members isolated the infectious patient within the home. Secondary stigma – or stigma by association – was difficult to differentiate from anticipated or internalised LTBI stigma; however, some family members clearly stated that others would fear them because of their close association to the patient. Across all types of stigmatising experiences, fear and lack of TB knowledge were common drivers and isolation was a prominent outcome.

Interventions to address stigma must not simply encourage personal resilience in affected individuals but must also attack the root causes of stigma, which are fear and misinformation about TB in the community.^{22,23} Participants in this study recommended that trusted primary care providers could effectively deliver TB education. This is aligned with recommendations from TB researchers and the WHO, who have suggested that TB programmes partner with trusted community organisations, including primary care providers to reduce stigma.^{22,24} TB programmes may have difficulty reaching ethnocultural communities with health promotion messages, given linguistic and cultural barriers;²⁵ forming partnerships with groups closely aligned with these communities is an important way to provide education, and reduce fear and isolation experienced by affected families.

Accessible government services

Participants in this study sought access to income support, public health insurance and immigration assistance to manage the strain of the infectious TB experience. The WHO has called upon Member States to consider income support and universal health cover-

age as essential components of TB care provided, not by TB programmes, but “beyond” TB programmes at higher levels of government.² Although income support and public health insurance programmes are available in Canada, patients in this study were not able to access these programmes when needed. Patients did not meet eligibility criteria and struggled to navigate application procedures not designed for people who are foreign-born. Lack of government assistance negatively affected the entire family, including young children.

In this study, the median number of years patients had lived in Canada at the time of diagnosis was 1.1. This is consistent with epidemiological data showing that foreign-born people are at highest risk of developing TB disease in early years post-migration.^{3,26,27} Newly resettled families have not yet developed resources such as a social network or language skills crucial for managing a crisis such as infectious TB.²⁸ In 2017, approximately 26% of all people (i.e., foreign-born and Canadian-born) diagnosed with TB in Canada received this diagnosis within 5 years of arrival.³ Thus, we agree with Reitmanova and Gustafson, who concluded that supports for people experiencing TB in Canada will not be effective until government programmes attend to the social determinants of health for foreign-born populations, particularly those who are recently resettled.²⁹ For example, participants in this study would have benefitted from programme information in diverse languages, inclusive eligibility criteria and expedited application processing. Due to low incidence, TB patient advocates in countries such as Canada struggle to generate political will required for equity-informed policy change. Governments must therefore recognise the significant needs faced by this group and act to facilitate access to these essential components of comprehensive TB care.

Strengths and limitations

This study fills an important gap in the literature because it contains a description of interconnected patient and family experience of infectious TB in the setting of prominent linguistic and structural barriers to adequate support. This strength may have been limited because the interviewer and the first author of this study did not share a common first language or culture with participants. Lack of shared background may have constrained the spontaneity, depth and nuance of participants’ responses, particularly on stigmatised topics.³⁰ This limitation was offset by following recommended practices for cross-cultural qualitative research such as asking probing questions and working closely with certified language interpreters.³¹

CONCLUSION

Improved supports for patients and families experiencing infectious TB is a central component of both the UN and the WHO global TB elimination plans.^{1,2} However, TB programmes cannot fully meet family needs alone, and collaboration is essential to improve support. We can suggest two partnerships to reduce the multidimensional strain and isolation experienced by families in our study. First, TB programmes could have outreach programmes with multilingual family physicians to reduce stigma in ethnocultural communities. Second, the federal government could work with TB programmes in Calgary and other major cities to support families in crisis because of infectious TB by fast-tracking processing of income support applications and family carer immigration visas.

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CONTEXTE : Les déterminants sociaux défavorables en matière de santé pour les personnes nées à l'étranger sont des facteurs clés d'inégalités face à la TB, notamment dans les pays à faible incidence. Les patients atteints de TB contagieuse et leurs proches sont confrontés à des difficultés psychosociales, qui peuvent creuser les inégalités préexistantes en matière de santé. Cependant, le ressenti des patients et de leurs proches concernant cette expérience est peu connu.

OBJECTIF : Analyser l'expérience des patients, nés à l'étranger, atteints de TB contagieuse et de leurs proches.

MÉTHODES : Cette étude est l'une des composantes d'une étude de cas qualitative et écologique réalisée à Calgary, AB, Canada. Les données ont été recueillies à l'aide d'entretiens semi-structurés, d'analyses des dossiers et de notes de terrain ; elles ont ensuite été analysées thématiquement.

RÉSULTATS : Huit familles étaient représentées dans l'échantillon, composé de six patients et de 13 proches. De nombreux patients et

proches ont décrit d'intenses niveaux de stress et de peur au cours des mois ayant suivi le diagnostic des patients. Les patients et leurs proches ont subi un isolement systématique aux multiples facettes. Au stade précoce de la maladie, lorsque la situation était la plus compliquée, l'aide intra-familiale s'est avérée essentielle pour la prise en charge des patients. Les familles n'ont reçu que peu d'aide en dehors du cadre familial et les tentatives effectuées pour obtenir l'aide des programmes gouvernementaux (rémunération du congé maladie et assurance maladie) se sont avérées infructueuses la plupart du temps.

CONCLUSION : Les patients et leurs proches, nés à l'étranger, ont subi un isolement pluridimensionnel en raison de la stigmatisation liée à la TB, de la barrière de la langue et du manque d'accès aux programmes gouvernementaux. Les programmes de lutte contre la TB ne peuvent pas satisfaire les besoins des familles à eux seuls. Des systèmes d'aide devraient être créés au travers de collaborations avec les institutions gouvernementales et les organisations œuvrant auprès des communautés ethnoculturelles.