

Chapter 4. Common Perceptions, Attitudes, and Beliefs About Tuberculosis Among Somalis

Findings from Tuberculosis-specific Behavioral and Social Science Research

In 2003, the Centers for Disease Control and Prevention (CDC) conducted an ethnographic study of 52 Somali-born people in the United States to understand better the tuberculosis (TB)-related experiences, perceptions, and attitudes of Somalis. In this chapter, this study is referred to as “the CDC study.” (See Appendix D for a description of the study design, methods, and study population.) The information presented in this chapter comes from both the CDC study and other TB-related behavioral and social science literature concerning the Somalis. It should be noted that the CDC study findings have limited generalizability because of the study’s small, non-randomly selected sample; thus, the information will not apply to all Somalis. Program staff should use discretion in determining how applicable the information may be for their specific context. However, taken as a whole, the research findings suggest several programmatic implications.

Suggestion



- Take time to understand the patient’s perceptions of TB and LTBI so that education can be tailored appropriately.
- Address the important differences between TB disease and LTBI; clarify that TB disease can be prevented through LTBI treatment.
- Focus education on TB transmission: explain how TB is and is not transmitted.

Somalis often have some knowledge of TB causation, transmission, symptoms, and prevention.

In the CDC study, almost all Somali respondents accurately described TB symptoms, and when asked to describe TB in their own words, understood it to be a lung disease that can also affect other parts of the body. A London-based study among Somali TB patients, contacts, and lay community members found that knowledge of symptoms was high (Shetty, Shemko, & Abbas, 2004). Research from Somali focus groups conducted in Seattle, Washington, revealed that respondents associated coughing with TB and were likely to distinguish TB from other illnesses on the basis of coughing up blood (Citrin, 2006; Kwan-Gett, 1998).

In the CDC and the London and Seattle studies, most respondents understood TB as a communicable disease, but cited a variety of transmission mechanisms (Kwan-Gett, 1998; Shetty et al., 2004). In the CDC study, only about one-third of respondents specifically mentioned airborne transmission. Beyond general person-to-person contact, other mechanisms mentioned were heredity, smoking, being too cold, hunger or malnutrition, injury to the chest, or lifting heavy items. Respondents identified other transmission factors, including hot weather and overwork, also sharing meals, utensils, clothes, or household items (Kwan-Gett, 1998). The London study also found misunderstanding of TB risk factors (Shetty et al., 2004).

In the CDC study, one-quarter of respondents mentioned the Bacille Calmette-Guerin (BCG) vaccine, and most respondents understood that TB is preventable; however, not all respondents diagnosed with latent TB infection (LTBI) believed this. Many Somali respondents did not understand the distinction between LTBI and TB disease, though those who were tuberculin skin test (TST)-positive and asked to start LTBI treatment generally did.

Many Somalis felt society-wide efforts should be made to prevent TB, such as providing poverty relief, universal health care, and public education about TB. Some respondents felt a healthy lifestyle, good nutrition, plenty of rest, and clean eating utensils played an important role in TB prevention at the personal level. One respondent said, “Good public education would be most helpful in preventing the spread of the TB disease. The spread of the disease is most common in the poor nations; therefore, eliminating hunger and poverty in the poor nations can enhance TB prevention. TB can also be prevented if anyone who gets the disease takes personal responsibility in seeking the proper treatment.”

Suggestion



- When discussing a TB diagnosis, explore with the patient the physical and emotional aspects of the disease.
- Clarify that patients' increased risk for TB largely comes from previous exposure in Somalia or in refugee camps.
- When appropriate, provide family education about TB transmission and the difference between TB disease and LTBI.

Although Somalis may consider TB a very serious disease, they may not consider themselves at great risk. When participants in the CDC study were asked what would happen if a person with TB did nothing at all, the most frequent response was that the person would die. One respondent said, “It will be a certain death for that person, and he will live in miserable life.” Most Somalis understood that treatment could cure TB. Many felt that TB would affect a person’s daily activities, and they often described the emotional impact as well as the physical ramifications. One individual commented that the person “would be worried about the disease and will lose the wish to live. Also, that person will feel alone and scared that he or she may never recover.”

Despite the perceived seriousness of TB disease, most respondents in the CDC study felt that their risk of TB was low, and they reported that their friends and family did not worry about TB. Many respondents felt that they were at low risk because they did not spend time around anyone with TB. In addition, respondents linked their low personal risk with their knowledge about TB and their perception of the United States as a safer environment with a better health care system. As one person stated, “[The U.S.] is TB-free.”

Somalis commonly perceive TB to be a highly stigmatizing disease that would result in a person's severe social isolation. The CDC study revealed that in Somali culture an intense stigma is associated with TB. Research from focus groups conducted in Seattle further supported this finding (Citrin, 2006; Kwan-Gett, 1998). In the CDC study, most respondents reported that TB would change how they felt about themselves, and only one-quarter of respondents stated that someone with TB would tell others.

One individual said, “A person with TB would not tell anyone about his or her sickness because that person would be afraid of being ostracized. His or her friends may have some reservations and may no longer be friendly with them. They may lose their job, and their loved ones may even no longer associate with them.”

In the CDC study, the majority of respondents felt that having TB would change the way others treat a person. Respondents described ostracism, family shame, loss of friendships, and the belief that family members would no longer share food, utensils, or other household items. Traditionally Somalis eat from the same plate; thus, the belief that TB patients cannot share meals may add to the sense of social isolation.

The data collected in Seattle revealed that TB stigma can be as severe as that of HIV/AIDS in Western culture (Citrin, 2006; Kwan-Gett, 1998). Respondents in both the CDC and Seattle studies acknowledged that persons may avoid seeking health care, or when the diagnosis is known, may deny the illness to themselves or others. In the London study, however, TB patients did not report ostracism by close family members (Shetty et al., 2004).

Suggestion



- Emphasize that TB can be cured.
- Ensure confidentiality for all patients by conducting consultations in private settings. Avoid announcing names in common areas.
- Discuss the social effects of TB with patients. Emphasize the need for only brief isolation during TB treatment to ease fears of social isolation. Clarify that social participation can continue after a diagnosis of LTBI or noninfectious TB.

Suggestion



- Consider adopting cultural case management, whereby patients are matched to bilingual, bicultural case workers for the duration of their TB evaluation and treatment.
- Aid patients in developing a reminder system that might involve a family member or friend or other measures, such as keeping pill bottles next to a toothbrush, refrigerator, or car keys, but safely out of reach of children.

Though most Somalis were aware of traditional healing techniques for TB, Somalis in the United States are likely to seek treatment from medical doctors. The most commonly described traditional healing method was *baan*, a practice of treating the sick with nutritious, fatty food (including blood, meat, animal fat, seeds, *ghee* [clarified butter], eggs, honey, milk, dates, and garlic). Typically, the sacrifice or slaughter of a sheep accompanies *baan*, and though the traditional healer or *dhaawayaal* recommends *baan*, the family is responsible for administering it.

These procedures, as well as cauterization of the chest with a hot stick and the use of herbal mixtures (*tire* or *khabayere*) to induce vomiting, were mentioned in both the CDC study and Seattle focus groups (Citrin, 2006; Kwan-Gett, 1998). One participant in the CDC study explained, “There were traditional medicine men who specialized in treating TB disease and other diseases. These medicine men knew different kinds of herbs, leaves, roots, and bark of certain trees mixed all together then fed to a sick person for some time. During the course of treatment, the patient will be well fed with fresh camel milk and meat and honey.”

Despite the existence of these traditions, the CDC and London studies found that Somalis trusted Western medicine to treat TB disease (Shetty et al., 2004). Respondents in the CDC study believed that if a Somali living in the United States suspected he or she had TB, that person would most likely seek the care of a medical doctor. However, respondents frequently stated that a person’s actions would depend upon his or her education level, access to care, and knowledge of TB. Several also stated that if someone felt ashamed about having TB, that person might not seek care.

Suggestion



- Provide education in oral formats preferred by Somalis, such as community talks or presentations, radio, television, and videos to watch in the waiting room.
- Develop culturally relevant TB prevention, treatment, or anti-stigma messages.
- Prioritize messages that are likely to ease TB stigma, such as the availability of effective treatment or the mechanisms by which TB is and is not spread.

Challenges with LTBI treatment are often physiological or logistical. Although the CDC study found that most respondents who were asked to start LTBI treatment generally understood the treatment and its purpose, some respondents did not understand. For example, one respondent who was TST-positive explained how he took treatment to prevent TB disease, “Three large pills that I took all at once before I left for America. That was to prevent getting TB.” One-half of the respondents reported experiencing difficulties with LTBI treatment, including the side effects, long treatment duration, and the number and bad taste of the pills. Other barriers included forgetting to take pills, the clinic’s schedule, the inability to communicate with clinic staff, and the lack of transportation to the clinic.

When Somalis discussed ways to make taking the medication easier, the most common response was to provide home delivery, either by outreach workers or the postal service. The few respondents who did not complete LTBI treatment either lacked transportation to the clinic or felt that the medication was unnecessary. Anecdotal evidence from program staff reinforces that Somalis are generally unaccustomed to the follow-up visits required for prolonged treatment regimens and that the lack of transportation is a deterrent to long-term treatment (Fritz & Hedemark, 1998).

In Seattle, Community House Calls, a field-tested intervention based on cultural case management, is designed to minimize barriers to LTBI treatment among Somalis (Goldberg, Wallace, Jackson, Chaulk, & Nolan, 2004). Bilingual, bicultural outreach workers mediate between the biomedical TB control system and the Somali community. Throughout the duration of a patient’s evaluation and treatment, a Somali case manager provides culturally appropriate TB education, reads TST results, conducts symptom checks, delivers LTBI medications to the home, and refers patients to other health and social services. The cornerstone of the model is the trusting relationship between the patient and the case manager. The Community House Calls approach significantly improved Somalis’ treatment completion rates to 92% from a pre-intervention rate of 38%.

Suggestion



- Wherever possible, assess potential barriers caused by lack of transportation and develop solutions such as providing transportation to the clinic, allowing patients to access medications outside of regular clinic hours, or having case managers deliver medication to the home.
- In all situations, ensure patients receive services in a language they understand and speak.

Many Somalis have preferences about how to receive information. Most Somalis in the CDC study wanted additional information about TB. One respondent commented, “Getting information of how TB is spread, how it is treated, and ways to be tested would indeed enlighten the communities. In general, Somali communities do have very limited knowledge of the TB disease. Many of them believe that it is a very dangerous disease and they hardly talk about it.” Another added that education would help ease the stigma, “People need to know that TB is not a shame disease but a disease like any other. They need to know TB can be successfully treated.”

Most respondents preferred educational formats that were oral and in the Somali language. These included community talks or presentations, radio, television, and videos to watch in the clinic waiting room. As one respondent explained, “Culturally, Somalis are an oral society, therefore...engaging informal and formal talks in the community centers and radio and TV spot ads could be an effective way of educating the Somali community about TB.”

A health initiative using Somali cultural themes as a means to convey health messages may be successful. Indeed, focus groups asserted that the use of health idioms and proverbs would help improve health service utilization because of the common belief that these expressions are always truthful. One participant explained, “People try to follow idioms to improve their life, so if the idiom was attached to a health message, it would be a very strong message.” One example mentioned in the focus group of a prevention-oriented idiom with a public health application was, “Before the flood comes, you make irrigation” (Palinkas et al., 2003).