

Promoting Cultural Sensitivity

A Practical Guide for Tuberculosis Programs That
Provide Services to Persons from Somalia



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL AND PREVENTION



Aqoon la'aani waa iftiin la'aan.
“Being without knowledge is to be without light.”
—Somali proverb

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Children at an orphanage in Afgooye, Somalia.
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**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL AND PREVENTION**

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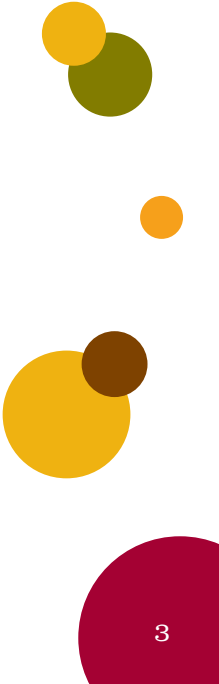
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Introduction

Promoting Cultural Sensitivity: A Practical Guide for Tuberculosis Programs That Provide Services to Persons from Somalia is one guide in a series that aims to help tuberculosis (TB) program staff provide culturally competent TB care to some of our highest priority foreign-born populations. Other guides in the series focus on persons from China, Mexico, Vietnam, and Laos.

Intended Audience

This guide is intended for health care providers, community-based workers, program planners, administrators, health educators, and resettlement agencies that work with Somali communities. This guide is designed to increase the knowledge and cultural sensitivity of health care providers, program planners, and any others serving persons from Somalia. The ultimate aim is to foster culturally competent TB care and services for Somalis in the United States.

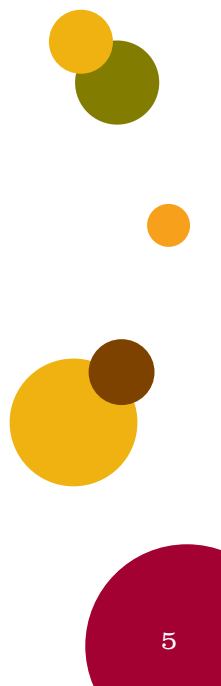
About the Guides

Each guide in this series includes the following:

- A two-page summary of program tips.
- Chapters on history and immigration; culture; health issues; and common perceptions, attitudes, and beliefs about TB.
- A concluding summary.
- Appendices, including additional resources for working with TB patients and interpreters.
- Useful resources.
- References.

Some of the information in the guides, such as the practical tips, can be applied directly, while other sections are more informative and will help providers better understand the background and sociocultural context of the population. A deeper understanding of pertinent issues will heighten the cultural sensitivity of TB care providers, enhance communication, and improve the overall effectiveness of organizations and staff in cross-cultural settings.

The content of these guides was gathered in two ways. First, an in-depth review of TB-related epidemiologic, behavioral, and ethnographic literature on Somalis in the United States was performed. Secondly, in 2003, the Division of Tuberculosis Elimination (DTBE) at the Centers for Disease Control and Prevention (CDC) undertook a qualitative study to describe ethnographic aspects of the increasing burden of TB among five foreign-born populations. Selected major findings from this study are presented in each of the guides.



How to Use This Guide

- The tips section at the front of the guide provides a summary of practical suggestions, which are also interspersed throughout the guide in textboxes. Keep these tips readily accessible and refer to them as often as necessary.
- The chapters on history, immigration, and cultural issues (Chapters 1 and 2) provide important background information on the cultural group. Depending on your needs and interests, you will want to read in depth or skim.
- Chapter 3 begins with “Health Statistics at a Glance,” which highlights TB and related health issues. The remainder of the chapter expands upon this information. If you provide direct health services, you may wish to read this section in depth.
- Chapter 4 contains findings from the CDC study on common TB perceptions, attitudes, and beliefs. If you work directly with TB patients, you will want to read this section thoroughly.
- Appendix A presents a set of questions that can be used to elicit a patient’s understanding or perception of his or her own health problems. You may wish to use these questions or slightly modified questions to begin a conversation with a new TB patient.
- Appendix B provides suggestions for working with interpreters. Refer to these suggestions when working with people with limited English proficiency.
- Appendix C provides a list of resources for both patients and providers. These resources include culture-specific educational materials and fact sheets. Use them to enhance communication with patients of different cultures.
- Refer to the other appendices as needed.

Background

Worldwide, tuberculosis (TB) is one of the most deadly infectious diseases. Although it is curable and preventable, TB claims the lives of more than 5,000 people every day (nearly 2 million deaths per year) (World Health Organization [WHO], 2006). TB disproportionately affects poor and marginalized groups of society who are often at higher risk for TB, both around the world and in the United States (Dubos & Dubos, 1952; Mitnick, Furin, Henry, & Ross, 1998; Sepkowitz, 2001).

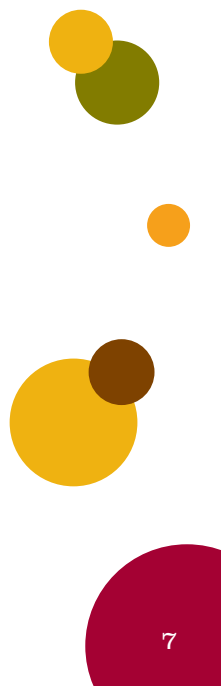
Domestically, the number of TB cases has decreased steadily since 1992, but this reduction has not affected all populations equally. In 2005, the TB case rate among foreign-born persons was almost nine times that of persons born in the United States (21.9/100,000 compared with 2.5/100,000). The same year, 55% of all TB cases in the United States were among foreign-born persons (Centers for Disease Control and Prevention [CDC], 2006b). Most cases among this group result from reactivation of latent TB infection (LTBI) acquired in countries of birth with high TB prevalence (Zuber, McKenna, Binkin, Onorato, & Castro, 1997).

The high incidence of TB in the United States among foreign-born persons poses challenges to public health programs across the country (CDC, 2006b). Although disparities between U.S.-born and foreign-born TB patients are caused by multiple factors, persons born outside the United States often face challenges related to personal or cultural beliefs, behaviors, and needs when accessing TB services. Attempts to control TB in foreign-born populations have sometimes been hindered by cultural and linguistic barriers, as well as challenges related to resettlement, employment, and socioeconomic position. Understanding these issues is crucial to the prevention and control of TB among foreign-born populations.

Cultural Competency in Tuberculosis Service Delivery

Cultural competence is an essential element of quality health care and can help improve health outcomes, increase clinic efficiency, and produce greater patient satisfaction (Brach & Fraser, 2000). Although there is no universally accepted definition of cultural competence, it may generally be understood to be a set of attitudes, skills, behaviors, and policies that enable organizations and staff to work effectively in cross-cultural situations. Furthermore, it reflects the ability to acquire and use knowledge of the health-related beliefs, attitudes, practices, and communication patterns of patients and their families in order to improve services, strengthen programs, increase community participation, and close the gaps in health status among diverse population groups (U.S. Office of Minority Health, 2006). Linguistically appropriate services are a key component of culturally competent health systems. In 2001, the U.S. Office of Minority Health issued Culturally and Linguistically Appropriate Service (CLAS) standards to help health care organizations move toward cultural competence (see Appendix C). Several of these standards are federal mandates supported by Title VI of the Civil Rights Act (1964), which prohibits discrimination on the basis of national origin and language. In summary, these standards aim to ensure that all federally funded health facilities provide services in a language understood by patients.

To move towards cultural competence, health care providers and other program staff should understand the ethnic and cultural needs of the populations they serve. Providing effective care involves taking the time to learn from patients what is important to them in the experience of illness and treatment. According to medical anthropologist Arthur Kleinman, finding out “what is at stake” for the individual will provide crucial information to use in communication and in tailoring a treatment plan (Kleinman & Benson, 2006). Culture does matter in the clinic, and providers must remember that they too bring a cultural perspective to the patient-provider relationship. Increasing staff knowledge of the cultural and ethnic backgrounds of populations served is one important aspect of the CLAS standards.



Considerations When Using This Guide

Although the information in this publication was gathered from many sources, it will not apply to all Somalis in the United States. Somali culture, as all others, is dynamic. Cultural perspectives may vary depending upon a person's age, sex, education, social class, or degree of acculturation. To ensure that TB services are both sensitive and appropriate, users of this guide are encouraged to use an approach grounded in an understanding of the cultural background of those served, while also appreciating each patient's individuality and uniqueness.

Further, providers must also recognize their own beliefs and biases, as these may inadvertently be communicated to patients and families. Awareness of one's own verbal and nonverbal communication styles will help avoid social gaffes that may offend others and adversely affect the relationship. Good patient-provider relationships are built on trust and respect; therefore, providers wishing to care effectively for their patients should heighten their sensitivities to both differences and similarities and use knowledge to guide their practice (Lipson & Dibble, 2005).



Somali children outside their home in Kenya.
© 1998 Sammy Ndwiga. Courtesy of Photoshare.

Tips for Providing Culturally Competent Tuberculosis Services to Persons from Somalia

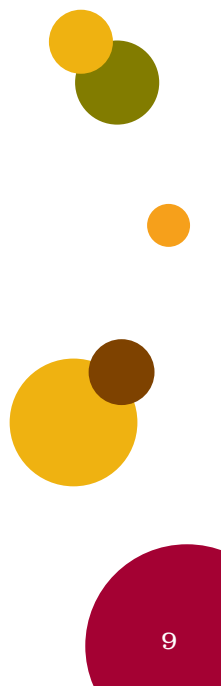
Below are practical suggestions presented in *Promoting Cultural Sensitivity: A Practical Guide for Tuberculosis Programs That Provide Services to Persons from Somalia*. These tips are intended for tuberculosis (TB) program staff, including program planners, managers, and providers who work with persons from Somalia. For additional background and resources, please consult the full version of the guide.

Interactions with Somali Patients and Family Members

- Recognize that not all persons from Somalia are ethnic Somali. The Bantus, a tribal group originally brought to Somalia as slaves, may have special needs because of their historical marginalization in Somalia and distinct language and culture.
- In all situations, ensure patients receive services in a language they understand and speak.
- Do not assume that Somalis can read English or Somali. The Somali script was introduced only 30 years ago and social upheaval severely disrupted education.
- Recognize the role of family, especially the male head of household, in medical decision making. In some families, it may only be acceptable for the husband or father to speak for a woman.
- When possible, attempt to match female patients with female interpreters and health care providers. This is especially important when performing physical examinations.
- Remember that some Somalis maintain Islamic traditional norms about handshaking, limiting physical contact to persons of the same sex.
- Somalis traditionally do not express gratitude or appreciation verbally. Do not assume that patients are ungrateful if they do not acknowledge gratitude directly.
- Ensure confidentiality for all patients by conducting consultations in private settings. Avoid announcing names in common areas.

Mental Health and Other Health Issues

- Be aware that some Somali refugees may have experienced rape, torture, or starvation. Some may be experiencing mental illness that could complicate adherence to TB medication.
- Recognize that female circumcision is an important but sensitive issue for many Somali women. Its illegal status (for girls younger than 18 years of age) in the United States has led to secrecy, and patients may feel uncomfortable discussing it with Western health care providers.
- Be aware of the practice of chewing *qat*, a leafy narcotic. Some Somalis may hesitate to initiate TB treatment because they believe they must discontinue chewing *qat* while undergoing treatment. *Qat* may affect one's ability to remember TB medication.



Tuberculosis Diagnosis and Treatment

- Consider adopting cultural case management, whereby patients are matched to bilingual, bicultural case workers for the duration of their TB evaluation and treatment.
- A poor health service infrastructure, combined with inappropriate treatment regimens, may contribute to the development of drug resistance. Ask patients about previous TB treatment and perform drug susceptibility testing whenever possible.
- Find out when Ramadan occurs each year and accommodate the observance by suggesting that patients take their medications at night. Usually a person in need of medical care can delay the fast, if required.
- Somalis often expect medication to be given for all illnesses; if none is given, explain the reason why.
- 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.
- 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.

Social Stigma

- Consider that the stigma associated with TB may impact a Somali's sense of family honor, which is an important value in Somali society.
- 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. Specifically address participation in family meals and activities.

Tuberculosis Education and Outreach

- Take time to understand the patient's perceptions of TB and LTBI so that education can be tailored appropriately.
- Provide education in formats preferred by Somalis, namely oral strategies 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.
- Although many Somalis have been exposed to Western medicine, Somali patients should be educated about preventive care.
- 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.
- Clarify that patients' increased risk for TB largely comes from previous exposure in Somalia or in refugee camps.
- Emphasize that TB disease can be cured.

Chapter 1. Somali History and Immigration to the United States

Somali Geography and History

Somalia is a long, narrow country on Africa's eastern coast that has a population of about 10 million (WHO, n.d.). Mogadishu, the capital, lies along the coast of the Indian Ocean (Samatar, 1993). Though scholars debate the origins of the Somali people and their arrival into present-day Somalia, references to Somalia can be found in ancient Egyptian and Greek texts. By the 12th century, clan families were established and the widespread conversion to Islam had begun (Putnam & Noor, 1999).

Since the mid-1800s, Somalia has faced periods of divisiveness, including colonization by France of the Northwest region, Great Britain of the North Central, Italy of the South, and Ethiopia of the inland region of Ogaden. When colonial powers determined the borders of the country in the 19th century, many ethnic Somalis were left out (in Ethiopia and Kenya), and this has continued to be a source of conflict. Colonial rule existed until 1960 when the Italian and British areas were united into an independent Somalia (Lewis, 1996).



Although the government of Somalia's initially socialist republic had a better relationship with the Soviet Union than with the United States, the government still encouraged democratic participation. However, by the late 1960s, the government was widely considered corrupt and inefficient. Shortly after the assassination of Somalia's president in 1969, a coup led by General Mohammed Siad Barre overthrew the civilian government. Barre then ruled Somalia for the next 22 years. Initially, Barre's rule was popular, but nepotism and lack of accountability led to widespread inequality, which was incompatible with Somali egalitarianism. Under Barre's oppressive, autocratic rule, clan-based opposition militias formed and were manipulated by Barre's regime. In 1990, a full-scale civil war broke out and ultimately led to Barre's overthrow and exile in 1991, and to the disintegration of the central government (Putnam & Noor, 1999). The civil war and ongoing clan violence have handicapped the country's infrastructure and economy.

Because of continued anarchy, clan warfare, and border disputes, civilians have suffered much violence, including torture and rape. Additionally, at least one million Somalis have fled to the neighboring countries of Djibouti, Kenya, Ethiopia, Burundi, and Yemen, contributing significantly to the large population of refugees in the Horn of Africa (Lewis, 1996). Currently, Somalia has no stable central government, and numerous warlords and factions fight for control of the capital and other regions of the country. An estimated 400,000 Somalis have died, and at least 45% of the population has been displaced (Kemp & Rasbridge, 2004). Mortality among female children is estimated to be 228 per 1000, and the average life expectancy for Somalis is 44 years (WHO, n.d.).

Suggestion



- Be aware that some Somalis may have experienced rape, torture, or starvation. Some may be experiencing mental illness that could complicate adherence to TB medication.
- When possible, attempt to match female patients with female interpreters and health care providers. This is especially important when performing physical examinations.

Immigration and Resettlement to the United States

The first Somali immigrants to the United States, mostly sailors, arrived in the 1920s and settled around New York. In the 1960s, Somali students began traveling to the United States, either supported by government scholarships or by family members living in the country. In the mid-1980s, small numbers were admitted as refugees; in the 1990s, the number of refugees increased because of the civil war (Putnam & Noor, 1999). The U.S. Office of Refugee Resettlement reports that during 1983–2004, 55,036 Somali refugees resettled in the United States. In 2004 alone, nearly 13,000 Somalis entered the country (U.S. Office of Refugee Resettlement, 2004). Current estimates of the number of Somali-born persons living in the United States range widely, from 35,760 (U.S. Census Bureau, 2000) to 150,000 (Lehman & Eno, 2003). The majority of Somalis have settled in Minnesota, California, Georgia, and Washington, D.C. (U.S. Office of Refugee Resettlement, 2004).

Because most Somalis enter the United States as refugees, the government resettlement process is relevant to TB control programs. Appendix F details specific TB screening procedures for refugee resettlement, but other government programs are also worth noting. The Department of Health and Human Services provides newly arrived refugees with transitional cash and medical assistance and provides a range of social and health services to refugees who have resided in the United States for fewer than five years. Employment services are the primary focus and include skills training, job development, orientation to the workplace, and job counseling. Transitional cash assistance benefits are provided to refugees on the basis of family composition: single adults and childless couples are eligible for Refugee Cash Assistance for up to eight months after arrival, and families with children are eligible for mainstream welfare for unemployed families for up to two years. In terms of health benefits, singles and childless couples are eligible for Refugee Medical Assistance for their first eight months in the United States, and families with minor children are covered by the Medicaid program. Though states must meet certain federal requirements, they have flexibility in designing their assistance programs; therefore, benefits and time limits vary by state.

Chapter 2. Overview of Somali Culture

This chapter provides an overview of the Somali culture in terms of ethnicity, language, religion, food and dress, family and social structure, values, education, socioeconomic status, and traditional health beliefs. Readers are cautioned to avoid stereotyping Somalis on the basis of these broad generalizations. Somali culture, as all others, is dynamic and expressed in various ways, owing to individual life experience and personality. Some Somalis living in the United States may be more or less acculturated to mainstream U.S. culture.

Ethnicity

Somalis consider themselves as sharing a common ancestor, Somaal, a mythical father figure (Putnam & Noor, 1999). Somalis, the dominant ethnic group in Somalia, make up 85% of the population, and share a uniform language, religion, and culture. In fact, Somalia has been characterized as one of the most ethnically and culturally homogenous countries in Africa. Several minority groups in current-day Somalia are Arabs, Southeast Asians, and the Bantus, who were brought from Southeastern Africa to Somalia as slaves (Putnam & Noor, 1999). An estimated 600,000 Bantus live in Somalia, and although some Bantus integrated into Somali society, others maintained their ancestral culture, languages, and sense of Southeast African identity. These Bantus, in particular, have been marginalized and persecuted in Somalia, and because of this historical subjugation, may have quite distinct needs from ethnic Somalis (Lehman & Eno, 2003).

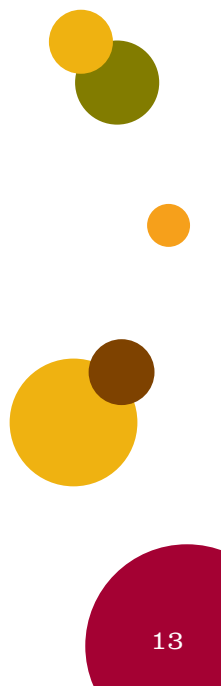
Language and Communication

The universal language in Somalia is Somali, a Cushitic language shared by people of Eastern Africa. Somali includes distinct regional variations. The two main variants, *AfMaay* and *AfMaxaa*, were the official languages of Somalia until 1972 when the government determined that *AfMaxaa* would serve as the official written language. Though the two languages are similar in written form, they are mutually unintelligible when spoken (Lehman & Eno, 2003).

As the majority of the population is Muslim, Arabic is the second most commonly spoken language. The formally educated in Somalia may also speak French, Italian, English, Russian, or Swahili. After 1972, however, when Somali became the official language of government and instruction, young people had little exposure to other languages; therefore, those who are currently at least middle-aged and educated are more likely than their younger counterparts to be proficient in English, Italian, Arabic, or Russian (Kemp & Rasbridge, 2004; Putnam & Noor, 1999).



Somalis and their camels at a watering point in Wajir district, Kenya. © 1998 Sammy Ndwiga. Courtesy of Photoshare.



Facility with speech is highly valued among Somalis, and Somalis tend to appreciate oral communication above all other art forms. The Somali language has a long and rich tradition of proverbs and idioms, which are passed down through generations and embellished by the individual speaker. Everyday Somali speech often includes these expressions, and some Somalis, finding English lacking in these terms, may translate and use Somali expressions (Putnam & Noor, 1999). Somali speakers may also use humor based on puns and word play to counter criticism, “save face,” or disentangle themselves from uncomfortable or embarrassing situations (Samatar, 1993). In Somali society, one’s abilities as a leader, warrior, or suitor may depend largely on the ability to speak eloquently and with humor.

Naming convention among Somalis does not include the use of surnames; instead, Somalis typically use three names, their given name and their father’s and grandfather’s given names. These names can be used interchangeably. Additionally, most Somali names connote birth time, birth order, or physical characteristics. For example, first children are often called either Faduma or Mohammed, and male twins are frequently named Hassan and Hussein. Many Somalis have nicknames that are used in public (Putnam & Noor, 1999). Health care workers can inquire about a person’s nickname and verify whether this name should be used. Lastly, women do not change their names at marriage (Lewis, 1996). A list of common Somali names and their meanings is located in Appendix E.

The common way to greet a person is to say *asalamu alaykum* (peace be with you) and, when greeters are of the same gender, to shake hands. (The Islamic tradition that women and men do not touch each other is observed.) Upon departing, the appropriate phrase is *nabad gelyo* (goodbye). Elders are often given respect by being addressed as aunt or uncle, even if they are strangers (Lewis, 1996).

Suggestion



- Recognize that not all persons from Somalia are ethnic Somali. The Bantus, in particular, may have special needs because of their historical marginalization in Somalia and distinct language and culture.
- Remember that some Somalis maintain Islamic traditional norms about handshaking, limiting physical contact to persons of the same sex.

Religion

Islam is the primary religion in Somalia, and the majority of Somalis are Sunni Muslims. Almost all social norms, attitudes, customs, and gender roles among Somalis derive from Islamic tradition (Lewis, 1996). The five pillars of Islamic faith are 1) faith or belief in the Oneness of God and the finality of the prophet Muhammad, 2) prayer five times a day, 3) giving 2.5% of one’s income to charity, 4) making a pilgrimage to Mecca, Saudi Arabia, at least once in one’s lifetime, and 5) fasting from dawn until dusk every day during the period of Ramadan (Samatar, 1993).

Suggestion



- Learn when Ramadan occurs each year and accommodate the observance by suggesting that patients take their medications at night. Usually a person in need of medical care can delay the fast, if required.
- Observant Muslims do not consume alcohol. Consider this when asking routine questions about alcohol consumption when prescribing TB or LTBI treatment.

During the ninth month of the lunar calendar, Muslims, including Somalis, observe Ramadan to mark the initial revelations to the prophet Muhammad (Lewis, 1996). Because the lunar calendar is about 11 days shorter than the calendar used in the United States, Ramadan varies each year, though it will occur in the autumn months until 2020. During the 30 days of Ramadan, people pray and fast between sunrise and sunset. Pregnant women, the ill, and children are exempted from the fast (Lewis, 1996). During this period, Somalis may only take medication at night.



A Somali woman goes to collect water in Kenya.
© 1998 Sammy Ndwiga. Courtesy of Photoshare.

Food and Dress

Although diet varies depending upon geographical region and livelihood, generally the Somali diet is low in calories and high in protein. Pastoral nomads, who are a significant proportion of the Somali population, traditionally eat mostly milk, *ghee* (clarified butter), and meat. As Muslims, Somalis do not consume pork, lard, or alcohol, and all animals must be slaughtered in a specific way, called *xalaal*, to be considered clean. It is customary for Somali family and friends to eat with their hands from the same plate of food and drink from a shared cup (Putnam & Noor, 1999).

One of Somalia's principal imports, *qat* (pronounced chaat or caat), also referred to as *khat*, *quatt*, *kat*, and *tchat*, is a leafy narcotic that originated in Ethiopia and spread to Eastern and Northern Africa. Chewing *qat* has become a cultural phenomenon. Users report euphoria, stimulation, clarity of thought, and increased sociability. The U.S. Drug Enforcement Agency (DEA), however, reports that users' concentration, motivation, and judgment are impaired and that the drug can cause anorexia, hypertension, insomnia, and gastric disorders (U.S. Drug Enforcement Agency, n.d.). In the United States, the DEA classifies *qat*

as an illegal drug that has no accepted medical use and a high potential for abuse. Thus, persons who use *qat* may hesitate to admit it (Lewis, 1996).

Suggestion



- Because sharing meals is an important Somali custom, clarify that having LTBI or noninfectious TB disease need not affect this custom.
- Be aware of the practice of chewing *qat*, a leafy narcotic. Some Somalis may hesitate to initiate TB treatment because they believe they must discontinue chewing *qat* while undergoing treatment. *Qat* may affect one's ability to remember TB medication.

Dress among Somalis is diverse. In formal and public settings, such as work or school, most Somalis wear Western dress. However, traditional dress is generally favored in rural areas and in non-formal settings (Putnam & Noor, 1999). Traditional dress for men consists of two lengths of white cotton wrapped as a skirt and a brightly colored shawl. Men may also cover their heads with a cap called a *benadiry kufia*.

Though women's traditional dress varies, depending upon region, marital status, or religious beliefs, women usually wear a full-length dress or a traditional *guntiino*, which is similar to an Indian *sari*, but made of simple white or red cotton. In cities and in the rural North, women are more likely to wear cotton or polyester dresses or *hejab* over a full length slip (Putnam & Noor, 1999). Married women traditionally cover their heads with scarves, while unmarried women braid their hair. Women in religiously conservative families may wear a veil. These customs are relaxing, however, particularly in the United States, and, with increased urbanization, the distinctions in the dress of married and unmarried women are blurring (Lewis, 1996; Putnam & Noor, 1999). Hand and foot painting using henna or *khidaab* dyes signifies a happy occasion, such as marriage or the birth of a baby (Putnam & Noor, 1999).

Social Structure, Family, and Gender

The family is deeply valued in Somali culture, as are family honor and loyalty. In Somalia, nuclear families usually live together. Approximately one-fifth of the population lives in polygamous (one husband, multiple wives) household situations, with wives having their own residences. Because they are seen as a way to establish clan alliances, marriages traditionally have been arranged, but marriages based on love are increasingly permitted. Preferred gender roles are for men to work outside the home and women to care for children. Though women have important economic roles, it is important for the male to be perceived as the person in control; therefore, viewed from the outside, Somali culture is male-centered. The previous socialist regime made some efforts to improve opportunities for women so that Somali women generally have more freedom to learn, work, and travel than most other Muslim women. Owing to recent war, drought, and male migration, many women are heads of household (Kemp & Rasbridge, 2004; Lewis, 1996; Putnam & Noor, 1999).

In Somalia, family life is also based upon the societal structure of patrilineal clan and subclan membership, and clans often imply ethnic, geographic, and social class orientation. Some ethnic Somali clans include the Benadir, Barawans, Daarood, Dir, Isaaq, Hawiye, Digil, and Raxanweyn (Kemp & Rasbridge, 2004; Lewis, 1996; Putnam & Noor, 1999).

Clans can serve as a source of conflict or solidarity. They often form alliances for protection, access to water, or political power. Though unstable, these alliances are very important to many Somalis and can outweigh their allegiance to a unified country of Somalia (Kemp & Rasbridge, 2004). The importance of family and clan membership is reflected in the comments of one historian, “When Somalis meet each other they don’t ask: *Where are you from?* Rather they ask: *Whom are you from?*” (Putnam & Noor, 1999).



Four Somali sisters and their three brothers in Kenya.
© 1998 Sammy Ndwiga. Courtesy of Photoshare.

As a society, Somalis are fundamentally democratic, though decisions are traditionally made by a council of men, and factors such as age, lineage, wealth, and gender can influence decision making. Egalitarian social relationships are the norm, and it would not be uncommon for a poor, uneducated nomad to feel comfortable approaching a high government official as an equal when discussing state affairs (Putnam & Noor, 1999).

Suggestion



- Consider that the stigma associated with TB may impact a Somali’s sense of family honor, which is an important value in Somali society.
- Recognize the role of family, especially the male head of household, in medical decision making. In some families, it may only be acceptable for the husband or father to speak for a woman.

Common Values

Somalis and people in the United States share many values, such as independence, democracy, individualism, egalitarianism, and generosity. However, Somalis may not express gratitude or appreciation verbally. Somalis are also known to respect strength and pride, and may challenge others to test limits. Sometimes, this can lead others to interpret their demeanor as boasting or opinionated; however, when presented with adequate evidence, Somalis are often willing to reconsider their views (Putnam & Noor, 1999).

Education and Literacy

Before Somalia was colonized, most education was provided by Koranic schools. The colonial era brought Western-style education. The British North mostly trained young men for administrative and technical positions, while the Italian South trained in agriculture, commerce, and maritime studies. Educational opportunities and literacy expanded after the Somali script was made official in the 1970s. Also in the 1970s, the government sponsored literacy campaigns, and primary education was made free. However, secondary education still remained out of reach for most of the population. In 2000, the literacy rate in Somalia was 24% (Putnam & Noor, 1999; U.S. Department of State, 2005).

Socioeconomic Position in the United States

The 2000 U.S. Census reported that 42% of Somalis (16 years of age and older) in the United States were unemployed. Somalis were less likely to have finished high school; 64% had a diploma or equivalent, compared with 80.4% of the U.S. general population. Among Somali families in the United States, 27% had an annual income less than \$10,000. Their median annual income was approximately \$19,000, compared with \$50,000 for the general U.S. population. In 2000, 46% of Somali families lived below the poverty line, compared with 18% of foreign-born persons in the United States and 9.2% of the U.S. general population (U.S. Census Bureau, 2000).

Suggestion



- Do not assume that Somalis can read English or Somali. The Somali script was introduced only in the 1970s and social upheaval severely disrupted education.
- Somalis traditionally do not express gratitude or appreciation verbally. Do not assume that patients are ungrateful if they do not acknowledge gratitude directly.

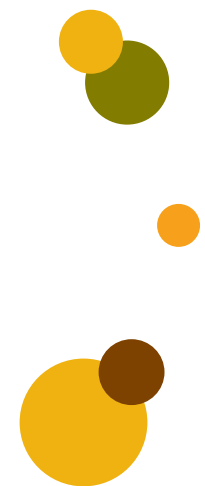
Traditional Health Beliefs and Practices

One traditional health belief among Somalis is that illness can be caused by angry spirits or the “evil eye,” which can stem from excessive praise of someone (i.e., flattery about a person’s beauty can curse the person receiving the compliment). To treat illnesses, Somalis may use extensive herbal medicine traditions or other rituals such as prayer and fire burning, which entails applying to the skin a heated stick from a particular tree (Kemp & Rasbridge, 2004). This procedure is practiced by traditional doctors, or *dhaawayaal*, usually older men in the community who learned their skill from family members. Somalis may seek traditional doctors to treat illnesses and injuries such as hepatitis, measles, broken bones, or other illnesses thought to be caused by spirits (Lewis, 1996).

Most Somalis, especially those from urban areas, have been exposed to Western medicine. When Somalis utilize Western health care systems, they commonly expect to receive medication for every illness. For this reason, Somali patients may be disappointed when nothing is prescribed (Lewis, 1996). Additionally, Somalis often prefer that health care professionals of the same sex treat them; this is due in part to Islamic social norms (Lewis, 1996). Lastly, the concept of preventive medicine may be unfamiliar to Somalis; thus, adherence to preventive measures may be low (Lewis, 1996).

Before their tenth birthday, an estimated 98% of girls in Somalia undergo some form of circumcision, known as female genital mutilation (FGM) or female genital cutting (W. Jones et al., 1997; Toubia, 1994). Circumcision is a common cultural practice that is considered an important rite of passage, a source of pride, and necessary for marriage, as the uncircumcised can be considered unclean (W. Jones, Smith, Kieke, & Wilcox, 1997). The U.S. Department of Health and Human Services notes that FGM is practiced in 28 African countries, including Somalia. The practice also occurs in other parts of the world, including the United States and Canada (The National Women’s Health Information Center, 2005a). The precise prevalence of FGM in the United States is unknown (Center for Reproductive Rights, 2004).

Despite federal legislation in the 1990s to outlaw FGM procedures for girls younger than 18 years of age (“Federal prohibition of female genital mutilation act of 1996,” 1996) and 16 states adopting legislation to target FGM (Center for Reproductive Rights, 2004), evidence suggests that female circumcision is still practiced in the United States. Using the 1990 Census, the Centers for Disease Control and Prevention estimated that 168,000 African girls and women living in the United States either have had the procedure or are at risk (Center for Reproductive Rights, 2004; W. Jones et al., 1997). More recently, the African Women’s Health Center used the 2000 Census to estimate that 228,000 women in the United States either have had FGM or are at risk (The National Women’s Health Information Center, 2005b). Other reports indicate that Somali girls are often sent back to Somalia to have the procedure performed (W. Jones et al., 1997).



Suggestion



- Somalis often expect medication to be given for all illnesses; if none is given, explain the reason why.
- Although many Somalis have been exposed to Western medicine, Somali patients should be educated about preventive care.
- Recognize that female circumcision is an important but sensitive issue for many Somali women. Its illegal status in the United States has led to secrecy, and patients may feel uncomfortable discussing it with Western health care providers.

Chapter 3. The Health of Somalis

Health Statistics at a Glance

Tuberculosis

In Somalia

- In 2005, the estimated tuberculosis (TB) incidence was 224 per 100,000 (WHO, 2007b).
- In 2004, 1.4% of new TB cases were multidrug-resistant (WHO, 2007b).

In the United States

- Among Somalis, 56% of TB cases are extrapulmonary (CDC, 2006c).
- In 2005, 2% of TB cases among foreign-born persons occurred among persons from Somalia (CDC, 2006b).

HIV/AIDS

- In Somalia, the prevalence of HIV/AIDS in adults is 1% (WHO, 2004).
- HIV prevalence among TB patients in Somalia may be as high as 7% (WHO, 2002).

Tuberculosis Among Somalis

In Somalia

Because of the war and ongoing civil unrest, the health of Somalis deteriorated rapidly after 1990. The high incidence of disease, including TB, malaria, and other infectious and parasitic diseases, persists today. TB kills an estimated 12,000 people each year in Somalia. In 2005, the estimated incidence of TB was 224 per 100,000, while the prevalence was 286 per 100,000 (WHO, 2007b).

More than 50% of the Somali population is estimated to be infected with *Mycobacterium tuberculosis* (Kempainen, Nelson, Williams, & Hedemark, 2001; Laughlin & Legters, 1993; Oldfield, Rodier, & Gray, 1993). Additionally, some groups within Somalia may have a higher incidence of TB, such as the nomadic and semi-nomadic populations, estimated to be 40%–60% of the Somali population (U.S. Department of State, 2005). These groups are more difficult to treat than urban Somalis because of their migratory lifestyles (Samatar, 1993).

Although the World Health Organization (WHO) estimates that population coverage with directly observed treatment short-course (DOTS) is high, the case detection rate is 68% (WHO, 2007b). One study in Somalia found that physicians who treated TB patients often had poor knowledge of TB symptoms and appropriate treatment regimens. Additionally, private practitioners had suboptimal knowledge of proper diagnostic procedures (Suleiman, Houssein, Mehta, & Hinderaker, 2003).

Owing to Somalia's instability, many people do not have access even to basic health services. These factors, combined with poor infrastructure and migratory lifestyles, may contribute to an environment conducive to the development of drug resistance. According to WHO reports, 1.4% of all TB cases in Somalia in 2004 were multidrug-resistant, defined as resistant to at least isoniazid and rifampin (WHO, 2007b).

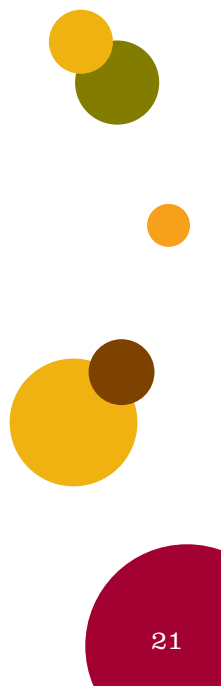
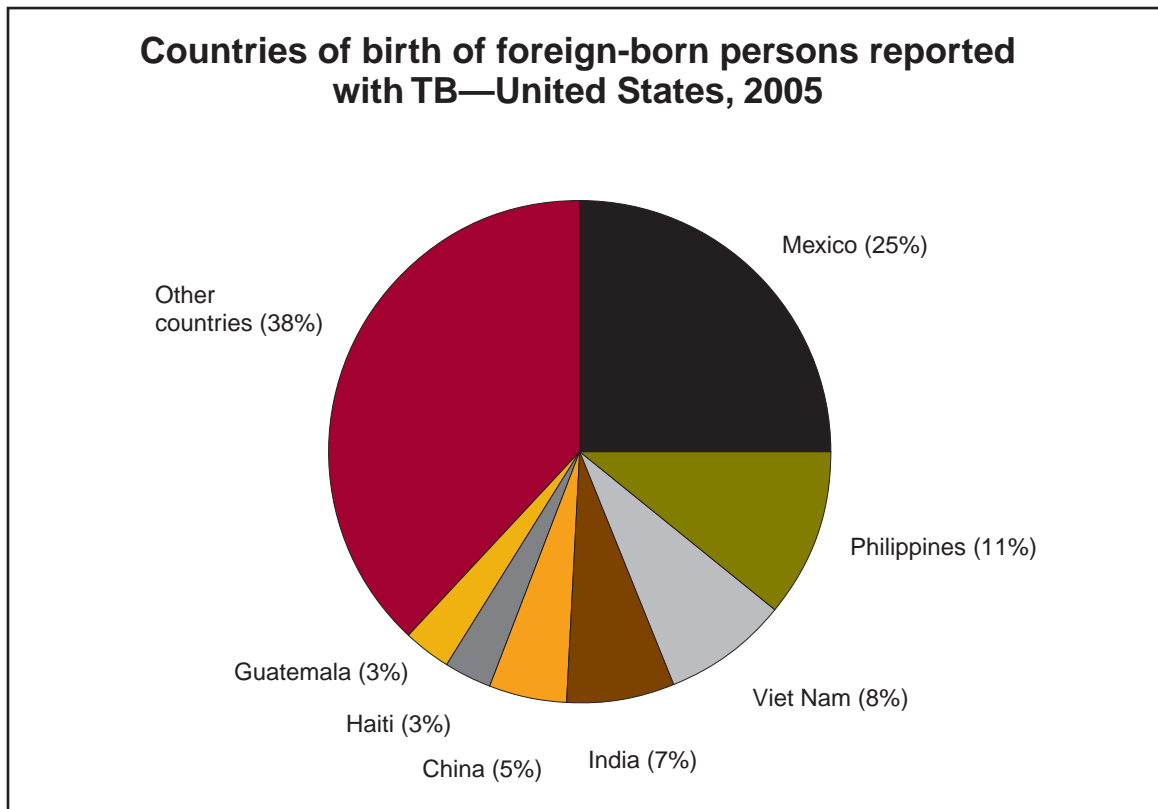


Figure 3-1.



Source: CDC Tuberculosis Surveillance Reports.

In the United States

Although previous exposure in Somalia is a common source of *M. tuberculosis* infection, other factors, such as poverty, overcrowding, and limited medical resources, contribute to the large TB burden among Somalis in the United States (Kempainen, Nelson, Williams, & Hedemark, 2001). In 2005, persons from Somalia comprised 2% (n=147) of TB cases among all foreign-born persons in the United States (CDC, 2006b).

During 2000–2004, the TB case count was 709, and of those cases, 9% were determined to be resistant to isoniazid, and 56.4% were extrapulmonary. In 2005, 45% of reported adult TB cases among Somalis (n=126) occurred among those who had been in the United States for less than 1 year, 24% for 1–4 years, and 25% for 5 or more years. For the remainder, the number of years in the United States prior to diagnosis was unknown (CDC, 2006b). Please see Appendix F for information on the 2007 Technical Instructions for Tuberculosis Screening.

Bacille Calmette-Guérin

Bacille Calmette-Guérin (BCG) is used in many parts of the world as a vaccine against TB. In Somalia in 2006, BCG vaccine coverage at birth was 50% (WHO, 2007a). Post-vaccination tuberculin reactivity is not an indicator of the protective efficacy of BCG vaccination, because it is not an indicator of immunity to *M. tuberculosis*. Reaction to a tuberculin skin test (TST) caused by BCG vaccination wanes rapidly in individuals who receive the vaccine in the neonatal period and more slowly in those vaccinated at an older age (Menzies, 2000).

The Centers for Disease Control and Prevention's current TB testing guidelines state that a positive reaction to tuberculin in BCG-vaccinated persons indicates infection with *M. tuberculosis* when the person tested is at increased risk for recent infection or has medical conditions that increase the risk for disease. (See Table 7 in the June 09, 2000 *MMWR* for criteria for tuberculin positivity.)* Therefore, a history of BCG vaccination should not influence decisions about treatment of latent TB infection (LTBI) (CDC, 2000).

Tuberculosis-related Health Issues

Understanding other health issues affecting the lives of Somali patients provides critical information for TB care providers. Conditions that can increase the risk of LTBI progressing to TB disease include the following (CDC, 2004):

- HIV/AIDS.
- Previous TB (in a person who received inadequate or no treatment) indicated by chest radiograph findings.
- Prolonged corticosteroid therapy and other immunosuppressive therapy.
- Recent infection with *M. tuberculosis* (within the past 2 years).
- Substance abuse (especially intravenous drug use).
- Silicosis.
- Diabetes mellitus.
- End-stage renal disease.
- Cancer of the head and neck.
- Hematologic and reticuloendothelial diseases.
- Intestinal bypass or gastrectomy.
- Chronic malabsorption syndromes.
- Low body weight (10% or more below ideal).

Of these conditions, those that are most relevant to Somalis are further explored here.

* Centers for Disease Control and Prevention. (2000). *MMWR Weekly: Targeted tuberculin testing and treatment of latent tuberculosis infection*. Retrieved November 8, 2007, from <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr4906a1.htm>.

HIV/AIDS

Once a person is infected with *M. tuberculosis*, HIV infection is the strongest known risk factor for developing TB disease. While the average probability of progressing from TB infection to disease is less than 10% over the lifetime of a person not infected with HIV, the risk is 5%–8% per year for those who are HIV-infected and not on Highly Active Anti-Retroviral Therapy (HAART) (Markowitz et al., 1997; Selwyn et al., 1989), a combined use of several antiretroviral drugs that inhibits the ability of the virus to multiply in the body (National Cancer Institute, n.d.).

The effect of HAART on the progression from TB infection to TB disease is not well understood (Markowitz et al., 1997; Selwyn et al., 1989), though some evidence indicates that it may have a protective effect on the risk of developing TB (Badri, Wilson, & Wood, 2002; Girardi et al., 2000; Girardi et al., 2004; Jones, Hanson, Dworkin, & DeCock, 2000; Santoro-Lopes, Felix de Pinho, Harrison, & Schechter, 2002). In addition, research suggests that active TB disease accelerates the course of untreated HIV infection, which may lead to more opportunistic infections and earlier death (Lopez-Gatell et al., 2007; Thomas, 2006; Whalen et al., 1995; Whalen et al., 2000; Zar et al., 2007).

The degree to which the pan-African HIV epidemic has permeated Somalia is difficult to judge because of the fragmented health services, the lack of public health surveillance, and the social stigma associated with the disease. However, several small-scale studies suggest that the HIV/AIDS rates are lower in Somalia than in other East African nations. WHO estimates that the prevalence of HIV among adults was about 1% in 2003. These calculations were made on the basis of previously published estimates and recent trends in HIV surveillance in various Somali populations (WHO, 2004). In 1999, a special study among TB patients in Somalia found an HIV prevalence of 6.9% among the 641 screened (WHO, 2002). Even though the prevalence of HIV is lower in Somalia than in neighboring countries, population mobility and the return of refugees from camps in Ethiopia and Djibouti increase the HIV threat to Somalis (WHO, n.d.).

Because statistics are reported by race and not country of birth, the rates of HIV/AIDS among Somalis in the United States are unknown. Black, non-Hispanic (the category into which Somalis are placed) comprise about 40% of the total diagnosed AIDS cases (CDC, 2005). Table 3-1 presents the estimated number of diagnosed AIDS cases in the United States in 2005 and cumulatively since the beginning of the epidemic.

Substance Use

Both TB and drug use are prevalent in crowded, low-income areas. As a result, drug users are 2–6 times more likely to contract TB than nonusers (CDC, 2004). WHO has suggested that *qat*, a leafy narcotic particularly popular among men in Eastern and Northern Africa, may be one reason why one-third more men develop TB than women. Chewing sessions usually take place in crowded huts with poor ventilation. Further, the woody stalks are an appetite suppressant, which WHO indicates may lead chewers to become malnourished and susceptible to infections (WHO, 2000).

Table 3-1. Total AIDS cases in the United States by race/ethnicity

Race/Ethnicity	Estimated AIDS cases in 2005	Cumulative estimated AIDS cases through 2005	Percentage of total AIDS cases	Rate per 100,000 population
White, non-Hispanic	11,780	385,537	39.1	5.9
Black, non-Hispanic	20,187	397,548	40.4	54.1
Hispanic	7,676	155,179	15.8	18.0
Asian/Pacific Islander	483	7,659	0.8	3.6
American Indian/Alaska Native	182	3,238	0.3	7.4

Special Issue

Mental Health

Among refugees, the trauma associated with war, torture, rape, mass violence, severe poverty, and famine has long been associated with mental illness. Refugees may experience post-traumatic stress, anxiety, depression, and somatization (in which anxiety is expressed physically) (Jaranson et al., 2004; Palinkas et al., 2003). Furthermore, once refugees have relocated to the United States, social isolation, feeling a lack of control over one's life, and social degradation may compound the risk for depression and anxiety. The largest U.S. study to examine social and psychological problems among Somali and Oromo (an ethnic group from Somalia and Ethiopia) refugees found that 44% (502/1134) had been exposed to torture (Jaranson et al., 2004). Torture, which was experienced equally among men and women, was associated with social and psychological problems, including post-traumatic stress disorder. Another qualitative study found that substantial anxiety and depression resulted from living for long periods in refugee camps and having little hope for the future (Stutters & Ligon, 2001).

Suggestion



- A poor health service infrastructure, combined with inappropriate treatment regimens, may contribute to the development of drug resistance. Ask patients about previous TB treatment and perform drug susceptibility testing whenever possible.
- Consider the effect of mental illness on a patient's desire or ability to take treatment for TB disease or latent TB infection.
- Be mindful that over half of TB cases among Somalis in the United States are extrapulmonary.

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).

Conclusion

To meet the challenge of controlling tuberculosis (TB) in the United States, the care and treatment of all patients should be appropriate and effective, regardless of country of origin, language, or cultural factors. That entails not only addressing the linguistic and cultural needs of populations with or at risk for TB, but also focusing on the individual's perspective. This guide is intended to provide an understanding of the social and cultural setting from which some Somali patients may come. It is not meant to stereotype or stigmatize; on the contrary, the authors of this guide fully recognize and appreciate the rich diversity of the myriad groups who have settled in the United States.

This guide aims to remind TB care providers that culture does matter in the clinic and that they too bring a cultural perspective to the patient-provider relationship. Providing effective TB care involves taking the time to learn from patients what is important to them personally in the experience of illness and treatment. In the words of Arthur Kleinman, ascertaining “what is at stake” for the individual will provide crucial information to use in tailoring the treatment plan. Being “Somali” may not be a significant issue to a patient; being responsible for the care of multiple family members and juggling two part-time jobs without health insurance may. In short, focusing on the patient as an individual and maintaining open, two-way communication will foster effective TB care.



Appendix A. Using Kleinman's Questions to Understand Patients' Perceptions of Tuberculosis

While this guide encourages a broad understanding of Somali culture, it is also essential to remember that each individual has personal beliefs. Several methods exist to help health care providers understand how an individual thinks about his or her own health problems. One method is to use a series of questions developed by medical anthropologist Arthur Kleinman (CDC, 1999; Kleinman, 1986). These questions, which have been tailored to tuberculosis (TB) here, can help provider see the illness from the patient's point of view by eliciting the patient's understanding of TB—its name, cause, timing, effects, severity, and treatment.

These questions also address the fears a patient may have, how TB may impact the patient, and the effects TB may have on his or her family or friends. Health care providers can use these questions to discuss TB with patients. The questions also can be adapted to address issues related to latent TB infection. These questions may be incorporated into an existing health assessment or an ongoing assessment of a patient's educational needs and treatment adherence. Questions can be reworded in accordance with a patient's cultural, linguistic, and educational backgrounds. The number and sequence of the questions also can be tailored to the circumstances.

Suggestion



Use Kleinman's questions to understand your patients' perceptions of TB.

- What do you call your illness (the problem)?
- What do you think causes TB?
- Why do you think you got sick when you did?
- What do you think TB does to your body?
- How severe is your sickness?
- What kind of treatment do you think you should receive?
- What are the most important results you hope to receive from this treatment?
- What are the main problems TB has caused?
- What do you fear most about TB?
- How do your family members or close friends feel about you having TB?



Appendix B. Tips for Working with Interpreters

A good interpreter is able to communicate effectively across cultures and convey important nuances. The most effective interpreters have been trained and assessed for active listening skills and for the ability to extract meaning and use descriptions when there are no language equivalents (CDC, 2006a). Whenever possible, make an effort to match the sex, general age, and social class of the patient and interpreter. In general, avoid using family members as interpreters, especially if sensitive topics are being discussed. An unknown third party may better be able to maintain confidentiality and provide unbiased communication (CDC, 2006a).

When communicating through an interpreter, speak slowly and clearly. Use a positive tone of voice that conveys your interest in the patient. Face the patient, not the interpreter. Speak in short units of speech, allowing sufficient time for the interpretation. Avoid medical terminology or professional jargon, as well as slang and idiomatic expressions. Clear, simple, lay language is generally most effective.

Encourage the interpreter to translate the patient's words as closely as possible and not to paraphrase, polish, or omit anything that may result in loss of the patient's true meaning. Be aware of nonverbal communication such as silence, distance between individuals, eye contact, emotional expressiveness, and body movements (CDC, 2006a). You may wish to ask the interpreter for clarification of the meaning of any nonverbal cues to be sure you have understood correctly any cross-cultural meaning. Above all, be patient: careful interpretation often takes considerable time.

Appendix C. Tuberculosis and Cultural Competence Resources

The following resources contain additional information on tuberculosis (TB) education and culturally competent care. See Appendix G for additional references used in the guide. Web site addresses for nonfederal organizations are provided solely as a service to the users of this guide; the Centers for Disease Control and Prevention (CDC) is not responsible for their content. Provision of these addresses does not constitute an endorsement of any organization by CDC or the federal government, and none should be inferred. At the time this guide went to press, all links were active.

General Tuberculosis Resources

Centers for Disease Control and Prevention, Division of Tuberculosis Elimination

<http://www.cdc.gov/tb>

This Web site is for health care professionals, patients, and the general public. The site can be used to search for TB guidelines, surveillance reports, education and training materials, and other TB-related Web links and resources.

Office of Refugee Resettlement, U.S. Department of Health and Human Services, Administration for Children and Families

<http://www.acf.hhs.gov/programs/orr>

This Web site outlines the types of refugee assistance provided by the U.S. government. It also contains retrospective data about countries of origin and destination states.

Tuberculosis Education and Training Resources

<http://www.findtbresources.org>

This Web site is for health care professionals, patients, and the general public. The site can be used to search for TB education and training materials in various languages and to locate TB-related Web links.

Resources For Somali Patients

EthnoMed

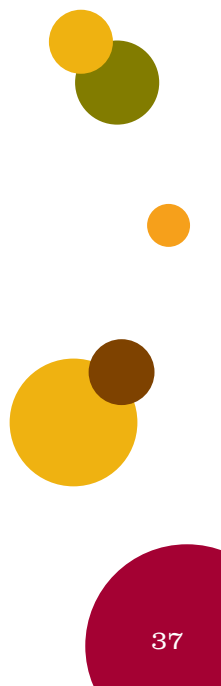
http://ethnomed.org/patient_ed/somali/som_tb_index.html#summary

This 17-minute audio recording is a conversation between five Somali friends who have gathered to celebrate the naming of a baby. Through discussion, younger participants learn from an elder the difference between active TB and latent TB infection (LTBI) and the medical rationale for taking LTBI treatment.

Healthy Roads Media

<http://www.healthyroadsmedia.org>

This Web site contains free multimedia health education materials in a number of languages, including Somali. Titles of materials include, “Do I Need a TB Test?,” “TB and BCG,” “STOP TB Infection Before It Makes You Sick,” “TB Disease: You Need Treatment To Make You Well,” and “TB and HIV: A Dangerous Partnership.”



Tuberculosis and One Man's Story

<http://www.health.state.mn.us/divs/idepc/diseases/tb/videos.html>

This 26-minute video was produced by the Minnesota Department of Health Tuberculosis Program. Ordering information is available on the Web site. Through an engaging story, the video addresses the fear and stigma associated with TB in the Somali culture, describes the symptoms of TB disease, explains how TB is transmitted, clarifies the difference between TB disease and LTBI, and stresses the importance of working with physicians and other health professionals. The video is in Somali and comes with an English translation.

Tuberculosis Fact Sheets in Somali

<http://www.health.state.mn.us/divs/idepc/diseases/tb/factsheets/translations.html#somali>

This series of fact sheets in Somali is available through the Minnesota Department of Health Tuberculosis Program. The five fact sheets provide general information about TB, including symptoms, complications, tests, and treatment; LTBI treatment and the prevention of TB disease; what a TB contact investigation is and why it is important; step-by-step directions for giving a sputum sample; and how the skin test is given and read and what the results mean.

Tuberculosis Fact Sheets in Somali

http://www.bphc.org/bphc/pdfs/tb/cdc_tb_positive-tb-what-is-tb_somali.pdf

These two fact sheets in Somali are available through the Boston Public Health Commission. The titles are “TB Skin Test” and “What Is TB.”

Virginia Division of Tuberculosis Control

<http://www.vdh.virginia.gov/epidemiology/DiseasePrevention/Programs/Tuberculosis/Patients/brochureLanguage.htm>

This Web site offers Somali language brochures about TB. Titles include “Do I Need a TB Skin Test?,” “Just the Facts About BCG and TB,” “Stop TB Infection Before It Makes You Sick,” “TB and HIV: A Dangerous Partnership,” “TB Disease: You Need Treatment To Make You Well,” “What Is a TB Skin Test?,” and “What You Should Know About Taking Tuberculosis Medicines.”

Resources For Providers

The American Medical Association

<http://www.ama-assn.org>

<http://www.ama-assn.org/ama/pub/category/6759.html>

The American Medical Association offers a *Cultural Competence Compendium*, a 460-page resource guide, to help physicians and other health professionals communicate with patients and provide individualized, respectful, patient-centered care. Selected sections of the book are available at the Web site.

The Center for Cross-Cultural Health

<http://www.crosshealth.com>

The Center for Cross-Cultural Health has produced materials to guide communities faced with the challenge of providing culturally competent care. Sample language policies, guidelines for working with interpreters, instruments to help measure an organization's cultural competency, and lists of translated health education materials are available.

Cough It Up!<http://www.dshs.state.tx.us/lab>

This videotape, available at the Texas Department of State Health Services' Web site, provides information about how to supply health care providers with a sputum sample.

Culturally and Linguistically Appropriate Services in Health Care<http://www.omhrc.gov/clas>

The National Standards on Culturally and Linguistically Appropriate Services (CLAS), the CLAS Standards, makes recommendations for national standards for culturally and linguistically appropriate services in health care. Based on an analytical review of key laws, regulations, contracts, and standards currently in use by federal and state agencies and other national organizations, these standards were developed with input from a national advisory committee of policy makers, health care providers, and researchers. Each standard is accompanied by commentary that addresses the proposed guidelines' relationship to existing laws and standards and offers recommendations for implementation and oversight to providers, policy makers, and advocates.

CulturedMed<http://culturedmed.sunyit.edu/index.html>

CulturedMed is a Web site promoting culturally competent health care for refugees and immigrants. The library also houses a research center containing relevant print materials. The bibliographies and links found on the Web site contain items that discuss health beliefs or ethnographic information about various ethnic groups.

DiversityRx<http://www.diversityrx.org>

DiversityRx is a clearinghouse of information on how to meet the language and cultural needs of minority, immigrant, refugee, and other populations seeking health care.

EthnoMed<http://www.ethnomed.org>

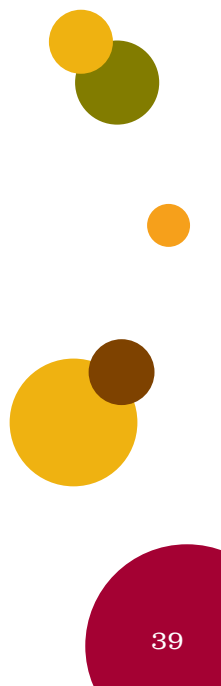
The EthnoMed Web site hosted by Harborview Medical Center, University of Washington, Seattle, contains information about cultural beliefs and medical issues pertinent to the health care of recent immigrants to Seattle, many of whom are refugees fleeing war-torn parts of the world.

Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons<http://www.hhs.gov/ocr/lep/reviselep.html>

This Web site offers guidance to help federally funded programs comply with regulations affecting people with limited English proficiency.

Linguistic and Cultural Aspects of Tuberculosis Screening and Management for Refugees and Immigrantshttp://ethnomed.org/ethnomed/clin_topics/tb/tb.html

This site presents the transcript of a presentation that focused on TB screening, management of active cases, and linguistic and cultural differences between Western and non-Western approaches to medicine.





Refugee Health Information Network

<http://www.rhin.org>

The Refugee Health Information Network is a database of multilingual public health resources for refugees, asylees, and their health care providers. Available resources include health education materials in various languages and formats (including brochures, fact sheets, and videos), information on populations and cultural competence for providers, and links to a variety of Web sites.

Tuberculosis and Cultural Competency: Notes from the Field

<http://www.umdnj.edu/globaltb/start.html>

This newsletter was developed to provide an ongoing educational forum for cultural competency training. The content includes a “teaching case” that reflects the experiential knowledge of health care providers working in TB, as well as relevant information and resources for culturally proficient skills development. The newsletters, which are published twice annually, are available on the Web site of the New Jersey Global Tuberculosis Institute under “Product List A–Z.”

Title VI of the Civil Rights Act of 1964

<http://www.hhs.gov/ocr/discrimrace.html>

This Web site provides information regarding the Civil Rights Act of 1964. The Office for Civil Rights (OCR) within the U.S. Department of Health and Human Services (HHS) is responsible for enforcing the nondiscrimination requirements of Title VI of the Civil Rights Act of 1964. It applies to covered entities under the jurisdiction of OCR. This jurisdiction includes entities that conduct programs or activities that receive federal financial assistance from HHS.

Tuberculosis Training and Education Network

<http://www.cdc.gov/tb/tbetn/default.htm>

The Tuberculosis Training and Education Network (TB ETN) was formed to bring TB professionals together to network, share resources, and build education and training skills. Members include representatives from TB programs, correctional facilities, hospitals, nursing homes, federal agencies, universities, the American Lung Association, Regional Training and Medical Consultation Centers, and other U.S. and international organizations interested in TB education and training issues. TB ETN’s Cultural Competency Subcommittee has developed a cultural competency resource list that is available to health care professionals.

Appendix D. Centers for Disease Control and Prevention Study Summary

A total of 52 persons born in Somalia were selected to participate in the 2003 Centers for Disease Control and Prevention (CDC) study of tuberculosis (TB). These respondents were distributed among two study sites and involved public TB clinics administered by the state or local health department. The sites were recruited on the basis of local epidemiology, interest, and ability to participate. To elicit a range of responses, both TB patients and people recruited directly from the community (i.e., people who were not patients at the local TB clinic) were included.

In the CDC study, sites played an active role in choosing which foreign-born groups to recruit for the study. In general, CDC aimed to include the same group in two sites to facilitate analysis of the influence of local context on participant responses. Although this guide focuses on data from Somalis, four other groups included in the overall study were Mexicans, Vietnamese, Lao Hmong, and Chinese.

Study Population and Participant Recruitment

In DeKalb County, Georgia (Atlanta) and Ramsey County, Minnesota (St. Paul), participants born in Somalia were chosen by the study site staff to participate. This decision reflected the local epidemiological trends, as well as the need for TB-specific ethnographic information regarding this population.

This study used a convenience sampling strategy. In addition to country of birth, specific criteria and informal quotas for specific subgroups were identified, with local circumstances determining final sampling. The sample criteria were as follows:

- Persons aged 18 years or older.
- Persons residing within the area served by the local health department.
- Only one respondent per household.
- Approximately 50% of respondents with fewer than five years' residency in the United States.

Participants were recruited either through the community contacts of the bilingual, bicultural researchers (50%) or through recruitment of TB clinic patients by clinic staff (50%). The clinics recruited a balance of patients who 1) had a negative tuberculin skin test, 2) had received a diagnosis of latent TB infection (LTBI), or 3) had received a diagnosis of TB disease. The combination of quota and snowball sampling strategies was not random, but instead followed methodology appropriate to qualitative research. The demographics and TB status of the Somali study group are presented in Tables D-1 and D-2.

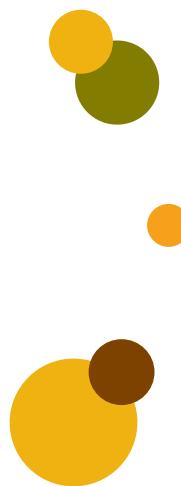


Table D-1. Description of Somali cohort

	N = 52, n (%)
Recruited from clinic/health department	26 (50)
Age at interview (mean, range)	39, 18–66
18–24	9 (17)
25–44	25 (48)
45–64	16 (31)
≥65	2 (4)
Years in United States (mean, range)	6, 0–23
1–4 years	24 (46)
≥5 years	28 (54)
Female	30 (58)
From urban area	32 (62)
Completed high school	37 (71)
English speaking	30 (58)
English literate	35 (67)
Any language literate	42 (81)

Table D-2. Tuberculosis (TB) status of Somali cohort

	N = 52, n (%)
Screened*	50/52 (96)
TB disease diagnosis	1/50 (2)
Started TB treatment	1/1 (100)
Completed or currently on TB treatment	1/1 (100)
LTBI [†] diagnosis	30/50 (60)
Started LTBI treatment	21/30 (70)
Completed or currently on LTBI treatment	17/21 (81)

* Screened by one or more methods, such as tuberculin skin test, chest radiography, symptom screening, or sputum.

[†] Latent TB infection.

Appendix E. Common Somali Names and Meanings

The following table includes a list of common Somali names and their meanings. Most Somali names have meanings that connote birth time, birth order, or physical characteristics. By no means is this list meant to be comprehensive. Rather, it is intended to give practitioners an idea of the types of names that their Somali patients may have.

Girls' names	Meanings	Boys' names	Meanings
Aasha	Long living, after the wife of the Prophet	Abdullah	Slave of God, father of the Prophet
Adey	Fair-skinned	Abukar	Father of Bukar, after the first Khalif
Alaso	Smooth, fair-skinned	Adam	Father of humanity, after the first man
Ambro	Of amber	Ali	The high, after the fourth Khalif
Awa	Lucky, optimistic	Arale	Clean
Awrala	Without blemish	Awaale	Lucky
Basr	The town of Basra, associated with sweet dates	Bahdoon	The one who looks for his clan, born away from home
Faadumo	Weaned early, after the daughter of the Prophet	Guleed	The victorious
Fathia	Opener of fortune	Gutaale	Leader of armies
Fawzia	Successful	Hassan/Hussein (names for twins)	Handsome, after the grandchildren of the Prophet
Haweeya	The elevated one	Khalid	Lasting, after an Islamic military leader
Hodan	Well-to-do	Mohammed	One worthy of thanks, after the Prophet
Leyla	Night, long dark hair	Omar	Long living, after the second Khalif
Magol	Early flowering	Othman	After the third Khalif
Maka	The town of Mecca	Samakab	Supporter of right
Mariam	Mother of Jesus (Mary), also a section in the Koran	Samatar	Does good
Sagal	Morning star	Waabberi	Sunrise, born in early morning
Sahra	Flower		
Sufia	Pure		
Ubah	Flower		

Appendix F. Tuberculosis Screening Policies for Persons Overseas

This section is adapted from the 1991 “Technical Instructions for Medical Examination of Aliens” issued by the Immigrant, Refugee, and Migrant Health Branch of the Division of Global Migration and Quarantine (DGMQ), Centers for Disease Control and Prevention (CDC) (CDC, 1991). As new 2007 technical instructions are being applied to specific groups over time, please contact CDC’s Immigrant, Refugee, and Migrant Health Branch of DGMQ at 404-498-1600 for up-to-date information. You may also access <http://www.cdc.gov/ncidod/dq/technica.htm>.

Technical Instructions for Tuberculosis Screening

A medical examination, which includes screening for tuberculosis (TB), is mandatory for all refugees entering the United States and for all applicants outside the United States applying for an immigrant visa. Aliens in the United States who apply for adjustment of their status to permanent resident also require an examination. Aliens applying for nonimmigrant visas (temporary admission) may be required to undergo a medical examination at the discretion of the consular officer overseas or immigration officer at the U.S. port of entry if there is reason to suspect that an inadmissible health-related condition exists.

CDC’s DGMQ provides the technical instructions and guidance to panel physicians conducting the medical examination. If an immigrant or refugee has an inadmissible health-related condition, a waiver is required for the applicant to enter the United States. This also applies for an applicant who is in the United States and applying for adjustment of status to permanent resident. Section 212(g) of the Immigration and Nationality Act provides for the waiver of health-related grounds of inadmissibility.

Table F-1. Requirements for tuberculosis evaluation

Procedure	Required for
Review of history	All applicants.
Chest radiograph	All applicants 15 years of age or older. Applicants 15 years of age or younger whose skin test is positive (see below).
Tuberculin skin test	Applicants 15 years of age or younger who are suspected of having TB or who have a history of contact with a known TB case.
Sputum smear examination	Any applicant with a chest radiograph suggestive of clinically active pulmonary TB.

NOTE:

- Pregnant women with symptoms suggestive of active TB must receive a chest radiograph. If the radiograph is compatible with active TB, sputum smears must be obtained.
- Applicants whose chest radiographs show only calcified granuloma, calcified primary complex, calcified lymph node, or fibrosis, scarring, or pleural thickening with no radiologic or clinical evidence of active TB are not required to have sputum smears.

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