



TUBERCULOSIS CASE MANAGEMENT:

A GUIDE FOR NURSES

RUTGERS

Global Tuberculosis
Institute

NEW JERSEY MEDICAL SCHOOL

TUBERCULOSIS CASE MANAGEMENT:

A GUIDE FOR NURSES

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The Global Tuberculosis Institute wishes to acknowledge the following individuals for their valuable contributions:

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Document Prepared By

Nisha Ahamed, MPH; Anita Khilall, MPH; Patricia Woods, MSN, RN

Case Study Contributors

Providing Patient-Centered Care: Danielle Weber, MS, RN

Medically Complex TB in a Child: Lillian Pirog, RN, PNP; Suzanne Tortoriello, MSN, RN, APN-C

Coping with a Dual Diagnosis: Dianne Fyffe-Washington, BSN, RN

TB in a Patient Experiencing Homelessness: Midia Fulano, MPH, BSN, RN; Sarah Koch, BSN, MS, RN; Helen Townsend, MPH, RN

TB in a Recently Incarcerated Patient: Ellen Murray, PhD, BSN

Reviewers

Carolyn Bargman, MA, RN-C

Rajita Bhavaraju, PhD, MPH

Marybeth Caruso, RN, FN-CSA

Janet Cashman, RN-BC

Sally Cook, RN

Dorothy Freeman, MSN, RN

Karen Galanowsky, MPH, BSN, RN

Shirlee Hasstedt, BSN, RN

Cherie Helfrich, MSN, RN

Laurie Hickstein, MPH, BSN, RN

Patricia Iyer, MSN, RN, BC

Lynette Leviste, BSN, PHN

Amy Lewis, MPH, MCHES

DJ McCabe, MSN, RN

Mary Ellen Moskowitz, BSN, PHN

Maureen Murphy-Weiss, BSN, RN, CPM

Ma Kine Min Naing, BSN, RN, PHN

Eileen Napolitano, BA

Larry Niler, MS, RN, CIC

Lillian Pirog, RN, PNP

Eva Reeder, BSN, PHN

Karen Smith-Sayer, MSN, RN

Debra Stephens, MPH, BSN, RN

Suzanne Tortoriello, MSN, RN, APN-C

Kimberly Townsend, MPA, BSN, RN

Danielle Weber, MS, RN

Needs Assessment Participants: Sally Cook, RN; John Caban, BSN; Maria Dalbey, MA, MBA, BSN, RN, RT (AART); Maureen Donovan, MGA, BSN, RN; Mimi Ford, RN, CCRN; Elizabeth Foy, BSN, BA; Karen Galanowsky, MPH, BSN, RN; Maryann Kuras, BA, RN; Karen Martinek, MPH, BSN, RN; Debbie Onofre, BSN, RN; Michele Roth, BSN; Esther Rudnick, BSN, RN; Judith B. Thomas, BSN, RN; Julie Tomoro, BSN, RN; Kimberly Townsend, MPA, BSN, RN; Christine Treadway, BS, CCM, ACLS, BLS; Elizabeth Zeringue, MPH, BSN, RN

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Graphic Design: Judith Rew

ORIGINAL EDITION: 2001

Original document prepared by: Minnie Campbell, DNSc, RN; Karen Galanowsky, MPH, BSN, RN; Debra Kantor, PhD; DJ McCabe, MSN, RN; Lillian Pirog, RN, PNP; Suzanne Tortoriello, MSN, RN, APN-C

Reviewers: Jo-Ann Arnold, RNC, BSN, MS; Judy Gibson, MSN, RN; Marty Huber, MPH, RN; Patricia J. Moulton, PhD, RN

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INTRODUCTION

According to the World Health Organization (WHO), health is “a state of complete physical, mental, and social well-being and not merely the absence of disease” (2017). This encompassing definition is implicit in the discipline of public health, which is the science and art of preventing disease, prolonging life, and promoting health. Looking at the definition from a holistic perspective, the Institute of Medicine defined public health as “what we, as a society do, collectively, to assure the conditions in which people can be healthy” (Institute of Medicine Committee for the Study of the Future of Public Health, 1988).

For tuberculosis (TB) nurse case managers, the focus of nursing practice is the individual sick with TB, and his or her impact on the health status of individuals, families, and groups who live and work in their respective community. The nurse case manager applies fundamental concepts of public health, including social, economic, ecologic, and global factors to facilitate all aspects of TB care and improve and protect the health of the individual and the greater community.

This document, *Tuberculosis Case Management: A Guide for Nurses*, was developed by the Global Tuberculosis Institute at Rutgers, The State University of New Jersey as a guide for staff at agencies or facilities who utilize or wish to implement a TB nurse case management system. The guide is designed to provide the reader with an understanding of the nurse case management process and how it is applied both when caring for patients with TB and in ensuring appropriate practices in TB prevention and control in the community. It focuses on the rationale for, and activities of TB case management for nurses, and is not intended to provide complete information on TB or TB nursing. We recommend that readers have a thorough understanding of the TB disease process, etiology, pathogenesis, diagnosis, treatment, and related nursing activities for TB infection and TB disease, as well as TB contact investigation, all of which inform the TB case management activities carried out by nurses.

The primary audience for this guide is nurses working within local or state public health settings (e.g., state or local health departments or chest clinics) who are, or will be, responsible for case management of patients with TB disease and TB infection (which is sometimes called latent TB infection or LTBI). Since the guide is intended for nurses, the terms nurse case manager and case manager are used interchangeably.

The guide was initially published as a set of self-study modules. To address the current epidemiology of TB in the United States (US) and challenges faced by TB nurse case managers today, this edition has been updated to include a new section on nurse case management approaches and interventions for specific groups or populations.

The guide is organized into three sections as follows:

Chapter 1: Fundamentals of Tuberculosis Nurse Case Management

This chapter describes core functions of public health, the nursing process, and case management as well as the key activities of TB case management. Brief information on contact investigation, collaborating with community providers, and delegation is also included.

Chapter 2: Providing Patient-Centered Tuberculosis Care

This chapter focuses on patient-centered TB care and describes strategies and approaches to improve adherence. A case study highlights patient-centered TB case management.

Chapter 3: Tuberculosis Nurse Case Management in Special Situations and Circumstances

This chapter provides information and case studies on TB in selected situations and circumstances, ranging from TB in people experiencing homelessness to those with TB and diabetes. Specific considerations in TB nurse case management for each co-morbidity or situation are identified, with a focus on practical approaches. A brief introduction regarding the condition and its impact on or interaction with TB is included, but this is not intended provide complete information on diagnosis, management, and treatment of TB in these situations.

Each chapter also includes appendices (e.g., tools, forms, or supplemental information) and a resource list.

The case studies included in this guide were provided by practicing public health nurses and present the activities and interventions implemented by those nurses within their TB program. The cases are intended as examples of effective TB case management. However, guidelines and practices vary by jurisdiction, so these activities may not be consistent with practices in other TB programs. TB nurse case managers utilizing this guide should follow the rules and regulations within their state or local TB program and should be familiar with national guidelines for the diagnosis and management of TB, which can be accessed at: [cdc.gov/tb/publications/guidelines/default.htm](https://www.cdc.gov/tb/publications/guidelines/default.htm)

The “Tricks of the Trade” included in the guide were also contributed by experienced public health nurses. These practical tips and suggestions are based on their many years of providing TB case management services.

We recognize that resources vary greatly and in many clinics and health departments the role of TB nurse and TB case manager may overlap, or one nurse may carry out both roles. Some health departments provide TB services using multidisciplinary teams that may include disease investigators, outreach workers, social workers, or others. We have made every attempt to make the content as universal as possible for applicability in a variety of locations and settings.

We recommend review of the *Core Curriculum on Tuberculosis: What the Clinician Should Know* and *Self-Study Modules on Tuberculosis* published by the Centers for Disease Control and Prevention (CDC) for the essential TB background that is a prerequisite for understanding and using this guide. These and other materials can be accessed at:
cdc.gov/tb/education/provider_edmaterials.htm

In addition, the National Tuberculosis Nurse Coalition (NTNC) has developed several resources that provide useful information on TB nursing and TB nurse case management, including core competencies for TB nurse case managers and the manual *Tuberculosis Nursing: A Comprehensive Guide to Patient Care*. These and other NTNC materials can be accessed at:
tbcontrollers.org/ntnc/

Finally, the *TB Training Roadmap for Public Health Nurses* includes a wide range of existing resources for nurses who are new to the field of TB prevention and control. The *Roadmap* is also useful for nurses who carry out TB case management activities and can be accessed on the Global Tuberculosis Institute website at:
globaltb.njms.rutgers.edu/educationalmaterials/productfolder/roadmap.php

CHAPTER 1

Fundamentals of Tuberculosis Nurse Case Management

I. INTRODUCTION

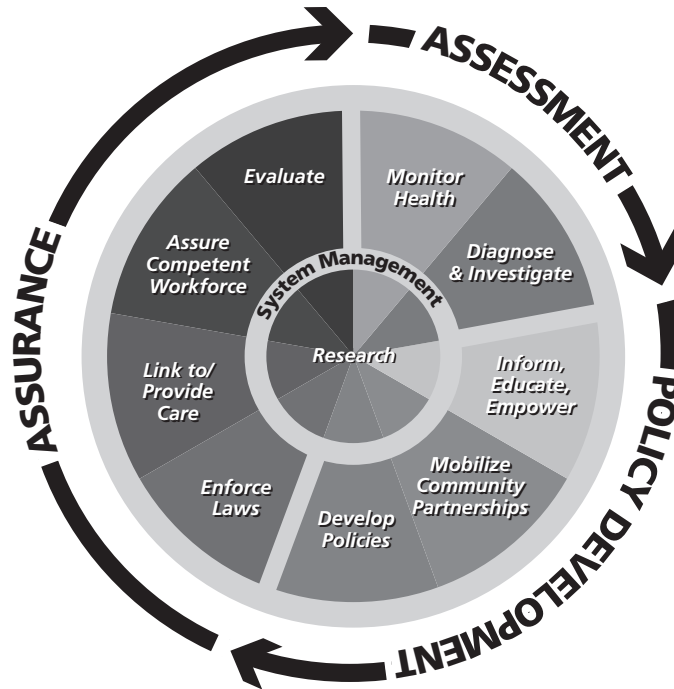
Since TB is an airborne infectious disease that impacts public health, efforts to prevent and control TB in the United States are centered within the public health system. Though there are many partners in TB prevention and control, and TB clinical care can occur in many settings, TB case management takes place primarily within state or local health departments. Nurses represent the largest segment of the public health workforce (Association of Public Health Nurses, 2017) and play an essential role in health departments and TB programs. Using the nursing process, they carry out essential public health activities. Thus, the tasks, activities, and responsibilities of nurses providing TB case management are situated within the framework of public health, the nursing process, and the case management approach. In order to specifically discuss TB case management for nurses, it is important to understand and recognize the interaction between public health, the nursing process, and case management. This chapter addresses the core functions of public health and the nursing process as they relate to case management, specifically TB nurse case management.

II. BACKGROUND CONCEPTS

a. Core Functions of Public Health

Public health is the science of protecting and improving the health of individuals and communities through promotion of healthy lifestyles, research for disease and injury prevention, and detection and control of infectious diseases. Overall, public health is concerned with protecting the health of entire populations (CDC Foundation, 2017).

These objectives are achieved through the implementation of the core functions of public health which include assessment, policy development, and assurance, as well as research that serves all core functions. The core functions comprise a framework of ten essential public health services, which is the basis of the National Public Health Performance Standards developed by CDC. Figure 1 illustrates this framework of the ten essential public health services that should be undertaken by all communities.



The Ten Essential Public Health Services

FIGURE 1: This figure shows a model of the framework of the core functions of public health and the ten essential public health services, which are detailed in the table below.
 Source: “The Public Health System & the 10 Essential Public Health Services” (CDC, 2017b).

Assessment
<ol style="list-style-type: none"> 1. Monitor health status to identify community health problems. 2. Diagnose and investigate health problems and health hazards in the community.
Policy Development
<ol style="list-style-type: none"> 3. Inform, educate, and empower people about health issues. 4. Mobilize community partnerships to identify and solve health problems. 5. Develop policies and plans that support individual and community health efforts.
Assurance
<ol style="list-style-type: none"> 6. Enforce laws and regulations that protect health and ensure safety. 7. Link people to needed personal health services and assure the provision of health care when otherwise unavailable. 8. Assure a competent public health and personal health care workforce. 9. Evaluate effectiveness, accessibility, and quality of health services.
Research Serving All Functions
<ol style="list-style-type: none"> 10. Research for new insights and innovative solutions to health problems.

These services are carried out by a variety of health care workers, including nurses. Although not all of the activities carried out within the framework will be performed by nurses, TB nurse case managers do have a role in each of the ten essential public health services.

In the public health framework, the core functions are as follows:

Assessment is comprised of systematic data collection, monitoring, and providing information about the health of a community. As it relates to TB, data are collected regarding the number of individuals with TB disease (and sometimes TB infection) in a community. Data are then analyzed to measure the success of efforts to treat those individuals and to prevent transmission of the disease (as measured by the occurrence of newly diagnosed individuals with TB, sometimes referred to as TB cases). An assessment of potential TB exposure in contacts of persons diagnosed with or being evaluated for infectious pulmonary TB is equally important so that they can be identified, evaluated, and treated for TB infection or disease, if indicated. Assessment can also include identifying groups within a community who have a high risk of exposure to TB, or have a high risk for progression to TB disease, if infected.

Policy development refers to the provision of leadership in the advancement of rules, regulations, and guidelines that support the health of populations. Policy development utilizes scientific knowledge in decision making, considers unique strengths and barriers within a given community, and should reflect an appropriate use of resources. Policy development often includes working with communities on health education, promotion, and developing partnerships that promote health improvement.

Policy development can occur at the national, state, and local levels. State and local policies and regulations for TB prevention and control may be derived from national guidelines or recommendations that are evidence-based and reflect best practices. Policies related to TB prevention and control involve the identification and reporting of people with TB infection and disease, standards for medical evaluation and treatment, and steps for follow up, where appropriate. Laws, regulations, and policies may also relate to areas such as contact investigation, outpatient infection control, hospital discharge, and use of legal interventions in cases of non-adherence to treatment or isolation requirements, when applicable.

Assurance refers to the role of public health in ensuring that all members of a community have access to essential health services. This includes access to a competent health care workforce in both the public and private sectors. In the treatment of TB, assurance addresses the issue of availability of and access to appropriate TB services provided by personnel who are knowledgeable about TB. Thus, TB programs may provide training and education to private health care providers or other partners. Assurance should also include ensuring that a patient-centered approach is utilized when caring for individuals with TB.

Research serving all functions refers to the identification and monitoring of innovative solutions and cutting-edge research to advance public health, making linkages between public health practice and academic and research settings, and conducting epidemiological studies, health policy analyses, and public health systems research. With regards to TB, this can include operational research on how to implement specific approaches to overcome identified barriers (such as targeted interventions to address adherence) or assessing trends in TB over a specific time period to identify populations at risk who may be prioritized for testing and treatment. This activity could also include clinical research on new diagnostic tests and treatment protocols, as well as determining how research findings can be translated into practice to improve outcomes.

b. The Nursing Process

The nursing process is the problem-solving method used in nursing practice. Elements of the nursing process include assessment, nursing diagnosis, outcomes/planning, implementation, and evaluation. This is a dynamic and interactive process; in today's complex clinical setting, nurses move back and forth within the steps (Jarvis, 2016), rather than taking a linear approach. This holistic perspective serves as a tool for evaluating and improving care. In addition, utilizing the nursing process helps avoid duplication of activities and mitigates the risk of omitting specific tasks, thereby contributing to comprehensive and consistent quality care. The steps and activities described in the nursing process clearly support the core functions of public health described above.

Overview of Nursing Practice Model
Assessment
This is the initial phase of the nursing process, identified by the American Nurses Association as the first standard for professional nursing practice (2017). Assessment is defined as the systematic collection and analysis of data culminating in a nursing diagnosis. Information collected may include physiological, psychological, sociocultural, spiritual, and economic data as well as risk behaviors and lifestyle factors. Assessment is a continuous aspect of the nursing process and involves collaboration with patients, caregivers, health care providers, and others.
Nursing Diagnosis
The nursing diagnosis is a statement of the nurse's clinical judgment relating to a patient's response to actual or potential health conditions or needs. A nursing diagnosis is made after information about a patient's health status is obtained, analyzed, and documented. The nursing diagnosis provides the basis for the selection of nursing strategies to achieve patient care outcomes for which the nurse is accountable.
Outcomes/Planning
In this phase, the nurse sets measurable and achievable short and long-range goals and establishes a care plan, including intervention strategies for each goal, based on assessment data and diagnosis. During the planning process, all interventions developed should be linked to an expected outcome, which should include a time frame for achievement. Outcome planning must include an indicator or description of how the expected outcome will be measured.
Implementation
This phase consists of execution and completion of the nursing strategies identified in the planning phase. Implementation requires communication of the plan to all participants involved in the patient's care, including the patient and family members. During this phase, the nurse continues to assess the patient and record progress.
Evaluation
This final phase of the nursing process documents the patient's response to interventions and the extent to which the expected outcomes have been achieved. The nurse assesses the patient's progress towards the stated goals, using the outcomes identified in the planning phase as criteria for evaluation. Both the patient's status and the effectiveness of the nursing care must be evaluated on an <i>ongoing</i> basis throughout treatment and the care plan should be modified as needed.

c. Case Management

Case management is the final concept or model that provides a framework and context for nurses working in TB. Though it may seem like a relatively new concept, the roots of case management can be traced back as far as 1863, when Massachusetts founded a board of charities to coordinate services for the sick and poor (Weil & James, 1985). Since that time, case management has been utilized by a variety of disciplines to coordinate health and human services and to help contain the costs of these services.

Case management has been defined in a variety of ways. The Commission for Case Manager Certification (CCMC) defines case management as “a collaborative process that assesses, plans, implements, coordinates, monitors, and evaluates the options and services required to meet an individual’s health needs, using communication and available resources to promote quality, cost-effective outcomes” (Tahan & Treiger, 2017). The American Nurses Association defines case management as a system of health care delivery designed to facilitate achievement of expected outcomes within an appropriate length of stay (Flarey, 1996). In *Clinical Pathways for Collaborative Practice*, the authors define case management as “a practice model that uses a systematic approach to identify specific patients and manage patient care to ensure optimal outcomes” (Ignatavicius & Hausman, 1995). According to the American Case Management Association (2017):

“Case management in hospitals and health care systems is a collaborative practice model that includes patients, nurses, social workers, physicians, other practitioners, caregivers, and the community. The case management process encompasses communication and facilitates care along a continuum through effective coordination of resources. The goals of case management include the achievement of optimal health, access to care, and appropriate utilization of resources, balanced with the patient’s right to self-determination.”

In summary, case management is efficient coordination of health care services to achieve specific and measurable outcomes. It has the potential to influence the quality of patient care in a positive way, while containing health care costs and benefiting both patients and providers.

Eight elements of the case management process have been identified: case finding, assessment, problem identification, development of a plan, implementation, outcome identification, evaluation, and documentation (Cesta & Tahan, 2002). The next section presents each element and discusses specific case management activities that lead to the desired outcomes for the patient with TB.

The case management process and the nursing process are similar and may be used interchangeably in many situations. In both processes, conclusions about the patient are based on assessment data and priority is placed on identification of patient problems and developing plans for interventions. In case management, strategies are often developed and assessments are validated by a multidisciplinary team. The TB nurse case manager may not always be involved in the provision of direct care; however, he or she is responsible for ensuring that the care plan is implemented appropriately. In the nursing process, evaluation includes analysis of conflicts or discrepancies that may become barriers and then making adjustments to the care plan as needed. Documentation is an essential activity in each step of both processes; it establishes the care plan as an internal standard by which the nurse and the multidisciplinary team are evaluated.

III. TUBERCULOSIS NURSE CASE MANAGEMENT

The TB nurse case management model assigns responsibility and accountability for individual patient outcomes including adherence to therapy, patient safety, and completion of treatment. The concept of TB case management was developed in response to identified program deficiencies and poor adherence rates resulting in lengthy, interrupted treatment regimens. It is widely recognized that a patient-centered case management approach is an essential part of a successful TB prevention and control program, as evidenced by its inclusion in the 2016 *Official American Thoracic Society/Centers for Disease Control and Prevention/Infectious Diseases Society of America Clinical Practice Guidelines: Treatment of Drug-Susceptible Tuberculosis*. The guidelines emphasize the important role of case management:

“Given that tuberculosis treatment requires multiple drugs be given for several months, it is crucial that the patient be involved in a meaningful way in making decisions concerning treatment supervision and overall care... The optimal organization of tuberculosis treatment often requires the coordination not only of primary and specialty clinical care services, but also community-based organizations and agencies in the public and private sectors. The inherent complexities of the health care delivery system combined with the diversity of characteristics of patients are best addressed by providing individualized patient-centered case management” (Nahid et al., 2016).

While TB case management may be implemented differently across programs and settings, as noted earlier, in many cases public health nurses have responsibility for TB case management and patient outcomes. The role of the TB nurse case manager includes coordinating services for the individual diagnosed with or being evaluated for TB, from initial presentation to completion of treatment, a change in the diagnosis, or death. Some TB programs or clinics also include case management services for individuals diagnosed with TB infection. TB nurse case management requires a proactive approach; potential problems are identified and appropriate measures to mitigate them are implemented *before* problems develop. Problems experienced by persons with TB are frequently confounded by multiple variables and it may be difficult to identify specific factors that are contributing to complex problems. Since a reactive approach often requires more time and resources, a proactive approach is preferable.

The role of the TB nurse case manager may vary depending on available resources. In addition to case management, nurse case managers within TB programs may also provide direct nursing care and/or be responsible for some or all of the essential activities for controlling TB.

a. Goals of TB Nurse Case Management

TB case management is directed towards accomplishing the following goals:

- All hospitalized individuals diagnosed with or being evaluated for TB disease receive uninterrupted care during transition from hospital to the outpatient setting.
- Disease progression and development of drug resistance is prevented.
- Each patient receives TB care and treatment according to published standards of care (Nahid et al., 2016).
- An integrated, coordinated system of health care allows patients to experience TB care along a continuum rather than in a fragmented manner.
- Patients complete TB treatment within appropriate time frames and with minimal interruption in lifestyle or work.
- Transmission of TB within the community is prevented through effective contact investigations and other essential activities for controlling TB, including identification and treatment of TB infection.
- The patient/family/community is educated about TB infection, disease, and treatment.
- Individuals diagnosed with or being evaluated for TB disease are reported according to applicable regulations.
- TB prevention and control activities are implemented according to standards set by CDC.
- State and local TB regulations and policies are followed.

b. Elements and Activities of the TB Nurse Case Management Process

TB case management activities span the continuum of care, from identifying, diagnosing, and treating patients to discharging them from care. The length of treatment and complexity of the disease, combined with individual situations necessitate inclusion of some case management activities at different points in the process. For example, education and training activities occur during case finding, assessment, and implementation.

i. Case Finding

Case finding is the early identification of persons with infectious TB who were previously unknown to public health officials or clinical providers. Case finding efforts support linkage to care and treatment and also promote public health reporting and prompt initiation of the essential activities for controlling TB (e.g., contact investigation and infection control measures) in order

to prevent transmission within the community. The nurse case manager should be familiar with facilities or organizations that provide services to clients at high risk of TB infection and disease. Collaborative relationships with these partners should be developed and sustained.

Case finding activities

- **Communicate with health care providers:** Communication, education, and networking with hospital infection control practitioners, pulmonologists, infectious disease (ID) specialists, and other physicians, especially those serving populations with a high risk of exposure to TB, can be an important element in case finding. These relationships help ensure early notification of persons diagnosed with or being evaluated for TB and support continuous care for patients with TB. Depending on local epidemiology, this may include providers at jails or prisons, infectious disease clinics, community health centers, or federally qualified health centers (FQHCs).
- **Utilize a system to identify and track patients diagnosed with TB in hospitals:** An established relationship with hospital infection control practitioners or infection preventionists will help to ensure that the TB program or local health department is notified when a patient is diagnosed with or being evaluated for TB disease in a hospital setting. Early notification allows for evaluation of prescribed therapy, conducting a home assessment prior to discharge, and development of a follow-up plan for both the patient and for contacts who may have been exposed to TB.
- **Ensure that all public health reporting regulations have been met and essential activities for controlling TB are initiated:** Essential activities include the TB interview, reporting, and contact investigation. If reports on patients with TB disease are not fully and accurately completed and made in a timely manner, there may be missed opportunities for preventing ongoing transmission and early initiation of treatment for individuals with TB infection or disease.
- **Ensure that a contact investigation is completed in accordance with state and local laws and policies:** Contact investigation is a systematic process used to identify persons (contacts) who were exposed to someone with infectious or potentially infectious TB disease (also referred to as the index case). The overall goal of the contact investigation is to identify, locate, evaluate, and, if appropriate, provide treatment to completion of therapy for contacts of people with TB disease as needed. This process should begin promptly, even if the patient is still hospitalized. In cases of pediatric TB, source case investigations can be considered for children < 5 years of age with any form of TB disease, and for children < 2 years of age with TB infection. Source case investigations attempt to identify the individual who transmitted TB to the child, if not previously known. Contact investigation utilizes a specific process and should follow national guidelines and state and local program policies (CDC, 2005). More information about contact investigation is included later in this chapter.

- **Provide education about TB infection and disease:** The TB nurse case manager often acts as a resource for other nurses and physicians as they identify individuals with TB disease or who should be evaluated for disease. Education should be provided to health care providers in the community to increase the awareness of TB. Awareness often raises the level of suspicion on the part of health care providers and may prevent delayed diagnosis and treatment as well as misdiagnosis.

ii. Assessment

Assessment is the gathering of data that guides TB treatment and care. Since many professionals are involved in the care of persons with TB, the data from which the initial assessment is developed can come from a variety of sources. Assessment data may be obtained from community agencies, primary care providers, schools, other health care facilities, and other sources.

The **initial assessment** should occur during the patient's hospitalization. Patients who are diagnosed during a hospitalization will require careful discharge planning. The case manager should ensure that appropriate care is being provided and should coordinate with the hospital discharge planner and other partners to ensure coordination of care upon release. This will ensure that treatment is not interrupted and reduce the risk of transmission in the community. Hospitals should promptly report any patient diagnosed with or being evaluated for TB disease and develop a plan for discharge with the responsible public health agency (Taylor, Nolan, & Blumberg, 2005). A home visit should be conducted before hospital discharge. Prior to the patient's first outpatient visit to the physician or TB clinic, the TB nurse case manager should ensure that the provider has access to the patient's hospital record including radiographic images and findings and lab reports. Complete medical records are important for appropriate decision making and medical management.

If the patient is not hospitalized, the initial assessment should take place at the first clinic visit or during a home visit. A home visit is essential to assess the appropriateness of home isolation, potential barriers to adherence, and accuracy of contact information gathered. The home visit also provides an opportunity for assessing household contacts who may need to be evaluated and assessing the need for living assistance or other social support services. Information gathered at the patient's home is often more revealing than assessments performed in clinical or health department settings and can lead to a better understanding of the patient's lifestyle.

Initial assessment activities

- **Obtain or review demographic information:** Key information required by state or local regulations including the name, address, telephone number(s), birth date, social security number (if allowed under policy or regulation), and health insurance information (if available) should be collected.

- **Ascertain the extent of TB illness:** Information related to the patient's clinical condition should be assessed. This includes acuity and duration of symptoms, TB test results, bacteriologic and radiographic findings, laboratory analyses, nutritional status, and vital signs, including baseline weight.
- **Obtain and review the patient's medical history:** Concurrent medical problems should be identified. These may include HIV infection or other immunosuppressive conditions, diabetes, drug use or other risk factors, allergies, baseline bloodwork, and all current medications (prescription, over the counter, traditional, or home remedies) as these may interact with TB drugs. The names, addresses, and telephone numbers of the patient's primary care provider and any specialists involved in his or her medical care, previous hospitalizations, and treatment of recent symptoms or illnesses should be obtained. It is also important to determine the patient's perception of their most important medical issue/health problem. The date of the last menstrual period and contraceptive use should be obtained from female patients.

It is important to know the patient's history of prior TB exposure and treatment for TB infection and disease, as well as the response to treatment. Individuals who have previously experienced treatment failure for TB disease or who relapse may be at high risk for developing multi-drug resistant TB (MDR-TB). These should serve as red flags for nurses when reviewing a patient's medical history. Information about the patient's country of birth, residence, or recent travel to TB-endemic countries or countries with a high rate of drug resistance is also useful for determining risk for drug resistance. Rapid molecular testing for drug resistance should be conducted for individuals who are at risk for drug resistance.

- **Determine infectiousness or potential infectiousness:** This assessment should include the initial onset, duration, and frequency of symptoms, especially cough, and a review of the radiographic and bacteriologic findings. The case manager may use this information for making decisions around initiation of appropriate infection control measures. If the patient is infectious or potentially infectious, the case manager should determine the period of infectiousness as outlined by national, state, or local guidelines. The parameters of a contact investigation, including the need for post-exposure testing for contacts who were initially negative, can then be determined, following appropriate policy.
- **Ensure that identified contacts are assessed and evaluated:** Once the infectious period is established and contacts are identified and located, those contacts should be tested, medically evaluated, and offered treatment, as appropriate, within the time period specified in state and local policy.
- **Evaluate the patient's knowledge and beliefs about TB and provide appropriate education:** The nurse case manager can assess TB knowledge by asking the patient what they understand about TB transmission, pathogenesis, and symptoms. Patient education should be based on current knowledge and ability to comprehend written, verbal, and

visual information. Written information should be provided in the patient's preferred language whenever possible. Selected examples of culturally and linguistically appropriate TB educational materials are included in the resource lists at the end of each chapter of this guide. Patient education can be documented on a form such as the one in Appendix 1 or incorporated into existing record-keeping systems.

- **Review the TB medication regimen:** Nurse case managers should ensure that TB medications and dosages are prescribed according to ATS/CDC/IDSA guidelines. The case manager should verify that the physician's orders are clear and concise. If the treatment is initiated during the patient's hospitalization, the case manager should contact the provider and/or the hospital nursing department to discuss the need for a standardized dosing schedule and directly observed therapy (DOT), where the ingestion of the medication is observed by a qualified and trained health care professional.

The patient's tolerance to TB medications should be noted and interactions with other medications should be determined prior to the patient starting TB medications. Drug dosage should be verified using the patient's recorded weight, either while in the hospital or during the initial visit.

- **Identify barriers or obstacles to treatment adherence:** This should include barriers to taking TB medications and keeping physician or clinic appointments. Availability of transportation, the patient's preferences for place and time of DOT, and the ability to swallow pills should be assessed. Many adolescents and adults who have difficulty swallowing pills are embarrassed to report this to the health care provider. It may be necessary to crush the pills and put them in food the patient likes, such as pudding or applesauce. The nurse case manager should determine whether there is a need for incentives and enablers and, in coordination with the patient, should identify the type of support that will be most valuable.
- **Review psychosocial status:** Some psychosocial conditions or situations may present barriers during treatment. The case manager should identify unmet needs, past and current history of alcohol and drug use, homelessness or residential instability, mental health status, and any pre-existing psychiatric diagnosis. It is important to obtain and document a comprehensive history of the patient's social circle (including addresses and contact information), in the event that the patient misses DOT visits or follow-up appointments.

An **ongoing assessment** should occur at each patient encounter. DOT visits and monthly appointments at the clinic, health department, or private physician's office offer opportunities to evaluate of the patient's progress. Additional assessments may be needed for patients experiencing problems in their TB treatment or for those patients who are non-adherent to DOT or follow-up appointments.

Ongoing assessment activities

- **Monitor the clinical response to treatment:** Vital signs, weight, TB symptoms, radiographic results, bacteriology reports, drug sensitivities, and lab results should be reviewed and compared to previous documented findings. This review is an important measurement of clinical improvement, worsening, or stabilization of the patient's condition. If a variation is noted, the patient should be re-evaluated to determine the potential cause. All bacteriological reports should be listed in chronological order and correlated with the patient's symptom history and radiographic reports. This method of monitoring allows for easy identification of patient progress and early recognition of inconsistencies, which may point to the possibility of issues such as medication malabsorption, drug resistance, or laboratory contamination. Any unexpected findings should prompt additional questions and should be brought to the treating physician's attention immediately.
- **Determine HIV status, assess risk factors for infection, and refer the patient for treatment, if indicated:** It is important for patients to understand the correlation between TB and HIV infection. The nurse case manager should provide appropriate education and ensure that HIV testing is performed as a part of the initial evaluation, following state and local policy and practice on HIV testing (e.g., opt-in vs. opt-out testing). Patients living with HIV who have documentation of their HIV status do not need to be re-tested. If a patient refuses HIV testing, an HIV risk assessment should be completed and test refusal documented. If the patient tests positive for HIV infection at the time of TB diagnosis, they should be referred to an appropriate provider for follow up. Services for TB treatment vary across programs. If the TB provider is different than the provider treating HIV, the case manager should collaborate with other providers to ensure coordination of care and information sharing.
- **Review additional co-morbidities and clinical conditions:** If the patient has chronic conditions such as diabetes, renal failure, viral hepatitis or other hepatic disease, HIV, or a mental health disorder, these conditions should be assessed to determine if treatment adjustment is warranted or a referral for additional care is necessary. Pregnancy may also require treatment adjustment. A list of all medications the patient is taking should be obtained and reviewed to assess for possible drug-drug interactions.
- **Review the treatment regimen:** One of the nurse case manager's primary responsibilities is to ensure that the patient completes treatment according to the care plan (e.g., ensuring that the appropriate number of doses are completed within the intensive and continuation phases). The treatment regimen may need to be adjusted based on clinical or microbiologic factors; thus, the nurse case manager must ensure that the treating physician is aware of adverse effects to TB medications, pregnancy, abnormal results of laboratory tests, or if sputum conversion has not occurred in the expected timeframe. The case manager should review any changes to the treatment regimen to confirm that it is consistent with current TB treatment guidelines and that the adjusted treatment plan meets the needs of the individual patient.

- **Assess adherence and factors influencing adherence:** The case manager should have an established plan to monitor adherence. Monthly rates of DOT adherence should be reviewed to ensure that all patients achieve the expected adherence as per program policy. Adherence should also be monitored more frequently, as interruption in treatment may be avoided if interventions are implemented immediately, rather than waiting until monthly adherence rates are calculated. If DOT is provided by another team member, missed doses should be reported promptly to the nurse case manager. Monitoring plans should include a notification system that explicitly states when the case manager should be informed of missed doses (e.g., if the patient misses more than two consecutive days of DOT). The effectiveness of enhancement methods (e.g., incentives, enablers, or agreement) should also be regularly monitored. This will be discussed further as part of patient-centered care in Chapter 2.

Patients may experience changes in their circumstances during TB treatment. At regular intervals during the course of treatment, the case manager should verify that the time and place for DOT administration originally agreed upon is still acceptable to both patient and provider. In some situations, it may be necessary to coordinate the arrangements for DOT with outside organizations, such as schools, drug treatment centers, etc. DOT is recommended for all patients with TB disease (Nahid et al., 2016), though DOT requirements vary across locations and programs.

If the patient is receiving treatment for TB infection via self-administered therapy (SAT), the case manager should ensure adherence to monthly clinic appointments in order to provide medications, assess adherence, and observe for side effects or adverse reactions. A plan should be established to assess adherence to therapy for these patients. For example, the use of daily reminders, text messages, or bringing the medication bottle to clinic appointments for a pill count may be helpful.

- **Determine any unmet educational needs of the patient:** It is important to assess the patient's understanding of basic TB information including transmission, diagnosis, and treatment of TB. The nurse case manager should identify and address the patient's concerns and anxieties around TB diagnosis and treatment. The educational needs of the patient and family may vary throughout the course of treatment and key concepts should be reinforced at each encounter. Education should be provided in a manner that is sensitive to the patient's beliefs about TB treatment, acceptance of the diagnosis, coping mechanisms, cultural values, and level of knowledge. The case manager should explore the effect that the diagnosis has on the patient's relationships with other family members, co-workers, and social contacts so that appropriate and culturally sensitive information can be provided.

- **Review the status of the contact investigation:** Patients may not reveal the names of all close contacts in the initial interview. As the case manager builds trust and rapport with the patient over time, more individuals may be identified. If secondary cases are identified, the contact investigation may need to be expanded to find additional contacts and prevent ongoing transmission in the community. Activities should be consistent with state and local policies. TB genotyping may also be useful in helping to establish or confirm epidemiologic links between patients, especially in situations with multiple secondary cases.

iii. Problem Identification

Existing or potential barriers to TB treatment adherence or completion are identified using the data collected during the assessment process. These data, along with additional information (e.g., problems identified by various members of a multidisciplinary team) are used by the nurse case manager to develop a care plan which address barriers and problems. Regardless of who collects data, the nurse case manager is responsible for reviewing and interpreting the data and documenting the assessment and identified problem in the medical record.

Problems may not be immediately evident when solely based on the medical record and initial interview. For example, if a patient has a history of leaving the hospital against medical advice and failure to keep clinic appointments, the case manager might conclude that non-adherence is the problem. However, if the reasons for the patient's previous behavior were never determined, it may be that the non-adherence is the result of a "real problem" that has not been identified. In this example, the underlying problem could be a lack of understanding of the severity of the disease, lack of childcare, or financial burdens caused by missing work due to illness.

Problem identification activities

- **Assess existing or potential health problems:** A clear problem statement that includes possible etiologies is extremely important to the TB case management process, as these may impact treatment adherence and completion. A nursing diagnosis should be used to document identified problems.
- **Conduct regular reviews of the patient record:** This includes a review of the patient assessment, medical record, and existing or emerging problems. Errors or gaps in problem identification may lead to unsuccessful interventions and outcomes. If there is a multidisciplinary team involved in treating the patient, regularly scheduled meetings should be held to discuss the assessment data and treatment plan. The team should provide input and feedback on the conclusions drawn from the assessment. Team meetings can provide additional information for planning patient care, clarify issues surrounding a specific problem, and provide a venue for team members to share information or discuss feelings or attitudes about patients or required tasks. The nurse case manager should utilize the patient record (or team meetings, if applicable) to identify problems as they arise to mitigate poor outcomes.

iv. Plan Development

Development of a plan is based on assessment data and problems identified by members of the health care team; planning begins when sufficient information has been gathered. The plan combines both medical management of the patient and nursing interventions. Planning for continued care requires critical thinking and decision making and should always include participation and commitment from all team members as well as the patient. This is essential to establishing an achievable plan that meets the needs of the patient. Due to the length of treatment for TB disease (6 to 24 months) and TB infection (12 weeks to 9 months), the plan must include intermediate goals and expected outcomes. The nurse case manager is responsible for the overall plan including documentation, monitoring patient response to interventions, plan modification as needed, and achievement of intermediate goals and expected outcomes. The nurse case manager also assigns activities or tasks to team members based on their roles and job descriptions.

The 2016 ATS/CDC/IDSA TB treatment guidelines identify several key considerations in developing a case management plan (Nahid et al., 2016). These include:

- Improving “treatment literacy” through educating the patient about TB and its treatment, including possible adverse effects.
- Discussing expected outcomes of treatment, specifically the ability to cure the patient of the disease.
- Reviewing methods of supervision and assessing response to therapy.
- Discussing infectiousness and infection control measures using terminology that is appropriate to the culture, language, age, and reading level of the patient.

The plan should be extended to include the monitoring of contacts to ensure evaluation and completion of treatment, as needed.

Plan development activities

- **Establish the care plan:** All key components should be included: assessment, nursing diagnoses, medical orders for required procedures (e.g., X-rays, blood draw, sputum specimen collection or induction, and auditory or visual acuity testing), medication orders, expected patient behaviors, essential activities for controlling TB (e.g., infection control and contact investigation), and intermediate goals and expected outcomes.

The nurse case manager should ensure development of a patient-centered care plan that has been discussed and reviewed with the patient. Patients should be involved in a meaningful way in the development of the approach for providing DOT. The plan will be used as the internal standard of care for the patient as well as the performance standard for the nurse

case manager and, thus, should include an approach for DOT that meets the patient's needs. Good planning will allow the patient to receive TB care and treatment along the health care continuum and prevent duplication and fragmentation of services. The plan should include approaches and activities for the patient's discharge from care after completion of treatment. The final plan should be discussed and validated with all team members and the patient. More detail on a patient-centered care and a sample care plan are included in Chapter 2.

- **Monitor the care plan and patient response according to established time frames:** Each component of the plan should be reviewed and cross-checked with data collected during the assessment to ensure that it addresses the patient's illness, required tests, barriers, and interventions. The achievement of intermediate goals and expected outcomes should be documented. Examples of intermediate and expected outcomes can be found in Appendices 2 and 3. This documentation will serve as the basis for the evaluation of expected outcomes.
- **Negotiate and adjust the care plan:** Changes should be made, as needed, to meet evolving patient circumstances and personnel resources. The plan should allow for flexibility and negotiation; plan modifications should be made in conjunction with the patient and other team members to adapt to new situations as they arise.

v. Implementation

Implementation includes all the interventions required to move the TB patient along a coordinated, sequenced health care continuum from diagnosis to treatment completion and achievement of cure. The nurse case manager must ensure that all aspects of the plan have been addressed in this implementation phase. Effective communication with all involved staff members is an essential component of successful implementation of the patient's care plan. Implementation requires educating, coordinating, monitoring, locating, referring, negotiating, documenting, decision making, and advocating for the patient.

In some settings, the nurse case manager may be responsible for all implementation activities; in other settings, some activities may be carried out by other team members such as social workers or outreach workers. In these cases, the nurse case manager is still responsible for ensuring that all activities are carried out according to the care plan, and should follow appropriate practices for delegation of tasks. More information on delegation can be found at the end of this chapter.

Implementation activities

- **Monitor the patient's response to TB treatment, interventions, and adherence:** The nurse case manager should ensure that the treatment is progressing according to the physician's treatment plan and that the patient continues to show signs of clinical improvement. Policies and procedures regarding DOT and non-adherence will allow the nurse case manager to identify events that require additional assessment or interventions. Although the plan should be patient-centered and the case manager should establish a positive patient-provider relationship, patients should also be informed about the consequences of non-adherence, including possible legal interventions. Changes in the patient's attitude toward the clinic and clinic staff should be noted and discussed with the patient.
- **Refer the patient to other health care providers, social services, or community agencies as needed:** The case manager should be familiar with community resources, as the referral process requires case managers to locate and coordinate accessible, available, and affordable resources for the patient. At the time of referral, case managers may establish a communication plan with the referral agency for monitoring and follow up. Immediate intervention may be necessary if the patient or the referring agency experiences problems or difficulties.
- **Broker and locate needed services relating to TB treatment:** This may include laboratory, auditory, or visual acuity testing, as well as radiographic studies or other tests. Depending on the patient, the case manager may need to schedule or assist the patient with scheduling appointments. Nurse case managers should monitor the patient's adherence to the appointment as well as the results. Familiarity with the patient's health insurance coverage or any need for financial assistance is helpful, since lack of resources or insurance may affect the patient's willingness to make or keep appointments. The case manager or other designated health care worker may need to discuss essential services with insurance companies or other health care providers in order to obtain the most cost-effective quality care.
- **Coordinate strategies to improve adherence:** The nurse case manager should be knowledgeable and proficient in strategies to improve patient adherence. A coordinated approach, which can help achieve treatment completion, should be utilized. Developing and maintaining a therapeutic relationship with the patient throughout the course of TB treatment is critical. Case managers should also be familiar with the principles and practices of using patient-provider agreements and behavioral modification approaches, two useful methods to improve adherence. If a multidisciplinary team is involved in caring for patients, collaboration with all team members is essential to obtain as much information as possible about strategies to improve adherence. Strategies to improve adherence will be discussed in more detail in Chapter 2.

- **Continue to educate the patient and caregivers:** It is important to provide ongoing education during the course of treatment for TB disease and TB infection. Although education is provided during earlier stages of the TB case management process, these messages should be reinforced throughout the continuum of care, from diagnosis to discharge from care. For example, the importance of identifying signs and symptoms of relapse should be emphasized later in treatment for patients with TB disease. Education on the importance of completing treatment may be important throughout treatment for patients with TB infection, for example, since they have no symptoms and, thus, may be less inclined to be adherent to the full course of treatment. Information should be relevant for the patient's literacy level. Education should be provided in the patient's primary language and should be culturally appropriate. In addition, health beliefs that conflict with educational information should be identified and addressed.
- **Advocate for the patient with team members and other service providers when necessary:** It is important to demonstrate respect and understanding of the patient's cultural beliefs and values and to ensure that team members do not impose their own values or beliefs on the patient. The nurse case manager should be able to communicate the patient's fears, anxieties, likes, dislikes, needs, and wants to the team members in a non-judgmental manner. It is the nurse case manager's responsibility to be a compassionate and caring role model for the team and to ensure that services and interventions are planned and carried out for the patient's benefit. The case manager should also try to understand the perspectives of team members and should mediate, negotiate, and resolve differences of opinion regarding any aspect of care. Team building and conflict resolution are important competencies required for an effective nurse case manager; mentoring may be useful in developing these and other case management skills for new nurses.
- **Ensure that patient adherence is monitored appropriately and lapses in adherence are addressed promptly:** The patient and required activities should be promptly assigned to an outreach worker and completed according to established standards (e.g., an outreach worker has three days to bring an individual with infectious TB to the clinic). The nurse case manager should understand the skills and competencies of the public health workforce and utilize that knowledge to locate non-adherent patients and return them to care. Knowledge of public health policies and procedures relating to TB is also valuable for situations that require administrative interventions.

Policies and laws differ across TB programs and states; however, various levels of intervention may be available if patients are not in accordance with statewide standards and there is a resulting threat to public health. Legal or administrative interventions should begin with the least restrictive measure; for example, a letter from the health officer. However, when a patient-centered case management approach is implemented, in most cases, lapses in adherence can be addressed without any formal legal intervention.

- **Collaborate with hospital or community providers as needed:** When patients are under the care of other providers, such as during hospitalization while on outpatient TB treatment (or if they opt to be treated by private physicians), it is the nurse case manager's responsibility to monitor the patient's progress. This is true regardless of whether the hospitalization is related to TB. The nurse case manager should communicate regularly with the hospital case manager, physicians, floor nurses, and infection control practitioners to monitor the patient's care and progress. The frequency and type of communication will depend on the specific situation and the duration of the hospitalization. It may be necessary for the TB nurse case manager to visit the hospital to review the patient's medical record, see the patient, and discuss the patient's treatment with nurses and physicians. Visits to the hospital are best conducted in coordination with hospital personnel.

Clarification of roles and responsibilities with various staff and disciplines within the hospital may be necessary if problems with TB management occur during the patient's hospitalization. The case manager may need to discuss the situation with the physician managing the patient's outpatient TB care, or request assistance from the clinic's medical director. Working with hospital staff to ensure the patient receives the appropriate TB regimen will assure uninterrupted TB treatment, allow for appropriate discharge planning, identify and address problems, and increase the likelihood of treatment completion in a timely manner.

Case management does not end when the TB patient is hospitalized or if the patient is under the care of a private provider, unless the patient has completed treatment, or if TB disease is ruled out. Assessment, monitoring, and coordination must be continued. More information on collaborating with community providers is included at the end of this chapter.

vi. Outcome Identification

The outcome identification component of the TB case management process identifies expected outcomes and examines the discrepancies between the anticipated and actual patient care outcomes. As noted earlier, it is likely that the patient's situation will change and modifications to the care plan will be necessary since TB treatment occurs over an extended period of time. These adjustments may be a result of changes in the patient's personal situation, medical condition, or health care resources.

In conjunction with the patient and the health care team, the nurse case manager should identify any clinical, operational, or organizational problems that may impact the expected outcomes and make changes as necessary. Feelings of frustration on the part of the patient or members of the health care team can occur if identified problems are not addressed.

Outcome identification activities

- **Identify expected outcomes:** Expected outcomes should be based on state and local regulations and policies and the individual patient. Any needed changes should be implemented to overcome barriers and achieve completion of treatment during the specified time period. Examples of expected outcomes in TB case management can be found in Appendices 2 and 3 at the end of this chapter.
- **Review modifications in the care plan at specified intervals:** This review should include determining whether intermediate goals and expected outcomes were achieved. The case manager should review all assessments to determine if the outcomes are realistic.
- **Describe the reason(s) for the modification:** Adjustment to a care plan should be based on assessment findings and critical thinking.
- **Individualize to the specific patient as needed:** Changes in the patient's circumstances during the lengthy course of treatment often require adjustments to the care plan.

vii. Evaluation

Evaluation is an ongoing component of the TB case management process. Through evaluation, the nurse case manager utilizes skills such as problem solving, critical thinking, leadership, effective communication, negotiation, and networking to impact patient outcomes. By analyzing each intervention and the associated goal and outcome, the case manager can identify and implement measures to improve quality of care and support the achievement of TB treatment goals.

Evaluation activities

- **Answer the following questions:**
 - Were the TB treatment plan and essential activities for controlling TB implemented in a timely manner?
 - Were intermediate goals and expected outcomes achieved?
 - Was the patient satisfied with the services or care?
 - Were the case manager and the team members satisfied with the plan and outcomes?
- **Monitor the care plan at least monthly:** More frequent monitoring may be required, depending on the complexity of treatment and other patient variables. The appropriateness of interventions should be reviewed, as the dates of goal or outcome achievement should be noted. Attention should be given to how quickly the care plan was modified or updated based on identified need. The case manager should also determine if there were missed opportunities for improvement. An example of chart review, which can be used for this purpose, is found in Appendix 4.

- **Identify strengths or weaknesses in the health care system:** Health system factors may impact expected outcomes. A comprehensive evaluation will lead to positive changes for the patient and others.
- **Participate in cohort review (if established as part of overall TB program activities) to identify variances or common elements among the group:** Cohort review can be organized at a state or local level and is a systematic review of the management of patients with TB disease and their associated contacts. TB nurse case managers should ensure that all key information and staff are available in advance of the cohort review, and should ensure participation of key staff as required in their locality or state. In collaboration with the TB program manager, the nurse case manager may utilize information from the cohort review to make changes that improve care of the patient and prevent these variances from occurring with future patients. Additional information on cohort review can be found in the CDC materials *Understanding the Cohort Review Process*, available at: [cdc.gov/tb/publications/guidestoolkits/cohort/cohort.pdf](https://www.cdc.gov/tb/publications/guidestoolkits/cohort/cohort.pdf) (CDC, 2006).
- **Monitor the public health surveillance and reporting activities:** The case manager should ensure that all TB reporting is accurate, complete, and meets state and local standards.
- **Monitor the contact investigation:** The nurse case manager should ensure that contact investigation activities are completed correctly and in accordance with program standards.

viii. Documentation

Documentation is an integral part of all the steps in the TB case management process. Documentation chronicles patient care and outcomes and can be used to facilitate positive changes for TB patients, health care providers, and the health care facility or system. The nurse case manager must ensure that documentation by all members of the multidisciplinary team is complete and accurate, and is submitted to the appropriate people or agencies within the required time frame. For example, if legal action is necessary to address non-adherence in a patient who consistently misses DOT, the outreach staff must explicitly document all attempts to locate and communicate with the patient.

All interventions should be documented in a clear and concise manner to ensure continuation of appropriate care. Documentation regarding patients with TB should utilize existing record-keeping practices and systems, including online charting and electronic medical records as appropriate. Documentation for TB surveillance and reporting activities should utilize appropriate state or local health department forms or reporting systems.

The nurse case manager should remember the cardinal rule of documentation: 'If it isn't documented, it wasn't done.' Training on documentation may be required for clinical and TB program staff, including those who are not licensed health care professionals. The nurse case manager must review the documentation to assure that it meets internal and external standards, including any licensure requirements for providers. Proper documentation will enhance the continuity of care for patients with TB, particularly if different providers are involved over the course of treatment.

Documentation activities

- **Monitor the patient's medical record:** Appropriate documentation should be carried out for each clinic/physician visit. All team members should document information and interventions, services, and care in a timely manner. This includes provision of education and interventions to improve patient adherence. The medical record should be reviewed for completeness, compliance with external and internal standards of care, and clarity. The case manager should also ensure that all necessary documentation from private physicians or referral agencies is included in the patient's record and should update the multidisciplinary care plan as required. Variances from the usual plan should be documented, including the reasons why the variances occurred and the rationale for the change in plan. Achievement of intermediate and expected outcomes should be documented as they occur.
- **Document case management activities and elements of the TB case management process in the patient's medical record:** To be useful, documentation must be clear and concise. The use of a checklist can assist the case manager in documenting patient care in a timely, efficient manner. For example, TB education can be documented using a patient education documentation form such as the one found in Appendix 1. Charting by exception can be an efficient method for documenting assessments and interventions; however, there should be policies and procedures in place to ensure that documentation standards are met.
- **Assure patient confidentiality:** The nurse case manager should explain confidentiality standards to the patient and should emphasize that the health department will not reveal his or her name unless it is needed to protect the public's health, such as during a congregate setting contact investigation. If the patient's name is revealed in cases such as this, managers or supervisors at the congregate setting should be informed in writing that they should not share the patient's name with others. Any situation or circumstance where limited patient information will be shared should be explained to the patient. Written consent from the patient should be on file if it is necessary to obtain or provide any part of the patient's medical record with another provider, health care insurance agency, or community agency. Case managers should be familiar with their agency's policy on Health Insurance Portability and Accountability Act (HIPAA) compliance regulations regarding confidentiality.

IV. CONTACT INVESTIGATION

Contact investigation activities are an important element of TB case management. In some jurisdictions, the TB nurse case manager may be responsible for conducting contact investigations, while in other jurisdictions they may oversee staff who carry out this task. In some programs, the contact investigation process is managed under a separate organizational system. Regardless, it is important for the case manager to understand the rationale for TB contact investigations and to develop competency in contact investigation activities, in order to ensure that these activities are carried out appropriately, according to state and local policies.

Contact investigation activities are not confined to one area of TB case management. Activities related to contact investigation occur within case finding, assessment, outcome identification, evaluation, and documentation. The case manager's responsibilities may include interviewing the index patient to identify individuals exposed during the infectious period. A review of key contact investigation principles is included here; however, contact investigation is multifaceted and there are many nuances to conducting the investigation, interviewing patients, and determining an infectious period. Training and education on contact investigation should be provided to staff prior to initiating an investigation.

Since contact investigation can be complex, it is important to use critical thinking on a case by case basis when identifying and prioritizing contacts. This section is not intended to provide complete information on the contact investigation process. Additional guidance on contact investigation is available in the following CDC documents:

- *Self-Study Modules on Tuberculosis, Module 8: Contact Investigations for Tuberculosis*, available at: [cdc.gov/tb/education/ssmodules/pdfs/Module8.pdf](https://www.cdc.gov/tb/education/ssmodules/pdfs/Module8.pdf)
- *Guidelines for the Investigation of Contacts of Persons with Infectious Tuberculosis*, available at: [cdc.gov/mmwr/preview/mmwrhtml/rr5415a1.htm](https://www.cdc.gov/mmwr/preview/mmwrhtml/rr5415a1.htm) (CDC, 2005).

The contact investigation will identify individuals exposed to an infectious or potentially infectious TB patient. The contact investigation process includes:

- Conducting an initial interview and re-interview of the patient to elicit names and contact information of persons who may have been exposed.
- Identifying all contacts and prioritizing based on risk factors.
- Locating contacts and conducting a medical evaluation for TB infection and TB disease.
- Initiating treatment, if indicated, and ensuring appropriate treatment to completion of therapy.
- Determining the need for expansion of the contact investigation.

Since the likelihood of developing TB disease after an exposure can be influenced by specific medical conditions that impair immune competence (e.g., HIV), these conditions constitute a critical factor in assigning contact priorities. Additionally, children are at much higher risk of progression to disease than adults. Thus, in the contact investigation process, priority should be given to identifying children who may have been exposed to patients with infectious TB. Infants and young children < 5 years of age deserve special consideration and should be evaluated as soon as possible during a contact investigation. Children with an initial negative test result should be re-tested eight to ten weeks after the last exposure to the patient with infectious or potentially infectious TB. More information about TB infection and disease in children can be found in Chapter 3 of this guide.

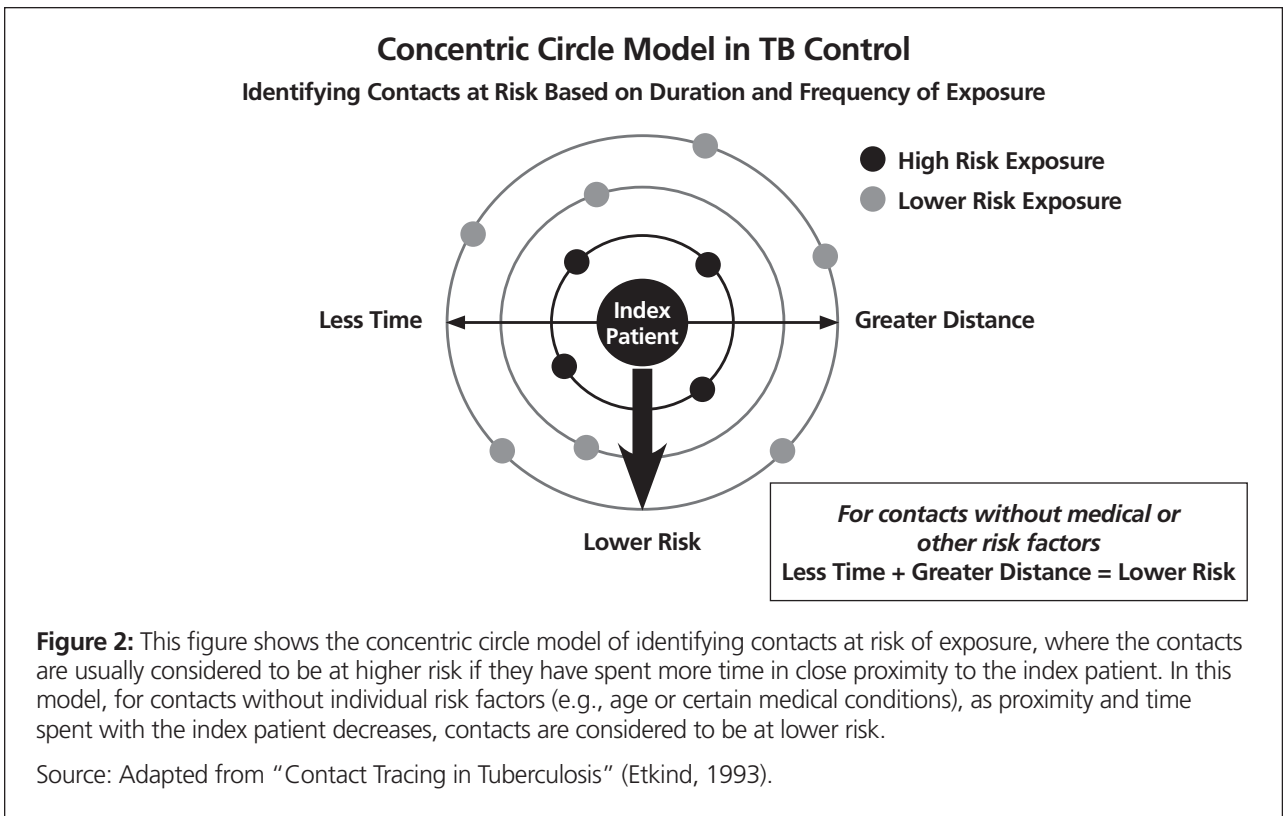
Contact investigations should include a home visit and must be initiated within the required time frame after the case has been reported. Contacts should be identified, and their locating information obtained. In cases of pediatric TB, source case investigations can be considered for children < 5 years of age with any form of TB disease, and for children < 2 years of age with TB infection. Source case investigations attempt to identify the individual who transmitted TB to the child.

The following factors should be considered when assessing for potential transmission:

- The extent of disease in the index patient (cavitation on chest X-ray, positive sputum smears, and presence of cough).
- The frequency and duration of exposure.
- Proximity and characteristics of the exposure environment (e.g., local air circulation, etc.).

After establishing the infectious period, all contact investigations should begin with identification of household and/or social contacts. All sites of potential exposure during the infectious period should be identified, particularly any congregate living situations, such as a prison, jail, homeless shelter, nursing home, boarding house, or foster care. Occupation and/or student status must be established and the name and address of any business or school should be documented. To identify those who have shared common air space with infectious, untreated patients with TB, it is necessary to understand the patient's lifestyle, social, and recreational activities, as well as how the patient spends their leisure time.

The concentric circle model seen in Figure 2 is a secondary tool that can be used to guide further expansion of the contact investigation, for example, within a congregate setting. Application of this model can help to establish priorities based on the risk of transmission to identified contacts considering the duration and frequency of exposure (shared time and place). However, individual risk factors including medical conditions and age (e.g., infants and young children) must also be considered when assessing risk and prioritizing contacts. The concentric circle model can also be used to determine the scope of the contact investigation and to avoid unnecessary testing.



However, it is important to consider that recent research involving TB genotyping suggests that the usual criteria used to determine close contacts of persons with infectious TB may not be sufficient. Transmission may still occur as a result of casual or limited exposure. More information on TB genotyping can be found at: cdc.gov/tb/publications/factsheets/statistics/genotyping.htm.

Once the contacts have been identified, it is equally important to ensure that they are evaluated for TB disease and TB infection and placed on appropriate treatment, if indicated. If resources allow, DOT should be considered for vulnerable patients and children receiving treatment for TB infection.

The TB contact investigation is an ongoing process. At the beginning of treatment, patients may be reluctant to name contacts for many reasons, or may simply forget about some contacts who may have been potentially exposed. There may also be distrust of the health department, which can be a particular concern for undocumented patients, who may be afraid of repercussions for themselves or their contacts who may also be undocumented. As the index patient builds trust and rapport with members of the TB care team during the course of treatment, new contacts may be identified. The case manager should be vigilant in identifying relatives, social contacts, or coworkers who may not have been initially identified, but may in fact have been exposed, especially if signs or symptoms consistent with TB are present. This is especially important for children, as risk of progression from infection to disease and risk of disseminated disease is higher in infants and young children.

V. COLLABORATING WITH COMMUNITY AGENCIES AND PRIVATE PROVIDERS

Coordination between public and private sectors is essential for the management of patients with TB. Assuring that essential health services are available in the community and keeping community health care providers informed about the proper management of TB is a core function of public health. Regardless of who provides the medical management for an individual with TB, the nurse case manager can facilitate strong collaboration and effective communication between the public and private sectors. This removes barriers and fosters achievement of public health objectives.

While the case management process is initiated in the public sector, it serves to link health departments and TB programs to the primary care providers in the community. This can be seen in the following steps:

- A report of a person diagnosed with or being evaluated for TB may be generated by a hospital infection control department, a clinical laboratory (smear or culture results), or a private physician. Once a TB patient has been identified, the case manager should communicate with the diagnosing physician, describe the available TB case management services, and encourage collaboration with the TB program. However, even if the physician is interested in managing the patient's care, certain case management activities and the monitoring of treatment outcomes are still the responsibility of the TB program.
- The case manager should send the physician information regarding the availability of collaboration in the treatment of the patient, including details of services provided (e.g., case management, DOT, sputum collection, etc.). In addition, the case manager should request written orders for medication, if DOT is to be provided by the health department, and should also request updates on the patient's treatment (e.g., chest X-ray, sputum smear and culture results, etc.) on an ongoing basis.
- Since the goal is to evaluate the patient and initiate DOT as soon as possible after receiving the referral information, the case manager should visit the patient to make an initial assessment, obtain written agreement from the patient for DOT, and introduce the assigned field staff member to the patient and family. Throughout the course of treatment, the case manager should maintain close communication with the patient and family, the private doctor, and field staff who provide DOT to ensure that all aspects of the patient's care are implemented in an appropriate time frame.
- Regardless of who is providing direct care to the TB patient, the case manager should obtain information about the patient's status and update the data periodically, reporting it to the appropriate department at the state level. Collaboration and cooperation between the TB program and the health care provider can help facilitate this process.

Knowledge of community resources and stakeholders can foster partnership; therefore, the TB nurse case manager should:

- Identify key partners in the jurisdiction in which services are being provided.
- Establish a line of communication between partners.
- Engage providers who are involved in the care of high-risk populations.
- Work together with stakeholders promoting a sense of responsibility and accountability to the needs of the community.
- Strengthen the partnership by utilizing all available resources, recognizing that each partner has something unique to offer.
- Develop a list of stakeholders that partner with TB programs nationwide.
- Have an awareness of current issues and topics related to TB and share information with community partners.
- Identify upcoming conferences, lectures, and seminars and share information with partners.

In addition, case managers can also promote public health policy and programs and, thus, should:

- Know the epidemiological profile of the program area as it pertains to TB.
- Work together with partners in formulating new policies and procedures associated with TB prevention and control and apply knowledge of state and national TB guidelines when assisting with patient management issues.
- Demonstrate knowledge of state and national guidelines.
- Assist private providers to ensure that:
 - The patient is on appropriate treatment and adheres to treatment until completion.
 - Adverse events and drug side effects are reported and response to treatment is monitored regularly.
 - The patient completes treatment within the recommended time frame.
 - All aspects of treatment are documented and reported using appropriate jurisdictional forms.
- Provide expert advice and consultation to other health care workers who provide care to patients with TB disease or TB infection.
- Intervene to prevent and minimize TB transmission.

- Provide oversight of contact investigation for persons with infectious TB disease.
- Ensure evaluation and treatment for TB infection or TB disease, if indicated, to prevent TB in high-risk persons (e.g., contacts, persons with TB classifications for travel from pre-immigration/departure medical screening by panel physicians, persons living with HIV).

A sample letter to community or private providers requesting an update on a TB patient can be found in Appendix 5.

VI. DELEGATION IN TUBERCULOSIS NURSE CASE MANAGEMENT

As indicated earlier, the nurse case manager is responsible for overseeing all case management activities described in this chapter, but may not directly carry out all the activities. Thus, during a patient's treatment for TB, it may become necessary for the nurse case manager to delegate responsibility to other health care professionals or unlicensed assistive personnel (UAP). Therefore, nurse case managers must develop the ability to delegate properly.

It is important to note that states and jurisdictions have different laws, rules, and regulations about delegation; all licensed nurses are responsible for knowing what is permitted in their state Nurse Practice Act (NPA) rules, regulations, and policies (National Council of State Boards of Nursing, 2016). The nurse is responsible for the nature and quality of all nursing care, including the assessment of the nursing needs, the plan of nursing care, the implementation, and the monitoring and evaluation of the plan (State of New Jersey, Department of Law and Public Safety, 2017). Nursing judgment or any activity that will involve nursing judgment or critical decision making should not be delegated. It is important to ascertain the competence of the person to whom a task is delegated and ensure education was provided and maintained.

Crucial components of delegation include:

- Supervision
- Monitoring
- Evaluation
- Follow up by the delegating nurse

The professional nursing functions of assessment, evaluation, and nursing judgment are **never** delegated. The person who accepts the delegation is accountable for his or her actions in carrying out the task, and the nurse case manager is accountable for appropriate delegation. For example, if a licensed practical nurse (LPN) or licensed vocational nurse (LVN) administers the wrong medication or an improper dose, the LPN or LVN is accountable for the error, but the registered nurse (RN) is accountable for delegating the task to a person who was not competent to perform the task.

The National Council of State Boards of Nursing (2016) offers the following “*Five Rights of Delegation*” as rules for nurses to follow when delegating a task:

- **Right task:** The task is one that can be delegated as determined by the specific patient care situation.
- **Right circumstances:** The patient setting is appropriate, resources are available, and other relevant factors are considered.
- **Right person:** The right person is delegating the right task to the right person.
- **Right direction/communication:** The task is clearly and concisely described, including its objectives, limits, and expectations.
- **Right supervision:** There is appropriate monitoring, evaluation, intervention (as necessary), and feedback.

VII. SUMMARY

A patient-centered case management approach is an essential component in treatment of TB and the larger efforts to prevent and control TB. With active input from the patient and health care providers, the TB nurse case manager, together with the patient, develops and implements an individualized care plan with interventions to address the identified needs and barriers for each patient (Nahid et al., 2016). Successful patient outcomes are influenced by the TB nurse case manager’s ability to implement an appropriate care plan by balancing the rights of the patient and the community.

APPENDICES

Appendix 1: Patient Education Documentation Form

PATIENT FACTORS THAT MAY AFFECT EDUCATION PROCESS (CHECK IF APPLICABLE)

- | | |
|---|---|
| <input type="checkbox"/> Cognitive impairment | <input type="checkbox"/> Physical impairment |
| <input type="checkbox"/> Visual impairment | <input type="checkbox"/> Family dynamics |
| <input type="checkbox"/> Speech | <input type="checkbox"/> Hearing impairment |
| <input type="checkbox"/> Primary language other than English | <input type="checkbox"/> Cultural/religious factors |
| <input type="checkbox"/> Literacy | <input type="checkbox"/> Emotional state |
| <input type="checkbox"/> Readiness/motivation/desire to learn | <input type="checkbox"/> Other |

EVALUATION SCORE KEY

- 1 = Unable to teach
- 2 = Teaching offered – refused
- 3 = Requires reinforcement of content
- 4 = Demonstrates with assistance
- 5 = Explains independently
- 6 = Demonstrates independently

EXPECTED OUTCOMES	TEACHING SESSIONS/LEARNER EVALUATION							
	Initials Date	Evaluation Score	Initials Date	Evaluation Score	Initials Date	Evaluation Score	Initials Date	Evaluation Score
Patient/family can:								
Verbalize an understanding that confidentiality will be maintained.								
Verbalize an understanding of the difference between TB infection and TB disease.								
Verbalize an understanding of TB transmission.								
Demonstrate techniques to prevent transmission (e.g., proper use of mask, covering mouth and nose when coughing, correct use and disposal of tissues).								
Verbalize an understanding that TB is curable.								
Verbalize an understanding of the consequences of not undergoing treatment for full length of time.								
Verbalize an understanding of causes and impacts of MDR-TB.								
Agree to participate in DOT.								
Verbalize an understanding of the medication regimen and potential side effects.								
Verbalize an understanding that non-adherence can result in legal consequences (e.g., involuntary confinement).								
Identify contacts.								
Verbalize an understanding of the importance of knowing HIV status and its effect on TB treatment.								

Appendix 2: Examples of Intermediate Outcomes in TB Case Management

<p>Activity: Initiate treatment with anti-TB medications</p> <ul style="list-style-type: none"> • Appropriate TB regimen is prescribed and DOT is planned at first visit.
<p>Activity: Directly observed therapy (DOT)</p> <ul style="list-style-type: none"> • DOT is initiated within one working day. • Patient's monthly adherence rate is compared to established objectives.
<p>Activity: Clinical monitoring of response to anti-TB treatment</p> <ul style="list-style-type: none"> • Sputum conversion (smear) occurs within two to three weeks and sputum remains negative. • Culture conversion occurs within eight to ten weeks, and culture remains negative. • Clinical improvement is subjectively and objectively noted in 80% of patients.
<p>Activity: Monitoring and follow up for side effects and adverse events</p> <ul style="list-style-type: none"> • Side effects of medications are minimized by adjusting method and timing of ingestion. • Baseline CBC, hepatic enzymes, and platelet count are obtained in 100% of patients placed on four first-line drugs. • Blood tests are repeated in 100% of patients who have abnormal baseline test results, are at high risk for side effects, or who present with signs or symptoms of adverse reactions to drugs. • Baseline visual acuity and color vision (Ishihara) test are performed at first visit on 100% of patients taking ethambutol and repeated monthly. • Baseline auditory and renal function studies are performed on 100% of patients taking an aminoglycoside. • Baseline uric acid and hepatic enzyme levels are obtained in 100% of patients taking PZA and repeated if abnormal or if patients present with symptoms of adverse reaction. • Baseline psychiatric evaluation and administration/monitoring protocol are in place for patients taking cycloserine.
<p>Activity: Adherence monitoring</p> <ul style="list-style-type: none"> • Continuity of TB treatment is ensured by patient keeping monthly appointments. • Barriers to adherence are identified within two days of missed DOT and addressed within three working days.
<p>Activity: Insight into TB disease process</p> <ul style="list-style-type: none"> • Education is provided to 100% of patients and caregivers regarding pathogenesis, transmission, and treatment of TB disease, the difference between TB infection and disease, and prevention of transmission in the community.
<p>Activity: Treatment plan documented</p> <ul style="list-style-type: none"> • Individualized, multidisciplinary care plan is developed during the first month of treatment.
<p>Activity: Community health*</p> <ul style="list-style-type: none"> • TB interview is conducted within three days after patient is reported as being evaluated for TB disease or diagnosed with TB disease. • Identified contacts are tested for TB infection, if previously negative, within 15 days after patient is reported as being evaluated for or diagnosed with TB disease. • Contacts with a positive TB test are medically evaluated within 30 days after the index case was reported.

* Follow state and local guidelines.

Appendix 3: Examples of Expected Outcomes in TB Case Management

<p>Activity: Treatment with anti-TB medications</p> <ul style="list-style-type: none">• Appropriate medication regimen is completed in expected time frame (varies according to patient's condition).
<p>Activity: Directly observed therapy (DOT)</p> <ul style="list-style-type: none">• Treatment is completed.• Patient maintains adherence rate that meets established objectives.
<p>Activity: Clinical monitoring of response to TB treatment</p> <ul style="list-style-type: none">• Sputum smears and cultures remain negative.• Patient no longer demonstrates signs or symptoms of TB.
<p>Activity: Adherence monitoring</p> <ul style="list-style-type: none">• Patient keeps appointments with physician, nurse, and other team members.• Patient does not miss DOT appointments.• Barriers are identified and issues addressed.
<p>Activity: Insight into TB disease process</p> <ul style="list-style-type: none">• Patient verbalizes an understanding of the TB disease process.• Patient understands importance of following TB treatment regimen as evidenced by adherence and completion of therapy.• Patient cooperates with the nurse and TB staff on contact investigation, infection control, and other efforts to prevent transmission of disease.
<p>Activity: Treatment plan documented</p> <ul style="list-style-type: none">• Individualized care plan, developed in the early stages of treatment, is reviewed at regular intervals and updated by team members, as needed.
<p>Activity: Community health</p> <ul style="list-style-type: none">• Contacts are identified, tested, evaluated, and started on treatment according to established guidelines.

Appendix 4: Example of Chart Review

Patient Name: _____

Intermediate Outcomes	Time frame	Date(s) accomplished					
TB contact investigation interview	3 days						
Contacts identified and tested	15 days						
Medical evaluation of contacts	30 days						
Appropriate medication regimen	At 1st visit/monthly						
DOT arranged	24 hours						
Testing/Screening	Baseline and PRN						
• Blood							
• Vision							
• Hearing							
• Sputum							
• X-rays							
• HIV test							
Sputum smear conversion	2-3 weeks						
Sputum culture conversion	8-10 weeks						
Clinical improvement	Monthly						
• Subjective							
• Objective							
Patient Education							
• Initiated	At 1st visit						
• Documented	Monthly						
Appointments							
• Physician follow up	Monthly						
• DOT adherence	Monthly						
• Referrals	PRN						
Nursing care plan							
• Initiated	At 1st visit						
• Documented	Monthly						

Appendix 5: Sample Update Request Letter and Form for Patients Treated by Private or Community Providers

Date:

Re:

DOB:

Dear *insert name*:

The *insert program name* requires a monthly status report on the above-named patient who is under your care and medical supervision for the treatment of tuberculosis.

Please complete and sign the attached Medical Update Form. All sections should be fully completed and returned within 7 days to *insert email address, fax number, and name of recipient*. If any smear, culture or sensitivity results have been received since the previous report please attach those as well.

According to HIPAA rule, PHI (protected health information) can be shared for public health, without individual authorization, to a public health authority. See [45 CFR 164.512(b)].

Your cooperation in this matter is appreciated. If you have any questions, please do not hesitate to contact this office at *insert number*.

Sincerely,

Insert name and contact information

Medical Update Form

Patient: _____ **DOB:** _____

Date of most recent physical exam: _____ **Weight:** _____

Symptoms:

- Cough: (if present, please specify if productive or non-productive): _____
- Weight loss
- Decreased appetite
- Hemoptysis
- Fever
- Chest pain
- Fatigue
- Night sweats
- Chills

Medications, frequency, and dosages: _____

Bacteriology: _____

Results of most recent chest X-ray (If abnormal, please indicate whether X-ray is stable, worsening, or improving): _____

TST or IGRA results:

<input type="checkbox"/> TST	<input type="checkbox"/> IGRA
Date administered: _____	Type of IGRA: _____
Date read: _____	Date: _____
Millimeter reading: _____	Result (including quantitative result): _____

HIV status: _____

Date TB treatment initiated: _____

Expected length of TB treatment: _____

Number of doses completed: _____

If completed, date of completion: _____

Comments: _____

Date of next appointment: _____

Signature of physician: _____ **Date:** _____

RESOURCE LIST

1. *Self-Study Modules on Tuberculosis*, CDC. Available at: cdc.gov/tb/education/ssmodules/default.htm
2. *Interactive Core Curriculum on Tuberculosis: What the Clinician Should Know*, CDC. Available at: cdc.gov/tb/education/ce/interactive-corecurr.htm
3. National TB Controllers Association/National TB Nurse Coalition website, NTCA and NTNC. Available at: tbcontrollers.org/ntnc/
4. *TB Training Roadmap for Public Health Nurses*, Global Tuberculosis Institute. Available at: globaltb.njms.rutgers.edu/educationalmaterials/productfolder/roadmap.php
5. The Public Health System and the 10 Essential Public Health Services web page, CDC. Available at: cdc.gov/stltpublichealth/publichealthservices/essentialhealthservices.html
6. Public Health Nursing webpage, American Nurses Association. Available at: nursingworld.org/MainMenuCategories/ThePracticeofProfessionalNursing/PublicHealthNursing
7. *Official American Thoracic Society/Centers for Disease Control and Prevention/Infectious Diseases Society of America Clinical Practice Guidelines: Treatment of Drug-Susceptible Tuberculosis*. Available at: cdc.gov/tb/publications/guidelines/pdf/clin-infect-dis.-2016-nahid-cid_ciw376.pdf
8. *Understanding the Cohort Review Process*, CDC. Available at: cdc.gov/tb/publications/guidestoolkits/cohort/cohort.pdf
9. *Guidelines for the Investigation of Contacts of Persons with Infectious Tuberculosis*, CDC. Available at: cdc.gov/mmwr/preview/mmwrhtml/rr5415a1.htm
10. *Tuberculosis Genotyping Fact Sheet*, CDC. Available at: cdc.gov/tb/publications/factsheets/statistics/genotyping.htm
11. *TB Toolkit for Community Health Centers and Federally Qualified Health Centers*, Global Tuberculosis Institute. Available at: globaltb.njms.rutgers.edu/educationalmaterials/productfolder/toolkitqhc.php
12. Additional CDC TB Resources:
 - I. TB Guidelines: cdc.gov/tb/publications/guidelines/default.htm
 - II. Health Care Provider and TB Program Materials: cdc.gov/tb/education/provider_edmaterials.htm
 - III. Patient and General Public Materials: cdc.gov/tb/education/patient_edmaterials.htm

CHAPTER 2

Providing Patient-Centered Tuberculosis Care

I. INTRODUCTION

The Institute of Medicine defines patient-centered care as “providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions” (2001). The overarching goal of patient-centered care is to improve the quality of health care by integrating the patient’s perspective. Patient-centered care focuses on individual care and personal relationships. This approach begins with viewing care from the patient’s perspective, and then adapting care to more closely meet the needs and expectations of the patient. A patient-centered care strategy has implications for patient-provider interactions, service delivery, and overall health system characteristics.

Within a patient-centered approach, health care providers work toward the goals of partnership, solidarity, empathy, and collaboration, rather than establishing a relationship based on authority (Epstein & Street, 2011). This approach helps patients to be more involved in their TB treatment and changes a health care provider dominated dialogue to one that engages patients as active participants.

a. Key Elements of Patient-Centered TB Care

TB is a public health issue that requires prompt diagnosis with effective treatment and identification of contacts. Given that TB treatment requires multiple drugs over several months, it is essential that the patient be involved in a meaningful way in making decisions concerning treatment supervision and overall care (Nahid et al., 2016). As discussed in Chapter 1, a plan that involves input from the patient while concurrently ensuring public safety is important to successful TB prevention and control efforts. In most settings, a patient will have a designated TB nurse case manager who will develop a care plan.

Key considerations when developing a plan include (Nahid et al., 2016):

1. Improving “treatment literacy.”
2. Discussing expected outcomes of treatment.
3. Reviewing methods of supervision and assessing response to therapy.
4. Discussing infectiousness and infection control measures using terminology that is appropriate to the culture, language, age, and reading level of the patient.

Other considerations should include (Nahid et al., 2016):

1. Use of medical interpretation services (preferred over using family or friends as interpreters for non-English-speaking patients).
2. Reinforcing relevant information at each visit.
3. Setting up patient reminders and systems for following up on missed appointments.
4. Using incentives and enablers.
5. Conducting field and home visits.
6. Integrating and coordinating TB care with the patient's primary and specialty care providers.
7. Utilizing legal interventions when indicated.

TRICKS OF THE TRADE

- *Implementing a patient-centered approach can help to encourage shared decision making about treatment and tailored patient support for ensuring successful outcomes.*
- *Training of staff to improve and maintain competencies for health education and communication skills, especially as it relates to special populations, can also be beneficial.*
- *Understanding the patient's beliefs, attitudes, and interpretations of illness and wellness as well as motivational factors, may go a long way in establishing patient buy-in and improving treatment adherence.*

When implementing a patient-centered approach, the problem identification and plan development activities discussed in Chapter 1 should be considered. It is important to identify and address concerns and barriers, which may be individual or specific to a cohort of patients who have common lifestyles, similar cultural backgrounds, or shared interests. For example, some patients may be afraid of others finding out about their TB diagnosis based on cultural beliefs or stigma around TB.

Patients who are undocumented may be fearful of being deported, and may be unable to access certain resources or services, which may impact their willingness to name contacts, or their ability to adhere to treatment.

b. Providing Culturally Responsive Care

Within the United States, the number of non-US-born persons with TB is increasing compared to the number of people with TB born in the country. When accessing TB services, persons born outside the US may encounter challenges due to personal or cultural beliefs, behaviors, and needs. At the same time, public health programs across the country may face challenges in reaching, providing TB-related care, and meeting the needs of the diverse populations they serve. Thus, ensuring culturally responsive care that recognizes, responds to, and respects cultural background and beliefs is essential to providing effective patient-centered TB case management, and to the larger effort to prevent and control the disease.

Providing culturally responsive care requires an understanding of the impact of culture on health and TB care, which is essential to the prevention and elimination of TB among non-US-born populations (CDC, 2008). In fact, this concept is important for working effectively with all patients, including those born in the US. Some important concepts to remember include:

- Culture is not related only to country of origin, race, or ethnicity.
- Individuals associate with multiple cultures, which may be based on where they come from, the language they speak, their religion, profession, or social groups, among other factors.
- Culture is shaped by an individual's life experiences and events, and contributes to their beliefs, values, attitudes, and behaviors.
- Culture can impact the ways in which individuals communicate verbally and non-verbally and can have a significant influence on *beliefs and actions around health*, including:
 - When, where, and from whom individuals seek care.
 - What type of care or treatment individuals think they should receive.

Patients may also face linguistic barriers, as well as challenges related to resettlement, employment, and socioeconomic status. Beliefs about the causes of TB, how it should be treated, and fear and stigma around the disease may also be influenced by culture.

In order to provide culturally responsive quality care, health care providers and health systems should aim for cultural competence.

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 (CDC, 2008).

Cultural competence reflects the ability to acquire and use knowledge of the health-related beliefs, attitudes, practices, and communication patterns of patients and their families to improve services, strengthen programs, increase community participation, and close the gaps in health status among diverse population groups (Strand et al., 2011). Within the health care field, cultural competency means having knowledge, abilities, and skills to deliver care congruent with the patient's cultural beliefs and practices (Purnell, 2000). A culturally competent system acknowledges cultural differences and incorporates appropriate care at the policy, provider, and consumer levels.

Health care providers interact with people from a wide variety of ethnic and cultural backgrounds. Differences in personal appearance, behavior, communication patterns, values, and beliefs must not be viewed as obstacles to communication, but rather, as opportunities for the provider to

learn and grow personally while providing health care that is culturally responsive and appropriate. A lack of knowledge of the patient's cultural beliefs, cultural values, and language abilities may have a negative impact on TB care and treatment outcome.

However, it is important to note that providing culturally responsive care does not mean utilizing a "cookbook" approach or making assumptions about patients based on their religion, language, country of origin, or any other cultural factor. There can be many cultural differences within countries or ethnic groups, based on factors such as individual or family history and experiences. Thus, researching a patient's culture, customs, and language should serve only as a starting point. Interactions with patients and decisions around care should be driven by information and preferences provided by individual patients and their families.

TB nurse case managers are not expected to become cultural experts; however, they should explore their own beliefs and culture and try to develop attitudes, knowledge, and skills that will allow them to provide effective cross-cultural TB care.

Consideration of the following four elements will assist in developing cultural competency:

- Awareness of one's own cultural values.
- Awareness and acceptance of differences across and within cultures.
- Development of cultural knowledge.
- Ability to adapt practice skills to fit the cultural context of the patient.

The first step towards cultural competency includes an exploration of personal feelings and reactions to individual or group differences. It is important to realize that an individual's values and beliefs reflect only a single point of reference. Recognizing that we all possess biases, some of which we may not be fully aware of, is the first step towards cultural awareness. With further exploration and education, this can contribute to the provision of culturally competent care for patients.

Developing cultural awareness can begin with an appreciation of the external signs of culture such as food, music, arts, or dress. Seeking out cultural experiences in these areas can help to raise cultural sensitivity and awareness. Cultural sensitivity should also be developed by being aware of things that may cause offense to others. The self-assessment checklist in Appendix 1 may be used to assess cultural awareness and identify areas for improving cultural sensitivity in providing TB case management. For additional guidance on cultural competency and TB care, consult the *Cultural Competency and Tuberculosis Care: A Guide for Self-Study and Self-Assessment* at: globaltb.njms.rutgers.edu/educationalmaterials/productlist_cultural.php (Global Tuberculosis Institute, 2008).

Another important aspect of providing culturally responsive care is ensuring culturally and linguistically appropriate services (CLAS). The National CLAS Standards aim to help eliminate health inequities and improve quality of care. By tailoring services to an individual's culture and language preferences, health care providers can help bring about positive health outcomes for diverse populations (Douglas et al., 2011). These 15 standards are intended to advance health equity, improve quality, and help eliminate health care disparities by establishing a blueprint for health and health care organizations. The standards are available at: thinkculturalhealth.hhs.gov/assets/pdfs/EnhancedNationalCLASStandards.pdf

According to the Joint Commission standards and federal law, patients have the right to effective communication, including access to interpretation and translation services. Interpretation refers to spoken language while translation refers to written text. Effective communication with patients is necessary for engagement in care and is a critical component of patient safety, education, and informed consent. Consider the following:

- Trained interpreters or telephone interpretation services should be used when the patient does not proficiently speak or understand English.
- Most organizations advise against the use of a patient's family or friends for interpretation for a variety of reasons, including lack of medical vocabulary, privacy and confidentiality concerns, and potential for lack of full disclosure or interpretation based on interpersonal factors.
- Bilingual clinic staff should not generally be used for interpretation if they have not been certified as medical interpreters.
- Patients may prefer interpreters of the same gender; ask patients if they have preference for a same gender interpreter, if resources are available to meet this request.

Time pressures, lack of knowledge about the availability of professional interpreters, or procedural difficulties in arranging for interpreters can present challenges. However, the use of untrained interpreters can lead to errors or misinformation, which may lead to poor outcomes with regard to adherence and completion of treatment.

It is also important to provide, or have a mechanism to provide, any written material such as forms and educational materials in the languages commonly used in the populations served.

II. STRATEGIES AND RECOMMENDATIONS FOR PATIENT-CENTERED CARE IN TUBERCULOSIS NURSE CASE MANAGEMENT

a. Approaches to Ensuring Adherence and Treatment Success

TB treatment requires a high pill burden for a long period of time, which can involve side effects and has the potential to impact a patient's work and social activities. Providing patient-centered care that considers the needs of the patient and family includes incorporating strategies to assist and encourage the patient in their treatment. Given the public health implications and the impact on individual patients, approaches for ensuring adherence to TB treatment are a major focus of the overall management plan. This includes adherence to taking medications as recommended throughout the course of treatment, as well as keeping clinic appointments and following up for any recommended tests. Strategies should include a broad range of approaches to assess and improve adherence in persons being treated for TB (Nahid et al., 2016).

Many variables affect a patient's adherence to treatment. The case manager should assess the following variables regularly:

- **Patient variables** which may be individual or specific to a cohort of patients who have common lifestyles, similar cultural backgrounds, or shared interests.
- **Treatment variables** related to medication and duration of treatment.
- **Disease or disorder variables** such as co-existing medical conditions.
- **Organizational or provider variables** including the quality of services provided, which are often overlooked and can influence patient adherence.

In most cases, using a patient-centered approach to assess and address the above variables can promote patient adherence and help to ensure successful treatment completion. However, in rare cases where patients are not in accordance with program standards and there is a resulting threat to public health, legal or administrative interventions may be used. Policies and regulations differ across TB programs and states, so it is important to follow the proper standards and obtain appropriate approvals prior to implementation. Any legal interventions should begin with the least restrictive possible measure and progress only if adherence to state and local policies cannot be established. For additional information on legal interventions, consult *Implementing Legal Interventions for the Control of Tuberculosis* available at:

globaltb.njms.rutgers.edu/educationalmaterials/productfolder/legalinterventions.php

As discussed in Chapter 1, assessment data may be obtained from team members and by interviewing, listening to, and observing the patient's behavior during TB treatment. The assessment of adherence requires knowledge of these variables and a review of the following indicators:

- Standards of adherence (e.g., monthly adherence rate)
- Self-reporting by patient (e.g., for weekend doses that are self-administered)
- Behavioral measures
- Clinical outcomes

i. Directly Observed Therapy

As described earlier, DOT is the practice of having a health care worker or another trained individual observe the patient swallow each dose of the prescribed TB medications. DOT is the most effective strategy for ensuring that patients with TB adhere to treatment (CDC, 2017a). By using DOT, health care workers can count the exact number of medication doses the patient has taken, in order to ensure the patient has completed the required number of doses within the recommended time frame prior to discharge from care.

TRICKS OF THE TRADE

- *Be sure to assess the patient's ability to swallow pills and develop approaches together with the patient. The medications may need to be cut, crushed, or taken with soft or blended foods.*
- *Mints, lemon drops, ginger candy, or other candy with a strong flavor can be helpful for patients having difficulty tolerating any aftertastes of the pills.*

DOT can aid in the early detection of side effects, adverse drug reactions, and clinical worsening of TB, as well as identification of barriers to adherence. Regular interaction and communication with health care workers offers the patient opportunities for support throughout the course of treatment and can facilitate linkage to other medical

care and services. To be consistent with the principles of patient-centered care, the DOT plan should be developed with input from the patient.

Specific considerations in developing a patient-centered DOT plan include:

- Determining the attitudes of the patient and family toward DOT and the health care provider.
- Ensuring that the time and place for DOT administration meets the patient's needs.
- Understanding the feelings of the patient regarding the TB medications.
- Evaluating the patient's tolerance to the medications, such as the ability to swallow medications and ingest all medications at once, rather than in divided doses.
- Evaluating the presence or possibility of interactions with other medications (prescription, over-the-counter, traditional, or home remedy).

Ongoing assessment will help in early identification of barriers that could unnecessarily prolong treatment, if not addressed. The simultaneous use of other interventions, rather than relying on DOT alone, has been shown to promote adherence.

One such adherence strategy is the use of intermittent therapy in the continuation phase of treatment, whereby medications are administered thrice weekly rather than five or seven days per week, after the intensive phase of treatment is completed. ***It is important to note that daily dosing is preferred throughout treatment.*** During the continuation phase, however, intermittent dosing using thrice-weekly DOT is a reasonable option for **some** patients when more frequent DOT is difficult to achieve. There are also additional alternate regimens that may be used in specific circumstances (Nahid et al., 2016).

Intermittent therapy may be beneficial when time is an issue for the patient, when health care personnel resources are limited, or if it is difficult for the health care provider to make daily visits. When intermittent therapy is used, it is important to:

- Follow national guidelines and state or local recommendations, as intermittent therapy in the continuation phase is **not** recommended for all patients.
- Monitor adherence rates weekly; if adherence is low, the patient should return to daily dosing.
- Administer all intermittent therapy using DOT. If the patient needs to self-administer for any period (e.g., when traveling), they should be returned to daily dosing while self-administering.

Another treatment strategy is the use of fixed-dose combination medications such as Rifamate® (isoniazid and rifampin) or Rifater® (isoniazid, rifampin, and pyrazinamide). When available, this treatment option will help decrease the pill burden. Some patients may also receive injections of TB medication as part of their treatment regimen. The nurse case manager must consider any problems patients may encounter with injections over time. If problems occur, this strategy can easily become a deterrent to adherence.

Assessing adherence to DOT

Assessment of adherence should be conducted at regular monthly intervals or at clinic or physician visits. However, it may be necessary to evaluate a patient's treatment adherence more frequently to avoid gaps in treatment. Episodes of non-adherence should be identified as soon as possible, documented, and discussed with the patient and team members to address barriers and implement appropriate interventions.

The standards for adherence established by the state TB program or individual health department or health care facility should be used to assess DOT adherence. The adherence rate is calculated by dividing the number of documented days that the patient was observed taking medications by the number of available days in the month and multiplying by 100. Weekends and holidays should not be counted in the denominator as days available for DOT unless DOT is provided seven days a week and on holidays.

$$\text{DOT adherence rate} = \frac{\# \text{ of documented observed days}}{\# \text{ of available days for observation}} \times 100 = \underline{\hspace{2cm}}\%$$

TRICKS OF THE TRADE

- *To easily track and assess adherence, use a calendar and a standardized documentation system (e.g., check marks on days where doses were provided under DOT, a large X for a missed dose, and circling SAT dates). This allows for frequent monitoring and early identification of issues with adherence, and can be understood by all staff in the clinic.*
- *Remember, every patient is different. Some patients may struggle with side effects, some with compliance, some with isolation, and some with guilt of transmitting the disease to others. Communication or cultural differences may be the primary issue for other patients. Using good observation and assessment skills are vital. Then work towards the solution, including the physician or other health care provider as necessary.*

The denominator may vary depending on the month and circumstances that arise, and some exclusions may apply to the denominator. For example, planned and agreed upon days when a patient may be unavailable for DOT (e.g., vacations or conflicting medical appointments) and days when medications are withheld for medical reasons should not be included in the denominator. If the patient must miss DOT, the case manager should ensure that the patient has enough medication for self-administration, and that the patient is knowledgeable about the medication administration, dosages, and

side effects. Self-administered doses are not included in the numerator and are not included when counting the total number of doses taken (which is one of the criteria for treatment completion).

If a patient is hospitalized during any given month, local policy and details of the specific situation should be considered. If there is no assurance that medications are administered under direct observation, the numbers of days in the hospital should be subtracted from the number of days DOT would have been available. Further, these doses should not be counted toward the required number of doses needed for treatment completion. Nurse case managers should attempt to become familiar with local hospital personnel and practices to ensure that TB medications are not left with the patient to self-administer during hospitalization.

If a case manager has collaborated with hospital staff to establish a mechanism for providing and documenting DOT (e.g., during a long hospitalization), the DOT adherence rate should be calculated during this time. In this case, the number of available days in the denominator would

include days while the patient was hospitalized, and the doses provided under DOT in the hospital would be counted toward the required number of doses needed for treatment completion.

Although the treating physician is responsible for developing the treatment plan and ordering the medication regimen, the nurse case manager should make proactive suggestions regarding strategies to improve adherence. If non-adherence is identified as a problem, the case manager should have a team discussion that includes the physician. Other useful strategies include scheduling appointments as soon as possible after the initial diagnosis, quickly following up on missed appointments, and using appointment reminders such as text messages.

ii. Patient-Provider Relationship

This relationship is one of the most critical factors in improving patient satisfaction and adherence and is closely tied to the concept of patient-centered care. Working collaboratively to identify barriers and develop strategies to meet patient needs will contribute to a positive patient-provider relationship. All adherence enhancement strategies discussed in this chapter will be most effective in the context of a concerned, compassionate relationship with the patient who is an active participant in TB treatment.

Team members should show compassion and understanding of patients' lifestyles and should exhibit a non-judgmental attitude. Patients can be extremely perceptive about health care providers' attitudes concerning their lifestyle, even when these attitudes are not communicated verbally. As part of establishing and maintaining a positive patient-provider relationship, the TB case manager should:

- Initiate open discussions with the patient about the treatment plan, including responsibilities of all participants.
- Ensure that all communication (written and oral) is understood by the patient.
- Obtain feedback regarding the clarity of the communication or information.
- Avoid criticism of patient behaviors.
- Demonstrate open-mindedness about patient beliefs and lifestyles.
- Avoid imposing personal values on patients.
- Be aware of opinions held by health care providers on the team and how those opinions affect the patient's willingness to adhere to treatment.
- Consider a change in provider if efforts to negotiate conflict with team members or re-establish a positive relationship are not successful.

The compassionate nurse case manager should also recognize and address the patient's feelings about the disease and the resulting illness. A diagnosis of TB disease may produce reactions of fear, anxiety, and hopelessness. Nurse case managers should support the patient in helping them work through the emotional aspect of coping with TB. If this does not occur in the early stages of the process, these fears may cause barriers to adherence later on that could interfere with the nurse-patient relationship and successful treatment.

iii. Incentives and Enablers

Incentives and enablers are tools that the case manager may use to promote adherence and positive patient outcomes. Incentives are small rewards given to patients to improve and maintain adherence and provide motivation to carry out the activities necessary for treatment. Incentives should be tailored to the individual's special interests or needs and be offered according to an established policy and plan that stipulates how they will be used. The team member who works most closely to achieve adherence should give the incentives to the patient. Incentives act as an immediate reward. If the reward is for keeping the clinic appointment, the nurse case manager may be the one to provide the incentive to the patient.

Enablers differ from incentives in that they help patients adhere to the treatment plan. An assessment, which identifies the barriers to care for patients, should be used to determine the need for enablers. The case manager, along with the multidisciplinary team and the patient, should determine which incentive and enabler will be most beneficial to the patient.

Assessment of incentives and enablers and the needs of the patient should be documented in the patient's medical record. Evaluation of adherence should occur regularly and may result in a change in the incentive and/or enabler during the course of TB treatment if the expected action of the patient deviates from the original plan.

Possible Components of a Multifaceted, Patient-Centered Treatment Strategy	
Enablers	Incentives
Interventions to assist the patient in completing therapy	Interventions to motivate the patient, tailored to individual patient wishes and needs and, thus, meaningful to the patient
Transportation vouchers	Food stamps or snacks and meals
Convenient clinic hours and locations	Restaurant and grocery store coupons
Clinic personnel who speak the languages of the populations served	Assistance in finding or provision of housing
Reminder systems and follow up of missed appointments	Clothing or other personal products
Social service assistance (referrals for substance abuse treatment and counseling, housing, and other services)	Books, movie tickets, etc.
Outreach workers (bilingual/bicultural as needed; can provide many services related to maintaining patient adherence, including provision of DOT, follow up on missed appointments, monthly monitoring, transportation, sputum collection, social service assistance, and educational reinforcement)	Stipends

iv. Patient-Provider Agreement

Use of written patient-provider agreements is another strategy often used by health care providers in TB programs. Agreements provide a useful means by which the patient's participation, responsibility, and accountability can be nurtured and managed. These agreements clarify treatment goals, patient **and** provider responsibilities, and minimize confusion.

When negotiating a patient-provider agreement:

- Utilize a patient-centered approach; the patient's choice, control, and involvement are essential.
- Review the importance of adherence.
- Have concrete discussions and agree on specific behaviors, expectations, and incentives and enablers.
- Discuss roles and responsibilities of the health care team (e.g., listen to the patient, address concerns, respond to phone calls within one day, etc.).
- Ask the patient about their expectations from the health care team and incorporate these into the agreement whenever possible.

During the course of TB treatment:

- Review the agreement with the patient regularly to assess whether both patients and providers have met the outlined expectations and responsibilities.
- Break down complex behavioral goals into small achievable components that progressively move the patient toward treatment objectives if problems or challenges occur.
- Provide incentives soon after the desired behavior is exhibited rather than at fixed intervals in order to reinforce positive behavior.
- Remind patients of the need for adherence to therapy and the medical impacts if the patient does not meet the stated expectations or responsibilities. Review the original signed agreement to reinforce the seriousness and the consequences of non-adherence if problems with adherence are present.
- Implement any actions that result from non-adherence with the agreement (e.g., discontinuation of incentives) within a stated time period. Patients should be aware of these impacts, since they were part of the original agreement.

v. Patient Education

Appropriate and effective patient education is an important element in ensuring adherence to treatment. Education is a two-way interactive process between the patient and health care provider; educational messages and approaches should be tailored to meet the specific needs of each patient. For example, information provided should be appropriate for the patient's age or stage of development, level of education or literacy, and current level of TB knowledge. Thus, an assessment of the patient's beliefs and knowledge about TB treatment should be carried out as part of the educational process. Based on the assessment of the patient, the nurse case manager will need to decide when, how, and who participates in the education process.

Effective communication techniques and educational materials will enhance this process. Simply providing written or verbal education around TB is not adequate. The case manager should:

- Assess whether the patient understands the information that has been provided.
- Utilize approaches such as plain language, repetition, and using different words to reinforce the concepts until the patient demonstrates understanding.
- Assess whether the patient fully understands the information provided by asking the patient to restate information in their own words rather than simply asking if they understand. For example, asking the patient to list what side effects they can expect from the medications and to identify serious side effects can provide an opportunity to assess the patient's knowledge and to reinforce symptoms that should prompt an immediate call to the clinic.
- Monitor nonverbal cues and consider questions the patient is asking, as these can indicate a need for further information and education.

When patients have immediate unmet needs that are a priority (e.g., housing, food, rent, etc.), the educational process may be negatively impacted. The nurse case manager should try to address these needs before attempting to educate the patient about TB. If a change in behavior or lifestyle is required, the nurse case manager should assess the patient's readiness for change, cultural beliefs and values, and expectations about the disease and treatment. Patients are more likely to be adherent if they believe they have a treatable disease, understand the treatment plan, and recognize the benefits of treatment.

Education should be provided throughout the duration of treatment in a planned, sequential manner, limiting the amount of information presented at any one visit, and repeating or emphasizing relevant messages, depending on the stage of treatment and the patient's individual circumstances. Messages around expected length of treatment and planning for discharge from care after completion of treatment should also be provided throughout the course of treatment, based on the patient's progress. For example, since treatment may need to be extended in certain cases, it may be best not to focus on a specific discharge date early in treatment, but rather discuss progress toward treatment completion at regular intervals throughout the course of care.

Appropriate information should be provided to patients in the time period leading to discharge from care. An individualized written discharge summary can be provided to patients who complete treatment. Since some patients form close relationships with providers over the course of treatment, discharge from care at the completion of treatment may be emotionally or psychologically difficult for the patient.

Depending on the individual patient, preparation for discharge from care after treatment completion may include:

- A discussion regarding the conclusion of the therapeutic relationship:
 - Cessation of case management services.
 - Need for self-sufficiency (or assistance from others) with regard to future coordination for primary health care and co-morbidities such as mental health disorders or diabetes.
- Referrals and reminders about the need for continued care for co-morbidities.
- Provision of documentation with TB testing and treatment completion information.
- Emphasis that patients should not be re-tested for TB with IGRAs or TSTs in the future.
- Review of the signs or symptoms of TB in case of relapse.
- Review of any long-term impacts of the patient's disease or treatment, if present (e.g., abnormalities on X-ray or diminished lung function).
- Scheduling for any future TB follow up as needed (e.g., for patients with MDR-TB).

Materials in the patient's primary language and at the appropriate level should be available so the patient can review the information at home and share it with family members. As noted earlier, if the nurse case manager or health care provider cannot speak the patient's language, a medical interpreter should be used rather than a family member.

Finally, patient education should be documented in the medical record as it occurs. See Appendix 1 in Chapter 1 of this guide for a template.

vi. Alternatives to Face-to-Face DOT

Face-to-face DOT can be time and resource-intensive and may not be feasible for all patients if resources are limited. In those circumstances, face-to-face DOT should be prioritized for patients who are more likely to present a transmission risk, have difficulty adhering to treatment, or have complications based on individual situation and the case manager's assessment (e.g., patients with hepatitis or immune suppression). Alternative methods of DOT may be considered for other patients. These approaches should still be implemented together with other methods for patient-centered care described in this chapter.

Electronic DOT

Electronic DOT (eDOT) is an alternative method to in-person DOT in which a patient is remotely observed (e.g., using a smart device) taking TB medication. This type of DOT is sometimes referred to as virtually observed therapy (VOT), mobile DOT (mDOT), remote DOT, video DOT (VDOT), and video-enhanced therapy (VET). Electronic DOT makes use of available technologies to remotely monitor TB patients ingesting their medications, either in real-time or using a recorded format.

Prior to implementing eDOT, it is important to consider factors such as the patient's medical condition, ensuring privacy and security of information, and the patient's access to and understanding of the technology used. Establishing a policy and specific criteria for using eDOT will help ensure that it is used appropriately and effectively. Prior to implementing eDOT, it is recommended that the health care team review *Implementing an Electronic Directly Observed Therapy (eDOT) Program: A Toolkit for Tuberculosis (TB) Programs* at: [cdc.gov/tb/publications/pdf/tbedottoolkit.pdf](https://www.cdc.gov/tb/publications/pdf/tbedottoolkit.pdf) (CDC, 2017a). It may also be helpful to contact other programs or partners who have successfully implemented eDOT for insights into policy development and best practices.

Self-administered therapy

SAT is not recommended for patients with TB disease, but is sometimes used on weekends (when DOT is provided five days a week), or if patients are traveling. However, these doses should not be counted toward the required number of doses needed for treatment completion. SAT is often used for patients being treated for TB infection.

One method for assessing patients who are self-administering TB medications is to directly ask the patient if the medications are being taken as directed. Self-monitoring forms or web-based applications may be used, but their accuracy is not guaranteed. Nevertheless, the simple act of self-monitoring and recording may serve as a reminder for the patient and thus, improve adherence. Unlike DOT, self-reporting cannot be considered a true indicator of adherence and is, therefore, a less reliable assessment tool.

Behavioral measures are frequently used to assess adherence. Some of these measures are also used for patients on DOT. The most commonly used methods to assess adherence to TB treatment are:

- Pill counts.
- Observation of patient behaviors.
- Record keeping of clinical appointments.

In cases where SAT is being used for patients with TB disease (e.g., while the patient is traveling for an extended period), clinical outcomes may also be helpful for assessing adherence and may be measured by:

- Symptom improvement such as weight gain, lessening of cough, increased appetite, or increased energy.
- Change in bacteriology results (smear positivity and culture conversion).
- Chest X-ray improvement.
- Therapeutic drug monitoring or serum drug levels.

Patients often experience symptom improvement after several weeks of treatment and may be inclined to stop taking TB medications once they start to feel better. The risk of non-adherence increases with the duration of treatment. Patients must be closely monitored throughout the course of treatment for DOT adherence and for any changes in their clinical status.

b. Addressing Organizational Barriers

If organizational barriers to care are present, patients may become uncooperative with health care providers, making delivery of care difficult. Patient satisfaction with the health care system and with individual providers is important for adherence. Therefore, nurse case managers should promptly identify and address any difficulties that patients are encountering in the clinic or with providers. If the case manager does not have authority to change the clinic system, it will be necessary to meet with the appropriate administrative staff to discuss the problems and assist in resolution.

The organization of TB services will impact adherence. Some basic guidelines for organization and provision of service include the following:

- The clinic should be physically safe and comfortable.
- Clinic staff should be courteous, respectful, and culturally sensitive.
- Interpretation services must be made available.
- Patient confidentiality must be maintained.
- Documentation of patient's medical care, nursing interventions, and other services provided should be in accordance with external and internal standards.
- Clinic services must be easily accessible and efficient, in order to minimize waiting time.

c. Sample Care Plan

The basic care plan on the next page can be used as a template when case managing patients with TB. This care plan lays out the minimum activities necessary for TB case management and is meant as a starting point for developing a care plan. Case managers should consider the elements and activities of TB nurse case management outlined in Chapter 1 and should modify the basic care plan based on individual needs and circumstances of specific patients as well as state or local policy and regulations. Specific additional considerations for patients with certain co-morbidities or circumstances are described in Chapter 3.

Sample Care Plan

Assessment

- Review all medical information, including information from other providers or agencies.
- Check that the medication regimen is correct for the patient's recorded weight.
- Review for accuracy with the patient at the first encounter.
- Assess for any co-morbidities that may impact TB treatment or outcomes.
- Investigate and assess overlapping side effects of TB and all other medications.
- Become familiar with the side effects of all medications the patient is taking.
- Assess for side effects and inform any other providers or partners involved in the patient's care.
- Assess the patient's understanding of TB and provide education, including specific risk factors as needed.
- Determine infectiousness (e.g., smear positivity and grade, chest X-ray findings such as cavitation, etc.).
- Begin the interview for the contact investigation.
 - Assess for possible worksite or congregate setting investigations.
 - Determine the infectious period.

Identification

- Identify adherence barriers to TB therapy (e.g., pill burden, cultural beliefs, support system, difficulty dealing with TB diagnosis, transportation, or unmet mental health needs).
- Identify drug-drug interactions between TB medications and other medications the patient is taking.
- Identify barriers to obtaining care for other co-morbidities (e.g., HIV, mental health disorders, etc.).
- Locate culturally and linguistically appropriate educational resources at the patient's preferred reading level.
- Locate community resources to meet the patient's needs.
- Use culturally and linguistically appropriate services for interpreting.

Planning

- Utilize a patient-centered communication style that incorporates individual preferences, assesses literacy and numeracy, and addresses cultural barriers to care.
- Review TB regimen and discuss any regimen or medication adjustments with the physician based on co-morbidities, drug-drug interactions, or identified barriers.
- Include strategies to address identified barriers.
- Become familiar with community providers for referral including:
 - Outpatient clinics.
 - Federally qualified health centers (FQHCs) or community health centers.
 - Other community providers or services.
- Provide support for patients, including referral for counseling, social worker, etc.
- Discuss where DOT will be provided and at what time, considering the patient's needs and wishes.
- Provide education for household contacts and at the patient's worksite or congregate setting, if applicable.

Sample Care Plan continued

Sample Care Plan Continued

Implementation

- Acknowledge and address the patient's perceptions and fears as part of regular communication.
- Conduct a thorough contact investigation of household, social, and work contacts.
- Begin DOT according to the plan developed in conjunction with the patient.
- Review the patient's chart frequently.
- Ensure collaboration between the TB physician and physician treating other conditions (e.g., HIV infection, diabetes, mental illness) and communicate changes in medication regimen or treatment length, as needed.
- Closely monitor patients with co-morbidities taking other medications and/or those with known alcohol or drug use for side effects and drug interactions; discuss with the TB physician as needed.
- Ensure connection with outside agencies, assistance programs, or other resources where available; refer and collaborate to ensure access to needed services.
- Offer incentives (e.g., gift cards or cash) and enablers that are valuable to the patient.
- Review the plan regularly and adjust accordingly.
- Address barriers to adherence for TB therapy.
- Address barriers to adherence to other treatment that impacts TB (e.g., diabetes medications or ART).
- Document all changes to the plan.

Evaluation

- Monitor response to treatment monthly including:
 - Sputum collection and time to culture conversion (evaluate the need for extending TB therapy).
 - Laboratory testing ordered by the physician (e.g., LFTs, bacteriology) monthly.
- Monitor treatment adherence including:
 - Adherence standards such as monthly adherence rate.
 - Behavioral measures, such as keeping clinic appointments.
 - Measurable clinical outcomes, including improvement of symptoms or radiographic findings.
- Review sensitivities and alert the physician when medications may be dropped from the regimen, in order to decrease pill burden.
- Assess and document completion of therapy.
 - Count doses for initial and continuation phase.

III. CASE STUDY: PROVIDING PATIENT-CENTERED CARE

Part 1: Patient and Household Contacts

Jane, a public health nurse from a rural county, received a call from a local hospital notifying her that a patient with TB had been admitted to its airborne infection isolation (AII) room. The hospital provided the following background information on the patient:

- 24-year old Mexican-born female who presented with cough, fever, and weight loss
- Chest X-ray revealed multiple cavities in left upper lobe
- Sputum smear positive (4+)
- Started on 4-drug therapy for TB
- Does not speak English very well

Jane arrived at the hospital with a Spanish language interpreter and found the patient extremely distraught. She was crying and speaking a mix of Spanish and another language. Through the interpreter Jane introduced herself to Maria, the patient, and tried to calm her down and begin the process of education and contact investigation. Maria explained that the doctor told her she would not be able to see her children. She said she does not know where she will go after she leaves the hospital if she cannot go home. She was also feeling very sick and lonely and was not eating. She told Jane that the food at the hospital did not “touch her heart.”

Maria had been sick for months and had gone to an FQHC where she had received medicine, which she said made her feel better for a little while. She told Jane that the medicine did not work and explained that if she was at home she would have gone to the healer in her village. She was fearful of others finding out that she has TB and worried about how she and her husband will be able to support their children if she cannot go back to work at the agricultural packaging facility where both she and her husband work. She was worried about her medical bills and said she has no idea how she would be able to pay them. Maria reported that her family lives in a very rural area, which is close to their work, but it is very lonely and far away from any stores. She explained to the interpreter that she has been in the country for five years and is largely fluent in Spanish, though she was originally from Oaxaca in southern Mexico and her native language is Mixteco.

Potential case management challenges	Approaches
<p>Lack of knowledge and fears about TB</p> <p>Cultural and linguistic barriers</p> <p>Presence of children in the home</p>	<p>Jane realized that to establish a care plan, encourage adherence, and conduct the necessary contact investigation, she needed to address Maria's lack of knowledge and fears. She utilized a number of strategies centered on educating and building trust in a way that was culturally and linguistically appropriate. These included:</p> <ul style="list-style-type: none"> • Providing TB education, including information on treatment and transmission to Maria through an interpreter. • Emphasizing the need for adherence to therapy while asking about Maria's beliefs around TB and demonstrating respect for them. • Reassuring Maria that TB is treatable and curable and emphasizing the need for adherence to treatment. • Gathering detailed information about household contacts (husband, 7-month old daughter, and 2-year old son) and explaining that Maria's family will need to be tested (but since the children were already exposed to TB, clarifying that it is unlikely that she will need to be separated from them). • Reassuring Maria that if her family is sick they will also be treated. • Using a Spanish language interpreter who is known to the community (while emphasizing confidentiality), but also asking if she was comfortable in Spanish or would prefer to use a telephone interpretation service to communicate in Mixteco. • Visiting the home and arranging for Maria's husband and children to be immediately evaluated by the health department. • Explaining to Maria that since her family has been evaluated and treatment will be initiated promptly, she can be released to home isolation when she is well enough. The 7-month old baby was diagnosed with TB disease and the two-year-old and the patient's husband were diagnosed with TB infection. • Discussing and agreeing on a plan for care and provision of DOT for Maria and her family that addressed potential barriers and challenges including: <ul style="list-style-type: none"> • Challenges with medical care for the 7-month old baby while Maria is on home isolation and her husband is at work; addressed by arranging for a health department nurse (with appropriate written departmental and parental consent) to bring the child for follow-up visits to the pediatrician. • Inability to get food and supplies in the isolated rural setting while Maria is on home isolation; addressed by arranging for health department nurses and friends to bring supplies such as diapers and food, and assisting with getting food and supplies for delivery. • Coordinating with the hospital for discharge of the patient when a plan is established and can be implemented.
<p>Feelings of fear, depression, and isolation</p> <p>Concern about financial implications of TB</p>	<p>Jane also addressed Maria's fears and feelings of isolation by:</p> <ul style="list-style-type: none"> • Explaining that anyone can get TB and offering to help Maria talk to her family. • Reiterating that TB is treatable and curable. • Asking about social support, including friends or family. • Assessing comfort, such as asking about favorite foods and arranging for meals to be delivered occasionally. • Emphasizing that Maria will not have to pay for her TB care and reaching out to the hospital benefits counselor to begin the process of applying for Medicaid and other available programs. • Addressing these feelings and challenges in the care plan through: <ul style="list-style-type: none"> • Providing ongoing education and emotional support to Maria during her treatment. • Connecting Maria to a social worker, who helped her to apply for the state's emergency assistance program which provided some benefits to help the family while Maria is out of work.
<p>Potential workplace exposure</p>	<ul style="list-style-type: none"> • Maria was extremely infectious (4+ on smear) so Jane also asked for information about her workplace, contacted the state TB Program Manager, and prepared to reach out to management at Maria's worksite.

Part 2: Contact Investigation and Treatment of Contacts

Jane called the manager at the agricultural packaging facility, without mentioning Maria's name initially. She made an appointment for an in-person visit the following day. During this initial meeting with management, she:

- Provided TB education to management, answered questions, and addressed concerns.
- Viewed the facility, which employed several hundred people, and determined that she needed to divulge the patient's name, in order to assess which workers needed to be tested.
- Obtained information about Maria's schedule, viewed her work station, and observed that there were multiple processing and packing lines and a common eating area.
- Drew a sketch of the facility and work stations so she could review the details with the TB Program Manager.
- Provided a written statement informing the facility manager that the patient's name should not be disclosed to other workers and followed up with a discussion on the need for confidentiality.

The facility manager informed Jane that many of the workers were from the same region of Mexico as Maria and some of them were not fluent in English or Spanish, and had limited literacy. He also informed her that the facility had very long work shifts and that some workers did not have fixed addresses or residences. After Jane reviewed the facility details, size, ventilation, and the location of assembly lines and workers with the TB Program Manager, 160 potential contacts were identified.

Potential case management challenges	Approaches
<p>Testing a large group of contacts</p> <p>Limited literacy, transportation, resources, long working hours, and mobility of population may make testing and treatment difficult</p> <p>Confidentiality</p>	<p>Jane utilized a variety of approaches for testing and treating contacts in this large congregate setting including:</p> <ul style="list-style-type: none"> • Working with the facility manager to arrange for onsite education and testing for workers; organizing a team of health department nurses to set up a mobile testing site outside the facility and: <ul style="list-style-type: none"> • Administering TSTs over lunch and during breaks to avoid interruptions in work schedules. • Arranging for extra Spanish language interpreters, and ensuring access to a telephone interpreter for those who spoke other languages. • Utilizing numeric identifiers and corresponding TB testing cards (to show on return) to assist with maintaining confidentiality and ensuring accuracy, since some patients did not have identification, or reported using different names. • Returning with the health department team two days later to interpret the TSTs. <ul style="list-style-type: none"> • Two symptomatic individuals were immediately transported to a local hospital for CXRs. • 81 contacts had positive TSTs. • 69 contacts were eligible for treatment for TB infection. • Conducting interviews and providing counseling for each contact prior to treatment initiation. • Establishing a plan for treatment of contacts with TB infection that would address potential barriers and maximize treatment adherence by: <ul style="list-style-type: none"> • Discussing challenges in providing treatment for TB infection to this population with the TB Medical Consultant, who ordered a 4-month rifampin regimen for eligible patients to increase adherence. • Working with management to provide monthly clinics onsite for all patients receiving treatment for TB infection. • Setting up a temporary medical office in a designated area within the work setting with a stretcher, supplies, and multiple nursing stations. • Arranging for equipment and a mobile lab onsite for blood draws, as needed, for HIV and liver function tests. • Developing and providing educational materials on treatment and side effects suitable for limited literacy non-English speaking population using pictures and drawings. • Protecting patient confidentiality to increase trust. • Streamlining “clinic” visits (since patients came over lunch breaks and had limited time) by: <ul style="list-style-type: none"> • Utilizing multiple nursing stations and abbreviated patient record for use onsite. • Offering educational messages and problem-solving for any difficulties taking medications. • Providing pregnancy tests (if indicated) and vital signs at each visit prior to the exam, and lab tests onsite as needed. • Providing monthly supply of medications and reviewing side effects with reminders to contact the nurse in case of specific symptoms.

Conclusion

TRICKS OF THE TRADE

- *If you don't have resources to provide typical incentives and enablers for patients being treated for TB infection, make treatment easy and convenient and provide other medical and case management services or referrals (based on program policies and available resources) for patients as needed. These can also act as incentives and enablers for patients and can assist with adherence.*
- *Using trained interpreters who are already known in the community and have previously established relationships with patients can help build trust and support adherence.*

Despite all the case management challenges, Maria and her family successfully completed treatment. Additionally, 56 of the 69 infected contacts who began treatment for TB infection received adequate treatment.

The remaining 13 patients did not complete treatment for TB infection for a variety of reasons, including the treating physician discontinuing therapy due to adverse reactions or patients becoming pregnant, patients

moving back to Mexico, or being lost to follow up. Jane also reached out to the FQHC where the patient had originally presented, to inform them that Maria had been diagnosed with TB and to provide educational materials for staff, as well as patient education materials. Jane suggested that the medical consultant in the area could provide an update on TB infection and disease, since some of the patients the health department was treating also seek care at the FQHC for other conditions.

Jane attributed the success in treating Maria, her family, and the infected workplace contacts to the intensive efforts the health department made to work with people, build relationships, meet their needs, address their concerns, and make the process easy and pleasant for all patients.

IV. SUMMARY

In summary, the role of the TB nurse case manager is comprised of many different components, ranging from overseeing patient care to TB elimination efforts such as identifying and treating contacts exposed to TB. Case management is further impacted by the diversity of each case, including different cultural issues, psychosocial barriers, and varying degrees of difficulty in treating some forms of TB disease. A patient-centered approach incorporating cultural responsiveness and a variety of adherence strategies will assist TB nurse case managers in their efforts to ensure that individual patients are cured **and** that public health goals of TB treatment are met.

APPENDIX: CULTURAL AWARENESS SELF-ASSESSMENT CHECKLIST

This checklist will help to build self-awareness and assess where you currently stand on the path of developing cultural competence. It can help uncover specific areas where you may be able to improve your cultural sensitivity. There is no answer key with correct responses and the checklist is intended to be only a tool for self-reflection. It is not intended to be an actual measure of cultural competence.

Directions: Please select A, B, or C for each item listed below.

A = Things I do frequently

B = Things I do occasionally

C = Things I do rarely or never

Physical Environment, Materials, and Resources

To the degree that I am able:

___ I ensure that magazines, brochures, and other printed materials in the reception and waiting areas are of interest to and reflect the different cultures of individuals and families served by my program or agency.

___ I ensure that printed educational information disseminated by my agency or program takes into account the average literacy levels of individuals and families receiving services.

Communication Styles

___ For individuals and families who speak languages or dialects other than English, I attempt to learn and use key words in their language so that I am better able to communicate with them during assessment, treatment, home visits, or other interventions.

___ I attempt to determine any familial colloquialisms (jargon or slang) used by individuals or families that may impact assessment, treatment, or other interventions.

I understand the principles and practices of linguistic competency and:

___ Apply them within my work or program.

___ Advocate for them within my program or agency.

Values and Attitudes

- _____ I avoid imposing values which may conflict or be inconsistent with those of cultures or ethnic groups other than my own.
- _____ I recognize and accept that individuals from culturally diverse backgrounds may desire varying degrees of acculturation into the dominant culture.
- _____ I understand and accept that family is defined differently by different cultures (e.g., extended family members, fictive kin, god parents).
- _____ I accept and respect that gender roles in families may vary significantly among different cultures (e.g., who makes major decisions for the family, expected social interactions).
- _____ I understand that age and life cycle factors must be considered in interactions with individuals and families (e.g., high value placed on the decision of elders, the role of eldest male or female in families, or roles and expectations of children within the family).
- _____ Even though my professional or moral viewpoints may differ from persons I serve, I accept that individuals and families are the ultimate decision makers for services and supports impacting their lives.
- _____ I recognize that the meaning or value of medical treatment and health education may vary greatly across and within cultures.
- _____ Before visiting or providing services in the home setting, I seek information on acceptable behaviors, courtesies, customs, and expectations that are unique to the culturally and ethnically diverse groups served by my program or agency.
- _____ I accept that religion and other beliefs may influence how a family responds to illness, disease, disability, and death.
- _____ I pursue professional development and training opportunities to enhance my knowledge and skills in the provision of services and supports to culturally, ethnically, racially, and linguistically diverse groups.

The items to which you responded "C" indicate areas where there may be room to improve your cultural sensitivity.

Source: *Cultural Competency and Tuberculosis Care: A Guide for Self-Study and Self-Assessment* (Global Tuberculosis Institute, 2008).

RESOURCE LIST

1. *Official American Thoracic Society/Centers for Disease Control and Prevention/Infectious Diseases Society of America Clinical Practice Guidelines: Treatment of Drug-Susceptible Tuberculosis*. Available at:
cdc.gov/tb/publications/guidelines/pdf/clin-infect-dis.-2016-nahid-cid_ciw376.pdf
2. *TB Training Roadmap for Public Health Nurses*, Global Tuberculosis Institute. Available at:
globaltb.njms.rutgers.edu/educationalmaterials/productfolder/roadmap.php
3. National TB Controllers Association/National TB Nurse Coalition website, NTCA and NTNC. Available at: tbcontrollers.org/ntnc/
4. *Cultural Competency and Tuberculosis Care: A Guide for Self-Study and Self-Assessment*, Global Tuberculosis Institute. Available at:
globaltb.njms.rutgers.edu/educationalmaterials/productlist_cultural.php
5. *Implementing Legal Interventions for the Control of Tuberculosis*. Global Tuberculosis Institute. Available at:
globaltb.njms.rutgers.edu/educationalmaterials/productfolder/legalinterventions.php
6. *National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care*, US Department of Health and Human Services, Office of Minority Health. Available at: thinkculturalhealth.hhs.gov/assets/pdfs/EnhancedNationalCLASstandards.pdf
7. *Implementing an Electronic Directly Observed Therapy (eDOT) Program: A Toolkit for Tuberculosis (TB) Programs*, CDC. Available at:
cdc.gov/tb/publications/pdf/tbedottoolkit.pdf
8. *What You Need to Know About Tuberculosis Patient Education Flipbook*, Global Tuberculosis Institute. Available at:
globaltb.njms.rutgers.edu/educationalmaterials/productfolder/whatyouneedtoknow.php
9. Additional CDC TB Resources
 - I. TB Guidelines: cdc.gov/tb/publications/guidelines/default.htm
 - II. Health Care Provider and TB Program Materials:
cdc.gov/tb/education/provider_edmaterials.htm
 - III. Patient and General Public Materials:
cdc.gov/tb/education/patient_edmaterials.htm

CHAPTER 3

Special Situations and Circumstances

I. INTRODUCTION

TB case management requires an intensive patient-centered approach, as outlined in Chapter 2 of this guide. Individuals with certain clinical or social conditions are at higher risk of exposure to *M. tuberculosis*, developing TB disease once infected, or having poor outcomes. The following variables can all play a role in an individual's risk of exposure to TB or progression to TB disease if infected; substandard and overcrowded living conditions in a congregate setting (e.g., in a shelter or correctional facility); pre-existing health conditions (e.g., HIV or other immunosuppression); inadequate access to food, shelter, and income; structural and attitudinal barriers to effective health care; and immigration and refugee issues (e.g., lack of access to health care) (Pachi, Bratis, Moussas, & Tselebis, 2013). Case management of patients with these clinical conditions or circumstances may be more challenging. Thus, these patients may require additional TB case management activities or strategies in order to achieve the goal of treatment completion.

This chapter provides brief background information and specific considerations for each of the following situations or circumstances, with a focus on practical approaches that can be used in case management of the following groups of patients:

- Children and adolescents
- Persons with diabetes
- Persons living with HIV
- Persons with mental health disorders
- Persons who use drugs
- Persons experiencing homelessness
- Recent immigrants and refugees
- Persons in correctional settings

The background information in this chapter briefly summarizes the issues that may make management of these patients more complex, focusing on nurse case management activities. However, in some cases, an awareness of clinical issues (such as drug-drug interactions with certain medications or additional recommended monitoring tests) is necessary to carry out the nurse case management tasks. While physicians oversee the medical management of TB patients, nurse case managers can play an important role in identifying potential clinical concerns and bringing them to the attention of the treating physician. More detailed information is provided on case management of TB in correctional settings, since there are specific considerations and mechanisms for collaboration needed in these settings.

This synopsis of each co-morbidity or circumstance can be used as a summary or reference when case managing patients in these situations, but is not intended to be a complete description of the diagnosis, management, and treatment of these patients. Therefore, nurse case managers are encouraged to utilize additional resources to gain a better understanding of these topics, including implications for the management of TB. Other situations or circumstances (e.g., TB in pregnant or breastfeeding women, elderly patients, those with renal disease, malnourished patients, or those in hospice care) may also have implications for medical or case management. Nurse case managers should utilize available resources and work closely with physicians, as needed, to better understand the issues and approaches for working with these patients.

When evaluating special populations, it is important to recognize the potential for overlapping challenges. Case management for these patients may need to incorporate approaches from more than one co-morbidity or situation included in this chapter. For example, there is a documented overlap between mental health and substance use disorders and persons experiencing chronic homelessness. Thus, some of the case studies in this chapter highlight more than one co-morbidity or special circumstance. The case studies, suggestions, and approaches in this chapter are based on best practices. As always, TB nurse case managers should follow recommendations or guidelines within their program.

Finally, TB nurse case managers should pay special attention to epidemiologic links to current and previous cases of TB in high-risk populations, such as people experiencing homelessness or those with substance use disorders, and should use available resources including TB genotyping to promptly identify and address any potential outbreaks.

II. TUBERCULOSIS IN CHILDREN AND ADOLESCENTS

Special consideration is warranted for TB exposure, infection, and disease in children. This is because children, especially young children, are at a much higher risk of developing TB disease if infected than adults. This risk is greatest for infants and children < 2 years of age who are more likely to develop severe forms of TB including disseminated disease or TB meningitis, which can have long term impacts. For example, TB meningitis kills or disables more children than any other form of TB (Starke & Donald, 2016).

In addition to infants and young children, children with certain medical conditions including HIV, diabetes mellitus, chronic renal failure, malnutrition, congenital or acquired immune deficiencies, and children receiving tumor necrosis factor (TNF) alpha antagonists are also at higher risk for progression from TB infection to TB disease and deserve special consideration (American Academy of Pediatrics, 2015).

Early diagnosis and appropriate treatment of TB infection is a critical step in preventing morbidity and mortality in children, due to risk of progression to disease and severe illness. Additional rationale for treatment of TB infection in children includes the following:

- Infection is likely to be recent in children and adolescents; half of the lifetime risk of infection occurs in the first two years after infection.
- Medications used to treat TB infection are safe and well tolerated by children and there is a low risk of toxicity.
- Children have more years to potentially develop TB disease.

Presentation

Young children (birth to puberty) manifest TB disease differently than both adults and adolescents. Young children with TB:

- Are often asymptomatic or present with non-specific symptoms (may present as fever, cough, poor appetite, and weight loss or failure to gain weight).
- Have fewer tubercle bacilli in their lungs.
- Lack the force to produce airborne bacilli while coughing.
- Are rarely infectious.

Extrapulmonary TB occurs more commonly in children than in adults. Common sites of extrapulmonary TB in children include cervical lymphadenitis or lymphatic TB, meningeal, miliary, and bone and joint TB (Waagner, 1993). However, adolescents manifest TB similar to adults in that they are more likely to present with pulmonary disease and can transmit TB to others.

Contact Investigations

Children who live in a household (or have other close contact) with an adult with infectious TB disease are at greatest risk for TB infection; thus identifying potentially exposed children, especially infants and children < 5 years of age, is a **high priority** in any contact investigation:

- While both IGRAs and TSTs can be used in children, the type of test selected should be based on age, BCG history, and availability, following national guidelines and program policy.
- Careful examination is needed to rule out TB disease in exposed children, who may be asymptomatic or have non-specific symptoms.
- Children identified in a contact investigation, especially infants and young children, should be evaluated as soon as possible and placed on appropriate treatment, if indicated.

- Always be vigilant regarding children who may have been exposed to a patient with infectious TB. During the process of treating patients, the case manager may find out about additional children who were not originally identified in the contact investigation. This may happen through seeing children while providing DOT, or through conversations, especially regarding children who are sick or not at the appropriate developmental level. **These children should be evaluated as soon as possible.**

- Children with an initial negative test result should be re-tested eight to ten weeks after the last exposure to the patient with infectious TB (or source case).
- Children < 5 years of age **or** with impaired immunity exposed to a person with infectious TB should be started on “window prophylaxis,” which is treatment for presumptive TB infection **as soon as TB disease**

is excluded, even if the *initial* TST or IGRA result is negative. Window prophylaxis should be continued until the results of the second test (8-10 weeks later) are negative, in most cases.

Considerations for TB Nurse Case Management

In addition to the TB case management activities outlined in Chapter 1 and the basic care plan in Chapter 2, the following case management activities are important for children with TB disease or infection:

- Ask the family about risk factors and contact with persons who may have TB disease to identify the source case for children who are < 5 years of age with TB disease or < 2 years of age with TB infection.
- Locate children identified in a contact investigation and ensure prompt evaluation and treatment (if indicated) for all children potentially exposed to TB, with particular emphasis on infants and young children, consulting a pediatrician with expertise in managing TB in young children whenever possible:
 - Assess children being evaluated for TB for non-specific symptoms including failure to thrive.
 - Assess whether the child is performing at the appropriate developmental stage.
 - Assess all children < 5 years of age or with impaired immunity who were identified in a contact investigation for window prophylaxis, regardless of their TST/IGRA result.
 - Discuss potential use of shorter regimens for treatment of TB infection with the physician and parents, in order to improve adherence.
 - Utilize DOT for treatment of TB infection in children whenever possible, especially in children < 5 years of age, immunocompromised children, or those who are contacts of a person with TB disease and/or on window prophylaxis.

- Emphasize the need for treatment of TB infection in children, utilizing written materials such as *What Parents Need to Know about Tuberculosis (TB) Infection in Children*, available in English at: globaltb.njms.rutgers.edu/educationalmaterials/productfolder/tbparentschild.php and in Spanish at: globaltb.njms.rutgers.edu/educationalmaterials/productfolder/whatparentsneedtoknow-spanish.php
- Ensure that adolescents have an opportunity to speak to providers alone.
- Assess the parent or guardian's understanding of TB diagnosis and treatment plan, including cultural and family beliefs about TB.
- Provide the family with ongoing education, explaining treatment, need for DOT, and approaches for medication administration:
 - Keep explanations simple and focused.
 - Include the child in the education process, depending on age, and utilize culturally, linguistically, and age-appropriate educational materials and methods.
 - Answer all questions about treatment and side effects.
- Consider medication administration:
 - Assess the child's ability to take medication.
 - Determine how the medication will be administered (e.g., in suspension form, crushed with food, etc.).
 - Locate a compounding pharmacy if medications need to be in suspension form.
- Establish and discuss the DOT plan in collaboration with the child and family:
 - Identify potential community locations and partners who can provide DOT, if partners agree to participate and parental authorization is obtained. School is an ideal setting for treatment of TB disease and infection, since school nurses can observe, document, and assess the child for medication side effects. The *Tuberculosis Handbook for School Nurses* provides more information and is available at: globaltb.njms.rutgers.edu/educationalmaterials/productfolder/tbedusn2.php
 - Determine who will be administering the medication.
 - Discuss medication administration with the child and family.
 - Ensure that enough time is allocated for provision of DOT, which may take time in children.
 - Suggest taking medications in association with daily routines such as meals, brushing teeth, or at bedtime (reminder notes taped on mirrors or the refrigerator or electronic device reminders can be used for children on SAT for TB infection).

- Provide instructions on medication administration and demonstrate how to crush pills and mix with food, if necessary, for all involved in medication administration:
 - Communicate regularly with the school nurse to determine whether the child is experiencing medication side effects, if the child is receiving medications at school.
 - Ensure that the child and family understand the need for TB medication and the method by which the medication will be administered.
 - Advise the family to call if the child experiences adverse side effects from the medication, such as persistent vomiting, severe headache, or rash.
- Adjust approaches for medication administration, as needed, to establish an effective strategy.
- Use age-appropriate adherence strategies such as:
 - Decorating medication cups.
 - Using decorative/crazy straws.
 - Making a game of taking medications.
 - Making a poster that shows treatment progress.
 - Giving rewards for taking medications.
 - Providing incentives that the child or adolescent likes.
- Assess for existing or potential problems in the treatment plan and adjust as needed.
- Carefully assess children on treatment at each visit:
 - Monitor the child's ongoing ability to take medications.
 - Assess the overall health, stage of development, and clinical presentation of the child and discuss any concerns with the physician; consider the need for medication adjustment based on weight changes.
- Monitor adherence to treatment including:
 - Adherence standards such as monthly adherence rate (or pill counts for children on SAT for TB infection).
 - Behavioral measures, such as keeping clinic appointments (including monthly clinic visits for children on SAT for TB infection).
 - Measurable clinical outcomes, including improvement of symptoms or radiographic findings.

- Ensure a discharge plan that includes instructions regarding future TB testing and chest X-rays:
 - Inform the family that the child's TST or IGRA may remain positive after treatment completion and that re-testing is not necessary.
 - Inform the family that regular follow-up chest X-rays are not indicated, unless the child is being evaluated for a respiratory illness.
 - Provide a treatment completion letter or card, emphasizing the importance of keeping this document throughout the child's life, as verification of treatment may be needed for clearance and/or entrance into college, military service, or certain types of employment.

TRICKS OF THE TRADE

- *Convincing parents to begin treatment for TB infection in their children can be challenging. Parents are often concerned about giving their outwardly healthy children medicine for extended periods of time and about potential side effects. It is important to connect with the parents and establish rapport, while convincing them of the need for treatment for TB infection in their children:*
 - *Emphasize that treatment for TB infection is a way to protect their child.*
 - *Ask parents if they give the child vitamins and explain that treatment for TB infection is a similar proactive way to keep their child healthy.*
 - *Show parents the pills needed for treatment of TB infection daily as compared to the handful of pills needed for treatment of TB disease.*
- *Discuss regimen selection for TB infection with the physician and family; many parents and children may be concerned about regimen length, cost, and time needed to obtain and administer medications, some may prefer shorter regimens, which can be used in many children.*
- *Some children with TB disease may not have significant symptoms. For parents of children who have TB disease but are concerned about the length of treatment and whether treatment is needed, show them the X-ray film for proof of the need for treatment and then review later X-rays to show improvement. Reviewing weight and stages of development with parents can also demonstrate clinical improvement.*

a. Case Study: Medically Complex TB in a Child

Part 1: Initial Presentation and Contact Investigation

Elena, the public health nurse at a local health department, received a call from the state TB nurse consultant to inform her that a US-born, 15-month old male had been admitted to a hospital in her county and diagnosed with TB meningitis. As a result, the child had multiple neurologic deficits requiring a gastrostomy tube (G-tube) and permanent tracheotomy. Elena understood the urgency of the situation and proceeded to initiate a source case investigation and develop a plan for case management of a hospitalized child with multiple medical needs.

At the hospital, Elena met with the parents who appeared to be overwhelmed with the diagnosis and poor prognosis for their son. They had limited financial resources and worked long hours, which would inhibit their ability to provide the care their son would need when he was discharged. Both parents were extremely upset. Elena was bilingual, and they told her in Spanish that they felt like they were not understood or listened to through interpreters during multiple visits to this hospital's emergency department (ED) over the last few months for their son's symptoms (fever, vomiting, lethargy, and decreased appetite). Miguel, the baby's father, told Elena that he felt his concerns were not being addressed because he was an immigrant. The parents reported that they have three other children who are three, five, and seven years of age.

Elena also conducted a home visit and found overcrowded living conditions with multiple families (including five additional children) all living in a large single-family dwelling in a suburban oceanside community. The household was unkempt and had a visible problem with roaches and rats. The house was several miles from public transit and the family did not have a car.

Potential case management challenges	Approaches
<p>Finding index (source) case</p> <p>Identifying and evaluating contacts in a large household with different schedules and some fear/mistrust of government</p>	<p>Elena utilized a variety of techniques to address the challenges:</p> <ul style="list-style-type: none"> • Using Spanish-speaking nurses and outreach workers whenever possible. • Providing testing at various times (including evenings based on work schedules of household contacts) so that all contacts could be tested and evaluated as needed. • Sending nurses to the home to ensure testing since accessing the clinic was difficult based on the lack of transportation. • Utilizing IGRAs rather than TSTs due to the history of BCG vaccination and the need for single visit. • Using observation and interviewing skills to identify the source case within the household. • Coordinating and communicating with the hospital infection control practitioner and health department team to facilitate admission for the source case and ensure appropriate infection control measures.
<p>Lack of adequate living conditions for a medically fragile child</p> <p>Financial concerns</p>	<p>Since the baby had a tracheotomy and a G-tube by which he would be receiving medications, as well as multiple neurologic deficits, ensuring a safe environment where he could receive TB treatment was essential. The parents could not afford to miss work, which presented challenges for providing the care the baby would need. Elena began to develop and implement a plan for discharge of the baby by:</p> <ul style="list-style-type: none"> • Scheduling a meeting with the hospital discharge planner, social worker, and physician to develop a discharge plan and to coordinate services for the baby. • Working with the team to identify and secure resources (transportation, financial, etc.) and working with other organizations and agencies to obtain access to food pantries, clothes, toys, etc. • Involving the parents in planning and decision making to build trust and rapport and increase the likelihood of adherence. • Advocating with the landlord for fumigation and screens for doors and windows. • Educating the family on how to properly maintain the clean environment needed for the sick child including food storage, overall cleanliness, and proper lighting for examining the G-tube, etc.
<p>Coordinating care for all patients with multiple providers</p>	<p>Since several other adults and children in the house were also being treated for TB infection and disease, Elena utilized a team approach and tried to ensure adherence by:</p> <ul style="list-style-type: none"> • Working with the family's schedule to provide DOT for all patients in the household based on preference (and parental preference for children on treatment for TB infection or disease). • Changing work schedules of the health department nurses to allow for flexible times for DOT and clinic visits, which would be convenient for patients. • Collaborating with the school nurse for DOT and maintaining weekly communication. • Establishing access to home nursing care for the child and ensuring a bilingual nurse. • Providing education to the home health nurse on medications, provision of medications through the G-tube, documentation of DOT, etc. • Utilizing appropriate delegation practices with team members including the home health care nurse, school nurse, primary care providers, and others.

Part 2: Ensuring adherence

The baby was released from the hospital, but required significant medical care both for TB and for the long-term impacts of TB meningitis. With the help of the health department, the mother received social security insurance and could stay home with the baby. However, there were many complex emotional and psychosocial components to providing care related to feelings of

TRICKS OF THE TRADE

- Remember to assess all the issues involved in ensuring appropriate care for children with TB, not just provision of DOT.
- Give parents clear instructions regarding side effects. For example, if a child is vomiting, parents should skip the dose and call the nurse. Vomiting may be unrelated to TB medications, for example, due to a virus. If it has not resolved the next day, the nurse case manager should instruct the parent to bring the child to the doctor.

fear, guilt, and loss on the part of the parents. Their son had been totally healthy a few months ago and was now facing a lifetime of disability. Medication administration was initially very challenging for their three-year old daughter who was receiving treatment for TB infection. The parents were fearful that she would get sick like their son, but also had safety concerns about

the medications and were afraid that that she would get hurt during the difficult medication administration process (refusing to swallow medications, crying, kicking, and screaming).

Potential case management challenges	Approaches
<p>Challenges in providing medications to young children</p> <p>Challenges of providing ongoing care to a baby with severe neurological deficits</p> <p>Impact of illness on the parents and parent-child relationship</p>	<p>Elena used a variety of approaches including:</p> <ul style="list-style-type: none"> • Providing ongoing education and support to the parents and tailoring the messages to the current challenges and stage of treatment. Some messages included: <ul style="list-style-type: none"> • Children tolerate medicines better than adults and side effects are rare. • Providing treatment for TB infection is the best way to prevent disease. • Being quick but pleasant and firm when giving medicines to children is the best approach. • Orange discoloration of bodily fluids is normal. • Demonstrating appropriate techniques for providing oral medications to young children by: <ul style="list-style-type: none"> • Paying attention to timing, volume, and texture. • Crushing and dissolving the pills in a very small amount of water (e.g., a teaspoon) to avoid granules and mixing with a small amount of food (using a small amount will ensure that the child takes the full dose). • Administering the medicine when the child is hungry and mixing with a favorite food. • Using a cold vehicle like ice cream or cold juice. • Distracting the three-year old while giving medicines and using small rewards such as stickers, bubbles, or other treats. • Trying different techniques until finding one that worked, but adjusting as needed during treatment. • Suggesting approaches to strengthen the parent-child bond, such as giving medications to the three-year old herself, and having parents provide the reward, until the child was used to the medication process, and it was no longer traumatic. • Ensuring that the parents knew the procedure for providing medications to the infant through the G-tube and how to do so safely, in order to facilitate bonding and help the parents feel empowered and involved in their son's care. • Providing instructions for future caregivers such as babysitters or new home health nurses on providing medications and ensuring appropriate practices for G-tube and tracheotomy tube. • Being attentive to challenges and concerns of the parents and addressing them promptly. • Ensuring that the parents knew how to contact her and felt comfortable doing so.

Conclusion

Everyone in the house who was being treated for TB infection or disease completed treatment. Elena took all the children to the boardwalk for ice cream to celebrate at the end of treatment. This outing had been mentioned as an incentive during the previous few weeks. Although the baby had permanent neurological damage and required ongoing medical care, he completed treatment successfully and Elena worked with the entire team of care providers to make recommendations for the future. Upon discharge, he was receiving services in the home and was being entered into an early intervention program as well as medical daycare. Given the original delayed diagnosis for the child, Elena also worked with the hospital to coordinate a grand rounds presentation on pediatric TB to increase knowledge and raise awareness among providers, so that they would consider TB in the differential diagnosis in the future, when appropriate.

III. DIABETES AND TUBERCULOSIS

Individuals with diabetes are at an increased risk of progression from TB infection to disease and are more likely to have poor TB treatment outcomes, including delayed sputum conversion, treatment failure, relapse, and death (Jeon, Murray, & Baker, 2012). Thus, persons with TB who have risk factors for diabetes (or all patients, if resources allow) should be screened for diabetes.

Clinical management of patients with TB disease and diabetes may include assessment and management of drug-drug interactions, change in dose frequency for patients with low creatinine clearance or who are on hemodialysis, and the need for therapeutic drug monitoring or treatment extension. Since poor glycemic control is associated with poor TB treatment outcomes, it is important to ensure effective control of diabetes in people with TB infection or TB disease (Chiang et al., 2015). Therefore, regular monitoring of blood glucose is necessary.

Finally, early detection of TB in individuals with diabetes can also help improve care and treatment outcomes of both diseases, since TB negatively affects diabetes and glycemic control. Thus, clinicians treating patients with TB and/or diabetes should familiarize themselves with recommended screening and management protocols for TB and diabetes and should educate patients about risks and provide referrals to services, as appropriate, based on local context (World Diabetes Foundation, 2014).

Considerations for TB Nurse Case Management

In addition to the TB case management activities outlined in Chapter 1 and the basic care plan in Chapter 2, the following case management activities are important for patients with diabetes:

- Ensure diabetes screening for patients with TB infection and disease, following TB program policy and national guidelines.

- Homeless patients with diabetes need secure places to keep their diabetic supplies and, if appropriate, refrigerator access to properly store insulin (American Diabetes Association, 2016); coordinate with homeless shelters or other locations where the patient may be staying.
- If adherence to diabetes medication is an issue, explore the possibility of providing DOT for TB and diabetes medications during the patient's TB therapy.

- Assess knowledge of diabetes in diabetic persons with, or being evaluated for, TB disease or TB infection, including progression, complications, and the severity of the disease (Rogers, 2007).
- Identify factors that may present challenges to diabetic patients and develop approaches to help with

medication adherence and other treatment options (Rogers, 2007) including:

- Lack of financial resources for medication, equipment, and medical follow up.
- Lack of financial resources to support healthy nutrition.
- Lack of education of the disease process and how it affects TB and the patient's overall health.
- Lack of education about diabetes medication and monitoring blood sugar levels.
- Barriers related to cultural beliefs or diet.
- Tailor educational messages specifically to patients with diabetes (e.g., explain why TB treatment is important for those with diabetes).
- Provide education on self-care behaviors (Rogers, 2007) including:
 - Healthy eating and active lifestyle.
 - Taking medications as prescribed.
 - Normal blood glucose ranges for specific patient (suggest keeping a log).
 - Problem solving (e.g., knowing symptoms of hypoglycemia and how to correct it quickly).
 - Healthy coping (e.g., understand, demonstrate, and integrate the knowledge and skills necessary for self-care).
 - Reducing risks (e.g., foot-care, regular eye exams).
- Ensure the patient has a medical provider and regular visits for follow-up care of diabetes (Rogers, 2007).
- Collaborate with the diabetes care provider.
- Monitor adherence to the diabetic plan and:
 - Review glucose results monthly and assess for poor glycemic control; review hemoglobin A1c results, if available.
 - Notify the TB physician of abnormal results.
 - Modify the plan regularly with the patient and health care team, if needed.
- Monitor sputum conversion closely, as sputum smear and culture conversion can be delayed in patients with uncontrolled diabetes.

IV. HIV AND TUBERCULOSIS

TB is the most common serious opportunistic infection among persons living with HIV globally, thus, individuals with HIV infection deserve special consideration. HIV infection significantly increases the risk of progression from TB infection to TB disease; among people with latent TB infection, HIV infection is the strongest known risk factor for progressing to TB disease (CDC, 2016). In addition, TB negatively affects HIV and may be associated with a higher HIV viral load and more rapid progression of HIV disease (AIDS Info, 2016). Therefore, all individuals diagnosed with TB infection or disease should receive an HIV test (Nahid et al., 2016).

Co-management of HIV and TB can be challenging due to drug-drug interactions, overlapping drug toxicities, concerns about adherence, and the potential for immune reconstitution inflammatory syndrome (IRIS) (Nahid et al., 2016) and, thus, requires careful clinical and case management:

- Due to the rapid progression of TB and additional mortality associated with delays in treatment, TB therapy should be started as early as possible in HIV-infected persons (Nahid et al., 2016).
- Antiretroviral therapy (ART) is life-saving among patients with TB and HIV (CDC, 2013a), and for patients not already on ART, it generally should be initiated early in TB treatment, based on CD4 count and site of disease (Nahid et al., 2016). Refer to CDC guidelines for details.
- Some ART medications have drug-drug interactions with TB medications (especially the rifamycins), and drug or dosage adjustments for TB medications may be necessary (Nahid et al., 2016).
- Daily dosing with DOT should be used throughout therapy for patients with HIV and TB disease (Nahid et al., 2016).
- People living with HIV are more likely to have extrapulmonary TB than HIV-uninfected individuals; treatment adjustment may be required with some forms of extrapulmonary TB.
- Treatment of TB infection is recommended in people living with HIV (CDC, 2013a).
- Prompt identification of contacts who are living with HIV, evaluation and successful completion of treatment for TB infection, if infected, is essential (including use of window prophylaxis, as indicated).

Considerations for TB Nurse Case Management

Close collaboration among clinicians, health care institutions, and public health programs involved in the diagnosis and treatment of persons living with HIV who also have TB infection or TB disease is necessary to integrate care, improve adherence and TB treatment completion rates, reduce drug toxicities, and maximize HIV outcomes. People living with HIV who have TB disease should receive treatment support, including adherence counseling and DOT, corresponding to their needs (CDC, 2012).

In addition to the TB case management activities outlined in Chapter 1 and the basic care plan in Chapter 2, the following case management activities are important for patients with HIV and TB infection or TB disease:

- Become familiar with the side effects of all medications the patient is taking.
- Investigate and assess overlapping side effects of the patient's TB and ART medications.
- Confirm HIV regimen and review for drug interactions with TB medications and adverse effects:
 - Rifamycins are crucial in both the initial and the continuation phase of TB treatment for persons with HIV, despite significant drug-drug interactions between rifampin and certain ART medications (Gray & Cohn, 2013).
 - Rifabutin may be used for patients with concomitant use of ART; however, dose adjustment may be needed.
 - Rifapentine may be used for treatment of TB infection in patients on certain ART regimens.
 - Consult aidsinfo.nih.gov or hivinsite.ucsf.edu/InSite for the most recent information on drug-drug interactions and recommendations for TB treatment for patients receiving ART.
- Facilitate communication between the TB physician and the physician treating HIV infection; communicate changes in medication regimen or treatment length; facilitate coordination to keep a rifamycin in the TB regimen, if possible.
- Assess the patient's psychosocial state in coping with TB and HIV.
- Identify barriers to obtaining HIV care or medications, especially for those newly diagnosed with HIV.
- Assess for side effects of TB medications and inform all members of the TB/HIV care team as needed.
- Assess for signs of IRIS (also known as paradoxical reactions), drug toxicity, and TB treatment failure.

- Inquire about adherence to antiretroviral therapy and follow-up appointments with HIV physician.
- Review CD4 count, viral load, and any laboratory test results (e.g., LFTs or therapeutic drug levels for TB and ART medications) ordered by the physician as soon as they are available:
 - Notify the physician of abnormal results.
- Ensure appropriate treatment to completion for TB infection in persons with HIV:
 - Promptly identify contacts who are living with HIV and who may need treatment, regardless of the TST or IGRA result (window prophylaxis).
 - Identify adherence barriers to treatment for TB infection; consider the use of DOT for TB infection, if resources allow.
 - Monitor adherence to ensure completion of treatment for TB infection, using pill counts for SAT.

a. Case Study: Coping with a Dual Diagnosis

Part 1: Patient History and Presentation

Chen, a 34-year old male, who had been born in China and immigrated to the US ten years ago, was referred to the county TB clinic by his primary care physician. While recovering from a neck injury sustained in a recent car accident, he noticed a painful swelling under his arm that persisted for several weeks. His primary care physician ordered an aspiration biopsy of the affected lymph node and the specimen tested positive for *M. tuberculosis*.

The physician at the county TB clinic ordered a chest X-ray, sputum specimen collection, and an HIV test. While meeting with Liz, the nurse case manager assigned to his TB care, Chen stated that the HIV test was unnecessary. He said he had tested negative before, used condoms, and had only one intimate partner, Alan, with whom he had lived for the last two years. Liz explained that HIV testing is the standard of care for all persons with TB. Although Chen's initial sputum smear was AFB negative and his chest X-ray was interpreted as normal, he was started on the standard 4-drug TB regimen based on a diagnosis of lymph node TB. The policy in this state was to provide DOT for all patients with TB, regardless of the site of disease, so Liz established a plan for providing DOT.

Liz received the results of the HIV test, and based on the positive result, she immediately scheduled a follow-up appointment for Chen. During this visit, Liz explained to Chen that his HIV test was positive and she counseled him on what this meant, including how it might affect his TB treatment. Initially, Chen was visibly upset, and then insisted that the test was wrong as it was impossible for him to have HIV. When Liz indicated that he should see an HIV specialist, he said it was not necessary. By the end of the visit, he was withdrawn and largely non-responsive when she asked him questions and tried to discuss setting up an appointment with an HIV specialist.

Potential Case Management Challenges	Approaches
<p>Psychosocial aspects of a dual diagnosis of TB and HIV</p> <p>Developing trust and rapport</p>	<p>Liz recognized that the shock, denial, and fear associated with receiving a positive HIV test result could impact Chen’s adherence to his TB treatment. Her strategy for addressing this included:</p> <ul style="list-style-type: none"> • Acknowledging Chen’s feelings and emphasizing that these emotions are normal and commonly experienced by those newly diagnosed with HIV and suggesting that he see a mental health provider to help him cope with the situation and emotions. • Scheduling a follow-up appointment to discuss the impact of his HIV diagnosis on TB treatment and other modifications to the care plan, since it was clear that Chen was distraught and needed time to absorb this new diagnosis. • Providing education at follow-up appointments and DOT visits to emphasize interaction between TB and HIV. • Explaining that HIV can be managed effectively with ART and people living with HIV can have long, active, and productive lives. • Regularly asking questions to establish Chen’s frame of mind and learn more about his cultural beliefs regarding TB and HIV.
<p>Reluctance to follow up for HIV care</p>	<p>As Liz continued to see Chen for his DOT visits, she emphasized the need for HIV care. Chen was overwhelmed and fearful that others would find out about his HIV status if he asked his insurance company about coverage for HIV services in order to receive HIV care through his plan. Liz tried to address these concerns by:</p> <ul style="list-style-type: none"> • Addressing Chen’s fears and explaining that there were laws protecting health information which all providers and insurance companies must follow. • Explaining that untreated HIV would impact his TB disease and could complicate TB treatment. • Offering assistance in locating an HIV specialist who would be covered under his insurance, and offering to set up an initial appointment and provide relevant medical records.

Part 2: Challenges and Barriers to Treatment

After a few weeks, Chen did see an HIV specialist at the ID clinic that Liz identified. She facilitated a consultation between the ID physician and the health department TB consultant. They decided to initiate ART as soon as possible, based on Chen’s CD4 count, and a risk-benefit analysis for early initiation of ART. Chen’s TB treatment regimen was modified based on drug-drug interactions with the prescribed ART medications and the physicians communicated, as needed, for management and treatment of both conditions. However, Chen began to develop symptoms of pulmonary TB shortly after initiation of ART. Another chest X-ray was performed and additional sputum specimens were collected. Based on his chest X-ray and AFB smear results, Chen was also diagnosed with pulmonary TB; the culture later grew *M. tb* and was pansensitive.

Over the next several weeks, Chen also struggled with increasingly severe symptoms of TB disease. The TB consultant explained to Chen that he was experiencing immune reconstitution inflammatory syndrome (IRIS). He was in a great deal of pain from his swollen lymph nodes and was depressed and discouraged. He was still grappling with the HIV diagnosis and now seemed to be consumed with grief and sadness. He expressed fear that he could not return to China to visit his family or even inform them about his health challenges, because the TB/HIV diagnosis would bring shame on the family.

Potential Case Management Challenges	Approaches
IRIS	<p>As Chen struggled with the severe symptoms of IRIS, Liz provided ongoing support, education, and guidance by:</p> <ul style="list-style-type: none"> • Explaining that IRIS is not uncommon in patients with HIV and TB since they can have a heightened inflammatory response. • Reassuring him that the symptoms would get better. • Re-emphasizing key messages around TB and HIV and the need for treatment of both diseases. • Implementing a pain management plan in conjunction with the treating physician. • Listening to Chen’s concerns and working through these complications together until the eventual resolution of his IRIS.
Depression/ mental health Fear of stigma	<p>Chen continually refused Liz’s suggestion for referral to a mental health provider. Liz was concerned about this but tried to provide as much support and reassurance as possible through:</p> <ul style="list-style-type: none"> • Using a screening tool to assess his mental health. • Scheduling appointments with the clinic social worker who helped with obtaining benefits and services, and was also able to assess Chen to ensure that he was not a danger to himself or others. • Actively listening to Chen’s worries and fears. • Offering encouragement and demonstrating empathy by reassuring Chen that these feelings were normal considering the situation. • Reiterating that with ART, people living with HIV can have long, active, and productive lives. • Sharing information on peer support groups for those with TB and HIV and providing links to websites with patient stories and testimonials, including stories from individuals from China. • Explaining that the IRIS actually signified that his immune system was beginning to work again, and thus, might be considered a positive overall sign. • Emphasizing confidentiality of medical information.

Conclusion:

As Chen’s physical health improved, so did his spirits. Liz’s bond with Chen grew stronger as they saw each other more, allowing him to confide in her and to receive more support. He also continued to see the clinic’s social worker occasionally for assistance in receiving services. Liz carefully monitored Chen’s health to make sure he was improving clinically (coughing less, feeling better, and gaining weight). She also ensured coordination of care with his ID physician, checking CD4 levels, and communicating any relevant changes in his condition or treatment regimen. Unfortunately, Chen’s sputum remained positive after two months of treatment, which resulted in an extension of the continuation phase of treatment. Eventually, he completed treatment for TB disease and remained adherent to his ART regimen while being treated for TB.

As part of the contact investigation, Chen’s partner Alan was tested for TB and diagnosed with TB infection. Alan also received an HIV test, and though he was HIV-uninfected, he was referred to the ID clinic to discuss HIV prevention strategies, including pre-exposure prophylaxis (PreP). Alan received DOT for TB infection at the same time Chen received his treatment, and successfully completed treatment for TB infection.

V. MENTAL HEALTH AND TUBERCULOSIS

Mental health is a state of well-being in which an individual can realize his or her own potential, cope with the normal stresses of life, work productively, and contribute to the community (WHO Regional Committee for Europe, n.d.). Mental health disorders, also known as mental illness, comprise a broad range of problems with different symptoms. They are generally characterized by some combination of disturbed thoughts, emotions, behaviors, and relationships with others. While all individuals experience a range of emotions and behaviors, especially in response to stressors, mental health disorders may be characterized as causing significant functional impairment of longer duration or greater severity than might typically result from that stressor. The causal relationships between mental disorders and TB are complex; some important considerations related to TB and mental health include:

- Severe mental disorders are associated with a high risk of TB acquisition and transmission and with poor adherence to TB treatment (Pachi et al., 2013).
- TB is associated with an increased risk of psychiatric co-morbidity (Pachi et al., 2013).
- Some TB medications can impact mental health:
 - Cycloserine can cause serious side effects including depression, psychosis, and suicidal ideation.
 - Other medications can cause the person such discomfort, that in combination with other factors (e.g., feelings of social isolation, patient's perception about their illness, etc.), may lead to depression.
- The additional psychosocial stress of receiving a TB diagnosis such as isolation, stigmatization, or unemployment due to TB may lead to exacerbation or emergence of mental health issues; thus, mental health should be assessed continuously throughout treatment for all patients, not just those individuals with a documented diagnosis of a mental disorder.
- Identifying and treating mental disorders in persons with TB is important in ensuring adherence and treatment completion.

Considerations for TB Nurse Case Management

In addition to the TB case management activities outlined in Chapter 1 and the basic care plan in Chapter 2, the following case management activities are important regarding mental health and mental illness:

- *For patients who do not have a diagnosable mental disorder after assessment and appropriate evaluation, but may be still be experiencing negative impacts of treatment on their mental health, emphasize self-care. Suggest achievable behaviors that may provide relief including journaling, mindfulness, getting fresh air and sunlight, talking to friends, participating in pleasurable hobbies or activities, etc.*
- *Some patients with TB may be feeling overwhelmed and may not be able to independently address challenges such as getting charity care, Medicaid, social security insurance, or other services due to lack of knowledge, access, transportation, or limited English proficiency or literacy.*
- *Providing assistance navigating the system can be very helpful. Taking concrete steps, such as making initial phone calls, setting up appointments, and printing out maps or bus schedules for how to access services can give patients confidence and help them to access needed services.*
- *Find health and human service resources visiting address urgent needs or everyday concerns by dialing 211 or visiting 211.org. Many states also have state-specific 211 websites that can help locate resources for basic needs (e.g., food banks, shelters, rental assistance, utility assistance), support for seniors and persons with disabilities, children, youth and families (e.g., meals on wheels, childcare, family resource centers), and physical and mental health resources.*

- Utilize an assessment tool to monitor the patient’s mental health status at baseline and at monthly clinic visits:
 - Monitor and assess mental health closely for patients on cycloserine.
 - PHQ-9, available at: [integration.samhsa.gov/images/res/PHQ%20-%20Questions.pdf](https://www.integration.samhsa.gov/images/res/PHQ%20-%20Questions.pdf)
 - Heartland National TB Center *Mental Health Assessment Tool*, available at: heartlandntbc.org/assets/products/mental_health_screening_tool.pdf
- Assess situational versus clinical distress; patients may be feeling overwhelmed, isolated, or anxious, etc. as a result of their TB diagnosis or treatment.
- Ensure appropriate assessment and intervention for patients who may be a risk to themselves or others.
- Assess whether there are other related co-morbidities such as substance use.

- Provide support for patients, including referral for counseling, social worker, etc.
- Utilize incentives and enablers that are valuable to the patient.
- Collaborate with providers treating mental health conditions.
- Address any barriers to adherence to TB and mental illness treatment.
- Monitor adherence to DOT weekly for patients whose mental illness is not being adequately treated and consider additional indicators of adherence including keeping clinic appointments.

VI. HOMELESSNESS AND TUBERCULOSIS

There are multiple definitions of homelessness. Broadly, this group can be said to include those who:

- Live in the streets or nonresidential structures, such as abandoned buildings.
- Utilize homeless shelters.
- Reside in temporary living accommodations (e.g., hotels, single room occupancy units, or transitional housing for those with mental illness).
- Have unstable living situations or alternate between multiple residences for short stays of uncertain duration.

People experiencing homelessness have an approximate 10-fold increase in TB incidence compared to the general population, higher rates of substance use, and lower rates of treatment completion (Bamrah, et al., 2013). The high incidence of TB in homeless populations has been attributed to poverty, overcrowded living conditions, poor nutrition, limited access to health care, poor mental health, substance use, and high rates of HIV infection (Paquette et al., 2014).

Homelessness results in fundamental issues and impacts on health (see Appendix 1), which may increase risk of TB infection and progression to TB disease and can also impact diagnosis and treatment of TB. As a result of some of these complex issues, TB case management for people experiencing homelessness may present challenges including conducting contact investigations and providing DOT. Therefore, the impacts of homelessness should be considered in development of the care plan.

Considerations for TB Nurse Case Management

In addition to the TB case management activities outlined in Chapter 1 and the basic care plan in Chapter 2, the following case management activities are important for patients experiencing homelessness:

- Assess circumstances of homelessness including:
 - How long the patient has been experiencing homelessness.
 - Whether homelessness is a result of a TB diagnosis.
 - Presence of other underlying issues that may contribute to homelessness, such as substance use or mental illness.
- Investigate and identify the patient's outlook towards their homelessness.
- Identify barriers to testing and treatment related to homelessness.
- Utilize a regimen for TB infection that the patient is more likely to complete given a transient lifestyle (since there is a greater likelihood of treatment completion with shorter regimen).

- *Finding housing for patients with TB who are experiencing homelessness can be an incentive for the patient, and can also make provision of DOT easier and more efficient. However, it is important to consider the patient's individual situation and needs. Shelters or transitional housing often have rules, for example, curfews or exclusions based on substance use. Considering these rules and communicating with the patient in advance can help ensure a successful housing placement.*
- *If resources are available, consider providing or loaning the patient a cell phone, which can both serve as an incentive and make it easier to locate the patient.*
- *Be persistent. These patients will often require more work, patience, dedication, and creativity.*

- Utilize available resources based on the circumstances of homelessness and the patient's outlook, including:
 - Housing, nutritional, or financial assistance, if available.
 - Support from family or community members.
- When establishing temporary housing for patients, consider additional needs the patient may have (e.g., where will the patient get food? Can they get to these locations easily? Do they know how to get to the clinic or other medical appointments from their new housing?).

- Communicate regularly with the facility or support team where the patient will be housed.
- Communicate clearly with the patient and others to confirm where DOT will be provided each day.
- Utilize incentives and enablers that are valuable to the patient.
- Identify barriers to completing the TB contact investigation, including challenges related to eliciting and locating contacts:
 - Coordinate with shelters and other facilities for the contact investigation, screening, testing, and infection control measures.
- Check whether resources provided to the patient such as housing or food assistance are used appropriately and remind patients of available resources and encourage they be used.
- Monitor adherence to DOT weekly and consider additional indicators of adherence, including keeping clinic appointments.

- *Establish close relationships with homeless service providers and other community partners to facilitate collaborative solutions when the need arises. Get to know what resources they have so you can ensure appropriate services for patients.*
- *Be respectful and remember that you are on their turf; it may take some time to develop trust with shelter staff and clients.*
- *Be flexible when working with shelters, as some may not have medical staff and they may ask for advice or suggestions on other common medical issues such as bedbugs, MRSA, etc.*
- *Offer shelters assistance with developing guidelines or policies on TB. This could include TB clearance cards, cough logs, staff training, etc.*
- *Consider offering regular screening events for high-risk sites.*

The Curry International Tuberculosis Center (CITC), in collaboration with CDC, National Health Care for the Homeless Council, US Interagency Council on Homelessness, and other partners has created an online toolkit with resources focused on TB in people experiencing homelessness.

The toolkit is available at:

currytbcenter.ucsf.edu/sites/default/files/product_tools/homelessnessandtbtoolkit/index.html

a. Case Study: TB in a Patient Experiencing Homelessness

Part 1: Initial presentation

Mark is the nurse case manager assigned to Brian, a 31-year old homeless man, who had been admitted to the hospital after presenting to the ED with a two-month history of productive cough, fevers, night sweats, and shortness of breath. Brian's chest X-ray showed an infiltrate in the left upper lobe and a chest CT showed cavitation. He was sputum smear positive (3+) and had a positive nucleic acid amplification (NAA) test. Prior to his hospital admission, Brian had been staying in a local homeless shelter. Mark reviewed Brian's medical record and found that he had been diagnosed with HIV three years ago, but had not received any treatment and was reported as being lost to follow-up. He had a history of bipolar disorder, schizophrenia, and alcohol addiction. Hospital records revealed recent encounters for a stab wound and suicidal ideation.

When Mark met Brian at the hospital, Brian provided the name of the shelter where he had been staying, but would not provide any contacts. Brian reported that he had been taking his psychiatric medications recently and felt fine when he took them.

Potential case management challenges	Approaches
Unstable living situation Psychiatric condition Alcohol addiction	Mark recognized that these factors could present challenges for provision of DOT and worked closely with the hospital staff. He asked to be informed of any changes in Brian's status and: <ul style="list-style-type: none"> • Emphasized the importance of communication around discharge with the hospital staff, so that a plan could be in place to ensure DOT. • Coordinated with a social worker who interviewed Brian and identified a shelter where he could go for a 30-day stay after discharge. • Established a plan for providing DOT at the shelter. • Reached out to Brian's mental health provider (with his permission) to discuss medications and keep track of when refills or follow-up appointments were needed.
Untreated HIV	<ul style="list-style-type: none"> • Ensured coordination between the ID physician and pulmonologist at the hospital and the health department's TB medical consultant to discuss timing of ART initiation and drug-drug interactions.
Overcrowded shelter and high resident turnover	Mark reached out to the shelter and: <ul style="list-style-type: none"> • Scheduled a meeting with management to discuss potential exposure. • Provided education for the shelter staff and explained the need for confidentiality. • Requested bed lists for the previous 5 months (based on the infectious period identified). • Worked closely with the staff to identify Brian's potential contacts and schedule screening and evaluation for shelter clients and staff. • Offered incentives for shelter clients who attended the screening and returned for TST readings. • Established an ongoing relationship and encouraged staff to reach out to the health department regarding any questions or if they saw clients who were coughing or had other TB symptoms. • Answered questions, addressed concerns, and provided educational materials for staff and shelter clients.

Part 2: Ensuring care in the community

Ten days into Brian's hospital stay, he left against medical advice. Mark called several shelters and found that he had stayed at a local shelter the previous night, though he was no longer there. Mark continued to follow up with nearby shelters, and emphasized the importance of informing the health department if Brian returned to their shelter.

After several days, a community health worker found the patient at a day shelter and returned him to the hospital, where he remained until he was discharged after receiving 17 doses of TB medications via DOT. He was smear negative and clinically improving so he met the state's discharge criteria as being non-infectious. Prior to the patient's discharge, Mark had spoken to the local health officer and received a directive ordering the patient to comply with TB treatment, which he explained to Brian and obtained his signature confirming receipt. However, the day after his release, Brian called Mark and said he was leaving the shelter, but arranged to meet for DOT the next day.

Potential case management challenges	Approaches
Ensuring DOT during treatment while the patient is living in a shelter	<ul style="list-style-type: none"> • Met with Brian to ask about reasons for leaving the shelter and learned that Brian thought the house rules, including curfew and zero tolerance for alcohol, were too restrictive. • Coordinated with the health department’s social worker to find immediate short-term shelter for Brian that met his needs. • Provided assistance and coordination for housing during the remainder of treatment, including extending shelter stays. • Provided daily bus passes when Brian had to come to the health department, which acted both as an enabler to access care and an incentive, because he could continue to ride the bus after his appointment. • Provided food cards weekly, based on adherence to treatment. • Built a relationship of trust and following through on all promises and commitments.
Alcohol use, mental health issues, and other co-morbidities	<ul style="list-style-type: none"> • Counseled Brian about the risk for hepatotoxicity with continued alcohol use and the need for regular assessment of LFTs. • Asked about alcohol use before providing medicines and encouraged DOT earlier in the day, prior to alcohol consumption. • Assisted in obtaining Brian’s birth certificate from another state, which was needed to apply for Medicaid. • Arranged for other needed medical appointments including HIV care and mental health follow up and prompted Brian to attend. • Provided assistance in obtaining medications for these conditions and coordinated with providers to discuss medications and review for drug-drug interactions. • Offered referral for alcohol/substance use but listened and was respectful when Brian refused.

Conclusion:

Brian completed therapy with the appropriate number of doses within the required time frame, though he did miss a total of 24 doses. When he missed DOT, his nurse case manager was diligent about calling or visiting day shelters or other locations where Brian liked to hang out. The nurse case manager also strengthened the health department’s relationship with shelters in the area and coordinated closely with them for testing and treatment of contacts identified within the shelters. Additionally, he contacted providers in the community such as FQHCs and other clinics to let them know that there were active cases of TB within the homeless community and asked them to be vigilant and ‘think TB’ in patients presenting with signs and symptoms consistent with TB.

VII. SUBSTANCE USE AND TUBERCULOSIS

The risk of TB is higher among persons who use drugs (PWUD), including alcohol, illegal drugs, or prescribed medication without medical justification. Substance use is associated with an increase in TB transmission, sputum smear-positive disease, treatment failure, and increased likelihood of being part of a genotype cluster. Additionally, substance use is frequently associated with many epidemiological factors that confer additional risks, including tobacco use, homelessness, alcohol use, and incarceration. Together, these physiological and epidemiological factors may contribute to observed outcomes: drug users are more likely to be infectious, take longer to achieve negative culture, and are at increased risk of mortality (Deiss, Rodwell, & Garfein, 2009). Additional considerations include the following:

- Excessive alcohol use presents an increased risk for hepatotoxicity when taking TB medications.
- Rifampin increases drug clearance and reduces the half-life of methadone; a concomitant increase in methadone dose may be needed to avoid withdrawal symptoms.
- Factors associated with substance use may also present barriers to adherence.

Considerations for TB Nurse Case Management

In addition to the TB case management activities outlined in Chapter 1 and the basic care plan in Chapter 2, the following case management activities concerning substance use should be carried out:

TRICKS OF THE TRADE

Patients may not be forthcoming about drug use; therefore, patients need to feel confident about their privacy and confidentiality in order to feel comfortable sharing their risk behaviors or lifestyle factors with providers. An established rapport will also be beneficial for identifying contacts.

Counseling and other behavioral therapies (relapse prevention, motivational interviewing, etc.) are critical components of effective substance use treatment. A patient-centered approach that emphasizes building rapport and trust is essential for engaging patients in care.

- Assess for alcohol or illicit drug use (injection or non-injection):
 - Ask patients about substance use in the year before TB diagnosis.
 - Utilize a screening instrument for drug use, when possible.
 - Assess behaviors, symptoms, or other indications of excessive alcohol or drug use.
- Assess whether there are other related co-morbidities such as mental

illness, HIV, etc. and concurrent medications or substance use that may cause drug interactions or amplify the risk of hepatotoxicity.

- *Providers cannot force someone to seek treatment for substance use; the patient needs to be ready and recognize that they need help. Thus, providing information and options, and helping someone to recognize the impacts of their substance use on their life is a useful approach.*
- *Co-location of services, TB testing and treatment combined with drug rehabilitation, can improve TB medication adherence and drug treatment outcomes.*
- *When possible, working with drug treatment programs to offer DOT combined with the use of incentives can improve TB completion rates.*

- Investigate and identify psychosocial barriers or aids to TB care related to substance use such as:
 - Current living situation (e.g., homeless, shelter, rehabilitation facility).
 - Mental health issues.
 - Financial situation.
 - Social or family support system.
 - Current treatment for drug or alcohol use.

- Explore the patient's perspective regarding their substance use and assess willingness to seek substance use treatment; understand the patient's perspective of their substance use and work within that perspective.
- Identify and address barriers to adherence for TB therapy and treatment for substance use.
- Locate, refer to, and collaborate regularly with facilities and agencies for treatment, counseling, or other support services:
 - Consider alternatives for provision of DOT, including staff at drug treatment centers.
- Closely monitor patients for side effects or drug interactions, including hepatotoxicity and communicate regularly with the treating physician.
- Utilize incentives and enablers that are valuable to the patient.
- Facilitate communication between the TB physician and the physician managing substance use for any required medication adjustments (e.g., methadone dose).
- Monitor continuously for signs of possible substance use relapse during treatment.
- Review any laboratory testing ordered by the physician (e.g., LFTs or bacteriology) monthly, or more frequently as needed.
- Monitor response to treatment monthly or more frequently, as needed, including sputum collection and time to culture conversion (evaluate need for extending TB therapy).
- Monitor adherence to DOT weekly and consider other indicators such as keeping clinic appointments.

VIII. TUBERCULOSIS SCREENING IN IMMIGRANTS AND REFUGEES

Caring for immigrants and refugees with TB infection or disease presents its own unique set of challenges. Some of the approaches discussed in Chapter 2 as part of providing patient-centered care in a culturally responsive manner are also useful for interacting with these individuals. Developing cultural competence will help to improve the quality of care provided to immigrants and refugees (e.g., providing culturally and linguistically appropriate patient education, utilizing trained medical interpreters, understanding the patient's beliefs, attitudes, and values, and addressing cultural perceptions and stigma about TB, etc.).

There are also specific requirements and policies related to screening immigrants and refugees, which will be discussed briefly here. Additional information on TB examination, treatment, and classifications can be found in the 2009 CDC *Technical Instructions for Tuberculosis Screening and Treatment: Using Cultures and Directly Observed Therapy*, available at: cdc.gov/immigrantrefugeehealth/exams/ti/panel/tuberculosis-panel-technical-instructions.html (CDC, 2009):

- Immigrants and refugees resettling in the US may carry a significant burden of infectious diseases because of exposures in their countries of origin and the circumstances of their migration.
- There is a specific formal process for TB screening, testing, and treatment for immigrants and refugees. This process is established by CDC's Division of Global Migration and Quarantine (DGMQ):
 - A refugee is defined as "any person who is outside the country of such person's nationality or, in the case of a person having no nationality, is outside the country in which such person last habitually resided, and who is unable or unwilling to return to, and is unable or unwilling to avail himself or herself of the protection of that country because of persecution or a well-founded fear of persecution for reasons of race, religion, nationality, membership of a particular social group, or political opinion" (US Department of Health and Human Services, 2017). Refugee status is granted overseas by the Department of Homeland Security and individuals and families are brought to the US by the Department of State.
 - Immigrants are citizens from other countries (sometimes referred to as aliens) **who are seeking entry and permanent residence in the US.**

Many agencies and partners are involved with refugees and immigrants seeking entry to the US. These include the Departments of Homeland Security and State, the Office of Refugee Resettlement (ORR), and voluntary agencies designated to provide assistance for refugees with resettlement and integration into the US. Refugees are eligible to receive ORR benefits and services from their date of arrival in the US (US Department of Health and Human Services, 2017).

Knowledge of guidelines and standards and close collaboration with partners involved is necessary, as is prompt completion of screening and related paperwork within designated time frames.

Overseas Pre-Departure TB Screening:

- Persons overseas applying for US immigration status (including refugees) are required to have an overseas medical examination, which includes screening for TB, performed by a designated DGMQ approved “panel physician” in the country of origin prior to entering the US.
- Classifications are assigned by panel physicians before individuals enter the US. Refer to the website referenced above for the most current information and additional details on the classification categories. The following categories are included in the current *Technical Instructions for Tuberculosis Screening and Treatment: Using Cultures and Directly Observed Therapy* (CDC, 2009):
 - No TB classification
 - Class A TB with waiver
 - Class B1 TB, Pulmonary
 - Class B1 TB, Extrapulmonary
 - Class B2 TB, Evaluation for TB Infection
 - Class B3 TB, Contact Evaluation

TB Screening after Arrival in the US:

- After arrival in the US, refugees receive a “Domestic Refugee Screening for Tuberculosis” (in addition to wide range of other health tests and screenings). Based on their classification, some refugees may be sent to the health department or TB program for additional evaluation.
- Some immigrants may also need follow-up examination by the health department upon arrival in the US based on the TB classification assigned by the panel physician.

Multiple socioeconomic, cultural, environmental, and political factors account for migration of these individuals and should be taken into consideration when providing TB care to newly arrived immigrants and refugees:

- Challenges faced by this group may include communication problems due to language barriers, loss of social support and feelings of isolation, adapting to new surroundings and difficulty with acculturation, challenges navigating new systems for health care and other essential services, and experiences with and fear of discrimination and stigma, fear of authority, and potential physical or emotional injury or trauma as a result of war, violence, persecution, or other causes.
- These can be amplified by fear of TB, stigma linked to a TB diagnosis, lifestyle adjustments, and perceived complications of TB treatment.

Considerations for TB Nurse Case Management

In addition to the TB case management activities outlined in Chapter 1 and the basic care plan in Chapter 2, the following case management activities are important for recent immigrants and refugees being screened or treated for TB:

- Review all medical documents received prior to the first visit and review with the patient during the first encounter:
 - Determine if the patient has an X-ray from the evaluation done prior to entering the US and obtain the X-ray image and/or report, if possible.

TRICKS OF THE TRADE

- *Be sure to review the entire file/screening form received for refugees. There may be other relevant information that will be helpful in screening and potentially diagnosing and treating the patient, such as co-morbidities and other risk factors.*
- *Remember to utilize the principles of patient-centered care and cultural competence when working with patients who are refugees. These patients may have had traumatic experiences and may experience post-traumatic stress, or other psychosocial impacts.*

- Determine potential testing needed based on medical documentation and state policy.
- Assess for any co-morbidities and mental health status, and collaborate with partners for referrals as needed.
- Ensure all appropriate testing is conducted:
 - Ensure physician examination.
 - Schedule all diagnostic tests.

- Investigate the circumstances of the patient's migration as it relates to potential barriers to TB treatment and adherence.
- Assess the perceptions of TB and health beliefs, which can play an important role in evaluation and treatment of TB:
 - Examine knowledge, attitudes, and beliefs about TB, health seeking behaviors, access to care, and factors influencing treatment initiation and adherence.
 - Provide education and emphasize the importance of adherence to treatment.
- Use culturally and linguistically appropriate services for interpretation and provide educational resources at appropriate reading level and in the patient's preferred language.
- Initiate TB treatment or discharge plan as indicated.
- Coordinate with refugee settlement agencies and others to coordinate TB care and refer for additional services, if needed.
- Complete appropriate forms and reporting as required and share with partners:
 - Complete and submit the required Electronic Disease Notification System (EDN) worksheet.
 - Return final EDN worksheet to the appropriate agency upon discharge.

IX. TUBERCULOSIS IN CORRECTIONAL SETTINGS

Approximately four to six percent of persons with TB reported in the United States are incarcerated at the time of diagnosis. The incarcerated population contains a high proportion of people at greater risk for TB than the overall population and individuals returning to the community with untreated TB present a serious public health concern.

Effective TB prevention and control measures in correctional facilities include:

- Early identification of persons with TB disease through entry and periodic follow-up screening.
- Successful treatment of TB disease and TB infection.
- Appropriate use of infection control measures (e.g., airborne infection isolation (AII) room, environmental controls, and personal respiratory protection).
- Comprehensive release planning.
- Thorough and efficient contact investigations when a person with infectious TB disease has been identified.

These measures should be instituted in close collaboration with local or state health departments, TB programs, and other key partners. Ongoing education of inmates, detainees, and correctional facility staff is necessary to maximize cooperation and participation. To ensure TB prevention and control measures are effective, periodic program evaluation should be conducted together with health department, TB program, and correctional medical staff (CDC, 2013b).

Diagnosing and treating TB disease and infection in correctional facilities reduces the risk of TB transmission among incarcerated individuals and correctional staff, as well as in the community. Prevention and control of TB can be challenging in correctional facilities because the incarcerated population includes a higher proportion of people at greater risk for TB than the overall population. Within correctional settings, risk factors for infection include close living quarters, overcrowding, and poor or re-circulated ventilation. Risk factors for progression from infection to disease that may be relevant in correctional settings include persons with a history of injection (and non-injection) drug use, alcoholism, homelessness, low socio-economic factors (poor access to care), and persons with other underlying medical conditions, including relatively high rates of HIV and hepatitis.

Persons in correctional facilities at the time of TB diagnosis can reside in federal or state prisons, local jails or detention facilities, juvenile correction centers, or other facilities. Other correctional facilities include Immigration and Customs Enforcement (ICE) detention centers, jails administered by a sovereign American Indian Tribal Nation, police lockups (temporary holding facilities for persons who have not been formally charged in court), military stockades and jails, or federal national park facilities.

Diagnosing and treating TB disease in correctional facilities is a key component to eliminating TB in the United States. CDC works with state and local health departments to ensure that diagnosing TB in inmates during entry and periodic follow-up screenings, and completing treatment are important priorities. Annual surveillance of the number of persons diagnosed with and treated for TB in correctional facilities is essential to these efforts and each state is required to have a designated correctional liaison within the TB program.

TRICKS OF THE TRADE

- *"History is subjective, but incarceration can be verified!"* For patients with a history of recent incarceration that could have occurred during the infectious period, be sure to contact the facility.*
 - *Like many other organizations, correctional facilities have very specific terminology; nurse case managers should get to know what specific terms mean within the confines of the correctional facility.*
- *Ellen Murray, Southeastern National TB Center

When case managing TB in a correctional facility, it is important to establish a collaborative approach between the TB nurse case manager and the medical management team at the correctional facility where the patient resides. Collaboration and regular communication should be part of the plan in order to facilitate successful treatment of patients,

effective efforts to control TB within the facility, and proper release planning and arrangements for follow-up care. Tools and forms can be shared with providers in correctional facilities to help staff identify and case manage inmates who have, or are being evaluated for TB disease or infection.

Considerations for TB Nurse Case Management

TB case management in correctional settings requires specific activities regarding collaboration and management. The list on the following page outlines the particular considerations for case management in these settings.

Assessment
<ul style="list-style-type: none"> • Assess TB knowledge of the staff at the correctional facility and determine if there is a need for education. • Assess infection control capabilities of the facility when an inmate may be considered infectious and assist with a plan for infection control: <ul style="list-style-type: none"> • Does the facility have a place for isolation or a place where inmates can be transferred to if identified? Is this part of their policy? • Is the use of the appropriate Personal Protection Equipment (PPE) for transporting infectious patients, for both the inmate and the custody staff, understood? • Review protocols for contact investigation, DOT, and documentation. • Collaborate with the correctional facility to assess the need for a congregate setting contact investigation: <ul style="list-style-type: none"> • Assess all contacts identified or ensure all contacts are assessed, including those contacts who have been released or transferred to other facilities.
Identification
<ul style="list-style-type: none"> • Meet face-to-face at least once with the medical team in the correctional facility. Establish the following: <ul style="list-style-type: none"> • A point of contact for all correspondence. • That the patient is on the correct medications and the proper dosages. • A plan for medication administration, including provision of medication (obtained by the health department clinic or the correctional facility).
Planning
<ul style="list-style-type: none"> • Schedule monthly follow-up visits with the TB physician identified in the initial meeting. • Provide written documentation of each visit to the correctional medical team and confirm any new orders, as applicable. • Collaborate with the medical team in advance for inmates being released while on treatment for TB disease or TB infection to ensure continuity of care. • Address any concerns regarding treatment with the patient and the health care provider in the correctional facility; ensure that all information and decisions discussed with the patient are shared with the correctional provider.
Implementation
<ul style="list-style-type: none"> • Ensure provision of DOT by the medical staff in the correctional facility by emphasizing to the staff the need for <u>watching</u> the inmate swallow the medications; review records as part of the evaluation process. • Ensure appropriate frequency and dosage of medications given to the patient. • Ensure testing and treatment of all contacts. • Coordinate follow-up care if the patient is to be released while still on treatment. • Ensure monthly medical follow-up visits.
Evaluation
<ul style="list-style-type: none"> • Collaborate regularly with the medical staff on the treatment plan and expected outcomes. • Monitor adherence to treatment by reviewing medication administration records (MAR) regularly, including: <ul style="list-style-type: none"> • Standards, such as monthly DOT adherence rate. • Behavioral measures, such as not refusing clinic appointments or medications. • Measurable clinical outcomes, including improvement of symptoms or radiographic findings. • Regularly evaluate the need for further education of staff, especially if new members are added to the team during the course of treatment.

The following websites have tools and resources that can be used by TB programs and providers in correctional facilities for TB case management in these settings:

- *Southeastern National Tuberculosis Center Corrections Toolkit*: sntc.medicine.ufl.edu/CorrectionsToolkit.aspx
- National TB Controllers Association (NTCA) Correct TB Resources: tbcontrollers.org/resources/correcttb/

Related Links:

- American Correctional Association: aca.org
- Federal Bureau of Prisons: bop.gov
- National Commission on Correctional Healthcare: ncchc.org
- National Institute of Correction: nicic.gov
- National Institute of Justice: nij.gov
- United States Department of Justice: justice.gov
- United States Immigration and Customs Enforcement: ice.gov

a. Case Study: TB in a Recently Incarcerated Patient

Part 1: Initial Presentation

Sara, a 37-year old female, presented to the ED at a local hospital with cough, night sweats, fatigue, sinus congestion, right-sided chest pain, and flu-like symptoms. She was diagnosed with pneumonia, placed on Moxifloxacin, and released. The following week, Kamala, a county health department nurse, received a call from the hospital stating that they had just received Sara's sputum smear results, which were 4+. Kamala immediately requested the patient's contact information from the hospital. The hospital records indicated several addresses and Sara had reported that she was "couchsurfing" with various friends and family and babysitting in exchange for a place to sleep.

Kamala set out to find Sara, begin the contact investigation process, and bring her in for medical evaluation. Kamala located the patient at her cousin's house and Sara agreed to come to the health department for evaluation. Based on her physical exam and sputum smear results, Sara was diagnosed with pulmonary TB. She was re-admitted to the hospital and placed in an All room. Kamala provided education on TB and the contact investigation process, and emphasized the need for Sara to be hospitalized in order to protect others around her from getting TB.

During the TB interview, Sara informed Kamala that she had been in prison but had been released several months earlier. She also told Kamala that she had not been sick with TB in prison. She was currently on parole and had a history of diabetes, schizophrenia, and substance use.

Potential case management challenges	Approaches
Unstable housing	Kamala recognized that these co-morbidities and situations may present challenges for adherence. She worked closely with the social worker to try to ensure access to services for Sara and management of her co-morbidities. Strategies included:
Mental illness	<ul style="list-style-type: none"> • Arranging housing for Sara when she was discharged through a state health department grant. • Referring Sara for mental health and substance use services.
Substance use	<ul style="list-style-type: none"> • Asking Sara if she was going to her mental health and diabetes care appointments and taking her medications as prescribed.
Diabetes	<ul style="list-style-type: none"> • Utilizing a mental health assessment tool at monthly appointments to assess for symptoms of mental illness regularly. • Asking Sara about her diabetes and reviewing glucose levels at monthly appointments.
Extremely infectious patient in the community	<ul style="list-style-type: none"> • Contacting <u>all</u> the friends and relatives Sara had stayed with recently and visiting each location to identify and assess contacts. • Ensuring that <u>all</u> the children identified, especially infants and young children, were promptly evaluated.

Part 2: Collaboration with Correctional System

Kamala contacted the correctional liaison through the State Department of Health (DOH), who retrieved the patient’s record and concluded that Sara had actually been released from prison two weeks prior to her ED visit. The correctional liaison then contacted the state Department of Corrections (DOC) TB nurse, who advised her the patient had not been diagnosed with TB while incarcerated, and did not appear to be infectious during that time. The state DOC TB nurse reviewed the electronic record of the patient, as well as the five chest X-rays ordered throughout the patient’s 11 months of incarceration. She conferred with the prison doctor, who agreed that the patient was not infectious during her incarceration.

However, Kamala and the state DOH correctional liaison requested the medical record in its entirety (which took approximately 26 days to obtain). Once the state DOH correctional liaison reviewed the complete record, approximately 30 sick calls were noted that had not originally been entered into the electronic record for the patient. Many of the sick calls included laryngitis, talking in a whisper, difficulty swallowing, cough, fever, scratchy or sore throat, and a dry hoarse voice. These symptoms are all consistent with laryngeal TB, which is highly infectious. After discussion with the health department physician, a throat culture was obtained, which was also 4+ on AFB smear. Sara was additionally diagnosed with laryngeal TB.

Potential case management challenges	Approaches
Potential exposure and contact investigation in a correctional setting	<p>Kamala collaborated with the state correctional liaison to coordinate with the state DOC and the medical department at the prison from which Sara had just been released. Approaches utilized included:</p> <ul style="list-style-type: none"> • Requesting Sara’s full record (not just her medical record) from the prison. • Asking for the complete medical record with all loose pages and reports rather than just the electronic medical record. • Determining a new infectious period based on the complete medical record that included multiple “sick calls,” which were important factors for consideration as related to her laryngeal TB, (sore throat, hoarseness, fever, fatigue). • Meeting with the warden to provide information and education, gather additional data, and facilitate cooperation from all prison staff. • Working with the classification/custody division to identify Sara’s movements within the prison and the larger correctional system in order to identify potential contacts, including both inmates and prison staff. • Working with the warden, prison medical department, and TB program manager to determine all contacts who should be tested for TB and ensure testing and medical evaluation as needed. • Providing checklists and tools that the prison staff could use to assist in the contact investigation process and testing of staff and inmates.

Part 3: Re-incarceration

After her release from the hospital, Sara was initially very grateful for the housing assistance and was adherent to treatment. Her smears converted, and she was no longer infectious. However, after four months of treatment, Kamala started to see a deterioration in Sara’s behavior. She was unkempt, argumentative, and began to manifest symptoms of schizophrenia. Kamala suspected that she was using drugs again. She counseled Sara and referred her for substance use treatment, but Sara did not follow up on the referral. One Monday morning, Kamala went to Sara’s hotel accommodation and found that she was not there. She was not there the next day either.

Potential case management challenges	Approaches
Unable to locate patient Re-incarceration	<p>Kamala recognized the importance of locating Sara and returning her to care and used a variety of approaches to do so, including:</p> <ul style="list-style-type: none"> • Contacting Sara’s cousin, where she had been staying after her initial release from the hospital, to try to locate her. Kamala learned that Sara was back in jail. She had failed a drug test which violated her parole and she was sent back to the local jail to await her hearing. • Reaching out to the county jail after finding out that Sara was re-incarcerated and informing management that Sara was currently being treated for TB, though she was not infectious. • Bringing Sara’s medication to the county jail at the beginning of her incarceration. • Providing Sara’s medical records from the health department and ensuring access to previous medical records from the prison. • Discussing treatment with the nurse at the jail to ensure that medications were available for the course of treatment and offering to provide medications, if needed. • Facilitating communication between the DOH medical consultant and the contracted medical providers for the jail regarding the patient’s care, including education on the risk for relapse, the potential need for dose adjustments, therapeutic drug monitoring and/or extension of therapy in patients with diabetes.

- *Much of an inmate's history is documented but not necessarily by the medical division. ALWAYS work with the classifications (custody) division who have all non-medical information about the patient, and can document contacts and movement of the patient within the facility and correctional system.*
- *Be sure to look at the entire history, not just the medical record; grievances and behavior issues could be triggered by medical issues (e.g., complaints from the patient, "Food in here is awful, I'm wasting away.").*
- *Always remind patients to tell the medical and intake departments that they are being treated for TB if they end up back in jail. Give the patient a card with your name and the health department phone number and ask them to have the medical staff contact you if they are re-incarcerated.*
- *As with any congregate setting, there can be widespread fear. Provide education sessions to describe TB symptoms, transmission, and explain who will be tested.*
- *Often the correctional staff will be assessed by a workers' compensation facility offsite. Ensure that the medical staff at this facility has access to information from the contact investigation on who was exposed or who is considered a close contact.*

Conclusion

Sara eventually completed her TB treatment in the county jail. Although the DOT was provided by a nurse in the county jail, Kamala continued to carry out key case management responsibilities such as monitoring medication adherence, side effects, and overall completion of treatment.

The contact investigation in the prison was complex and challenging and revealed many secondary TB cases. It was eventually classified as an outbreak, with a total of 31 individuals diagnosed with TB disease in the correctional facility where Sara had been incarcerated. This exposure and eventual outbreak was identified and managed through careful and thorough review of the patient's incarceration and medical history and close collaboration with the correctional facility. This collaboration and provision of education to the

prison medical staff involved may also lead the staff to be more vigilant in recognizing TB and preventing future outbreaks.

X. SUMMARY

Treatment of TB can be a long and difficult process for any patient, with each having a specific set of challenges that may need to be addressed. While a patient-centered case management approach should be utilized for all patients with TB, the special populations and circumstances described in this chapter are frequently encountered by TB nurse case managers and often merit special consideration. The suggestions and approaches outlined in this chapter should be used as a guide to build upon to develop a tailored plan that considers the needs and circumstances of the individual patient.

APPENDIX: COMMON CHALLENGES FOR PEOPLE EXPERIENCING HOMELESSNESS

Issue	Impact on Health and Health Care
Unstable housing	Increased risk for serious health problems; may exacerbate existing illness and complicate treatment.
Limited access to nutritious food and water	Individuals must eat whatever is available which may result in malnutrition or increased risk of chronic disease such as diabetes or heart disease.
Higher risk for abuse	Physical and sexual abuse have been identified as both a cause and a consequence of homelessness.
Behavioral health problems	Two-thirds of homeless adults report a substance use and/or mental health problem, and about one in four meets the criteria for a serious mental illness.
Physical/cognitive impairments	Physical and cognitive impairments can precipitate and prolong homelessness.
Developmental discrepancies	Homeless children, adolescents, and young adults frequently exhibit developmental levels that do not match their chronological age.
Higher risk for communicable disease	Higher rates of infectious or other communicable diseases.
Serious and complex medical conditions	Increased risk for acute and chronic diseases with multiple co-morbidities.
Discontinuous/inaccessible health care	Health care is frequently interrupted and uncoordinated.
Lack of health insurance/resources	Over half of surveyed homeless service users nationwide have no health insurance which impacts seeking and accessing care.
Cultural/linguistic barriers	May not trust outsiders, or those working in government.
Limited education/literacy	Homeless adults are more likely to have dropped out of high school and less likely to have completed education beyond high school, compared to all US adults, which can impact the ability to access health information and health care.
Limited or no access to transportation	May make health care inaccessible for many homeless people and is a primary obstacle to employment, particularly in rural areas.
Lack of social support	Permanent housing with supportive services is often a prerequisite to re-establishing or developing connections with family or the community.
Chronic stress	Constant state of stress that can have negative effects on health.
Criminalization of homelessness	Frequently arrested for activities that are permissible in the privacy of a home such as loitering, sleeping, urinating, or drinking. This results in a criminal record which prevents them from getting access to needed services, jobs, and housing.

Adapted from (Bonin et al., 2010).

RESOURCE LIST

1. *Official American Thoracic Society/Centers for Disease Control and Prevention/Infectious Diseases Society of America Clinical Practice Guidelines: Treatment of Drug-Susceptible Tuberculosis*. Available at:
cdc.gov/tb/publications/guidelines/pdf/clin-infect-dis.-2016-nahid-cid_ciw376.pdf
2. *Self-Study Modules on Tuberculosis*, CDC. Available at:
cdc.gov/tb/education/ssmodules/default.htm
3. *Interactive Core Curriculum on Tuberculosis: What the Clinician Should Know*, CDC. Available at: cdc.gov/tb/education/ce/interactive-corecurr.htm
4. *TB Training Roadmap for Public Health Nurses*, Global Tuberculosis Institute. Available at: globaltb.njms.rutgers.edu/educationalmaterials/productfolder/roadmap.php
5. National TB Controllers Association/National TB Nurse Coalition website, NTCA and NTNC. Available at: tbcontrollers.org/ntnc/
6. *Tuberculosis Handbook for School Nurses*, Global Tuberculosis Institute. Available at: globaltb.njms.rutgers.edu/educationalmaterials/productfolder/tbedusn2.php
7. *What Parents Need to Know About Tuberculosis (TB) Infection in Children*, Global Tuberculosis Institute. Available in English at:
globaltb.njms.rutgers.edu/educationalmaterials/productfolder/tbparentschild.php
Available in Spanish at:
globaltb.njms.rutgers.edu/educationalmaterials/productfolder/whatparentsneedtoknow-spanish.php
8. Mental Health and Substance Use Screening Tools. Available at:
<https://www.integration.samhsa.gov/clinical-practice/screening-tools>
9. *Mental Health Assessment Tool*, Heartland National Tuberculosis Center. Available at:
http://www.heartlandntbc.org/assets/products/mental_health_screening_tool.pdf
10. *Homelessness and TB Toolkit*, Curry International Tuberculosis Center. Available at:
currytbcenter.ucsf.edu/sites/default/files/product_tools/homelessnessandtbt toolkit/index.html
11. *Tuberculosis Screening and Treatment Technical Instructions (TB TIs) using Cultures and Directly Observed Therapy (DOT) for Panel Physicians*. Available at:
cdc.gov/immigrantrefugeehealth/exams/ti/panel/tuberculosis-panel-technical-instructions.html
12. *Corrections Toolkit*, Southeastern National Tuberculosis Center. Available at:
sntc.medicine.ufl.edu/CorrectionsToolkit.aspx
13. National TB Controllers Association (NTCA) Correct TB Resources. Available at:
tbcontrollers.org/resources/correcttb

14. Additional CDC TB Resources

- I. TB Guidelines:
[cdc.gov/tb/publications/guidelines/default.htm](https://www.cdc.gov/tb/publications/guidelines/default.htm)
- II. Health Care Provider and TB Program Materials:
[cdc.gov/tb/education/provider_edmaterials.htm](https://www.cdc.gov/tb/education/provider_edmaterials.htm)
- III. Patient and General Public Materials:
[cdc.gov/tb/education/patient_edmaterials.htm](https://www.cdc.gov/tb/education/patient_edmaterials.htm)



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225 Warren Street, Newark, NJ 07103
(973) 972-3270
globaltb.njms.rutgers.edu