Self-Study Modules on Tuberculosis, 6-9

Module 6

Managing Tuberculosis Patients and Improving Adherence

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention
National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention
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Contents

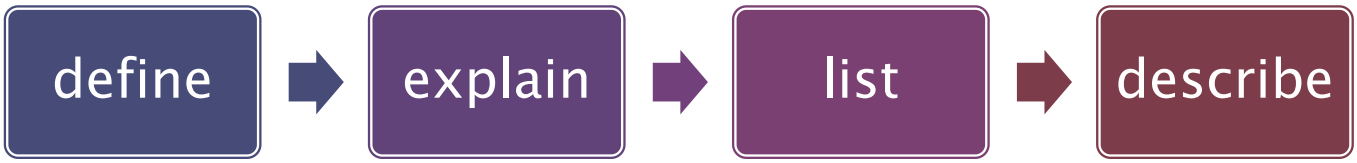
Background

In this module, you will learn about managing TB patients and improving adherence to TB treatment. Patients with TB disease must follow their recommended course of treatment and complete treatment in a timely manner in order to cure TB and prevent drug resistance. Ensuring patient adherence to treatment can be difficult because TB disease treatment requires many drugs given for at least 6 months. It is important that health care workers help patients adhere to treatment, because nonadherence can have serious consequences.

This module describes case management activities and methods health care workers can use to improve patient adherence. Case management is a strategy to provide patient-centered care and ensure all public health activities related to TB care are completed. This module also describes several methods for promoting adherence, including directly observed therapy (DOT), the use of incentives and enablers, education, and legal remedies.

Note: This module does not cover all topics relevant to nursing case management. For in-depth information on nursing case management for TB, please refer to *Tuberculosis Case Management: A Guide for Nurses*, from the Global Tuberculosis Institute at Rutgers, the State University of New Jersey and the *Tuberculosis Nursing: A Comprehensive Guide to Patient Care*, 2nd edition from the National Tuberculosis Nurse Coalition.

Objectives



After working through this module, you will be able to

1. List the four priority activities of TB prevention and control.
2. Describe the activities associated with TB case management.
3. Describe directly observed therapy (DOT).
4. Discuss TB treatment adherence strategies.
5. Explain considerations for TB case management in special settings.

New Terms

New terms introduced in this module are included below. Please refer to the *Self-Study Modules 1-5 Glossary* if you encounter unfamiliar terms related to TB that are not defined in the glossary below.

active case finding— identifying unreported cases of TB disease by actively searching for them through, for example, laboratory and pharmacy audits

adherence agreement— a written document that describes understanding between a health care worker and a patient regarding TB treatment adherence and completion

adherence plan— a written plan that is based on the patient's understanding and acceptance of the TB diagnosis and recommended treatment. It addresses barriers to adherence and details the method chosen to deliver treatment and monitor adherence for that specific patient.

adherence to treatment— following the recommended course of treatment by taking all of the prescribed medications for the entire recommended time

barriers— anything that may prevent a patient from being able to adhere to a TB treatment regimen

case management— a strategy health departments can use to manage patient care and help ensure patients successfully complete treatment

case manager— a specific health care worker who is assigned primary responsibility for the patient

case review— the systematic, regular review of a patient's progress by the case management team. Case reviews should be weekly and real-time.

clinic-based directly observed therapy (DOT)— DOT that is delivered in a TB clinic or comparable healthcare facility

cohort review— the systematic review of the management of a specific cohort of TB patients and their contacts. A "cohort" is a group of TB cases counted over a specific period of time, usually 3 months.

court-ordered directly observed therapy (DOT)— DOT that is administered to a patient by order of a public health official or a court with the appropriate authority

cultural competence— having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by patients and their communities

discharge planning— the preparation for continued and comprehensive care of a patient after that patient's discharge from a hospital or institution

electronic directly observed therapy (eDOT)— DOT that is delivered remotely (e.g., over a smartphone, tablet, or computer). eDOT can either be real-time or recorded.

enablers— things that make it possible or easier for patients to receive treatment by overcoming barriers

field-based directly observed therapy (DOT)— DOT that is delivered in a setting outside of the TB clinic or healthcare facility

genotype— distinct genetic pattern of an organism

genotyping— a laboratory-based method that can determine the genetic pattern of the strain of *M. tuberculosis* that caused TB disease in a person

incentives— small rewards given to patients to encourage them to either take their medicine or keep their clinic or field DOT appointments

nonadherence— a patient's inability or refusal to take TB drugs as prescribed

open-ended questions— a question that cannot be answered with a simple "yes" or "no." Open-ended questions are designed to elicit the patient's knowledge, feelings, and beliefs.

passive case reporting— required reporting of suspected or confirmed TB cases to a public health authority

patient assessment— talking to a patient about his or her medical history, knowledge about TB, and beliefs about TB treatment

quality assurance— the review and evaluation of the quality of care and effectiveness of the TB program

TB Genotyping Information Management System (TB GIMS)— a secure CDC-sponsored online national database of genotyping and case information

Goals of TB Prevention and Control

In the United States, state and local health departments have legal responsibility for the prevention and control of TB in their communities. As such, each TB program should focus on four fundamental priority prevention and control activities. The priority activities, in order, include

1. Identifying and treating persons who have TB disease;
2. Finding and assessing persons who have been in contact with TB patients to determine whether they have latent TB infection (LTBI) or TB disease and providing them with appropriate treatment;
3. Using targeted testing strategies to identify and treat persons with LTBI at risk for developing TB disease; and
4. Identifying settings in which there is a high risk for transmission of *M. tuberculosis* and applying effective infection control measures

The identification and treatment of TB disease is aimed at both helping the individual patient sick with TB disease and protecting the public by reducing the further transmission of *M. tuberculosis*. To identify TB patients effectively, health departments should collaborate with other providers, partners, and organizations including private physicians, laboratories, community health centers, migrant health centers, correctional facilities, hospitals, hospices, long-term care facilities, and homeless shelters.

Once TB patients are identified, the health department needs to ensure that a plan is in place for patients to receive appropriate follow-up and treatment. **Case management** is a strategy health departments can use to manage patient care and help ensure patients successfully complete treatment.

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Identifying TB Cases

The two basic methods health departments should use for identifying suspected or confirmed TB cases are:

- Passive case reporting
- Active case finding

Passive Case Reporting

Passive case reporting is the required reporting of suspected or confirmed TB cases to a public health authority. TB programs should receive a case report when a suspected or confirmed TB case has been identified by any health care provider or institution. This is the most common way health departments identify TB patients. Laboratories should report positive results on smears and cultures within 24 hours by telephone or fax to the state or local TB control program, as required by law.

Passive case reporting is the required reporting of suspected or confirmed TB cases to a public health authority.

Active Case Finding

Health departments may also identify cases by **active case finding**.
In active case finding, the TB program identifies unreported cases of TB disease by actively searching for TB cases. Active case finding can be implemented in several ways, depending on local needs and practices. Examples of active case finding activities include

- Contact investigations
- Laboratory and pharmacy audits
- Facility and organization inquiries

Active case finding is identifying unreported cases of TB disease by actively searching for them.

Contact Investigations

Public health workers actively find TB cases through the assessment of contacts to patients with infectious TB. A TB contact investigation is a systematic process to:

- Identify persons (contacts) exposed to someone with infectious TB disease

- Assess contacts for infection with *M. tuberculosis* and TB disease
- Provide appropriate treatment for contacts with LTBI or TB disease

Contact investigation is discussed in more detail in *Module 8, Contact Investigations for Tuberculosis.*

Laboratory and Pharmacy Audits

Some TB control programs may collaborate with pharmacies and mycobacteriology laboratories to identify unreported TB cases by conducting laboratory or pharmacy audits. Active case finding with laboratories or pharmacies require special agreements regarding the sharing of information. The ability to perform this activity depends on local confidentiality laws and regulations. In many areas, active case finding will be most effective when targeted to specific laboratories or pharmacies with the goal of reviewing specific data. Because it can be difficult to gain access to laboratory databases to search for unreported cases, public health workers may need to request reports from laboratories. Acid-fast bacilli (AFB) smear, culture, and nucleic acid amplification test (NAAT) results should be reviewed periodically to identify unreported suspected or confirmed TB cases.

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Pharmacy surveillance can also help to identify unreported cases of TB disease. When patients are being treated for TB based on a clinical diagnosis, pharmacy records can be an important active case finding tool. If possible, the pharmacy may be able to provide information regarding patients who are taking TB treatment drugs. Local confidentiality laws and regulations must be considered.

Facility and Organization Inquiries

TB program staff should be familiar with facilities or organizations that provide services to persons considered to be at high risk for TB infection and TB disease. Relationships with staff from these facilities (e.g., homeless shelters, correctional facilities, community health centers) should be developed and sustained. The TB program should educate these staff about TB public health reporting regulations. In addition, educating healthcare providers and staff about TB infection and disease may help prevent delayed diagnosis or misdiagnosis.

TB program staff should be familiar with facilities or organizations that provide services to persons considered to be at high risk for TB infection and TB disease.

Study Questions 6.1 – 6.2

6.1 What are the four priority TB prevention and control activities?

6.2 Name two methods health departments use to identify TB cases.

Answers to study questions are on pages 80–87

Case Management

Once persons with TB infection or TB disease are identified, successful TB treatment is primarily the responsibility of medical providers and health care workers, not the patient. Public health workers in TB programs and other facilities play an integral role in helping patients complete TB treatment through the use of a strategy referred to as case management. The strategy's goal is to provide patient-centered care for completion of treatment and to ensure all public health activities related to stopping TB transmission are completed. Patient-centered care can help ensure successful treatment outcomes because it emphasizes tailoring treatment to address both the patient's clinical and social concerns. For example, to help some patients through the lengthy TB treatment process, it may be necessary to provide treatment incentives and enablers, housing assistance, or a referral for substance abuse treatment.

Successful TB treatment is primarily the responsibility of medical providers and health care workers, not the patient.

In the case management approach, a specific health care worker (i.e., a **case manager**) is assigned primary responsibility for ensuring that all treatment and public health activities affiliated with the TB patient are completed. Although one person is assigned primary responsibility, case management usually involves a team of persons who work together to provide continuity of care. These team members may include clinic supervisors, outreach workers, health educators, nurses, nurse practitioners, physician assistants, pharmacists, physicians, and social workers. Some specific responsibilities may be assigned to other team members; however, the case manager is ultimately responsible for ensuring that needed activities are performed. Although some patients may undergo their evaluation and treatment in settings other than the health department, such as hospitals or correctional facilities, it is still the health department's duty to monitor and ensure the quality of all TB-related activities in their jurisdiction. Thus, all TB patients should be assigned a case manager, whether they receive TB care in a health department clinic or from a private provider. For more information about TB case management in special settings, refer to page 73 of this module.

A case manager is assigned primary responsibility for ensuring that all treatment and public health activities affiliated with the TB patient are completed.

The case manager is responsible for ensuring the following activities are completed for all TB patients to whom they are assigned:

- Establishing a trusting relationship with the patient
- Educating the patient about TB and its treatment
- Developing a treatment and monitoring plan
- Ensuring the patient adheres to and completes treatment
- Conducting quality assurance through systematic regular review of patient progress

This module covers the basic case management strategies; it does not cover all topics relevant to nursing case management. For in-depth information on nursing case management for TB, please refer to *Tuberculosis Case Management: A Guide for Nurses* from the Global Tuberculosis Institute at Rutgers, the State University of New Jersey and the *Tuberculosis Nursing: A Comprehensive Guide to Patient Care*, 2nd Edition from the National Tuberculosis Nurse Coalition.

Study Question 6.3

6.3 What is the goal of TB case management?

Answers to study questions are on pages 80–87

Working Effectively with TB Patients

In order for case management to be successful, it is very important that the TB case manager is able to effectively work with patients. Working effectively with patients includes

- Getting to know the patient
- Developing a good relationship with the patient that is built on trust and rapport
- Educating the patient about TB disease
- Addressing language barriers
- Discussing health beliefs and misconceptions

Getting to Know the Patient

Once a patient has been reported to the health department and a case manager has been assigned, the case manager or another health care worker on the case management team will need to visit the patient as soon as possible. During this visit, the case manager should try to learn as much as possible about the patient. To do so, the case manager should conduct a **patient assessment**. Specific topics that the health care worker should discuss with the patient during the assessment include

- Medical history
- Knowledge, attitudes, and beliefs about TB
- Ability to follow the TB treatment plan
- Resources (e.g., family, other social support, finances)
- Anticipated barriers (e.g., lack of transportation) and perceived barriers (e.g., TB medications will be very expensive) to treatment
- History of adherence to previous TB regimens or other medication

The case manager should conduct a patient assessment to discuss with the patient his or her medical history, knowledge about TB, and beliefs about TB treatment.

How is the Patient Assessment Conducted?

One way that health care workers can conduct an assessment is to ask several **open-ended questions**. An open-ended question is one that cannot be answered with a simple "yes" or "no." Open-ended questions are designed to elicit the patient's

knowledge, feelings, and beliefs by beginning with words that require an explanation, such as

- What?
- Why?
- Who?
- When?
- How?

In addition, phrases that begin with "Tell me about" or "Explain to me" may be helpful in eliciting information from the patient.

The questions in Table 6.1 are examples of questions that can be used to assess TB patients' knowledge, attitudes, and beliefs regarding TB. These questions are a starting point; the health care worker should adapt such questions according to the patient's age, family situation, education level, and cultural background. These questions are useful during the initial patient assessment and later on during other interactions with the patient. Throughout treatment, the health care worker should ask the patient about his or her concerns about TB and adherence to the TB regimen.

Table 6.1
Examples of Open-Ended Questions for Patient Assessment

- What are some difficulties you have taking medicine?
- How do your family members or close friends feel about your TB?
- How do you feel about taking your TB medication?
- How severe do you think your illness is?
- What problems has your illness caused for you?
- What are the most important results you hope to get from this treatment?
- What do you know about TB?
- What causes TB?
- What do you think TB does to your body?
- What treatment do you think you should receive for TB?
- What caused you to go to the doctor who diagnosed your TB?
- What did you think when you were told you had TB?
- How do you think you got TB?

Establishing Rapport and Building Trust

Establishing rapport, trust, and good communication with the patient is critical. If the patient and the health care worker have a good relationship with each other, the patient is more likely to adhere to treatment, name contacts, and follow the health care worker's instructions and advice.

Establishing rapport, trust, and good communication with the patient is critical.

The relationship with the patient will develop over time; however, the foundation from which a trusting relationship is established begins immediately. Therefore, health care workers should begin to establish rapport with the patient at the initial visit. Ways to develop rapport include

- Using effective communication skills
- Finding common ground
- Displaying respect and empathy

Examples of effective communication skills include active listening, using appropriate nonverbal communication, and communicating at the patient's level of understanding (for more information regarding effective communication skills, refer to page 17 of this module). Additionally, it is important that the health care worker is objective and nonjudgmental. The health care worker should keep in mind that judgments about the patient's lifestyle, beliefs, and behaviors may be conveyed through nonverbal body language. This can negatively affect the health care worker's relationship with the patient.

Examples of effective communication skills include active listening, using appropriate nonverbal communication, and communicating at the patient's level of understanding.

To build a good relationship, the health care worker should

- Treat the patient with dignity and respect
- Listen carefully to the patient
- Communicate clearly
- Speak openly, honestly, and politely about differences in ideas; correct misconceptions about TB tactfully, and allow time for questions

- Involve the patient in the development of the treatment plan and be flexible in meeting the patient's needs
- Listen and try to understand the patient's knowledge, beliefs, and feelings about TB disease and treatment
- Be open minded about the patient's cultural beliefs
- Recognize and address the patient's fears about the illness
- Understand and fulfill the patient's expectations about treatment, when possible
- Avoid criticizing the patient's adherence behavior; suggest behavior changes respectfully
- Be consistent in what is done and told to the patient

Educating the Patient About TB

TB education should begin at the initial patient visit and continue with each encounter. This includes information regarding

- TB transmission and pathogenesis
- Expected outcomes of treatment
- Benefits and possible adverse effects of the treatment regimen
- Methods of supervision, such as directly observed therapy (DOT)
- Assessment of treatment response
- Infectiousness and infection control

TB education should begin at the initial patient visit and continue with each encounter.

Information obtained from the patient assessment should guide education efforts. As soon as the health care worker begins to work with a patient, it is important to ask what the patient understands and believes about TB disease and treatment. If the patient does not understand the rationale for a lengthy treatment regimen and the need for finishing treatment, adherence will be very difficult. If a patient has some understanding of the disease and its treatment, the health care worker should confirm the accurate information and correct any misconceptions the patient may have. To be sure a patient has an accurate understanding of their TB disease and treatment, the health care worker should ask the patient to repeat back and explain what they understood. This should be done with concern and care so the patient does not feel threatened. The health care worker may have to spend extra time reviewing important information.

As soon as the health care worker begins to work with a patient, it is important to ask what the patient understands and believes about TB disease and treatment.

Health care workers should take the time to clearly explain to patients what medication should be taken, how much, how often, and when. Patients need to be informed about possible adverse reactions to the medications and when to seek necessary medical attention. Providing patients with information regarding the consequences of not taking TB medicine correctly is very important.

Effective Communication and Education Techniques

When educating a patient, health care workers should use effective communication and education techniques such as the following

- Use simple, nonmedical terms
- Use the appropriate language level
- Limit the amount of information
- Discuss the most important topics first and last
- Repeat important information
- Listen to feedback and questions
- Use concrete examples
- Make interactions with the patient as positive as possible
- Provide patient education materials

Use Simple, Nonmedical Terms

Do not use medical jargon and be specific about the behaviors that are expected by the patient. For example, it is usually more helpful to say, "This pill will help kill the TB germs in your body so you get better," than to say, "This drug, isoniazid, is a bactericidal agent that is highly active against *Mycobacterium tuberculosis*." Using words that are familiar to patients can make the information relevant to them.

Use the Appropriate Language Level

Written information should match the patient's reading level. Persons with a limited education may only be able to understand basic materials. Highly educated patients may prefer more detailed information. If a patient does not read or write, health care workers should give instructions verbally and leave visual cues or reminders, such as a picture of each medication, with the time the patient should take it written in large numbers.

Limit the Amount of Information

If too much information is given at one time, the patient may not remember all of it. To avoid overwhelming the patient, the topics discussed should be organized in the order of importance. In the first session, the most essential topics (such as the names of exposed contacts) should be discussed, in case the patient does not return for follow-up care.

Discuss the Most Important Topics First and Last

People remember information presented at the beginning and at the end of a session more easily than they do the information presented in the middle. Health care workers should tell the patient what is expected of him or her before they explain test results, the expected outcome of a procedure, or treatment. For example, early in the first session the health care worker might say, "To get well, you must take four of these pills every day." This information should be reviewed before leaving the patient.

Repeat Important Information

People need to hear new information several times before they will remember it. Health care workers should repeat key messages throughout the session; have the patient repeat back the information; then in later sessions review previously presented material first. The topic can be introduced by saying, "As we discussed last time…"

Listen to Feedback and Questions

Communication with the patient should always be a two-way interaction. The health care worker should listen to feedback and questions from the patient to ensure the patient understood the message.

Use Concrete Examples

Use examples to make information easy to remember. This is especially important for patients who are not on DOT. For example, visual descriptions of pills can be helpful. The health care worker could say, "Take two Rifamate capsules in the morning when you get out of bed. These are the big red pills in the little brown bottle." If there is something the patient does every morning, such as brushing teeth, a picture or note placed on the mirror near the toothbrush can serve as a reminder.

Make the Interaction with the Patient a Positive Experience

It is not only what is said and done, but how it is said and done, that will help the patient adhere to treatment. The health care worker should be encouraging and

supportive. A warm, concerned, and respectful attitude toward the patient will make the experience more pleasant and successful.

Provide Patient Education Materials

When educating patients, it may be helpful to give them written educational materials on TB that they can keep. Culturally and linguistically appropriate patient education materials can be found on the CDC website (www.cdc.gov/tb) and the Find TB Resources website (https://findtbresources.cdc.gov).

Addressing Language Barriers

If the patient and health care worker do not speak the same language, it can be a barrier to successful care and treatment. TB programs should provide language assistance services, such as bilingual staff and interpreter services, at no cost to patients with limited English proficiency.

Using Interpreters

Using an interpreter can help the health care worker and patient communicate. It is best to use trained medical interpreters whenever possible (Figure 6.1). Language lines can also be used to do over-the-phone interpretation. If a trained interpreter is not available, other persons who could be used as interpreters include other health care workers who speak the patient's language, or people from the patient's community (with the patient's prior permission). Using family members as interpreters is strongly discouraged, but do not exclude them if the patient wants them to be part of the clinic visit. If family members must be used to interpret, children should not be used.

It is best to use trained medical interpreters whenever possible.

If family members must be used to interpret, children should not be used.

Guidelines for Interpreters

After the health care worker has identified an interpreter, he or she should follow these guidelines to make the best use of the interview:

- Ask for the patient's permission to use an interpreter.
- Plan the interview and decide what key points to talk about with the patient.
- Meet with the interpreter before the interview to talk about the goals for the interview, to give instructions and guidance, and to make sure the interpreter is comfortable with the questions and topics that will be discussed.
- Remind the interpreter that all information in the interview is confidential.
- Ask the interpreter to refrain from adding his or her own comments.
- Address the patient directly, not the interpreter.
- Ask the interpreter to explain questions or answers that are not clear.
- Keep the messages simple and factual; use short phrases and focus on one topic at a time.
- Give the interpreter time to translate each phrase before continuing; do not interrupt the interpreter.
- Ask the interpreter to translate the patient's and the health care worker's own words exactly.
- Give the patient time to answer questions.

Figure 6.1 Health care worker interviewing a patient with the assistance of an interpreter.

Discussing Health Beliefs with Patients

Sometimes cultural, religious, or other personal beliefs affect a patient's TB care and treatment. This may include beliefs about how TB is transmitted, how TB is treated, and the significance the disease has for the affected person. The long history of TB has led to various theories about its cause, including beliefs that certain factors, such as poor hygiene, pollution, or hard labor, may cause TB and contribute to its progression. Furthermore, remedies for symptom relief and cure of the disease can vary. Patient beliefs about TB may differ from the medical model of TB treatment.

Sometimes cultural, religious, or other personal beliefs affect a patient's TB care and treatment.

It is important to respect patient health beliefs while providing information about the rationale for medical TB treatment in a non-judgmental fashion. Health care workers and their organizations should strive to be culturally competent. **Cultural competence** means having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by patients and their communities.

Cultural competence means having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by patients and their communities.

While it is important to respect the patient's beliefs, it is just as important for the health care worker to clearly present the rationale for taking prescribed TB medication for a full course of treatment. In order for treatment to be successful, the patient must agree to take TB medicines. The health care worker can do a great deal to help the patient adhere and incorporate his or her beliefs into the treatment, but it is crucial that both come to an agreement about taking TB medication. For example, traditional or folk medicine can complement Western medicine, but should be overseen by the treating clinician.

While it is important to respect the patient's beliefs, it is just as important for the health care worker to clearly present the rationale for taking prescribed TB medication for a full course of treatment.

Study Questions 6.4 – 6.6

6.4 During a patient assessment, what specific topics should the health care worker discuss with the patient?

6.5 In the list below, there are closed-ended and open-ended questions. Mark an X next to the open-ended questions.

- ☐ What is TB?
- ☐ Do you think TB can be cured?
- ☐ How is TB spread?
- ☐ Do you have difficulty taking medicine?
- ☐ What are some of the difficulties you have taking medicine?
- ☐ Why do you think you need to take medicine?
- ☐ Is TB curable?
- ☐ How is TB cured?

6.6 Explain the importance of building rapport and establishing a trusting relationship with the patient.

Answers to study questions are on pages 80–87

Study Questions 6.7 – 6.8

6.7 **List at least four effective communication and education techniques that health care workers should use when educating a patient.**

6.8 **List at least six guidelines for working with an interpreter that can help the health care worker make the best of the interview.**

Answers to study questions are on pages 80–87

Case Study 6.1

Thanh is a cook at a local restaurant. He went to see his physician because he was feeling extremely tired, had lost his appetite, and had been coughing for several weeks. His physician suspected TB and admitted Thanh to the hospital for further tests.

His sputum smears were positive and he was started on appropriate therapy. The physician called the local health department to report the diagnosis. A case manager was assigned and visited Thanh in the hospital.

- **How should the case manager assess Thanh's knowledge, beliefs, and feelings about TB disease and treatment?**

- **Why is it important to assess Thanh's knowledge, beliefs, and feelings about TB disease and treatment?**

Answers to case studies are on pages 88–93

Developing a Treatment and Monitoring Plan

A specific treatment and monitoring plan should be developed for each TB patient. This should be done within one week of the suspected diagnosis. This plan should include

- A description of the treatment regimen
- Methods of monitoring for adverse reactions
- Methods of assessing and ensuring adherence to the treatment
- Methods for evaluating treatment response

A specific treatment and monitoring plan should be developed for each TB patient.

For more information about developing a treatment and monitoring plan, refer to *Module 4, Treatment of Latent Tuberculosis Infection and Tuberculosis Disease*. For detailed information on treating TB, refer to the *ATS, CDC, and IDSA Treatment of Drug-Susceptible Tuberculosis Guidelines*.

Adherence to Treatment

Helping patients adhere to and complete TB treatment is a key component of case management. **Adherence to treatment** means following the recommended course of treatment by taking all medications as prescribed, for the entire recommended time. **Nonadherence** is a patient's inability or refusal to take TB drugs as prescribed.

Examples of nonadherent behavior include

- Taking medications inconsistently
- Missing clinic appointments
- Missing DOT appointments
- Refusing medications

Nonadherence to treatment for TB disease can lead to serious consequences such as acquired drug resistance, an increase in the severity of illness, ongoing TB transmission, and even death. (For more information on drug resistance and treatment, refer to *Module 4, Treatment of Latent Tuberculosis Infection and Tuberculosis Disease.*)

It is also important that persons with LTBI adhere to the prescribed treatment regimen. Completion of LTBI treatment can prevent the development of TB disease.

Adherence to treatment means following the recommended course of treatment by taking all medications as prescribed, for the entire recommended time.

Explaining the Importance of Adherence

As part of patient education, health care workers should explain the importance of why people with TB disease need to take their medicine. Health care workers should explain how adhering to TB treatment is good for the patient and for others. For example, adhering to treatment can help a patient feel better sooner, cure their TB, and help them return to normal activities. Likewise, a patient's adherence to treatment can prevent the further spread of TB to others.

Health care workers should explain to the patient that some people have trouble staying on the medication schedule. The health care worker should help patients identify and address potential adherence problems. Patients are more likely to be adherent if they help make the decisions and choose solutions rather than being told what to do. For example, the health care worker can ask the patient to provide feedback on the site and time for DOT. Patients are more inclined to pay attention to information that is relevant to their needs and does not require abrupt changes in their behavior.

The health care worker should help patients identify and address potential adherence problems.

Parents of children and adolescents with TB disease should be educated about TB and the importance of adherence. Additionally, parents should be educated about the problems their children might have during TB treatment and possible solutions. Children may resist taking medications, have adverse reactions to the medications, or have problems swallowing pills. When parents can anticipate possible problems that may come up during their child's treatment, they can cope with and help solve problems as they arise.

Why Are Some Patients Nonadherent?

Each patient is unique, and there are many reasons why a patient might be unable or unwilling to complete TB treatment. Some patients may face **barriers**, which can prevent them from adhering to TB treatment. Many health care workers think they know which patients will be adherent; however, there is no way to predict who will take their medicine correctly or not.

Below are some reasons why patients may be nonadherent to TB treatment.

Improved or No Symptoms

TB symptoms can improve dramatically during the first 2 months of treatment. When patients no longer feel sick, they sometimes stop taking their TB drugs. However, unless patients continue treatment for at least 6 months, some tubercle bacilli may survive, putting patients at risk for a relapse of TB disease and the development of drug resistance.

In addition, people with LTBI do not have symptoms; therefore, they may not see treatment for LTBI as a priority since they are not sick.

Lack of Knowledge

Patients sometimes do not fully understand the treatment regimen, how to take their drugs, or the reasons for the long duration of TB treatment. This lack of knowledge can lead to an inability or lack of motivation to complete treatment.

Cultural Beliefs

Some patients have strong personal or cultural beliefs about TB disease (including what causes the disease, how it is transmitted, and who is affected), how it should be treated, and who they should go to for help. When TB is diagnosed or TB treatment conflicts with these beliefs, patients may display a variety of behaviors, such as becoming fearful, anxious, or alienated from their health care workers.

Language Barriers

When a patient and the health care worker do not speak the same language, it can lead to problems with adherence. Health care workers should try to accommodate this language barrier through various means, including the use of an interpreter.

Lack of Access to Healthcare

Lack of access to healthcare can also be a barrier to successfully completing TB treatment. For example, patients may have work schedules that conflict with clinic hours or lack transportation to the clinic.

Poor Relationship between the Patient and the Health Care Worker

When patients and health care workers fail to establish a trusting relationship, this can negatively affect patient adherence. If a patient develops trust with the health care worker, he or she may be more likely to follow instructions and to cooperate. Patients may also be more likely to bring questions and concerns to the health care worker's attention.

Competing Priorities

Some patients have many competing priorities in their lives such as familial obligations, legal issues, substance abuse, homelessness, or other diseases (e.g., HIV). Because of these competing priorities, taking TB medication may not be considered a priority to them.

Stigma

Patients may fear job loss, stigmatization, or being ostracized by their family, spouse, or community. As a result, they may deny their diagnosis and refuse treatment.

Mental Health

Patients' mental health issues, including addiction, can adversely impact TB treatment adherence and completion, as well as successful contact investigation.

Above are some of the reasons why patients may be nonadherent. It is important to keep in mind that any patient can have problems with adherence. The more the health care worker knows about the patient, the better he or she will be able to understand and address the patient's potential adherence problems. Each patient is different and may require different approaches to ensure adherence.

It is important to keep in mind that any patient can have problems with adherence.

Study Questions 6.9 – 6.11

6.9 What is adherence to treatment?

6.10 What are four serious consequences that can result when a patient with TB disease is nonadherent?

6.11 Give eight reasons why a patient might be nonadherent.

Answers to study questions are on pages 80–87

Providing Directly Observed Therapy (DOT)

What is DOT?

DOT is the most effective strategy for ensuring patients take their medicine correctly. It is recommended as a standard of care worldwide. DOT means that a health care worker or other designated individual watches the patient swallow every dose of the prescribed drugs. DOT can reduce the development of drug resistance, treatment failure, or relapse after the end of treatment. Good patient-centered case management, which includes establishing a relationship with the patient and addressing barriers to adherence, facilitates successful DOT.

DOT is the most effective strategy for ensuring patients take their medicine correctly.

DOT visits can also be an opportunity to include a number of other case management functions, such as

- Helping patients keep appointments
- Monitoring for adverse side effects of the medication
- Providing effective education
- Offering incentives and enablers to encourage adherence
- Providing social services

For example, some health departments provide an array of services, such as help in finding housing for homeless patients; or providing specially trained community service aides, transportation to clinics, and delivery of drugs to the patient's home, workplace, or other convenient site.

Who Should Receive DOT?

DOT is the preferred treatment strategy and should be considered for all patients because it is impossible to predict which patients will be adherent. Even patients who intend to take their medicine might have trouble remembering to take their pills every time.

DOT is the preferred treatment strategy and should be considered for all patients because it is impossible to predict which patients will be adherent.

DOT should be used for all children and adolescents with TB disease. Even when drugs are given by DOT, adherence to and tolerability of the regimen must be monitored closely. Parents should not be relied on to supervise DOT.

DOT is highly recommended for patients on intermittent regimens (e.g., patients receiving treatment three times a week).

Other persons who should be considered a high priority for receiving DOT include

- Patients with drug-resistant TB
- Patients with positive sputum smears
- Patients with delayed culture conversion
- Patients with treatment failure or relapse
- Patients with HIV infection
- Persons at high risk for nonadherence, such as
    - Persons experiencing homelessness or persons with unstable housing
    - Persons who abuse alcohol or use illicit drugs
    - Persons who are unable to take pills on their own due to mental, emotional, or physical disabilities
    - Children and adolescents
    - Persons with a history of nonadherence
- Residents at correctional or long-term care facilities
- Patients who have been previously treated for TB disease or LTBI

DOT for Latent TB Infection Treatment

DOT for LTBI treatment should be considered for persons who are at especially high risk for TB disease and are either taking an intermittent regimen or are suspected of nonadherence. Persons who are at high risk for TB disease include young children, persons living with HIV/AIDS, and other immunosuppressed persons.

DOT for LTBI treatment should be considered for persons who are at especially high risk for TB disease and are either taking an intermittent regimen or are suspected of nonadherence.

DOT is especially appropriate if the person in need of LTBI treatment lives with a household member who is on DOT for TB disease, or lives in an institution or facility where treatment for LTBI can be observed by a staff member. Because persons with LTBI have no symptoms, it is very important that they understand the need for medication so that they are motivated to start and finish LTBI treatment.

The use of DOT for LTBI is one strategy that can improve patients' adherence to treatment for LTBI. However, if resources are limited, DOT for TB disease should be prioritized over DOT for LTBI.

Tasks Involved in Delivering DOT

DOT for TB disease and DOT for LTBI involve more than watching the patient swallow each pill. At each DOT encounter, the health care worker should perform the following tasks:

- Check for side effects
- Verify medication
- Watch patient take pills
- Document the visit

Check for Side Effects

Health care workers should ask if the patient is having any adverse side effects at each visit, before the drugs are given. Examples of side effects include fever, rash, vomiting, upset stomach, changes in eyesight or hearing, yellow skin or eyes, aching joints (see *Module 4, Treatment of Latent Tuberculosis Infection and Tuberculosis Disease* for more information on potential side effects of treatment). If the patient has symptoms of serious adverse reactions, a new drug supply should not be given; the patient should stop taking medication immediately. The health care worker should tell their supervisor that the drugs were not given and notify the prescribing clinician about the adverse reaction. The health care worker should arrange for the patient to see the clinician as soon as possible.

Verify Medication

Each time DOT is delivered, the health care worker should verify that the right drugs are delivered to the right patient, and that he or she has the correct amount of medication. If this cannot be confirmed, the drugs should not be given to the patient. The supervisor should be contacted for clarification.

Watch Patient Take Pills

Health care workers should watch for techniques some patients may use to avoid swallowing medication. Some patients may hide pills in their mouth and spit them out later, hide medicine in clothing, or vomit the pills after the DOT visit. The health care worker or the patient should get a glass of water or other beverage before the patient is given the pills. The health care worker should watch the patient continuously from the time each pill is given to the time he or she swallows it. If it is necessary to make sure that the patient swallows the pills, the health care worker may have to check the patient's mouth, or ask the patient to wait for a half hour before leaving so the medication can dissolve in the patient's stomach. Medication should not be left for the patient to take on his or her own unless self-administered therapy has been prescribed for non-DOT days, such as weekends.

Document the Visit

The health care worker should document each visit with the patient and indicate whether or not the medication was given. If the medicine was not given, the reason and follow-up plans should be included. Instances of nonadherence should be documented. It is important to correct any interruption in treatment as soon as possible. Figure 6.2 is a sample form used to monitor and document a patient's DOT.

At each DOT encounter, the health care worker should check for side effects, verify medication, watch the patient take pills, and document the visit.

CLIENT NAME:		DATE OF BIRTH: / /	AGE:
SSN#:	STATE CASE#:	CITY/COUNTY CASE#:	
DIAGNOSIS:	SPECIAL ATTENTION REQUIRED: (EXPLAIN)		
ADDRESS:			
OTHER LOCATION INFO:		TELEPHONE:	
DOT START:		DOT INCENTIVE:	
DOT DISCONTINUED:		DOT SITE:	
CLINICIAN:		HEALTH CARE WORKER:	

Drug	INH					Signature of person observing or giving medicine	Time medicine observed	Comments
Dosage								
Date								
1								
2								
3								
4								
5								
6								
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MEDS TAKEN (NUMBER OF DAYS):_____/ AVAILABLE DAYS:_____ = _____% ADHERENCE

Figure 6.2 Sample DOT form.

Delivering DOT in the Clinic and the Field

DOT can be given anywhere the patient and health care worker agree upon, provided the time and location are convenient and safe. It is important that the location is convenient for the patient. **Clinic-based DOT** is delivered in a TB clinic or comparable healthcare facility (Figure 6.3). When a patient cannot easily get to the TB clinic, the health care worker must go to the patient. DOT delivered in a setting outside of the TB clinic or healthcare facility is called **field-based DOT** (Figure 6.4 and Figure 6.5). Field DOT can be given at almost any site:

- Patient's home
- Patient's workplace
- Public park or other agreed-upon public location
- School
- Restaurant
- Church

DOT can be given anywhere the patient and health care worker agree upon, provided the time and location are convenient and safe.

Figure 6.3 Clinic-based DOT.

Figure 6.4 Field-based DOT in the patient's home.

Figure 6.5 Field-based DOT at an agreed-upon public location.

DOT is usually given by TB clinic personnel such as an outreach worker, nurse, or other health care worker. Sometimes staff at other healthcare settings, such as outpatient treatment centers, can be asked to give DOT to a patient who can travel to an alternative healthcare setting more easily than to the TB clinic.

Likewise, staff may choose a person other than a health care worker to watch the patient take medicine. Family members should NOT be responsible for watching the patient take medicines. Because of strong emotional ties, the family may be unwilling

to ensure the patient takes treatment if he or she refuses treatment. However, other persons—such as school or employee health nurses, clergy, or other responsible persons who do not have strong emotional ties with the patient—can provide DOT, if the patient agrees to this arrangement. These arrangements must be approved in advance by supervisory clinical and management staff and should be monitored closely to ensure there are no problems.

Family members should NOT be responsible for watching the patient take medicines.

Regardless of the arrangement, it is always important to protect the patient's confidentiality. For example, the patient may not want the health care worker to tell neighbors why he or she is visiting. If home visits create confidentiality problems, the health care worker and the patient should work together to identify another location. (For more information on confidentiality, refer to *Module 7, Patient Rights and Confidentiality in Tuberculosis Control.*)

Another critical consideration for conducting field DOT is the health care worker's own safety. Health care workers should become familiar with policies and recommendations of local law enforcement agencies and health department administration regarding personal security. Current information on local high-risk areas for crime can be very valuable in planning and conducting safe field visits. (For more information on safety in the field, refer to *Module 8, Contact Investigations for Tuberculosis*.)

Electronic DOT (eDOT)

Electronic DOT (eDOT) is an alternative method to in-person DOT in which a patient is remotely observed (e.g., over a smartphone, tablet, or computer) taking his or her TB medication. eDOT can be either real-time or recorded. During a real-time eDOT visit, the health care worker and the patient schedule a specific day and time to meet virtually, and the health care worker watches the patient take his or her medication. In contrast, recorded eDOT is when the health care worker and the patient do not set a specific time to meet, and the patient records himself or herself taking the medications. The patient then saves the recording and sends it to the health department for review. This option may be useful when patient schedules do not align with the health department, and the health care worker is unable to watch the patient live. For more information on eDOT, please refer to *Implementing an Electronic Directly*

Observed Therapy (eDOT) Program: A Toolkit for Tuberculosis (TB) Programs, available on the CDC website (www.cdc.gov/tb).

Advantages and Challenges to DOT

DOT has many advantages, but it also has a few challenges (Table 6.2). When used as a collaborative effort with the patient, the advantages of DOT over self-administered therapy include

- Ensuring that the patient completes an adequate regimen
- Enabling the health care worker to monitor the patient regularly for side effects and response to treatment
- Helping the health care worker solve problems that might interrupt treatment
- Ensuring the patient takes every dose of medicine, which helps the patient become noninfectious sooner

DOT does have a few challenges because it

- Is time consuming*
- Is labor intensive*
- Can be perceived as insulting to some patients
- Can imply that the patient is incapable or irresponsible
- Can be perceived as demeaning or punitive

It is important to explain the benefits of DOT to each patient and stress the fact that DOT is not a punishment; rather, DOT is a highly effective way for the patient and health care worker to collaborate so that the patient will successfully complete an adequate regimen. Health care workers can also inform the patient that DOT is the national standard of practice for the treatment of TB disease.

Table 6.2
Advantages and Challenges to DOT

Advantages	Challenges
▪ Ensures that the patient completes an adequate regimen ▪ Allows the health care worker monitor the patient regularly for side effects and response to therapy ▪ Helps the health care worker solve problems that might interrupt treatment ▪ Helps the patient become noninfectious sooner by ensuring the patient takes every dose of medicine	▪ Time consuming* ▪ Labor intensive* ▪ Can be insulting to some patients ▪ Can imply that the patient is incapable or irresponsible ▪ Can be perceived as demeaning or punitive

*eDOT may not be as time consuming or labor intensive as clinic-based or field-based DOT. For more information on the advantages and challenges of eDOT, please refer to *Implementing an Electronic Directly Observed Therapy (eDOT) Program: A Toolkit for Tuberculosis (TB) Programs.*

Study Questions 6.12 – 6.14

6.12 What is DOT?

6.13 List and explain four tasks that are part of the DOT encounter.

6.14 What are four advantages of DOT?

Answers to study questions are on pages 80–87

Case Study 6.2

You are an outreach worker at a TB clinic and have been assigned to deliver DOT to Mrs. Wilson, a 76-year-old woman who lives alone in the house that she and her husband bought many years ago. Mrs. Wilson was recently released from the hospital. Upon discharge from the hospital, she received education about TB and about the need to take medications until she completes treatment. She was told that she would be started on DOT and a health care worker would visit her at home to help her take her medication. Mrs. Wilson is excited to have some company. She happily offers you cookies and wants to "talk awhile" before she takes her medication.

- **How should you respond to Mrs. Wilson's request to "talk awhile"? How could your reaction affect her adherence?**

Answers to case studies are on pages 88-93

Addressing Barriers to Adherence

Even with education and DOT, some patients may still face barriers to adhering to their treatment. The health care worker should identify the specific reasons why a patient is not being adherent. Different patients will have different reasons. Once a patient's specific set of adherence problems are known, the health care worker can develop an individualized plan of action to overcome the difficulties and promote adherence.

There are several additional strategies health care workers can use to address barriers to adherence:

1. Create an adherence agreement
2. Help patients keep appointments
3. Use incentives and enablers to improve adherence
4. Encourage the patient to seek support
5. Give TB drugs in easy-to-take preparations
6. Coordinate other services

1. Create an Adherence Agreement

For some patients, a formal **adherence agreement**—a written understanding between the health care worker and a patient—may be useful. If many barriers are identified, it may be appropriate to have an adherence agreement at the very beginning of treatment. A sample adherence agreement is presented in Figure 6.6. A patient should write down the activities he or she agrees to carry out (such as taking medicine as prescribed), in return for specific services, activities, or incentives from the health care worker. For some patients, this written commitment increases the likelihood of adherence. The patient should be asked to sign the agreement and be given a copy. The health care worker should review the agreement with his or her patient periodically to assess how well both are doing and make changes as needed.

TB Treatment Agreement

Patient Name: _____ Date: _____
Patient Address: _____ Provider Name: _____

I, _____, understand that I have been diagnosed with infectious pulmonary tuberculosis and have been prescribed medication by a physician to treat this disease. If my disease goes untreated, there may be serious consequences:

- My illness may be longer or more severe
- I may spread TB to others
- I may develop and spread drug-resistant TB
- I can die from TB

The _____ Health Department has the responsibility of seeing that I complete adequate treatment for my tuberculosis and that I do not expose others to danger. To ensure that this happens, the Health Department will:

1. Supply all medication, x-rays, and laboratory testing required to monitor my disease.
2. Provide medical consultation relating to tuberculosis.
3. Make visits _____ to give me medication under supervision and to evaluate for any adverse reactions to the medications.

To complete my treatment and protect my family and friends, I will:

1. Come to the health department clinic to give sputum specimens when requested.
2. Keep all appointments for medical evaluation and x-rays.
3. Be at the agreed-upon location when the health care worker comes to give my medications.

Visit Day(s): _____ Time: _____ Location:_____
If a scheduled visit or appointment falls on a holiday, the health care worker will work with me to make an adjustment in my schedule.

I have read this agreement and understand the following (initial each box):

- ☐ My adherence to this treatment regimen is very important.
- ☐ I am responsible for the three tasks mentioned above.
- ☐ If I fail to complete these tasks, legal action may be taken to make sure I complete treatment.

Signed: _____ Date: _____

Health Department Representative
Signed: _____ Date: _____

Figure 6.6 Sample adherence agreement.

2. Help Patients Keep Appointments

Throughout the course of treatment, TB patients will have many appointments they need to keep, such as DOT encounters and clinic visits. For a variety of reasons, some patients may have difficulty keeping all of these appointments.

To help patients remember scheduled visits, health care workers can give patients an appointment card or calendar. If the patient has a home address, the health care worker can send a reminder postcard. If the patient has a telephone, the health care worker should call the patient to remind them of the scheduled appointment. Using telephone reminders gives the health care worker an opportunity to counsel the patient and help the patient solve scheduling and transportation problems or other barriers to adherence. Health care workers should be aware of confidentiality issues when leaving telephone messages for TB patients. (For more information, refer to *Module 7, Patient Rights and Confidentiality in Tuberculosis Control*.)

If a patient fails to keep an appointment, the health care worker should immediately call or text the patient to find out why he or she missed the appointment. If the health care worker is unable to reach the patient, he or she should visit the patient at home. Once the health care worker reaches the patient, he or she should counsel the patient and attempt to identify and solve problems that interfere with appointment keeping. If the patient repeatedly misses appointments, the health care worker may need to try several different strategies, such as discussing the matter with the other health care team or providing incentives or enablers.

If a patient fails to keep an appointment, the health care worker should immediately call or text the patient to find out why he or she missed the appointment.

3. Use Incentives and Enablers

Incentives are small rewards given to patients to encourage them to either take their own medicine or keep their DOT appointments. Incentives should be chosen according to the patients' special needs and interests. Incentives are usually used on an ongoing basis– weekly, monthly, or when key milestones are reached.

When offering incentives, health care workers should make a verbal or written agreement with the patient. For example, be clear that if the patient keeps all DOT

appointments, they will receive the agreed-upon incentive. If the patient does not keep their end of the agreement, health care workers should withhold the incentive and kindly but firmly explain why the incentive was not given and what the patient needs to do to receive it.

Enablers are things that make it possible or easier for patients to receive treatment by overcoming barriers, such as a lack of transportation to get to the clinic. Health care workers should identify barriers that interfere with the patient's ability to adhere to treatment and provide an enabler that will help overcome that specific barrier. For example, if the health care worker knows that transportation is a problem, he or she could offer bus tokens, bus fare, or taxi fare as an enabler. Figure 6.7 shows examples of incentives and enablers.

Incentives and enablers are not "bribes." Incentives should be used to motivate and must not be used as coercion. Furthermore, using incentives and enablers should not necessarily be routine or "automatic" for all TB patients. Not everyone needs this type of help to finish treatment.

Sources of Incentives and Enablers

Programs can obtain incentives and enablers from many different sources. Possible sources for obtaining incentives and enablers include

- The state or local American Lung Association chapter
- Community organizations, such as church groups
- Businesses that can donate items such as food or food coupons or gift vouchers
- Volunteers who can contribute goods and services, such as baked goods or childcare
- TB program staff who are willing to devote extra time and attention

Table 6.3 is a list of examples of incentives and enablers.

Table 6.3
Examples of Incentives and Enablers

Money
- Gift cards

Food
- Nutritional supplements
- Fast food
- Sandwiches
- Canned food
- Food vouchers
- Fruit
- Ice cream

Beverages
- Juices
- Milk
- Coffee
- Tea

Clothing
- Socks
- Gloves
- Stockings
- Sweaters
- Coats/Scarves
- Shoes

Automotive
- Battery
- Gasoline
- Motor oil

Fishing supplies
- Fishing pole
- Crickets

Services
- Social service referrals
- Help in obtaining housing, social security, food stamps
- Help in obtaining drug treatment
- Help in paying rent
- Help in obtaining other medicines
- Child care
- Legal services
- Help in obtaining birth certificate
- Help in obtaining driver's license
- Repairing bicycle

Household
- Paying rent or mortgage
- Cooking utensils
- Furniture
- Pre-paid cell phone
- Cell phone minutes or data

Transportation
- Bus and subway fare
- Taxi fare
- Bicycle
- Transportation provided by staff

Seasonal
- Special seasonal treats
- Homemade holiday cookies
- Food baskets
- Birthday cakes and cards

Personal care
- Toiletries
- Contraceptives (e.g., condoms)
- Razors
- Shaving cream
- Face cream
- Makeup
- Nail polish

Garden
- Flowers
- Flower bulbs

For children
- Toys
- Books
- Painting child's nails
- Tea party
- Playing games
- Stuffed animals
- Grab bag with assorted treats
- Chewing gum
- School supplies
- Crossword puzzle books

Source: Adapted from Using Incentives and Enablers in the Tuberculosis Control Program. Columbia: American Lung Association of South Carolina and South Carolina Department of Health and Environmental Control, Division of Tuberculosis Control, 1989.

Figure 6.7 Examples of incentives and enablers.

4. Encourage the Patient to Seek Support

The support of family, friends, and others can be important to patients trying to complete treatment. Some health departments may use former TB patients as peer workers to support patients currently going through TB treatment. The health care worker should ask his or her patients to identify persons who support their TB treatment and can help them remember to take medications or keep their DOT appointments. However, the health care worker should remember that they are ultimately responsible for ensuring the patient completes treatment.

The support of family, friends, and others can be important to patients trying to complete treatment.

Persons who may be able to support the patient throughout treatment include

- Family members
- Friends
- Teachers
- Social workers
- Clergy
- Neighbors
- Peer educators

With the patient's permission, family members, friends, or others may be included in educational sessions so that they also understand the patient's diagnosis, and what the patient needs to do. Educating a patient's family and friends also helps to reduce TB stigma.

5. Give TB drugs in Easy-to-Take Preparations

Particularly with children, it can be helpful to give TB drugs in easy-to-take preparations. For example, isoniazid (INH) and pyrazinamide (PZA) pills can be crushed and given with small amounts of food, such as apple sauce or yogurt. Some patients may find it difficult to take multiple pills at once. Health care workers should check with the patient's clinician about the option of using combined capsules or liquid medication.

Particularly with children, it can be helpful to give TB drugs in easy-to-take preparations.

6. Coordinate Other Services

The health care worker may identify problems other than TB that patients are struggling to overcome. These problems may include other medical conditions, inadequate housing, poverty, mental health issues, family dysfunction, or substance abuse. Unless these problems are addressed, patients may have serious barriers that prevent them from adhering to the prescribed regimen and keeping clinic appointments.

When patients have other issues, the health care worker has an opportunity to help them by providing appropriate referrals for support and assistance. By helping patients with these other issues, providers and public health workers are also helping patients complete TB treatment successfully. Table 6.4 presents some examples of the service providers the public health worker may want to contact for eligible patients. Relationships with such providers can often be improved by means of formal referral agreements and educational sessions for staff about TB, including information on services the TB program has to offer.

When patients have other issues, the health care worker has an opportunity to help them by providing appropriate referrals for support and assistance.

In some cases, the patient and his or her family may already be receiving visits from social workers or public health nurses for other conditions or problems. If this is the case, the team should coordinate efforts. By helping to coordinate care provided to a single patient, the public health worker can often improve patient adherence and maximize the use of public health resources.

Table 6.4
Service Providers with Benefits for Eligible TB Patients

Service Provider	Examples of Benefits Available to Qualified Persons
Public health nursing services	▪ Integrated home healthcare ▪ Public health clinic services ▪ Patient incentives
HIV/AIDS services	▪ HIV testing, counseling, and treatment programs ▪ Patient support groups ▪ Meal programs
Housing services	▪ Temporary shelter ▪ Location of available housing options
Social services	▪ Food stamps ▪ Medicaid ▪ Unemployment or disability support
Emergency assistance programs	▪ Shelter for battered women ▪ Placements for victims of child abuse
Substance abuse treatment programs	▪ Detoxification programs ▪ Methadone treatment programs and other medication-assisted treatment programs
Mental health services	▪ Counseling ▪ Psychiatric care

Service Provider	Examples of Benefits Available to Qualified Persons
Medical services	▪ Medicaid ▪ Low income clinics

Table 6.5 provides additional methods for overcoming specific barriers to adherence.

Table 6.5
Methods to Overcome Adherence Barriers

Barriers to Adherence	Examples of Methods to Overcome Adherence Barriers
Lack of knowledge	■ Assess patient's knowledge, beliefs, and feelings about TB ■ Use health education, provide written materials
Forgetfulness	■ Get help from family or friends ■ Simplify the regimen or use combination pills ■ Link pill taking with other activities ■ Provide special pill dispensers and memory cues ■ Send reminder text message or phone call ■ Use DOT
Lack of motivation	■ Point out the dangers of nonadherence and benefits of therapy ■ Increase the frequency of visits ■ Provide incentives and set short-term goals ■ Use DOT
Fear of side effects	■ Allow extra time to discuss known side effects ■ Provide reassurance ■ Make staff available to answer questions ■ Use DOT
Lack of skills in pill taking	■ Demonstrate correct pill taking ■ Have the patient practice with guidance ■ Use DOT
Lack of support from family or friends	■ Make home visits ■ Encourage family or friends to accompany patient on clinic visits ■ Use DOT

Poor relationship with the health care worker	■ Develop communication skills of staff ■ Be accessible throughout care ■ Work on staff attitudes about patients and DOT ■ Provide cultural competency training for staff ■ Change health care workers ■ Provide social services
Lack of money to pay for healthcare	■ Provide free care, facilitate third-party payment ■ Refer to social worker
No sick leave available	■ Provide clinic appointments during off hours ■ Use DOT at work site or nearby location
Long clinic waiting time	■ Keep to scheduled appointment times ■ Make efficient use of patient visits ■ Have separate appointments for drug refills
Other medical conditions or physical limitations	■ Use a home health nursing service ■ Use DOT
Complex regimen	■ Simplify the regimen ■ Associate the regimen with other activities ■ Use combined capsules ■ Use DOT
Medication side effects	■ Take medication before or after meals, as indicated ■ Evaluate medication options ■ Change drugs or dosages

Study Questions 6.15 – 6.17

6.15 What is a formal adherence agreement?

6.16 What are incentives and enablers?

6.17 Describe at least three strategies health care workers can use to address barriers to adherence.

Answers to study questions are on pages 80–87

Case Study 6.3

Mr. Sivaraman is a recent immigrant from India who is working two jobs to support his wife and three children. He has been on DOT for two months and his TB symptoms have greatly improved. Mr. Sivaraman has kept daily DOT appointments with the health care worker, but recently has missed two appointments and skipped his last clinic visit.

- **What do you know about Mr. Sivaraman's history that might lead to nonadherence?**

- **What steps can the health care worker take to help Mr. Sivaraman keep his appointments and adhere to treatment?**

Answers to case studies are on pages 88–93

Legal Remedies to Nonadherence

Patients who are unwilling or unable to adhere to treatment may be required to do so by law or may be isolated until noninfectious. State governments have legal responsibility for TB control activities, including treatment protocols for nonadherent patients; the health care worker should refer to the laws in his or her state for those procedures as TB control laws vary considerably from state to state. Health care workers should notify the appropriate supervisory clinical and management staff when patients are repeatedly nonadherent.

Patients who are unwilling or unable to adhere to treatment may be required to do so by law or may be isolated until noninfectious.

Progressive Interventions

State and local TB control programs should have a treatment plan that goes step-by-step from voluntary participation to involuntary confinement as a last resort (Figure 6.8). The plan should begin with learning the possible reasons for nonadherence and addressing the identified problems using methods such as DOT, incentives and enablers, and an adherence agreement. The patient should be told verbally and in writing of the importance of adhering to treatment, the consequences of failing to do so, and the legal actions that will have to be taken if the patient refuses to take medication.

If the patient does not adhere to DOT voluntarily, the next step may be court-ordered DOT. **Court-ordered DOT** is DOT that is administered to a patient by order of a public health official or a court with the appropriate authority. It is used when patients have been nonadherent despite the best efforts of TB program staff. It can be successful in convincing a patient that his or her TB treatment is an important public health priority. Figure 6.9 is an example of a letter given to patients who demonstrate nonadherent behavior and who may be candidates for legal action.

Court-ordered DOT can be successful in convincing a patient that his or her TB treatment is an important public health priority.

TB control programs should not begin procedures for confining patients to a treatment facility until after the patient has shown that he or she is unable or unwilling to follow a treatment regimen implemented outside such a facility. Involuntary confinement or isolation for inpatient treatment should be viewed as the last step. Confinement can be either in a hospital or in some other institution with TB isolation facilities. An order to confine a patient should require that he or she be isolated until no longer a public health threat.

Involuntary confinement or isolation for inpatient treatment should be viewed as the last step.

When deciding whether to legally confine a TB patient to protect the public, local health officials must decide whether the person is at real risk of infecting others (now or in the future). To determine this risk, these factors need to be considered

- Laboratory results (i.e., sputum smears and cultures)
- Clinical signs and symptoms of infectious TB
- An abnormal chest x-ray, especially if cavities are present
- A history of nonadherence
- The opportunity to infect others

Throughout the process, there must be detailed documentation of the patient's nonadherence and the steps taken to address it. Although nonadherence laws are available in some areas, they may be hard to enforce and should be used only when all other measures have failed. When legal steps are taken, the health care worker must make sure that the patient's rights are protected; patients undergoing these procedures should have legal counsel.

Throughout the process, there must be detailed documentation of the patient's nonadherence and the steps taken to address it.

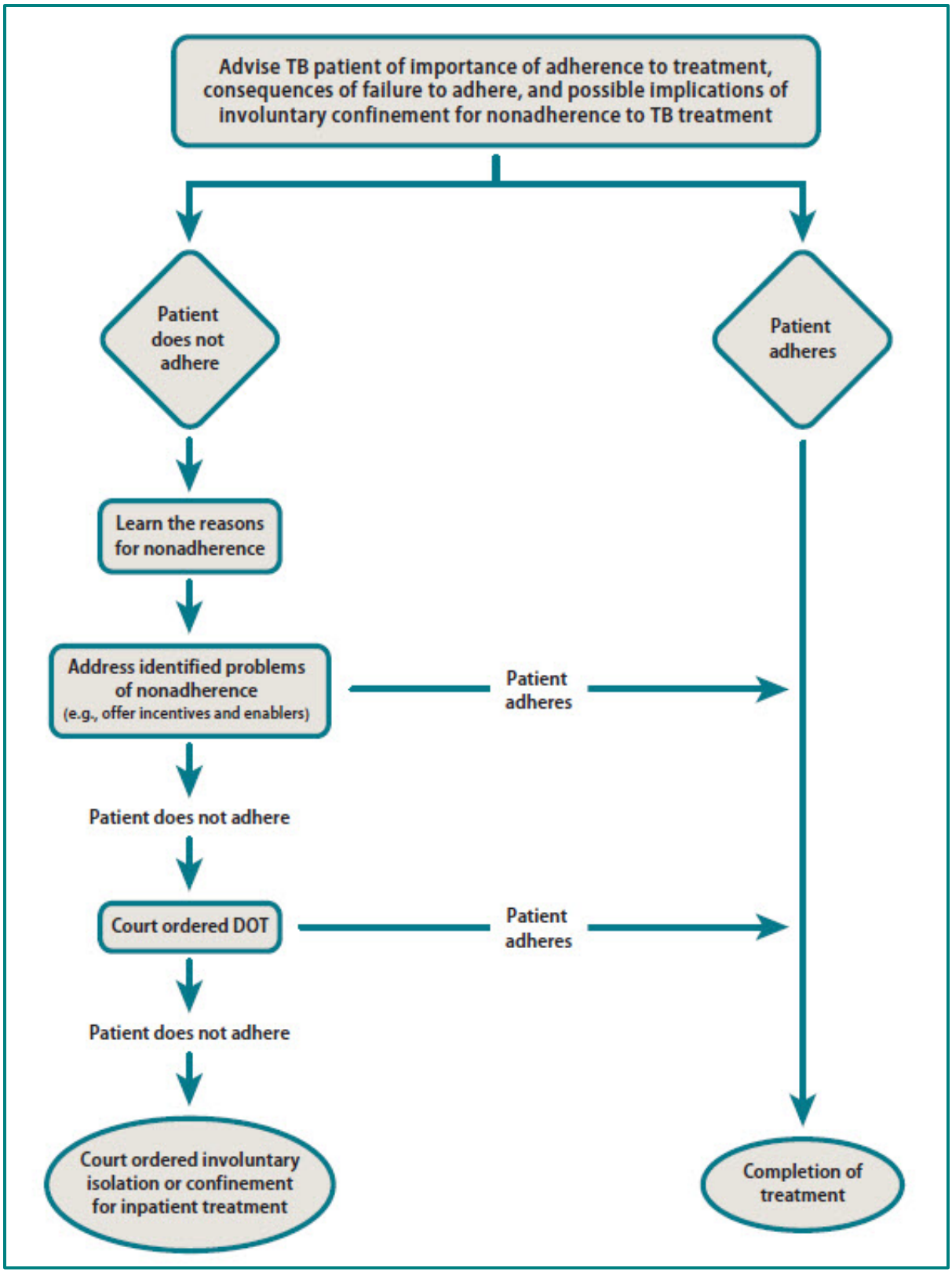


Figure 6.8 Example of progressive intervention for nonadherent patients to a TB treatment plan.

Tuberculosis Program

September 30, 2013

John Doe
Route 1 Box 000
City, State 88888

Dear Mr. Doe:

You have been found to have infectious tuberculosis (TB) of the lungs. If you do not take the medicine prescribed for you to treat this disease, you present a serious public health problem. You can spread germs to other people and may make them sick.

The health department nurses have attempted to help you take your medicine, but you have not cooperated with them. The law in this state says you can be taken to court and the judge will order you to take your medicine. If you still do not cooperate and take your TB medicine, the judge will order you to be taken to the state hospital where you will remain confined until you have completed your treatment for TB.

It is not our desire to have you confined to the state hospital. However, if you do not take your medicine, we have no choice. We will use the public health laws to protect other people from getting sick with TB.

The health department nurse will contact you next week. We suggest that you take your medicine as has been prescribed by the doctor. If you do not do this, the health department will start legal action immediately.

If you would like to talk with me about your disease and the reasons why you must take your medicine, please call me at (123-456-7890)

Sincerely,

Joe Smith, M.D.
District Medical Director

Figure 6.9 A sample letter given to patients who demonstrate nonadherent behavior and who may be candidates for legal action.

Study Questions 6.18 – 6.19

6.18 Describe the progressive interventions that should be attempted before a court orders involuntary confinement.

6.19 List the criteria for deciding if a patient should be confined.

Answers to study questions are on pages 80–87

Case Study 6.4

Walter is a 50-year-old male who was diagnosed with TB one month before he was released from prison. The prison doctor called the health department to report the case and asked them to take over managing Walter's TB treatment upon his release. The case manager assigned a health care worker to work with Walter. The health care worker met with Walter while he was still in prison and set up a plan to continue DOT upon Walter's release.

For the first two weeks after his release, Walter adhered to treatment. He then began missing appointments at the arranged DOT site and at the clinic. The health care worker offered to meet Walter in other locations for DOT. He also provided incentives and enablers.

When Walter continued to miss appointments, the health care worker called and texted Walter to discuss the missed appointments. Unable to reach Walter via phone, the health care worker then went to Walter's house. Walter became agitated and stated that he feels "okay" and does not like the health care worker "harassing" him in front of his friends. The health care worker documented all of his efforts to get Walter to adhere to treatment.

- **What should the health care worker do next?**

Answers to case studies are on pages 88–93

Quality Assurance in Case Management

To ensure appropriate care and treatment for each patient, a variety of **quality assurance** activities should take place throughout the case management process. Quality assurance is the review and evaluation of the quality of care per established protocols and the effectiveness of the TB program. In quality assurance, problems are identified, prioritized, and addressed. Quality assurance should be continuous and ongoing. Case management is never complete without quality assurance.

Quality assurance should be continuous and ongoing.

Quality assurance activities include:

- Documentation
- Case review
- Cohort review

Documentation of all steps in the case management process is essential. The case manager must ensure that documentation is completed regularly by all members of the case management team. All interventions should be documented in a clear and concise manner to ensure continuity of care, particularly if different providers are involved. The case manager should remember the cardinal rule of documentation "If it isn't documented, it didn't happen."

Case review is the systematic, regular review of a patient's progress by the case management team. Case reviews should be weekly and real-time. Case reviews conducted in real time assist in identifying and resolving problems early and prevents a patient from "slipping through the cracks." For example, during the first week after a pulmonary case is reported, it is important to review the patient's progress to ensure that sputum smear and culture tests have been ordered and results are documented in the patient record.

Cohort review is the systematic review of the management of TB patients and their contacts. A "cohort" is a group of TB cases counted over a specific period of time, usually 3 months. Cohorts are typically reviewed 6 to 9 months after being reported.

Case managers are expected to prepare information on each case, present the information at the cohort review session, and follow-up on suggestions made at the cohort review session. Table 6.6 lists some of the differences between case review and cohort review. Please refer to CDC's *Understanding the TB Cohort Review Process: An Instruction Guide* for more information on how to conduct a cohort review.

Table 6.6
Differences between Case Review and Cohort Review

Case Review	Cohort Review
Weekly	Quarterly; biannually
Real time, ongoing review of single patient management and care issues	Retrospective review of ALL counted TB patients and contacts during specified time period
Monitor individual patient progress and treatment outcome	Monitor group progress toward treatment outcomes
Identify patient care issues	Identify programmatic issues

Other TB Control Practices to Complete

It is important that TB programs ensure that appropriate TB control practices are completed for the patient, including:

- A contact investigation is performed
- TB genotyping results are obtained

Performing a Contact Investigation

A contact investigation is required for all confirmed cases that have infectious forms of TB disease (e.g., TB disease of the lungs, airway, or larynx). Patients who have noninfectious forms of TB disease do not require a contact investigation (e.g., TB disease in the brain, the kidneys, or the bones and joint). In most health departments, a case manager is responsible for ensuring that a contact investigation is completed for the patient, if necessary. A contact investigation is a systematic process to:

- Identify persons (contacts) exposed to a person with infectious TB disease;
- Assess contacts for infection with *M. tuberculosis* and TB disease; and
- Provide appropriate treatment for contacts with LTBI or TB disease.

For more information about initiating and performing TB contact investigations, refer to *Module 8: Contact Investigations for Tuberculosis*.

Obtaining TB Genotyping Results

TB **genotyping** is a laboratory-based method that can determine the genetic pattern of the strain of *M. tuberculosis* that caused TB disease in a person. Each strain has a distinct genetic pattern, or **genotype**. Genotyping is done for culture-positive cases of TB disease. TB programs should work with laboratories to ensure that TB genotyping results are obtained for all culture-positive cases they are assigned. At the local level, this typically requires ensuring that the isolate has been sent to the State Health Department or the State Laboratory. For case managers at the state level, this typically requires ensuring that the isolate has been sent to the appropriate genotyping laboratory. This process may vary by jurisdiction.

TB programs should work with laboratories to ensure that TB genotyping results are obtained for all culture-positive cases they are assigned.

In the United States, genotyping information on individual cases is available to state and local health departments through the **TB Genotyping Information Management System (TB GIMS)**, a secure online national database of genotyping and case information. Local health departments obtain access to genotyping data in various ways, usually either through TB GIMS directly or from the state TB program.

Applications of Genotyping

Genotyping has applications at both the population level and the individual patient level. At the population level, genotyping is most commonly used for detecting, refuting, and monitoring TB outbreaks. For more information about the use of genotyping in TB outbreaks, refer to *Module 9, Tuberculosis Outbreak Detection and Response*.

At the patient level, TB genotyping has three uses:

- Distinguishing relapse from reinfection
- Detecting false-positive culture results
- Conducting contact investigations

Distinguishing Relapse from Reinfection

Some patients previously treated for TB disease may develop TB disease again. This could be due to a relapse or reinfection. Genotyping results can be used to distinguish relapse from reinfection.

Recurrence of TB disease after treatment is generally known as a relapse of TB disease. Relapse can occur for several reasons including inappropriate treatment, nonadherence to treatment, or unidentified drug resistance. If genotype information from the first episode of TB is available, it can be compared with genotype information from the second episode. If the genotypes match, it is likely the TB disease was not completely cured the first time it was treated.

If the genotypes from the two episodes of TB disease do not match, it is likely the second episode occurred because the person became infected with a different strain of *M. tuberculosis* (reinfection).

Detecting False-Positive Cultures

Genotype information can alert laboratory and public health staff to situations where specimens from different patients, processed within the same facility and time period, share genotypes. When this situation occurs, the laboratory can follow a process to determine if an error has been made, and one or more of the cultures are falsely positive. False-positive TB cultures can be caused by cross-contamination of a specimen in the laboratory, clerical error such as mislabeling of specimens, or contaminated equipment such as a bronchoscope used to collect the samples.

Identifying false-positive cultures is important because doing so helps prevent unnecessary treatment and contact investigations for persons who would otherwise be misdiagnosed with TB disease.

Conducting Contact Investigations

Typically, genotype information will not be available during the early stages of a contact investigation; however, when it is available, genotype results can help confirm, disprove, or detect connections among patients. If two patients have matching genotypes, they might be connected even if the connection is not recent or obvious. For example, two persons whose TB strains match by genotype may not know one another, but they might have both been exposed to the same infectious TB case several years earlier.

At the patient level, TB genotyping can be used for distinguishing relapse from new infection, detecting false-positive culture results, and conducting contact investigations.

Study Questions 6.20 – 6.21

6.20 List three applications of genotyping.

6.21 Explain the difference between a cohort review and case review.

Answers to study questions are on pages 80–87

Inter-Jurisdictional and International Referrals

Inter-Jurisdictional Referrals

Some patients may move to another jurisdiction at some point during their treatment. For example, seasonal migrant farm workers may move between health jurisdictions based on the growing seasons. A patient may move to a health jurisdiction within the same state, to another state, or another country. The public health worker needs to be familiar with the guidelines and case referral processes in their health jurisdiction. This will aid in transferring information on TB patients who move, as well as facilitate follow-up to ensure continuity of care. The end goal is completion of therapy for all TB patients.

The public health worker needs to be familiar with the guidelines and case referral processes in their health jurisdiction in order to transfer information on TB patients who move, as well as facilitate follow-up to ensure TB patients' continuity of care.

When a patient leaves a health jurisdiction before completing TB treatment, patient information should be sent to the health jurisdiction at the patient's destination. The following procedures should be followed:

- Patients who are taking treatment for TB disease should be given (1) a copy of records they can take with them to indicate their current treatment and diagnostic status, and (2) a supply of medications to self-administer during the transition of care. Special care should be taken to instruct these patients on how to take their medications and how and where to get additional medication and medical care at the destination site.
- Patients should be asked to provide their new address and phone number, if known. Patients can also be asked to provide the name and phone numbers of family or friends whom staff in the new jurisdiction could speak with, in order to connect with the patient during or after the move.
- All relevant medical information, including TB laboratory reports, and patient contact information should be forwarded to the destination jurisdiction. Some

jurisdictions use a standard form when referring patients between health jurisdictions. See Figure 6.10 as an example of a referral form.

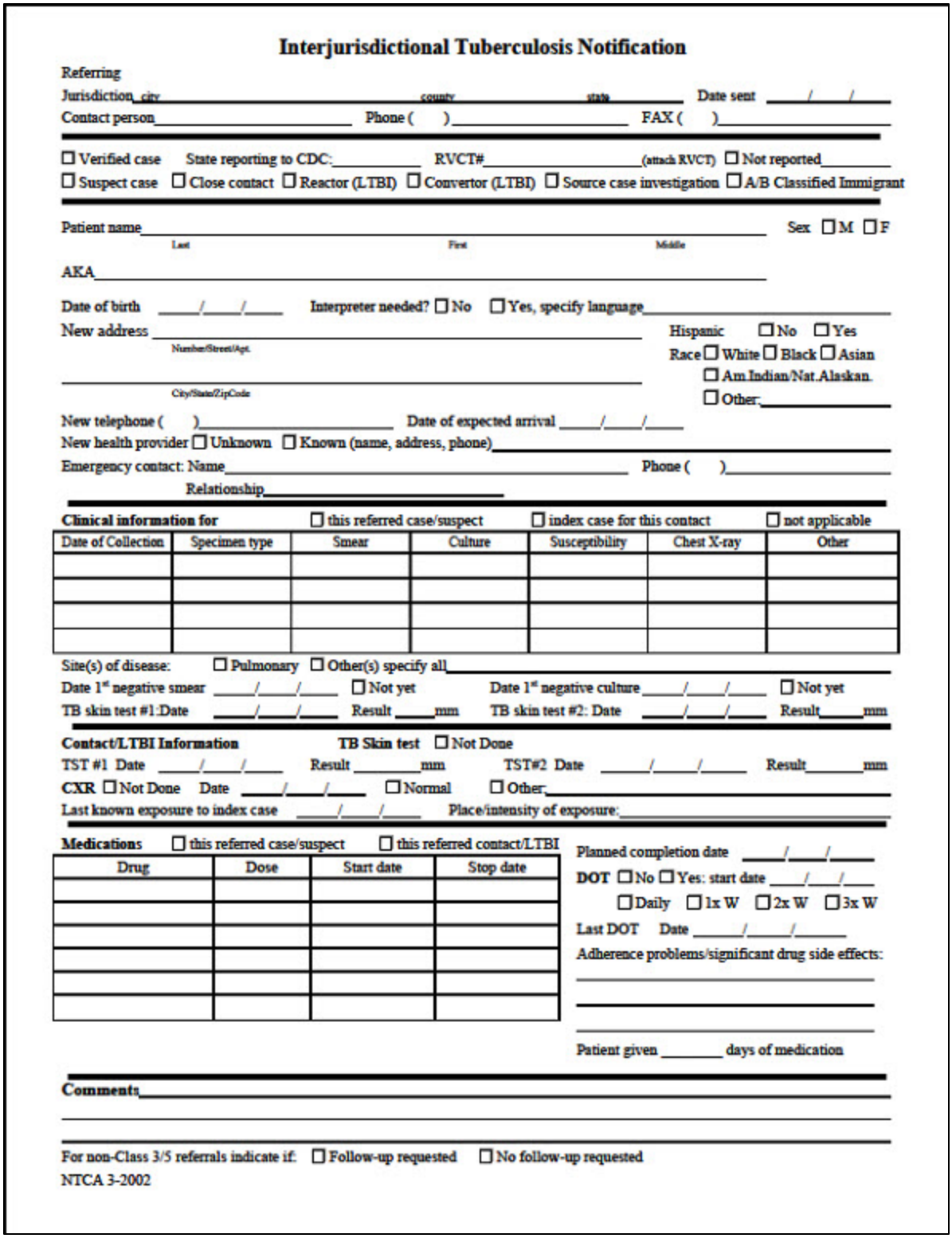
- The state health department TB control officer should be contacted and made aware of the need for follow-up and the next possible destination of the patient.
- Although sharing necessary information between health departments is encouraged to ensure continuity of care, as well as protect the public, measures should be taken to ensure confidentiality.

International Referrals

Some patients under treatment for TB disease in the United States move to another country before completing treatment. To assist in treatment completion and continuity of care, the CDC has developed a process for international notification:

- Notification of TB control personnel in the patient's country of destination
- TB control personnel in that country advise patient to complete treatment
- Patient is advised and educated on the importance of completing treatment

To access the International Tuberculosis Notification Form, visit the CDC website: www.cdc.gov/tb/programs/international/PDF/internat_proces.pdf.



Interjurisdictional Tuberculosis Notification

Referring
Jurisdiction city _____ county _____ state _____ Date sent ____/____/____
Contact person _____ Phone ( ) _____ FAX ( ) _____

☐ Verified case State reporting to CDC: _____ RVCT# _____ (attach RVCT) ☐ Not reported _____
☐ Suspect case ☐ Close contact ☐ Reactor (LTBI) ☐ Convertor (LTBI) ☐ Source case investigation ☐ A/B Classified Immigrant

Patient name _____ Sex ☐ M ☐ F
Last First Middle
AKA _____

Date of birth ____/____/____ Interpreter needed? ☐ No ☐ Yes, specify language _____
New address _____ Hispanic ☐ No ☐ Yes
Number/Street/Apt. Race ☐ White ☐ Black ☐ Asian
☐ Am Indian/Nat Alaskan
City/State/ZipCode ☐ Other: _____
New telephone ( ) _____ Date of expected arrival ____/____/____
New health provider ☐ Unknown ☐ Known (name, address, phone) _____
Emergency contact: Name _____ Phone ( ) _____
Relationship _____

Clinical information for ☐ this referred case/suspect ☐ index case for this contact ☐ not applicable

Date of Collection	Specimen type	Smear	Culture	Susceptibility	Chest X-ray	Other

Site(s) of disease: ☐ Pulmonary ☐ Other(s) specify all _____
Date 1st negative smear ____/____/____ ☐ Not yet Date 1st negative culture ____/____/____ ☐ Not yet
TB skin test #1:Date ____/____/____ Result ____mm TB skin test #2: Date ____/____/____ Result ____mm

Contact/LTBI Information **TB Skin test** ☐ Not Done
TST #1 Date ____/____/____ Result ____mm TST#2 Date ____/____/____ Result ____mm
CXR ☐ Not Done Date ____/____/____ ☐ Normal ☐ Other: _____
Last known exposure to index case ____/____/____ Place/intensity of exposure: _____

Medications ☐ this referred case/suspect ☐ this referred contact/LTBI

Drug	Dose	Start date	Stop date

Planned completion date ____/____/____
DOT ☐ No ☐ Yes: start date ____/____/____
☐ Daily ☐ 1x W ☐ 2x W ☐ 3x W
Last DOT Date ____/____/____
Adherence problems/significant drug side effects:
_____
_____
_____
Patient given _____ days of medication

Comments _____
_____
_____

For non-Class 3/5 referrals indicate if: ☐ Follow-up requested ☐ No follow-up requested
NTCA 3-2002

Figure 6.10 Sample Inter-jurisdictional Tuberculosis Notification Form, available from the National TB Controllers Association Website: http://tbcontrollers.org/docs/IJ_Form_Page1.pdf.

Study Question 6.22

6.22 Explain the procedures for sending patient information from one health jurisdiction to another.

Answers to study questions are on pages 80–87

Case Study 6.5

You are a health care worker at a County Health Department. You have been working closely with Juan, a 35-year-old Hispanic agricultural worker. Juan was diagnosed with TB about 2 months ago. You have been providing DOT to Juan at a local farm where he picks oranges. Orange season is coming to an end and you realize that Juan will soon be heading North to look for more work. You have spoken to him about where he will be going next. He tells you that he is going to a farm in the next state over. He is not exactly sure where it is, but he thinks he remembers the farm is located near a town called Jasper.

- **What steps will you take before Juan leaves to ensure the continuity of care?**

Answers to case studies are on pages 88-93

Considerations for TB Case Management in Special Settings

Management of TB cases often includes working in various environments and with other facilities. These may include hospitals, correctional facilities, homeless shelters, workplaces and long term-care facilities. Maintaining confidentiality and building partnerships with these facilities are very important.

A first step in establishing a good working relationship in a facility or institution is for a public health worker to visit key staff and explain his or her role as a liaison between the facility and the TB program. The health care worker should provide TB education and offer resources as needed. It may be helpful for the public health worker to show the staff an official letter of introduction from the TB program stating the purpose of his or her assignment and the legal authority of the TB program.

A first step in establishing a good working relationship in a facility or institution is for a public health worker to visit key staff and explain his or her role as a liaison between the facility and the TB program.

As liaisons with the TB program, public health workers support facility or institutional staff by

- Providing information on a patient's TB history
- Providing information on services available through the TB program
- Supplying educational materials for patients and hospital or institutional staff
- Helping to plan for follow-up care for TB patients upon discharge

Health departments should assist facilities in developing and updating policies, procedures, and record systems for TB control. The health department should also provide access to expert TB medical consultation and ensure that facilities have access to laboratory services. A specific health department contact person should be designated to provide epidemiologic and case management assistance to facilities. Health departments should also provide consultation for contact investigations for each case within facilities and ensure appropriate examinations of contacts.

Discharge Planning

When TB patients leave a facility, such as a hospital or correctional facility, it is important to ensure continuity of treatment and quality care. **Discharge planning** is the preparation for comprehensive care of a hospitalized or institutionalized patient after that patient's discharge.

Discharge planning is the preparation for comprehensive care of a hospitalized or institutionalized patient after that patient's discharge.

It is usually a team effort, led by a nurse or a facility's discharge planner. In some cases, a case manager assigned by the public health department may be in charge of planning for a patient's discharge. Team members often include at least two or more of the following:

- The discharge planner or case manager
- Nurses or therapists involved in the patient's care
- A social worker
- The patient's physician
- Expert consultants, if required
- DOT outreach worker

An institution-based public health worker can also provide input and share responsibility for ensuring that the TB patient is appropriately managed after discharge.

The discharge planning team should meet while the patient is in the facility to review the patient's treatment plan and develop an **adherence plan**. An adherence plan is written and based on the patient's understanding and acceptance of the TB diagnosis. It addresses barriers to adherence, and details the method chosen to deliver treatment and monitor adherence for that specific patient. This is especially important in correctional facilities, as correctional facilities do not always know when a patient will be discharged. If possible, the patient should be included in this meeting to aid in decision-making.

The discharge planning team should meet while the patient is in the facility to review the patient's treatment plan and develop an adherence plan.

Whenever possible, the person responsible for the patient's follow-up care should visit the hospital or institution to meet the patient and explain the program that will be followed. The discharge planner or case worker should notify the provider of the date of discharge and of any changes in the treatment or adherence plan.

The public health worker is responsible for conveying relevant information on discharged patients to the TB program. This information is very important for other team members assigned to the case who will provide follow-up care in the community.

The public health worker is responsible for conveying relevant information on discharged patients to the TB program.

Study Question 6.23 – 6.24

6.23 List four ways that public health workers support hospital or institutional personnel.

6.24 Explain the purpose of discharge planning and briefly describe the public health worker's role.

Answers to study questions are on pages 80–87

Case Study 6.6

You have just been assigned to work in the state prison. The prison has several hundred prisoners; typically three to six prisoners are diagnosed with active TB disease each year. Currently, two prisoners are taking TB medication and seven are on regimens for the treatment of LTBI.

When prisoners with TB disease are released, the current procedure is to notify the health department immediately before the prisoner is released. The health department makes a clinic appointment for the patient, the patient is informed of the appointment and provided the clinic's contact information. If the patient does not keep the appointment, the health department sends a reminder card to the patient's address (supplied by the prison administration). The treatment completion rate for these cases has been very low.

- **One of the prisoners with TB disease is near the end of his sentence and is scheduled to be released in a week. What can you do to plan for TB care upon his release?**

Answers to case studies are on pages 88–93

Additional Resources

1. CDC. Essential Components of a Tuberculosis Prevention and Control Program: Recommendations of the Advisory Council for the Elimination of Tuberculosis. *MMWR* 1995; 44 (No. RR-11). www.cdc.gov/mmwr/preview/mmwrhtml/00038823.htm.

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6. Global Tuberculosis Institute at Rutgers, The State University of New Jersey. Cultural Competency and Tuberculosis Care: A Guide for Self-Study and Self-Assessment. http://globaltb.njms.rutgers.edu/educationalmaterials/productfolder/culturalcompetency.php.

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9. Heartland National Tuberculosis Center. Case Studies in TB – Nurse Case Management Training Tools for Patient Success; 2017. www.heartlandntbc.org/assets/products/case_studies_tb_ncm_training_tools.pdf.

10. Nahid P, Dorman SE, Alipanah N, Barry PM, Brozek JL, Cattamanchi A, Chaisson LH, Chaisson RE, Daley CL, Grzemska M, Higashi JM, Ho CS, Hopewell PC, Keshavjee SA, Lienhardt C, Menzies R, Merrifield C, Narita M, O'Brien R, Peloquin CA, Raftery A, Saukkonen J, Schaaf HS, Sotgiu G, Starke JR, Migliori GB, Vernon A. Official American Thoracic Society/Centers for Disease Control and Prevention/Infectious Diseases Society of America Clinical Practice Guidelines: Treatment of Drug-Susceptible Tuberculosis. Clinical Infectious Disease 2016:1-49. https://academic.oup.com/cid/article/63/7/853/2197067.

11. National Tuberculosis Nurse Coalition. Tuberculosis Nursing: A Comprehensive Guide to Patient Care, 2nd edition; 2011. www.tbcontrollers.org/resources/tb-nursing-manual/.

12. Southeastern National Tuberculosis Center. Country Specific Quick Reference Guides; 2010. https://sntc.medicine.ufl.edu/home/index#/products.

Answers to Study Questions

6.1 What are the four priority TB prevention and control activities?

The four priority TB prevention and control activities are:

1. Identifying and treating persons who have TB disease;
2. Finding and assessing persons who have been in contact with TB patients to determine whether they have LTBI or TB disease and providing them with appropriate treatment;
3. Using targeted testing strategies to identify and treat persons with LTBI at risk for developing TB disease; and
4. Identifying settings in which there is a high risk for transmission of *M. tuberculosis* and applying effective infection control measures.

6.2 Name two methods health departments use to identify TB cases.

Health departments typically identify TB cases by either passive case reporting or active case finding. Contact investigations, pharmacy and laboratory surveillance, and facility and organization inquiries are examples of active case finding activities.

6.3 What is the goal of case management?

The goal of case management is to provide patient-centered care for completion of treatment and to ensure all public health activities related to stopping TB transmission are completed.

6.4 During a patient assessment, what specific topics should the health care worker discuss with the patient?

Conducting an assessment involves talking to a patient about his or her medical history, knowledge about TB, and beliefs about TB transmission and treatment. Specific topics that the health care worker should find out include

- Medical history
- Knowledge, attitudes, and beliefs about TB
- Ability to follow the TB treatment plan
- Resources (e.g., family, other social support, finances)
- Anticipated barriers to treatment (e.g., lack of transportation)
- Perceived barriers to treatment (e.g., TB medications will be very expensive)

- History of adherence to previous TB regimens or other medication

6.5 In the list below, there are closed-ended and open-ended questions. Mark an X next to the open-ended questions.

- X What is TB?
- □ Do you think TB can be cured?
- X How is TB spread?
- □ Do you have difficulty taking medicine?
- X What are some of the difficulties you have taking medicine?
- X Why do you think you need to take medicine?
- □ Is TB curable?
- X How is TB cured?

6.6 Explain the importance of building rapport and establishing a trusting relationship with the patient.

Establishing rapport, trust, and good communication with the patient is critical. The quality of the patient-health care worker relationship is especially important in TB control, where long-term adherence to treatment is necessary. If the patient and the health care worker have a good relationship with each other, the patient is more likely to adhere to treatment, name contacts, and follow the health care worker's instructions and advice.

6.7 List at least four effective communication and education techniques that health care workers should use when educating a patient.

There are several effective communication and education techniques that can be used when educating patients:

- Use simple, nonmedical terms
- Use the appropriate language level
- Limit the amount of information
- Discuss the most important topics first and last
- Repeat important information
- Listen to feedback and questions
- Use concrete examples
- Make interactions with the patient as positive as possible

6.8 List at least six guidelines for working with an interpreter that can help the health care worker make the best of the interview.

Health care workers should follow these guidelines to make the best use of the interview when working with interpreters:

- Ask for the patient's permission to use an interpreter
- Plan the interview and decide what key points to talk about with the patient
- Meet with the interpreter before the interview to talk about the goals for the interview, to give instructions and guidance, and to make sure the interpreter is comfortable with the questions and topics that will be discussed
- Remind the interpreter that all information in the interview is confidential
- Ask the interpreter to refrain from adding his or her own comments
- Address the patient directly, not the interpreter
- Ask the interpreter to explain questions or answers that are not clear
- Keep the messages simple and factual; use short phrases and focus on one topic at a time
- Give the interpreter time to translate each phrase before continuing; do not interrupt the interpreter
- Ask the interpreter to translate the patient's and the health care worker's own words exactly
- Give the patient time to answer questions

6.9 What is adherence to treatment?

Adherence to treatment means following the recommended course of treatment by taking all medications as prescribed, for the entire recommended time.

6.10 What are four serious consequences that can result when a patient with TB disease is nonadherent?

Nonadherence to treatment for TB disease can lead to serious consequences, such as acquired drug resistance, an increase in the severity of illness, ongoing TB transmission, and even death.

6.11 Give eight reasons why a patient might be nonadherent.

There are many reasons why a person might have trouble completing a regimen of TB drugs. Here are a few examples.

- Improved or no symptoms
- Lack of knowledge
- Cultural beliefs

- Language barriers
- Lack of access to healthcare
- Poor relationship between the patient and the health care worker
- Competing priorities
- Stigma
- Mental health

6.12 What is DOT?

DOT stands for directly observed therapy. DOT means that a health care worker or other designated individual watches the patient swallow every dose of the prescribed drugs. It is the most effective strategy for ensuring patients take their medicine correctly.

6.13 List and explain four tasks that are part of the DOT encounter.

During DOT encounters, health care workers should do the following:

Check for Side Effects

Health care workers should ask if the patient is having any adverse side effects at each visit, before the drugs are given. If the patient has symptoms of serious adverse reactions, a new drug supply should not be given; the patient should stop taking medication immediately. The health care worker should tell their supervisor that the drugs were not given and notify the prescribing clinician about the adverse reaction. The health care worker should arrange for the patient to see the clinician as soon as possible.

Verify Medication

Each time DOT is delivered, the health care worker should verify that the right drugs are delivered to the right patient, and that he or she has the correct amount of medication. If this cannot be confirmed, the drugs should not be given to the patient. The supervisor should be asked for clarification.

Watch the Patient Take Pills

Health care workers should watch for techniques some patients may use to avoid swallowing medication. Some patients may hide pills in their mouth and spit them out later, hide medicine in clothing, or vomit the pills after the DOT visit. The health care worker should watch the patient continuously from the time each pill is given to the time the patient swallows it.

Document the Visit

The health care worker should document each visit with the patient and indicate whether or not the medication was given. If not given, the reason and follow-up plans should be included. It is important to correct any interruption in treatment as soon as possible.

6.14 What are four advantages of DOT?

- DOT ensures that the patient completes an adequate regimen
- DOT lets the health care worker monitor the patient regularly for side effects and response to therapy
- DOT helps the health care worker solve problems that might interrupt treatment
- By ensuring the patient takes every dose of medicine, it helps the patient become noninfectious sooner

6.15 What is a formal adherence agreement?

A formal adherence agreement is a written understanding between the health care worker and a patient. A patient should write down the activities he or she agrees to carry out (such as taking medicine as prescribed), in return for specific services, activities, or incentives from the health care worker. For some patients, this written commitment increases the likelihood of adherence.

6.16 What are incentives and enablers?

Incentives are small rewards given to patients to encourage them to either take their own medicine or keep their clinic or field DOT appointments. Enablers are things that make it possible or easier for patients to receive treatment by overcoming barriers, such as a lack of transportation to get to the clinic.

6.17 Describe three strategies health care workers can use to address barriers to adherence.

There are several additional strategies health care workers can use to address barriers to adherence:

- Create an adherence agreement
- Use incentives and enablers
- Encourage the patient to seek support
- Give TB drugs in easy-to-take preparations
- Coordinate other services

6.18 Describe the progressive interventions that should be attempted before a court orders involuntary confinement.

State and local TB control programs should have a treatment plan that goes step-by-step from voluntary participation to involuntary confinement as a last resort. The plan should begin with learning the possible reasons for nonadherence and addressing the identified problems using methods such as DOT, incentives, and enablers. The patient should be told verbally and in writing of the importance of adhering to treatment, the consequences of failing to do so, and the legal actions that will have to be taken if the patient refuses to take medication.

If the patient does not adhere to DOT voluntarily, the next step may be court-ordered DOT. Court-ordered DOT is DOT that is administered to a patient by order of a public health official or a court with the appropriate authority.

TB control programs should not begin procedures for confining patients to a treatment facility until after the patient has shown that he or she is unable or unwilling to follow a treatment regimen implemented outside such a facility. Involuntary confinement or isolation for inpatient treatment should be viewed as the last step. When deciding whether to confine a TB patient legally to protect the public, local health officials must decide whether the person is at real risk of infecting others.

Throughout the process, there must be detailed documentation of the patient's nonadherence and the steps taken to address it.

6.19 List the criteria for deciding if a patient should be confined.

When deciding whether to legally confine a TB patient to protect the public, local health officials must decide whether the person is at real risk of infecting others. To determine this risk, these factors should be considered

- Laboratory results (i.e., smears and cultures)
- Clinical signs and symptoms of infectious TB
- An abnormal chest x-ray, especially if cavities are present
- A history of nonadherence
- The opportunity to infect others

6.20 List three applications of genotyping.

At the patient level, TB genotyping has three uses:

- Distinguishing relapse from reinfection
- Detecting false-positive culture results
- Conducting contact investigations

At the population level, genotyping is most commonly used for detecting, refuting, and monitoring TB outbreaks.

6.21 Explain the difference between a cohort review and case review.

Case Review	Cohort Review
Weekly	Quarterly; biannually
Real time, ongoing review of single patient management and care issues	Retrospective review of ALL counted TB patients and contacts during specified time period
Monitor individual patient progress and treatment outcome	Monitor group progress toward treatment outcomes
Identify patient care issues	Identify programmatic issues

6.22 Explain the procedures for sending patient information from one health jurisdiction to another.

When a patient leaves a health jurisdiction before completing TB treatment, patient information should be sent to the health jurisdiction at the patient's destination. The following procedures should be followed

- Patients who are taking treatment for TB disease should be given (1) a copy of records they can take with them to indicate their current treatment and diagnostic status and (2) a supply of medications to self-administer during the transition of care. Special care should be taken to instruct such persons on how to take their medications and how and where to get additional medication and medical care at the destination site.
- Patients should be asked to provide their new address and phone number, if known. Patients can also be asked to provide the name and phone numbers of family or friends whom staff in the new jurisdiction could speak with, in order to connect with the patient during or after the move.

- All relevant medical information, including TB laboratory reports, and patient contact information should be forwarded to the destination jurisdiction.
- The state health department TB control officer should be contacted and made aware of the need for follow-up and the next possible destination of the patient.
- Measures should be taken to ensure confidentiality.

6.23 List four ways that public health workers support hospital or institutional personnel.

- Providing information on a patient's TB history
- Providing information on services available through the TB program
- Supplying educational materials for patients and hospital or institutional staff
- Helping to plan for follow-up care for TB patients upon discharge

6.24 Explain the purpose of discharge planning and briefly describe the public health worker's role.

The purpose of discharge planning is to prepare for comprehensive care of a hospitalized or institutionalized patient after that patient's discharge. The public health worker is responsible for conveying relevant information on discharged patients to the TB program. This information is very important for other team members assigned to the case who will provide follow-up care in the community.

Answers to Case Studies

6.1 Thanh is a cook at a local restaurant. He went to see his physician because he was feeling extremely tired, had lost his appetite, and had been coughing for several weeks. His physician suspected TB and admitted Thanh to the hospital for further tests.

His sputum smears were positive and he was started on appropriate therapy. The physician called the local health department to report the diagnosis. A case manager was assigned and visited Thanh in the hospital.

- **How should the case manager assess Thanh's knowledge, beliefs, and feelings about TB disease and treatment?**
  One way to learn about Thanh's knowledge, beliefs, and feelings about TB disease is to ask open-ended questions. For example, the health care worker could ask Thanh
  - What do you know about TB?
  - What causes TB?
  - What are the most important results you hope to get from this treatment?

- **Why is it important to assess Thanh's knowledge, beliefs, and feelings about TB disease and treatment?**
  It is important to assess Thanh's knowledge, beliefs, and feelings about TB disease and its treatment because the more the health care worker is aware of Thanh's ideas and concerns, the better prepared the health care worker will be to anticipate and resolve problems that can arise. An assessment will help the health care worker better understand Thanh's views and will help determine areas in which he needs education.

  An assessment may also give the health care worker some idea of Thanh's ability to adhere to a treatment regimen. For example, asking Thanh what problems the illness has caused him can help the health care worker assess the strength of his family and social support, and potential job-related problems.

6.2 **You are assigned to deliver DOT to Mrs. Wilson, a 76-year-old woman who lives alone in the house that she and her husband bought many years ago. Mrs. Wilson was recently released from the hospital. Upon discharge from the hospital, she received education about TB and about the need to take medications until she completes treatment. She was told that she would be started on DOT and a health care worker would visit her at home to help her take her medication. Mrs. Wilson is excited to have some company. She happily offers you cookies and wants to "talk awhile" before she takes her medication.**

- **How should you respond to Mrs. Wilson's request to "talk awhile"? How could your reaction affect her adherence?**
  Establishing rapport, trust, and good communication with the patient is critical. The relationship with the patient will develop over time; however, the foundation from which a trusting relationship is established begins immediately. To develop rapport with Mrs. Wilson, you should be open, friendly, and willing to "talk awhile" at the DOT visit. If you immediately refuse to talk with her, it may negatively affect rapport and damage the patient-health care worker relationship. If you are uncomfortable eating the cookies she has offered, you should respectfully decline to eat them.

6.3 **Mr. Sivaraman is a recent immigrant from India who is working two jobs to support his wife and three children. He has been on DOT for 2 months and his TB symptoms have greatly improved. Mr. Sivaraman has kept daily DOT appointments with the health care worker, but recently has missed two appointments and skipped his last clinic visit.**

- **What do you know about Mr. Sivaraman's history that might lead to nonadherence?**
  Mr. Sivaraman may be having difficulties keeping appointments with his busy work schedule. In addition, since his symptoms have improved, he may be less motivated to continue treatment. Sometimes the health care worker can find out what problems a patient is having by contacting them with either a phone call on the same day or with a home visit.

- **What steps can the health care worker take to help Mr. Sivaraman keep his appointments and adhere to treatment?**
  The health care worker should call Mr. Sivaraman right away to schedule a new clinic appointment and reconfirm the DOT schedule. The health care worker should use this discussion to counsel him and to identify and solve problems that interfere with appointment keeping. If Mr. Sivaraman continues to break appointments, the health care worker may want to hold a conference with all members of the healthcare team so that the problem can be discussed and resolved with help from the entire staff. Mr. Sivaraman could also be included in this conference so he will be able to help make adjustments to the treatment plan.

  A formal adherence agreement may also be useful. Mr. Sivaraman should be asked to sign the agreement and be given a copy to keep. The health care worker should review the agreement with him periodically to assess how well both are doing and to make changes as needed. If Mr. Sivaraman becomes chronically nonadherent, the health care worker may need to try several different strategies to help him, and possibly even consider legal alternatives.

6.4 Walter is a 50-year-old male who was diagnosed with TB one month before he was released from prison. The prison doctor called the health department to report the case and asked them to take over managing Walter's TB treatment upon his release. The case manager assigned a health care worker to work with Walter. The health care worker met with Walter while he was still in prison and set up a plan to continue DOT upon Walter's release.

For the first two weeks after his release, Walter adhered to treatment. He then began missing appointments at the arranged DOT site and at the clinic. The health care worker offered to meet Walter in other locations for DOT. He also provided incentives and enablers.

When Walter continued to miss appointments, the health care worker called and texted Walter to discuss the missed appointments. Unable to reach Walter via phone, the health care worker then went to Walter's house. Walter became agitated and stated that he feels "okay" and does not like the health care worker "harassing" him in front of his friends. The health care worker documented all of his efforts to get Walter to adhere to treatment.

- **What should the health care worker do next?**
  Since addressing the identified problems using methods such as DOT, incentives, and enablers did not work, the next step is to try DOT that is ordered by a public health official or a court. Court-ordered DOT may be successful in convincing Walter that his TB treatment is an important public health priority. Since Walter has recently been released from prison, court-ordered DOT may convince him to continue his treatment and come to the clinic for follow-up.

  The health care worker should not begin procedures for confining Walter to a treatment facility until after Walter has shown that he is unable or unwilling to follow a treatment regimen implemented outside such a facility. Involuntary confinement or isolation for inpatient treatment should be viewed as the last step. When legal steps are taken, the health care worker must make sure that Walter's rights are protected and he should have legal counsel.

6.5 **You are a health care worker at a County Health Department. You have been working closely with Juan, a 35-year-old Hispanic agricultural worker. Juan was diagnosed with TB about 2 months ago. You have been providing DOT to Juan at a local farm where he picks oranges. Orange season is coming to an end and you realize that Juan will soon be heading North to look for more work. You have spoken to him about where he will be going next. He tells you that he is going to a farm in the next state over. He is not exactly sure where it is, but he thinks he remembers the farm is located near a town called Jasper.**

- **What steps will you take before Juan leaves to ensure the continuity of care?**
  You need to find out Juan's destination and have locating/contact information for him (e.g., phone number) before he leaves. You should follow these procedures to help him continue his TB care
  - Juan should be given (1) records he can take with him to indicate his current treatment and diagnostic status and (2) a supply of medications to self-administer during the transition of care. Special care should be taken to instruct Juan on how to take his medications

and how and where to get additional medication and medical care at the destination site.

- All relevant medical information, including TB laboratory reports, and patient contact information should be forwarded to the destination jurisdiction.
- The state health department TB control officer should be contacted and made aware of the need for follow-up and the next possible destination of the patient.
- Although sharing information about Juan is encouraged to maintain continuity of care, measures should be taken to ensure confidentiality.

6.6 You have just been assigned to work in the state prison. The prison has several hundred prisoners; typically three to six prisoners are diagnosed with active TB disease each year. Currently, two prisoners are taking TB medication and seven are on regimens for the treatment of LTBI.

When prisoners with TB disease are released, the current procedure is to notify the health department immediately before the prisoner is released. The health department makes a clinic appointment for the patient, the patient is informed of the appointment and provided the clinic's contact information. If the patient does not keep the appointment, the health department sends a reminder card to the patient's address (supplied by the prison administration). The treatment completion rate for these cases has been very low.

- **One of the prisoners with TB disease is near the end of his sentence and is scheduled to be released in a week. What can you do to plan for TB care upon his release?**

  For TB patients who leave a correctional facility, discharge planning is necessary to ensure continuity of treatment and quality care.

  If possible, the patient should be included in discharge planning to aid in decision making. You should review both the treatment plan and the adherence plan. For this patient, specific incentives may be necessary to ensure that he keeps a follow-up appointment. The follow-up appointment for DOT or for continued monitoring should be made at a location that is convenient (and preferably, familiar) to the patient. As a representative of the TB program, you should discuss follow-up care with the patient and

explain the program that will be followed. You should notify the TB program of the date of discharge when it becomes known and of any changes in the treatment plan or adherence plan. This information is very important for coworkers assigned to the case who will provide follow-up care in the community.