

Self-Study Modules on Tuberculosis

Patient Adherence to Tuberculosis Treatment

**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
Centers for Disease Control and Prevention**

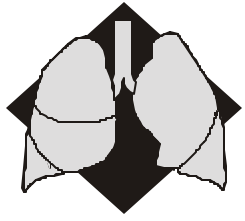
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Division of Tuberculosis Elimination**

**Public Health Practice Program Office
Division of Media and Training Services**



**Atlanta, Georgia
October 1999**





Patient Adherence to Tuberculosis Treatment

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BACKGROUND

In this module, you will learn how to help patients adhere to a TB treatment regimen. When medical treatment is complicated or lasts for a long time, as in the treatment for TB disease, patients often do not take their medication as instructed. This can lead to serious problems. A nonadherent TB patient may remain sick, spread TB to others, develop and possibly spread drug-resistant disease, and even die as a result of interrupted treatment. Likewise, it is also important that persons with latent TB infection (LTBI) who are prescribed a regimen for LTBI adhere to the regimen. Completion of therapy for LTBI can prevent people with TB infection from developing TB disease. The patient's success in completing a TB regimen depends to a large extent on the health care worker's ability to understand him or her, support the patient throughout therapy, and anticipate or solve problems as they arise.

This module describes methods the health care worker can use to get to know his or her patients, assess their ability and willingness to adhere to treatment, use proven methods to improve patient adherence, and solve common problems that arise during treatment. Also included is advice on the use of legal remedies to nonadherence when less restrictive methods have been exhausted and a patient does not cooperate with public health officials. By using the recommendations in this module, the health care worker should be able to help his or her patients remain adherent and successfully complete their TB treatment regimens.

Another important issue that is not addressed in this module is the adherence of health care workers to published recommendations and guidelines. The prescription of an inadequate treatment regimen (e.g., a 6-month regimen that does not contain rifampin) or the failure to order recommended diagnostic tests (e.g., drug susceptibility testing of the initial isolate from a patient's sputum) are serious problems that can lead to treatment failure. As you consider the problems that can lead to a patient's failure to adhere to a regimen, keep in mind that the burden of TB treatment completion does not rest solely on the patient.



OBJECTIVES

After working through this module, you will be able to:

1. Define adherence and describe why it is important to TB treatment.
2. List six reasons why a patient might be nonadherent.
3. Describe a case management system.
4. Explain why and when it is important to assess a patient's knowledge and beliefs about TB disease and its treatment.
5. Define open-ended questions and explain how they can help you learn about a TB patient.
6. Discuss the role of patient education in improving adherence.
7. List eight techniques that can be used to communicate effectively with patients.
8. List eleven guidelines that can help the health care worker make the best of an interview assisted by an interpreter.
9. Define DOT, list its advantages and disadvantages and who should be considered for DOT, and describe the tasks involved in delivering DOT.
10. Define incentives and enablers; describe what their purposes are, how to determine which ones to use for each patient, and what are some sources.
11. List five ways to promote adherence in children and describe why adolescents are at high risk for nonadherence.
12. Explain the purpose of a behavioral diagnosis, and list 13 examples of barriers to adherence and the methods to overcome the barriers.
13. Describe how a patient's beliefs about health or medical care can affect TB treatment.
14. List eight specific things that can be done to form an effective partnership with TB patients.
15. Describe who can provide support to a patient and the role they can play in helping or hindering the patient in being adherent.
16. Discuss how the treatment regimen can be tailored to the individual and why this may improve adherence.



17. Describe a formal adherence agreement.
18. Give three examples of methods to help patients keep appointments.
19. Give four examples of nonadherent behavior that could warrant legal action against the patient.
20. Describe the progressive interventions that TB control programs should attempt before a court orders involuntary confinement.



NEW TERMS

Lists of terms were introduced in each of the five core *Self-Study Modules on Tuberculosis* (Modules 1-5). Please refer to the core modules or their Glossary if you encounter unfamiliar terms related to TB that are not defined in this New Terms section.

Look for the following new terms in this module.

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

adherence agreement – a written understanding between a health care worker and a patient that indicates the activities they both agree to carry out. For some patients, this written commitment increases the likelihood of adherence

alternative medicine – health care other than conventional, scientifically tested, medicinal treatment; includes herbal remedies, yoga, meditation, acupuncture, and other practices intended to maintain or improve health

assessment – talking to a patient to find out about his or her medical history, knowledge about TB, feelings and beliefs about TB treatment, and other pertinent information

barrier – anything that can prevent a patient from being able to adhere to a TB treatment regimen

behavioral diagnosis – used to find out what is causing a patient to have problems with adherence and to develop strategies to improve the patient's treatment plan

case management – a system in which a specific health department employee is assigned primary responsibility for the patient, systematic regular review of patient progress is conducted, and plans are made to address any barriers to adherence

clinic-based DOT – directly observed therapy delivered in a TB clinic or comparable health care facility

combined pill – fixed-dose combination capsule or tablet that may enhance patient adherence. In the United States, the Food and Drug Administration has licensed fixed-dose combinations of isoniazid and rifampin (Rifamate) and of isoniazid, rifampin, and pyrazinamide (Rifater)

court-ordered DOT – directly observed therapy that is administered to a patient by order of a public health official or a court with the appropriate authority; used when patients have been nonadherent despite the best efforts of TB program staff



directly observed therapy for latent TB infection (LTBI) – a strategy devised to help patients at especially high risk of developing TB disease adhere to treatment for LTBI; a health care worker or another designated person watches the patient swallow each dose of the prescribed drugs

enablers – those things that can make it possible or easier for the patients to receive treatment

field-based DOT – directly observed therapy delivered in a setting outside the TB clinic or a comparable health care facility; possible sites for field DOT include a doctor’s office, the patient’s home or workplace, a school, a public park, or a restaurant

folk medicine – medicinal beliefs, knowledge, and practices associated with a particular culture or ethnic group. Folk medicine is usually handed down by cultural tradition and practiced by health care workers specially trained in that tradition; not all members of a given culture or ethnic group will use its folk medicine practices

health care worker – a person who provides health care or health services to patients, such as physicians, physician’s assistants, nurse practitioners, nurses, and outreach workers

incentives – small rewards given to patients to encourage them to either take their own medicines or keep their clinic or field DOT appointments

latent TB infection (LTBI) – also referred to as TB infection. Persons with latent TB infection carry the organism that causes TB but do not have TB disease, are asymptomatic, and are noninfectious. Such persons usually have a positive reaction to the tuberculin skin test

nonadherence – the patient’s inability or refusal to take TB drugs as prescribed

open-ended question – 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, by beginning with words such as “What,” “Why,” “Who,” “How,” and “When,” that demand an explanation. Such questions are used to explore complex issues that do not have a finite or predetermined set of responses

treatment for LTBI – medication that is given to people who have latent TB infection to prevent them from developing TB disease



READING MATERIAL

Patient Adherence to TB Treatment

.....
TB is nearly always curable if patients adhere to their TB treatment regimen.
.....

What is Adherence to Treatment?

Adherence to treatment means that a patient is following the recommended course of treatment by taking all the prescribed medications for the entire length of time necessary. **Adherence is important because TB is nearly always curable if patients adhere to their TB treatment regimen.**

.....
Nonadherence is the patient's inability or refusal to take TB drugs as prescribed.
.....

What is Nonadherence?

Nonadherence is the patient's inability or refusal to take TB drugs as prescribed. When medical treatment is complicated or lasts for a long time, as in the treatment for TB disease, patients often do not take their medication as instructed. This behavior is one of the biggest problems in TB control and can lead to serious consequences. A nonadherent patient with TB disease may

- # Remain sick longer or have more severe illness
- # Spread TB to others
- # Develop and spread drug-resistant TB
- # Die as the result of interrupted treatment

It is also important that persons with **latent TB infection** (LTBI) who are prescribed a regimen for LTBI adhere to the regimen. Completion of therapy for LTBI can prevent people with TB infection from developing TB disease.



Reasons for Nonadherence

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

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Once patients no longer feel sick, they often think it is all right to discontinue taking their TB drugs.
.....

Once **patients no longer feel sick**, they often think it is all right to discontinue taking their TB drugs. TB symptoms can improve dramatically during the initial phase of treatment (the first 8 weeks). 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-resistant organisms.

.....
Lack of knowledge can lead to an inability or lack of motivation to complete a regimen.
.....

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 a regimen.

.....
Some patients have strong personal or cultural beliefs about TB disease, how it should be treated, and who they can turn to for help.
.....

Some patients have strong **personal or cultural beliefs** about TB disease, how it should be treated, and who they can turn to for help. When TB treatment conflicts with these beliefs, patients can become fearful, anxious, or alienated from their **health care workers** (a person who provides health care or health services to patients, such as physicians, physician’s assistants, nurse practitioners, nurses, and outreach workers).

.....
Certain patients lack skills necessary for following a health care worker’s instructions and adhering to a prescribed regimen.
.....

Certain patients **lack skills** necessary for following a health care worker’s instructions and adhering to a prescribed regimen. Elderly patients with limited mobility or manual dexterity, patients with substance abuse or mental health problems, and young children are particularly at risk for problems with adherence.



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Lack of access to health care can be a significant barrier to successfully completing a TB regimen.
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A language barrier can present significant problems for adherence.
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Poor relationships with health care workers can influence patient adherence.
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Lack of motivation to adhere to a TB regimen may occur if a patient has many competing priorities.
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- **Lack of access to health care** can also be a significant barrier to successfully completing a TB regimen. Special efforts must be made to reach and provide care to patients without a permanent address or a means of transportation. Patients with jobs may have work schedules that conflict with clinic hours. Immigrants and refugees, as well as persons who inject illicit drugs, may need reassurance that their TB disease and treatment will be kept confidential and should not cause them legal problems.
- Some patients, especially recent immigrants, may not be able to find a health care worker who speaks their language. When a patient speaks little or no English, this **language barrier** can present significant problems for adherence, as patient education and support services can have little effect. Unless a good interpreter is found, such patients may be unable to continue treatment.
- Some patients have **poor relationships with health care workers**. When patients and health care workers fail to establish a trusting relationship, this lack of relationship can influence patient adherence. If a patient trusts or has confidence in his or her health care worker, he or she is more likely to follow instructions and advice and to cooperate with the health care worker. Patients may also be more likely to bring questions and concerns regarding adherence to the health care worker’s attention.
- Finally, some patients may have a **lack of motivation** to adhere to a TB regimen. If patients have many competing priorities in their lives such as substance abuse, homelessness, sickness from other diseases (e.g., HIV), taking TB medication may not be considered a priority by the patient.



.....
One of the best predictors of adherence is a patient's past adherence.
.....

Each patient is unique and may have his or her own reasons for nonadherence. One of the best predictors of adherence is a patient's past adherence. If a patient was nonadherent in the past, it is likely that he or she will encounter similar problems with the current treatment regimen. However, it is important to keep in mind that **any patient** can have problems with adherence.

Barriers are anything that can prevent a patient from being able to adhere to a TB treatment regimen. Many health care workers think they can tell which patients will be adherent, but research shows they are correct only about half the time (that is, their predictions are no better than flipping a coin). Although adherence is hard to predict, 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 problems.

.....
Patients and health care workers are both responsible for ensuring patients' adherence.
.....

Patients and health care workers are both responsible for ensuring patients' adherence. Patients must decide every day or week whether or not to take their medicine. What they decide often depends on how much help they get from the health care workers they see.



Study Questions 9.1-9.3

9.1 What is adherence to treatment?

9.2 Why is adherence to TB treatment important?

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

Answers on page 92.



Study Questions 9.4-9.6

9.4. Give eight reasons why a patient might be nonadherent.

9.5. Explain why a patient's adherence to a TB treatment regimen is difficult to predict.

9.6. Whose responsibility is it to ensure adherence?

Answers on pages 92-94.



Case Management

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Case management is one strategy that can be used to ensure that patients complete therapy.

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What is Case Management?

There are many strategies that may be used to ensure that patients complete treatment. One strategy that may be used is **case management**. There are three elements in a case management system:

- # Assignment of primary responsibility for the patient
- # Systematic regular review of patient progress
- # Plan to address any barriers to adherence

A health department employee (case manager) is assigned primary responsibility and is held accountable for ensuring

- # Each patient is assessed and a treatment plan is established
- # Each patient is educated about TB and its treatment
- # Therapy is continuous
- # Contacts are examined (see Module 6, Contact Investigations for Tuberculosis, for information on conducting contact investigations)

.....
Although one person is assigned primary responsibility, case management provides continuity of care by using a team of persons who work together to help each patient complete treatment.

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Although one person is assigned primary responsibility, case management provides continuity of care by using a team of persons who work together to help each patient complete treatment. Some specific responsibilities such as the patient interview, directly observed therapy (DOT), and patient education may be assigned to other persons (e.g., clinic supervisors, outreach workers, health educators, and social workers).



Case management uses a combination of patient-focused services in which the case management team performs the following tasks:

- # Assesses the patient and develops a treatment plan
- # Provides DOT
- # Provides effective education to patients and key individuals
- # Establishes efficient clinic systems for scheduling appointments, keeping records, and providing pharmacy services
- # Helps patients keep appointments
- # Communicates effectively with patients whose cultural and language backgrounds are different from their own
- # Offers incentives and enablers to encourage adherence
- # Provides patients with needed health or social services, or makes referrals to other appropriate service agencies
- # Establishes a trusting relationship with the patient



.....
The health care worker will need to learn as much as possible about the patient in order to assess potential adherence problems.
.....

Getting to Know the Patient

The health care worker will need to learn as much as possible about the patient in order to assess potential adherence problems. The health care worker will need to learn about the patient's

- # Medical history and current health problems
- # Knowledge, beliefs, and attitudes about TB
- # Ability to take responsibility for following the TB treatment plan
- # Resources (family, other social support, finances)
- # Barriers to treatment
- # History of adherence to previous TB regimens or other medication

This information can come from different people or places. Often, TB health care workers first find out about patients with active TB from health care workers in other health care settings such as doctors' offices, hospitals, prisons, jails, homeless shelters, nursing homes, and other public health clinics.

.....
Unless special efforts are made to identify patients' needs, some patients may be lost to follow-up care.
.....

Although the information from these other sites is important, TB health care workers usually do an additional **assessment**. Doing an assessment means talking to a patient to find out about his or her medical history, knowledge about TB, feelings and beliefs about TB treatment, and information on the other points listed above. A particular emphasis is placed on identifying the problems most important to the patient as treatment begins. Because TB treatment often begins abruptly, patients may have difficulties changing their behaviors as expected. Unless special efforts are made to identify patients' needs, some patients may be lost to follow-up care.



.....
The health care worker or other program staff should visit the patient to begin the assessment as soon as possible.
.....

The health care worker or other program staff should visit the patient to begin the assessment **as soon as possible**. If the health care worker is assigned to work with a hospitalized TB patient, he or she should visit before the patient leaves the hospital. If the patient leaves the hospital before the health care worker can get there, he or she should visit the patient at home as soon as possible. Health care workers should remember to follow infection control precautions while visiting a potentially infectious patient. These precautions may include using a personal respirator.

During the first meeting, the health care worker should get to know the patient, educate the patient about TB, learn the names of the patient’s close contacts so a contact investigation can begin, and look for factors that may affect the patient’s adherence to treatment. The information the health care worker finds out in this meeting is confidential; he or she should follow the agency’s or clinic’s rules for keeping patient information confidential (see Module 7, Confidentiality in Tuberculosis Control).

.....
At the start of treatment he or she should tell the patient about nonadherence and how it causes treatment failure and further TB transmission, then listen to the patient’s response and identify and resolve any barriers to adherence.
.....

The health care worker should discuss the treatment plan with the patient. At the start of treatment he or she should tell the patient about nonadherence and how it causes treatment failure and further TB transmission, then listen to the patient’s response and identify and resolve any barriers to adherence. For example, the health care worker can correct misinformation, reduce side effects by giving drugs at different times, or provide easy-to-open containers (with no safety locks). Remember, any changes in the TB regimen must be approved by the supervisory clinical and management staff.



.....
If the patient does not understand the importance of finishing treatment, adherence will be very difficult.

.....
One way that health care workers can learn about the differences between a patient’s beliefs and their own beliefs is to ask several open-ended questions.

.....
An open-ended question is one that cannot be answered with a simple “yes” or “no.”

Patient Assessment

When 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 importance of finishing treatment, adherence will be very difficult. Therefore, the health care worker should identify differences between what he or she believes and what the patient believes early in treatment. That way, the health care worker will have time to address the patient’s concerns and needs, correct any misconceptions, and provide the necessary education.

Open-ended questions. One way that health care workers can learn about the differences between a patient’s beliefs and their own beliefs 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 demand an explanation, like

- 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. Such questions are used when a health care worker needs to explore complex issues that do not have a finite or predetermined set of responses.



The questions in Table 9.1 have been used by some TB programs to assess TB patients' knowledge, beliefs, and attitudes regarding TB, and adherence to TB medicine. They may help the health care worker better understand the patient's views and suggest areas in which the patient needs education. They may also give the health care worker some idea of the patient's ability to adhere to a treatment regimen. For example, asking a patient what problems the illness has caused him or her can help the health care worker assess important factors such as the strength of family and social support; potential job-related problems; and, to some extent, the problem-solving skills of the patient.

Table 9.1
Examples of Open-Ended Questions for Patient Assessment

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



.....
Adapt questions according to the patient’s age, family situation, education level, and cultural background.
.....

Open-ended questions such as these are very useful during the initial health assessment and later during other interactions with the patient during the course of treatment. Throughout treatment, the health care worker should ask the patient about his or her concerns about TB and adherence to the TB regimen. The questions listed in Table 9.1 are a starting point only. Whenever possible, the health care worker should adapt such questions according to the patient’s age, family situation, education level, and cultural background. Remember that the more the health care worker is aware of the patient’s ideas and concerns about TB and its treatment, the better prepared the health care worker will be to anticipate and resolve problems that can arise.

.....
It is important that the patient be able to trust the health care worker.
.....

Trust. It is important that the patient be able to trust the health care worker. The patient will feel comfortable sharing his or her thoughts if the health care worker

- # Listens carefully to the patient and pays attention to hesitations, inconsistencies, or strong emotions
- # Speaks openly, honestly, and politely about differences in ideas; corrects the patient’s misconceptions tactfully and allows time for questions if he or she doesn’t understand fully
- # Shows the patient proof of what is being said, such as chest x-rays or laboratory reports, whenever possible
- # Involves the patient in the development of the treatment plan and is flexible in meeting the patient’s needs



.
Knowing and respecting the
patient's views will improve
the working relationship and
make the patient more likely
to be adherent.
.

When a patient's ideas are different from the health care worker's, the health care worker should accept that the patient has different views, and then make sure the patient knows the health care worker's point of view about TB. Health care workers can make it clear that even if they do not share the patient's views, they respect them. Knowing and respecting the patient's views will improve the working relationship and make the patient more likely to be adherent.

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 form of communication can also negatively affect the health care worker's relationship with the patient. The health care worker should be objective and nonjudgmental.



Study Questions 9.7-9.8

9.7. Describe a case management system.

9.8. To address the patient's specific needs, what kind of things does the health care worker need to learn about the patient?

Answers on pages 94-95.



Study Questions 9.9-9.10

9.9. How soon should the health care worker talk with the patient to begin the assessment?

9.10. What is an open-ended question and how can it help the health care worker learn about a patient?

Answers on page 95.



Study Questions 9.11-9.12

9.11. In the list below there are close-ended and open-ended questions. Mark an X for each open-ended question that the health care worker can ask the patient to find out his or her ideas and feelings about TB.

___ 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?

9.12. Why is it important to assess the patient's knowledge, beliefs, and attitudes regarding TB and adherence to TB medicine?

Answers on page 96.



Case Study 9.1

Mr. Howard is unemployed and homeless. The homeless shelter Mr. Howard frequents recently sent him to the hospital because he had TB symptoms. He was diagnosed with TB and admitted to the hospital for TB treatment. The hospital's infection control nurse immediately telephoned a TB case report to the health department TB clinic.

Mr. Howard remained in the hospital for 5 days. On the day he was discharged, a nurse instructed Mr. Howard to go to the TB clinic the following morning for an evaluation and a supply of medicine. He failed to keep the appointment.

A health care worker had been assigned to find Mr. Howard when his case was reported. When Mr. Howard missed his appointment, she set out to locate him and persuade him to come to the clinic. She eventually found him in a crowded bar, where she scolded him for his careless behavior and ordered him to return with her to the clinic.

What should the health care worker have done differently?

How can the health care worker get to know Mr. Howard better in order to assess potential adherence problems?

Answers on pages 110-111.



Case Study 9.2

Michael, 45 years old, is a cook at a local fast food restaurant. He went to see his physician because he was feeling fatigued, was unable to sleep, had lost his appetite, and had been coughing for several weeks. His physician suspected tuberculosis and admitted Michael to the hospital for further tests.

His sputum smears were positive for AFB and he was started on appropriate therapy. The physician called the local health department to report the diagnosis. A case manager was assigned and asked a health care worker to visit Michael in the hospital. The health care worker visited Michael in the hospital the next day.

How would you assess Michael's knowledge, beliefs, and feelings about TB disease and treatment?

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

Answers on pages 111-113.



Educating the Patient

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To be meaningful, health information must be right for each patient’s knowledge and awareness of the problem.
.....

.....
Education is an interactive process that requires the health care worker to take into account the specific needs of each patient.
.....

.....
The health care worker should help patients find ways to identify and deal with potential adherence problems.
.....

Explaining the Importance of Adherence

Giving patients the health information they need is a challenge for health care workers. As patients first learn of their new TB diagnosis, they may not be ready for detailed information on medications, side effects, and diagnostic procedures. All people go through different stages of absorbing information and changing their behavior based on this information. To be meaningful, health information must be right for each patient's knowledge and awareness of the problem.

For example, persons who do not know they are at risk for TB may not be aware of or concerned about the need for a tuberculin skin test. When people are worried about their risk for TB, they may become interested in learning how to get a skin test. Education is an interactive process that requires the health care worker to take into account the specific needs of each patient.

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 can be good for the patient and for others. For example, adhering to therapy can help a patient feel better sooner, cure their TB, and help them return to normal activities. Likewise, a patient’s adherence to therapy can prevent the further spread of TB to family, friends, coworkers, and the general public, and can prevent the development and spread of multidrug-resistant TB.



.....
Patients are more likely to be adherent if they help make the decisions and choose the solutions rather than being told what to do.

.....

.....
Patients are more likely to pay attention to information that is relevant to their needs and does not require abrupt changes in their behavior.

.....

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 find ways to identify and deal with 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 likely to pay attention to information that is relevant to their needs and does not require abrupt changes in their behavior. In general, patients may be more likely to follow the treatment plan if they understand their illness and the benefits of treatment.

Before the health care worker begins educating a patient about TB, he or she should find out how much the patient may already know about TB. Refer back to Table 9.1 for suggested open-ended questions that can help determine patient TB knowledge. For example, it is important to know what a patient thinks causes TB before the health care worker discusses the need for treatment with drugs.

Patients may have little or no knowledge about TB and TB treatment or may have misconceptions about TB or TB treatment. For example, some patients may not know that TB can be cured most of the time by adhering to treatment. Likewise, others may be confused about the difference between TB infection and TB disease.



.....
To be certain a patient has an accurate understanding, the health care worker should ask the patient what has just been explained and what is understood.
.....

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 certain a patient has an accurate understanding, the health care worker should ask the patient what has just been explained and what is 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.

Effective Communication Techniques

In presenting new information, health care workers should use effective communication 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 from the patients
- # Use concrete examples
- # Make the interaction with the patient a positive experience

.....
Use simple, nonmedical terms in explanations, and be specific about the behaviors that are expected.
.....

Use simple, nonmedical terms in explanations, and be specific about the behaviors that are expected. For example, it is much more helpful to say, “This pill will help 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.
.....

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 very basic materials. Highly educated patients may prefer more detailed information. If a patient does not read or write, health care workers should give instructions orally and leave visual cues or reminders, such as a snapshot of each medication, with the time the patient should take it written in large numbers.

.....
Limit the amount of information given at any one time.
.....

Limit the amount of information given at any one time. If too much information is given, the patient may not remember any of it. To avoid overwhelming the patient, the topics to be discussed should be organized in the order of their 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.
.....

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 capsules every day.” This information should be reviewed before leaving the patient.



.....
Repeat important information.
.....

Repeat important information. Some data indicate that 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 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 from the patients to be sure they received and understood the message.
.....

Listen to feedback and questions. Communication with the patient should always be two-way. This means that the health care worker should listen to feedback and questions from the patient to be sure they received and understood the message. The health care worker should use open-ended questions to assess the patient’s knowledge and beliefs.

.....
Use concrete examples to make information easy to remember.
.....

Use concrete 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 patients do every morning, such as brushing their 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.
.....

Make the interaction with the patient a positive experience. It’s 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. The health care worker’s warm, concerned, and respectful attitude toward the patient will make the experience more pleasant for both and will render the treatment more effective.



Study Question 9.13

9.13. List eight effective communication techniques that can help the health care worker present new information to patients.

Answer on pages 97-98.



Case Study 9.3

Willie, a 40-year-old construction worker, was just diagnosed with TB. The health care worker has completed her initial assessment and learned that Willie is very upset because he thinks he is going to die. He knows very little about TB, except he remembers his grandfather “wasting away” and dying from TB when he was young. He has a 2-year-old son at home who he is afraid will also die from TB. Willie did not complete school beyond the 8th grade. He is worried that he will lose his job once his employer learns he has TB.

The health care worker needs to educate Willie about TB and its treatment.

- **What should the health care worker do to effectively communicate with Willie?**

Answers on pages 113-114.



Working with an Interpreter

.....
If an interpreter is used, there can still be problems getting accurate, unbiased information and protecting the patient's confidentiality.
.....

Importance of Interpretation

The health care worker and the patient can have serious problems understanding each other if they do not speak the same language. If an interpreter is used, the health care worker can still have problems getting accurate, unbiased information and protecting the patient's confidentiality. For example,

- # Interpreters may not state accurately what the health care worker and the patient have said
- # Interpreters sometimes add their own ideas of what has been said
- # The patient might be uncomfortable talking about personal information that he does not want a third person, the interpreter, to know
- # Interpreters may have difficulty finding equivalent words or translating medical terms into the patient's language

.....
It is best to use trained medical interpreters whenever possible.
.....

Selecting interpreters. It is best to use trained medical interpreters whenever possible (Figure 9.1). If a trained interpreter is not available, other persons who are sometimes used as interpreters are other health care workers who speak the patient's language, the patient's family members, or people from the patient's community. If an interpreter is unavailable when the health care worker makes a home visit, the health care worker should call back to the office or clinic to see if someone there could translate for them over the telephone.



Figure 9.1 Health care worker interviewing a patient with the assistance of an interpreter

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

There are problems with using family members and some community members as interpreters because they are usually unfamiliar with medical terms. Also, they will hear personal information about the patient, and it is difficult to make sure that the information will be kept confidential. Occasionally, an interpreter who is familiar with the patient might know something about the patient that the patient does not wish to share with the health care worker. This could cause a conflict between the interpreter and the patient. If family members must be used to interpret, **children should not be used**; they will hear personal information and may be asked to translate things that the family feels children should not discuss, and this can be upsetting.



.....
If the health care worker knows a few words of the patient’s language, he or she should use them.
.....

.....
Meet with the interpreter before the interview to talk about the goals for the interview and to give instructions and guidance.
.....

.....
Remind the interpreter that all information in the interview is confidential.
.....

.....
Keep the messages simple and factual; use short phrases and focus on one topic at a time.
.....

Using the patient’s language. If the health care worker knows a few words of the patient’s language, he or she should use them. It will show respect and interest and make the patient feel more comfortable. If the health care worker works in an area with a large number of patients who do not speak English, the health care worker could consider learning their language, or at least some greetings and key words and phrases that are often used in TB prevention.

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 as exactly as possible
- # Give the patient time to answer questions

When a health care worker is serving as an interpreter for another, he or she should follow these guidelines:

- # Translate the patient's own wording as much as possible to give the health care worker a better idea of the patient's concept of TB
- # Remember that all information the health care worker hears is confidential
- # Be respectful of both health care worker and patient
- # Try to ensure that the health care worker and patient completely understand each other
- # When the health care worker does not understand, try to explain cultural and social issues that are affecting the patient's health



Study Questions 9.14-9.15

9.14. If the health care worker uses an interpreter, what are four problems the health care worker may encounter?

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

Answers on pages 98-99.



Case Study 9.4

Angelina, a 35-year-old Hispanic migrant farm worker, was referred to the health department by a local community college. The college conducted a health fair for the migrant farm workers at a farm in the area. Angelina's skin test was positive at 25 mm of induration. When asked about her health, she told the health fair staff that she had been coughing for a couple of weeks, felt tired, and had lost some weight.

After much coaxing by the health fair staff, Angelina, who speaks very little English, arrives at the health department for further tests. With her are her two 11-year-old twins. The twins speak English. No one in the TB program at the health department speaks Spanish, but the health care worker remembers that a nurse in the Maternal and Child Health program speaks Spanish.

- Who would you ask to interpret?

The nurse in the Maternal and Child Health program agrees to help the health care worker translate. He says he only has 5 minutes to spare. The nurse and the health care worker rush into the room where Angelina and her twins are waiting. The nurse begins to speak to Angelina without any prompting from the health care worker. Angelina looks startled and is reluctant to answer any questions. When Angelina does answer questions, the nurse does not seem to be listening to Angelina completely. He keeps cutting her off.

- # What should the health care worker have done differently?

- # What are some instructions the health care worker could have given to the nurse before the interview?

Answers on pages 114-116.



Using DOT to Improve Adherence

.....
DOT is the most effective strategy for making sure patients take their medicines.
.....

.....
DOT should be considered for all patients because it is difficult to reliably predict which patients will be adherent.
.....

.....
Many programs have substantially improved completion rates after deciding to make DOT the standard of care for TB treatment.
.....

Directly Observed Therapy (DOT)

A component of case management that helps to ensure that patients adhere to treatment is directly observed therapy (DOT). DOT is the most effective strategy for making sure patients take their medicines. DOT means that a health care worker or other designated individual watches the patient swallow every dose of the prescribed drugs. DOT should be considered for all patients because it is difficult to reliably predict which patients will be adherent. Even patients who intend to take their medicine might have trouble remembering to take their pills every time. All DOT visits should be documented. In many health departments, DOT is the standard of care. Figure 9.2 is an example of a form used to monitor and document a patient’s DOT.

Many TB programs use their area treatment completion rates to decide how to implement DOT. If the percentage of patients who finish therapy within 12 months is less than 90%, or is unknown, programs will often increase the use of DOT. Many programs have substantially improved completion rates after deciding to make DOT the standard of care for TB treatment.



Directly Observed Therapy Log For the Month of _____

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								
7								
8								
9								
10								
11								
12								
13								
14								
15								
16								
17								
18								
19								
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21								
22								
23								
24								
25								
26								
27								
28								
29								
30								
31								

MEDS TAKEN (NUMBER OF DAYS): _____ / AVAILABLE DAYS: _____ = _____ % ADHERENCE
--

Figure 9.2 Sample DOT form.



.....
All patients should be considered for DOT.
.....

All patients should be considered for DOT. However, there are certain groups of patients for whom DOT is often the best option, regardless of local treatment completion rates. These groups include

- # Patients with drug-resistant TB
- # Patients receiving intermittent therapy
- # Persons at high risk for nonadherence, such as
 - 9 Homeless or unstably housed persons
 - 9 Persons who abuse alcohol or illicit drugs
 - 9 Persons who are unable to take pills on their own due to mental, emotional, or physical disabilities
 - 9 Children and adolescents
 - 9 Persons with a history of nonadherence

.....
More and more TB programs are using DOT for LTBI.
.....

DOT for Latent TB Infection (LTBI)

In addition, more and more TB programs are using **directly observed treatment for latent TB infection (LTBI)**. DOT for LTBI is for persons who are at especially high risk of developing TB disease such as young children, and HIV-infected and other immunosuppressed persons.

DOT for LTBI is appropriate in institutions and facilities where pill ingestion can be observed by a staff member or for household contacts of a TB patient who is on DOT. Because persons taking treatment for LTBI have no symptoms of TB disease, it is very important that they understand the need for medication so that they are motivated to start and finish DOT for LTBI.



.....
The use of DOT for LTBI is one strategy that can improve patients' adherence to the regimen.
.....

Recent data indicate low completion rates among patients on regimens for treatment for LTBI. 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 the priority over DOT for LTBI.

.....
If resources are limited, DOT for TB disease should be the priority over DOT for LTBI.
.....

Tasks Involved in Delivering DOT

DOT for TB disease and DOT for LTBI are both more than watching the patient swallow each pill, although that is the crucial component of a DOT program. At each DOT encounter, the health care worker should perform the following tasks:

.....
DOT is more than watching the patient swallow each pill, although that is the crucial component of a DOT program.
.....

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

Table 9.2 details the tasks involved in a specific DOT encounter.



Table 9.2
Tasks Involved in Delivering DOT

Task	Description
Check for side effects	At each visit, before the drugs are given, the health care worker should ask if the patient is having any adverse side effects. Patients being treated for TB should be educated about symptoms indicating adverse reactions to the drugs they are taking, whether minor or serious. If the patient has symptoms of serious adverse reactions, a new drug supply should not be given; the patient should stop taking medication immediately (see Module 4, Treatment of Tuberculosis Infection and Disease, for more information on adverse reactions to TB medication). The supervisor should be told that the drugs were not given, and the prescribing clinician should be notified about the adverse reaction. The health care worker should arrange for the patient to see the clinician as soon as possible.
Verify the 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 the pills	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. 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.
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.



Often, DOT programs also include a number of other case management functions, such as

- # Helping patients keep appointments
- # Providing effective education to patients and key individuals in the patient's social environment
- # Offering incentives to encourage adherence
- # Providing social services to ensure patient's needs are being addressed so adherence to therapy can become a priority

For example, some DOT programs provide an array of services including DOT provision in locations convenient to patients, incentives and enablers to encourage patients to take medications, help in finding housing for homeless patients, a system to keep track of patients through hospital discharge planning, and a method of tracking inmates released from jail or prison. Other DOT programs include specially trained community service aides; transportation of patients to clinics; delivery of drugs to the patient's home, workplace, or other convenient site; and intermittent regimens after the patient completes an initial period of daily treatment.



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

.....

.....
When a patient cannot easily get to the TB clinic, the health care worker must go to the patient.

.....

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. **Clinic-based DOT** is delivered in a TB clinic or comparable health care facility (Figure 9.3). For some patients, DOT must not interfere with the patient’s work schedule, so DOT can be provided in a nonclinical setting or during nonbusiness hours. 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 health care facility is called **field-based DOT** (Figure 9.4 and Figure 9.5). Field DOT can be given at almost any site:

- # The patient’s home
- # The patient’s workplace
- # A public park or other agreed-upon public location
- # A school
- # A restaurant



Figure 9.3 Clinic-based DOT.



Figure 9.4 Field-based DOT in the patient's home.

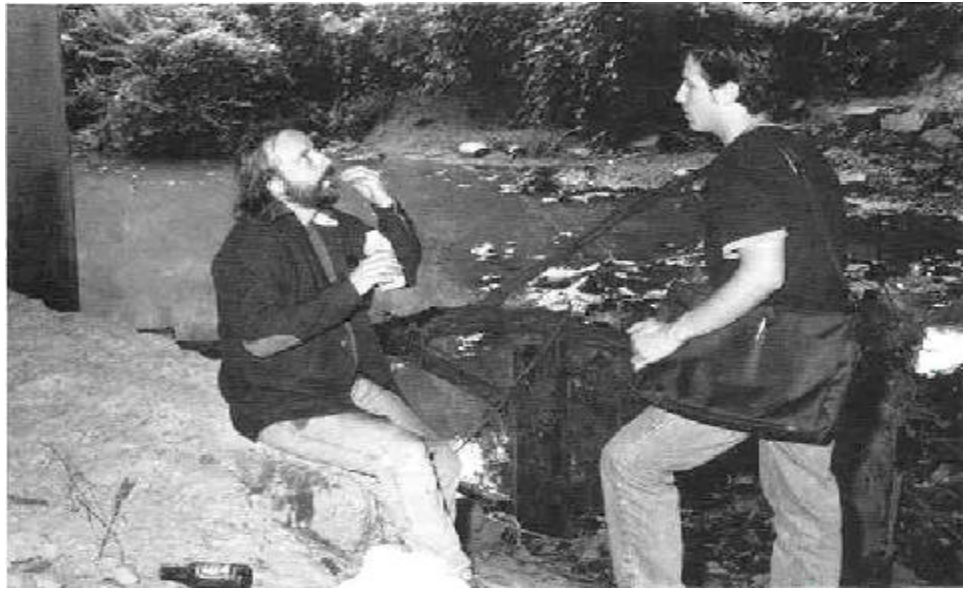


Figure 9.5 Field-based DOT at an agreed-upon public location.

.....
DOT is usually given by TB
clinic personnel such as a
nurse or other health care
worker.
.....

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



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

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, work supervisors, 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.

Other persons can provide DOT, if the patient agrees to this arrangement.

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 should choose another location. Another critical consideration for conducting field DOT is the health care worker’s own security. 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.

When conducting field DOT it is always important to protect the patient’s confidentiality; another critical consideration is the health care worker’s own security.



.....
Health care workers should watch for tricks or techniques some patients may use to avoid swallowing medication.
.....

Health care workers should watch for tricks or techniques some patients may use to avoid swallowing medication, such as hiding pills in the mouth and spitting them out later, hiding medicine in clothing, or vomiting the pills after leaving the clinic. 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 the clinic so the medication can dissolve in the patient’s stomach.

.....
DOT ensures that the patient completes an adequate regimen, lets the health care worker monitor the patient regularly, helps the health care worker solve problems, and helps the patient become noninfectious sooner.
.....

Advantages and Disadvantages of DOT

DOT has many advantages and disadvantages (Table 9.3). When used as a collaborative effort with the patient, DOT has many advantages over self-administered therapy:

- # It ensures that the patient completes an adequate regimen
- # It lets the health care worker monitor the patient regularly for side effects and response to therapy
- # It 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

Often patients who have successfully completed DOT are willing to describe their experience or share it with new patients. If this can be arranged, former patients may help encourage new patients to participate in the DOT program. Before the patients are introduced, both parties should provide prior approval to avoid a breach in confidentiality (see Module 7, Confidentiality in Tuberculosis Control).



DOT does have a few disadvantages because it

- # Is time consuming
- # Is labor intensive
- # Can be 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 punitive.

It is important to explain the benefits of DOT to each patient and stress the fact that DOT is not punitive; 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.

Table 9.3
Advantages and Disadvantages of DOT

Advantages	Disadvantages
# It ensures that the patient completes an adequate regimen	# It is time consuming
# It lets the health care worker monitor the patient regularly for side effects and response to therapy	# It is labor intensive
# It helps the health care worker solve problems that might interrupt treatment	# It can be insulting to some patients
# By ensuring the patient takes every dose of medicine, it helps the patient become noninfectious sooner	# It can imply that the patient is incapable or irresponsible
	# It can be perceived as demeaning or punitive



Study Questions 9.16-9.18

9.16. What is DOT?

9.17. Who should be considered for DOT?

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

Answers on pages 99-101.



Study Questions 9.19-9.20

9.19. Name at least five places where DOT can be given.

9.20. What are four advantages of DOT?

Answers on pages 101-102.



Case Study 9.5

You are assigned to deliver DOT to Mrs. Wilson, a 76-year-old woman who lives alone in the house 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 her home to help her take her medication. Mrs. Wilson is elated to have some company. She happily offers you cookies and wants to “talk awhile” before she takes her medication.

What are the tasks you complete when you deliver DOT to Mrs. Wilson?

Answers on page 116.



Using Incentives and Enablers to Improve Adherence

.....

Incentives and enablers help patients stay with and complete treatment.

.....

.....

Incentives are small rewards given to patients to encourage them to either take their own medicines or keep their clinic or field DOT appointments.

.....

.....

Enablers are those things that make it possible or easier for the patients to receive treatment by overcoming barriers such as transportation difficulties.

.....

.....

Incentives and enablers should be chosen according to the patients' special needs and interests.

.....

.....

The best time to begin using incentives is after a good relationship has been established with a patient.

.....

Incentives and Enablers

Just offering a DOT program is not enough. Patients must agree to participate in taking their medicine and stick with it. Incentives and enablers may help them do this. **Incentives** are small rewards given to patients to encourage them to either take their own medicines or keep their clinic or field DOT appointments. **Enablers** are those things that make it possible or easier for the patients to receive treatment by overcoming barriers such as transportation difficulties. Incentives and enablers are widely used in facilities providing TB services; they help patients stay with and complete treatment. Table 9.4 is a list of examples of incentives and enablers, and Figure 9.6 shows examples of incentives.

Incentives and enablers should be chosen according to the patients' special needs and interests, or the patients may not care if they receive them. 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. If transportation is not a problem, then he or she should offer something that is needed. Learning as much as possible about patients will help to identify their needs and interests and better motivate them to complete treatment. The best time to begin using incentives is after a good relationship has been established with a patient. Enablers, however, may be vital to the initiation of treatment and should be provided as soon as treatment starts.



Table 9.4
Examples of Incentives and Enablers

Money	Automotive	Household	Personal care
	Battery	Paying rent or mortgage	Contraceptives (e.g., condoms)
Food	Gasoline	Wood stove	Razor blades
Fast food	Motor oil	Kerosene	Shaving cream
Sandwiches	Fishing supplies	Fuel oil for heat	Face cream
Canned food	Fishing pole	Smoke alarm	Makeup
Food vouchers	Cricket	Cooking utensils	Nail polish
Applesauce or pudding (to mix medicine in)	Worms	Furniture	
Fruit	Services	Transportation	Garden
Homemade cakes and cookies	Social service referrals	Bus and subway fare	Flowers
Ice cream	Help in obtaining housing, social security, food stamps	Taxi fare	Flower bulbs
Beverages	Help in obtaining drug treatment	Bicycle	For children
Soft drinks	Help in paying rent	Paying friend for transportation	Toys
Juices	Help in obtaining other medicines	Transportation provided by staff	Reading stories
Milk	Child care	Seasonal	Painting child's nails
Nutritional supplements	Help in obtaining birth certificate	Special seasonal treats	Tea party
Coffee	Washing patient's clothes	Homemade Valentine cookies	Playing games
Tea	Help in obtaining driver's license	Easter baskets	Charts with stars and stickers
Clothing	Repairing bicycle	Food baskets	Stuffed animals
Socks		Birthday cakes and cards	Grab bag with assorted treats
Gloves			Chewing gum
Stockings			School supplies
Sweaters			Storybooks
Coats/Scarfs			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 9.6 Examples of incentives and enablers

.....
Programs can obtain
incentives and enablers from
many different sources.
.....

Sources of Incentives and Enablers

Programs can obtain incentives and enablers from many different sources. Possible resources 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
- # 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



For example, one TB clinic asked for donations from area businesses to add to their existing program. Some of the popular donations were recently or soon-to-be expired dietary supplements, pillows and blankets from a hospital, food coupons from area restaurants, and athletic shoes and clothes from an area manufacturer. Another TB control program paid the rent for a family’s house for one month to avoid eviction and possible disruption of therapy.

Barriers to Using Incentives

Some health care workers disagree about whether or not incentives should be used. The attitude one has about incentives is important. Some health care workers do not like using incentives because they think patients should want to get well and should consider it their duty to take their medicine. They believe that incentives are bribes.

.....
The reason for using incentives is to motivate the patient to complete treatment.

.....

.....
Incentives and enablers are not a substitute for a high-quality relationship with patients.

.....

At times, patients may also feel that the health care worker is trying to bribe them into accepting treatment. This is more likely to happen if the health care worker has not gained the patient’s trust, and has offered incentives before getting to know him or her. When incentives are used with an attitude of caring and concern for the patient, the patient will be less inclined to question the health care worker’s motives. The reason for using incentives is to motivate the patient to complete treatment. Above all, incentives and enablers are not a substitute for a high-quality relationship with patients based on trust, effective communication, and mutual respect. Many programs have shown success using incentives and enablers.



Study Questions 9.21-9.23

9.21. What are incentives and enablers, and what are their purposes?

9.22. How does a health care worker determine which incentives and enablers to use for each patient?

9.23. What are some sources of incentives and enablers?

Answers on page 102.



Case Study 9.7

Mrs. Chan has active pulmonary TB and is very reluctant to participate in the DOT program. She is afraid she will die from her disease, and is very anxious. Because of difficulties she had when she immigrated 5 years ago, Mrs. Chan doesn't trust health department staff or any other government employee.

A health care worker is assigned Mrs. Chan's case while she is hospitalized. During a visit to the hospital, the health care worker explains to Mrs. Chan that she is being offered DOT so that she will never forget to take her medicine. If she follows all the health care worker's instructions, Mrs. Chan will receive a supply of dietary supplements at each meeting and \$100 at the end of treatment. Mrs. Chan smiles and nods.

The health care worker is very surprised when Mrs. Chan doesn't show up for her first DOT appointment.

What can happen if a health care worker offers Mrs. Chan incentives before gaining the patient's trust?

How might the health care worker have done a better assessment interview with Mrs. Chan?

Answers on pages 118-119.



Improving Adherence with Children and Adolescents

.....
The health care worker should do everything that can be done to make sure that parents support their children’s TB treatment.
.....

Working with Parents and Caregivers

To improve adherence in children and adolescents, the health care worker should work with the parents or caregivers. The health care worker cannot assume that parents will give medications to their children as prescribed; sometimes they do not. The health care worker should do everything possible to make sure that parents support their children’s TB treatment, including

- # Educate parents
- # Warn parents of possible problems
- # Give DOT
- # Use incentives and enablers
- # Give TB drugs in easy-to-take preparations

.....
Educate parents of children and adolescents with TB disease.
.....

Educate parents of children and adolescents with TB disease. By assessing their knowledge and beliefs about TB, the health care worker can address concerns and needs, correct misconceptions, and help parents understand their child’s disease. If both the patient and his or her parents are knowledgeable about TB, the patient is more likely to successfully complete a regimen.

.....
Warn parents about the problems their children might have during TB treatment.
.....

Warn parents about the problems their children might have during TB treatment. Children may resist taking medications, may have adverse reactions to the medications, and may have problems swallowing pills and capsules (the common form of TB medications). When parents know in advance about problems that can come up during their child’s treatment, they can cope with and help solve problems as they arise.



.....
Give DOT to children with TB when parents' or caregivers' compliance with giving medications as prescribed cannot be ensured.
.....

.....
Use incentives and enablers to encourage a child to take medicine.
.....

.....
Give TB drugs in easy-to-take preparations.
.....

Give DOT to children with TB when parents' or caregivers' compliance with giving medications as prescribed cannot be ensured.

Use incentives and enablers, such as coloring books and toys, to encourage a child to take medicine. Giving incentives to parents and caregivers should be considered, too; this will encourage and reward their participation.

Give TB drugs in easy-to-take preparations. Rifampin can be made into a liquid suspension. Isoniazid can also be prepared as a suspension, although its stability varies. The health care worker can discuss the use of liquid medications with the patient's clinician. Isoniazid and pyrazinamide pills can be crushed and given with small amounts of food.

Although adolescents can be responsible for taking their own medications, they are also frequently nonadherent. They may be embarrassed about having to take TB medications because they are concerned about what their friends think. Also, they may not feel threatened by TB and may not take the condition seriously. For these reasons, adolescents are a high priority group for DOT.

Individualized treatment plans are needed for children and adolescents. Health care workers should be watchful in monitoring adherence and creative in finding ways to ensure adherence.



Study Questions 9.24-9.25

9.24. What are five ways the health care worker can help parents improve adherence in children?

9.25. Why are adolescents at high risk for nonadherence?

Answers on page 103.



Problem Solving

Behavioral Diagnosis

The goal of patient education is to help change patients' behaviors by teaching them the importance of following the treatment plan. However, past experience has shown that patient education alone is often not enough to ensure adherence. Problems such as scheduling conflicts or being inadequately motivated to adhere can lead to treatment failure even in a patient who is quite knowledgeable about TB disease. (In fact, health care workers have been known to fail to adhere to TB treatment!)

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To help patients complete treatment, the health care worker will need to assess the extent to which problems present barriers to adherence.

.....
A behavioral diagnosis for each patient can be used to identify the specific reasons why a patient is not being adherent and to develop strategies to improve each patient's treatment plan.

To help patients complete treatment, the health care worker will need to assess the extent to which such problems present barriers to adherence. A **behavioral diagnosis** can be used to find out what is causing a patient to have problems with adherence and to develop strategies to improve each patient's treatment plan. Table 9.5 presents some examples of this approach. The purpose of doing a behavioral diagnosis is to 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 devise an individualized plan of action to overcome the difficulties and promote adherence. Table 9.6 provides some additional methods to improve adherence through quality of interactions with the patient, patient education, treatment, and clinic operations.



Table 9.5
Behavioral Diagnosis: A Tool for Enhancing Adherence

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 # 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 # Be accessible throughout care # Work on attitudes about patients and DOT # Change health care workers # Provide social services
Lack of money to pay for health care	# 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
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



Table 9.6
A Quick Reference: Methods to Improve Adherence

Issues	Improvement Methods
Quality of interaction with the patient	<ul style="list-style-type: none"> # Create a partnership. # Ask patients when and how they take TB drugs, and what they take. Don't assume they are adherent. # Give each patient adequate time at every visit. # Don't intimidate or frighten the patient; be positive. # Get oral and written commitments from the patient. # Treat the person, not just the disease. # Understand and address different cultural values and beliefs. # Adapt treatment to lifestyle. # Make social service referrals.
Patient education	<ul style="list-style-type: none"> # Give vital information first in the patient interview. # Be clear with instructions; the patient is likely to be anxious after hearing the diagnosis. # Follow oral instructions with written instructions. # Be clear from the start about the length of the regimen. # Don't overload the patient with too much information at one time; avoid jargon. # Use educational materials that are culturally and linguistically appropriate for the patient. # Be alert for signs or indications that the patient may not be literate. # Assess the patient's beliefs about TB; when possible, integrate beliefs into the treatment plan. # Review instructions; ask patient for feedback to ensure understanding. # Describe the specific adherence behaviors required. # Clarify the patient's questions and respond clearly.
Treatment	<ul style="list-style-type: none"> # Schedule the initial appointment soon after diagnosis. # Use appointment reminders. # Follow up quickly on missed appointments. # Tailor the regimen to the patient's needs; allow the patient some options. # Keep the regimen as simple as possible. # Give clear instructions about medication side effects.
Clinic operations	<ul style="list-style-type: none"> # Ensure a physical environment that is comfortable to patients. # Ensure that staff are polite and courteous with patients and culturally sensitive. # Ensure that schedules and practices are tailored to the patients' needs. # Ensure that record keeping, pharmacy, and lab services are quick and easy for patients. # Nurture staff morale; provide training as needed. # Provide for strict confidentiality of patient information. # Provide appropriate services that match the demographic features of the patient population (e.g., meals or snacks for homeless patients). # Provide interpreters, if needed.

Adapted from Sumartojo E. Adherence to the tuberculosis treatment plan. In: Cohen FL, Durham JD, eds. *Tuberculosis: A Sourcebook for Nursing Practice*. New York, NY: Springer Publishing Co.; 1995: chap 7.



.....
Sometimes cultural, religious, or other personal beliefs affect a patient’s TB treatment. It is important for the health care worker to sincerely respect the beliefs of the patient.

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.....
If the patient thinks that the health care worker does not respect his or her beliefs, it could cause the patient to distrust the health care worker.

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.....
A discussion about the patient’s beliefs and health practices may help the health care worker to individualize treatment.

.....

Discuss Different Health Beliefs with Patients

Sometimes cultural, religious, or other personal beliefs affect a patient’s TB treatment. It is important for the health care worker to sincerely respect the beliefs of the patient. Sometimes patients seek medical advice from folk healers or alternative practitioners. The health care worker may encounter patients who use folk remedies along with their prescribed medications. For example, in some Asian cultures, TB medicines are considered “hot” and need to be countered with something “cold,” such as green leafy vegetables.

Take the time to learn about the patient’s cultural beliefs. If the patient thinks that the health care worker does not respect his or her beliefs, it could cause the patient to distrust the health care worker. A patient may come from a background that includes the use of **alternative medicine** (health care other than conventional, scientifically tested, medicinal treatment including herbal remedies, yoga, meditation, acupuncture, and other practices intended to maintain or improve health). Likewise, the patient may practice **folk medicine** (medicinal beliefs, knowledge, and practices associated with a particular culture or ethnic group. Folk medicine is usually handed down by cultural tradition and practiced by health care workers specially trained in that tradition; not all members of a given culture or ethnic group will use its folk medicine practices). The health care worker should find out if there are barriers to the acceptance of conventional medical practices. A discussion about the patient’s beliefs and health practices may help the health care worker to individualize treatment so that it is acceptable to the patient.



.....
When folk or alternative practices are safe, health care workers should consider including them in the treatment plan.
.....

When folk or alternative practices are safe, health care workers should consider including them in the treatment plan. For example, some people believe in the healing power of prayer. These persons may be more willing to take medications after saying a brief prayer, so accepting their belief in prayer is an important aspect of treatment. If a patient is taking an herbal remedy, the health care worker should check with the patient's physician or pharmacist to be sure it will not cause side effects or interact adversely with the patient's TB drugs. He or she should ask patients who have concerns about nutrition supplements or interactions with TB drugs to discuss this with their 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 TB drugs for a full course of treatment.
.....

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 TB drugs for a full course of treatment. 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.



.....
The health care worker must recognize the important role of the patient in making decisions about treatment.
.....

.....
Treat the patient with dignity and respect.
.....

Develop a Partnership with the Patient

Patients make independent decisions every day about whether they will take medication or participate in DOT. The health care worker must recognize the important role of the patient in making decisions about treatment. For this reason, the health care worker should develop a partnership with the patient. Effective partnerships call for specific behaviors from the health care worker:

- # Listen and try to understand the patient’s knowledge, beliefs, and feelings about TB disease and treatment
- # Be open minded about the patient’s beliefs and cultural expectations
- # Recognize and address the patient’s fears about the illness
- # Understand and fulfill the patient’s expectations about treatment, when possible
- # Communicate clearly so that the patient can understand the messages
- # Avoid criticizing the patient’s adherence behavior; suggest behavior changes respectfully
- # Treat the patient with dignity and respect
- # Be consistent in what is done and told to the patient



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

Encourage the Patient to Seek Support

The support of family, friends, and health care workers can be important to patients trying to complete 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. Such persons might include

- # Family members
- # Friends
- # Teachers
- # Social workers
- # Landlords
- # Clergy
- # Neighbors

.....
With the patient’s permission, family members, friends, or others may be included in educational sessions.
.....

With the patient’s permission (because of the patient’s right to privacy), family members, friends, or others may be included in educational sessions so that they also understand the patient’s diagnosis, and what he or she needs to do. However, a health care worker should avoid making a family member responsible for the patient’s adherence; this may be an unfair burden.

.....
A health care worker should avoid making a family member responsible for the patient’s adherence; this may be an unfair burden.
.....

On the other hand, parents, spouses, or others in authority in the family or community may prevent patients from taking medications, or may reject or cause problems for the person with TB. If this happens, the health care worker should try to educate such persons about TB and include them in discussions about treatment decisions. Always maintain the patient’s confidentiality (see Module 7, Confidentiality in Tuberculosis Control).



.....
To improve adherence, the medication regimen should be tailored to the patient.
.....

.....
If possible, the regimen should be simplified and changed within acceptable therapeutic limits to match the patient’s lifestyle.
.....

Individualize the Medication Regimen

To improve adherence, the medication regimen should be tailored to the patient. If possible, the regimen should be simplified and changed within acceptable therapeutic limits to match the patient’s lifestyle. For example, the patient’s physician can prescribe

- # An **intermittent regimen** for a patient whose schedule doesn’t permit daily DOT appointments
- # A **combined pill**, which is a fixed-dose combination capsule or tablet that may enhance patient adherence, for patients with difficulty swallowing. In the United States, the Food and Drug Administration has licensed fixed-dose combinations of isoniazid and rifampin (Rifamate) and of isoniazid, rifampin, and pyrazinamide (Rifater).

Patients who are not on DOT sometimes find it useful to monitor their pill-taking by checking off doses on a daily calendar. A calendar can help patients remember the days they need to take medicine and engage them in determining their own schedule. A weekly pill box may also help patients monitor their pill-taking.



.....
For some patients, a formal adherence agreement may be useful.

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.....
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.

.....

For some patients, a formal **adherence agreement** — a written understanding between the health care worker and a patient — may be useful. A sample adherence agreement is presented in Figure 9.7. A patient should dictate or 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 next to the health care worker’s signature and be given a copy to keep. The health care worker should review the agreement with his or her patient periodically to assess how well both are doing and to 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):

- G That my adherence to this treatment regimen is very important
- G That I am responsible for the three tasks mentioned above
- G That 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 9.7 Sample adherence agreement.



Help Patients Keep Appointments

There are three methods to help patients keep their appointments (Table 9.7):

- # Remind patient of appointment
- # Contact no-shows and make another appointment
- # Use other alternatives for patients who repeatedly break appointments

.....
 Different types of reminders
 can help patients keep
 appointments.

Different types of reminders can help patients keep appointments. If the patient has a permanent address, the health care worker can send a reminder postcard, mailed so that it arrives 1 or 2 days before the appointment. If the patient has a telephone, it might be better to call — that way the health care worker will know if the patient received the message. Another benefit of using telephone reminders is that it gives the health care worker an opportunity to counsel patients, and help them solve scheduling and transportation problems or other obstacles to adherence. Remember to be aware of confidentiality issues when leaving telephone or written messages for TB patients (see Module 7, Confidentiality in Tuberculosis Control, for information on maintaining confidentiality).

.....
 When a patient fails to keep
 an appointment, call right
 away to schedule a new
 appointment.

Patients can also be given appointment cards or appointment calendars at each visit to remind them of their next visit. Sometimes the health care worker can find out what problems a patient is having by contacting no-shows, either with a telephone call on the same day or with a home visit. When a patient fails to keep an appointment, call right away to schedule a new appointment. If the patient fails to keep the new appointment, visit the patient at home or call him or her on the phone. Use this discussion to counsel the patient and to identify and solve problems that interfere with appointment keeping.



.....
 If the patient repeatedly breaks appointments, hold a conference with all members of the health care team so the problem can be discussed and resolved.

If the patient repeatedly breaks appointments, use other alternatives. Hold a conference with all members of the health care team (physician, nurses, other health care workers, and staff) so that the problem can be discussed and resolved with help from the entire staff. The patient could also be included in this conference. The health care worker may need to try several different strategies to help the chronically nonadherent patient, and possibly even consider legal alternatives (see Legal Remedies, pages 80-85).

Table 9.7
Examples of Methods to Help Patients Keep Appointments

Remind patient of appointment	Contact the no-shows and make another appointment	Use other alternatives for patients who repeatedly break appointments
# Send a post card # Call the patient by phone (opportunity to counsel) # Give an appointment card # Give an appointment calendar	# Call the same day as the appointment # Visit the patient at home	# Hold a conference with all members of the health care team # Possibly include the patient in the conference # Consider legal alternatives



Study Questions 9.26-9.28

- 9.26. If a health care worker conducts a behavioral diagnosis, what methods can the health care worker use to help a patient whose adherence problem is:**
- a. Forgetfulness?**
 - b. Lack of motivation?**
 - c. A complex regimen?**
 - d. Poor relationship with the health care worker?**
- 9.27. Describe how cultural, religious, or other personal beliefs can affect the treatment for TB.**
- 9.28. Name eight specific things the health care worker can do to form an effective partnership with his or her patient.**

Answers on pages 104-105.



Study Questions 9.29-9.30

9.29. Who can provide support to a patient and help the patient remember to take medications?

9.30. What are two things the health care worker can do to tailor the regimen to the patient's lifestyle?

Answers on page 106.



Study Questions 9.31-9.32

9.31. What is a formal adherence agreement?

9.32. What three methods can be used to help patients keep their appointments?

Answers on page 107.



Case Study 9.8

Ms. Johnson is a 68-year-old widow with active TB disease. She has several other health problems, including obesity, osteoarthritis, and poorly controlled diabetes. She needs a cane to help her walk and often becomes anxious when she leaves her apartment. She lives in a low-income housing block 3 miles from the TB clinic and does not have transportation. Ms. Johnson's two children live outside the state and visit infrequently.

- # Conduct a behavioral diagnosis of Ms. Johnson's potential barriers to completing her TB treatment and the methods that can be used to overcome the barriers.**

Answer on pages 119-120.



Case Study 9.9

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.

Why might Mr. Sivaraman be nonadherent?

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

Answer on pages 120-121.



Legal Remedies

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

.....

.....
Nonadherent behavior includes taking medication inconsistently, missing clinic appointments, consistently failing to report for DOT, and refusing medications.

.....

.....
Before legal measures are taken against a patient who has been taking TB drugs on a self-administered basis, DOT should be offered to the patient.

.....

Patients' Rights and Due Process of Law

As a general rule, individuals have the right to ignore a doctor's advice or refuse treatment if they wish.

However, persons with infectious TB may lose that right if health officials believe these persons risk infecting others by not taking their prescribed medicine.

Patients who are unwilling or unable to adhere to treatment may be **required to do so by law** or may be quarantined or 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.**

The Advisory Council for the Elimination of Tuberculosis (ACET) defines nonadherent behavior as an inability or unwillingness to follow a prescribed treatment regimen. Examples of nonadherent behavior include

- # Taking medication inconsistently
- # Missing clinic appointments
- # Consistently failing to report for DOT
- # Refusing medications

Health care workers should notify the appropriate supervisory clinical and management staff when patients are nonadherent. The health official or a representative should find out why the patient is nonadherent and begin strategies that will help the patient finish treatment. Before legal measures are taken against a patient who has been taking TB drugs on a self-administered basis, DOT should be offered to the patient.



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

Progressive Interventions

ACET recommends that 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 (Figure 9.8). The plan should begin with learning the possible reasons for nonadherence and addressing the identified problems using methods such as DOT, incentives, and enablers. The patient should be told orally 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. Figure 9.9 is an example of a letter given to patients who demonstrate nonadherent behavior and who may be candidates for legal action. If the patient does not adhere to DOT voluntarily, the next step may be DOT that is court-ordered. **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.

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

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. However, when a patient with infectious TB refuses treatment and voluntary isolation, emergency detention to isolate the person is appropriate. Confinement can be either in a hospital or in some other institution with TB isolation facilities.

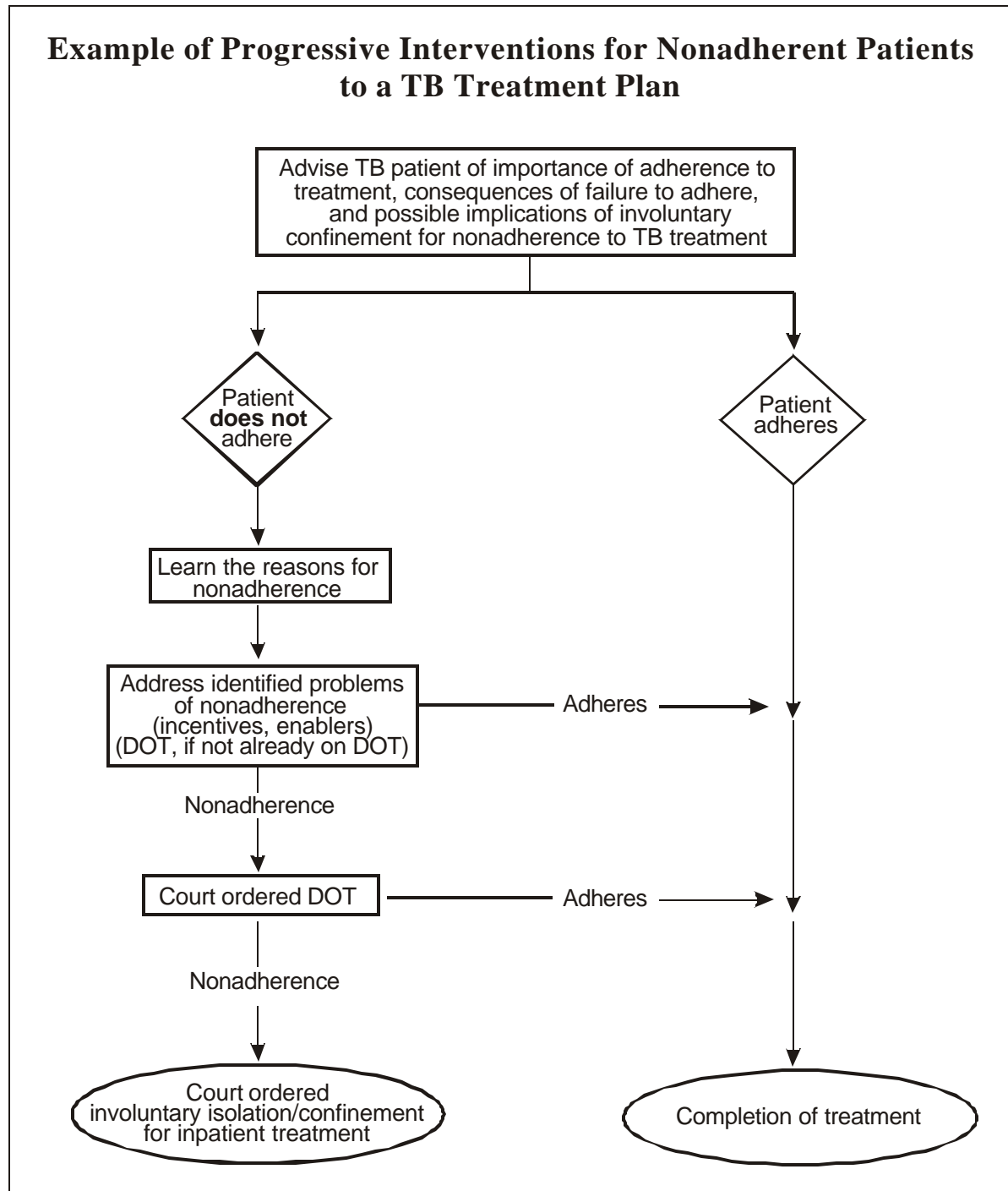


Figure 9.8 Example of progressive intervention for nonadherent patients to a TB treatment plan



Tuberculosis Program

P.O. Box 999
County, State 88888

January 1, 2000

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 tuberculosis.

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 (123-4567).

Sincerely,

Joe Smith, M.D.
District Medical Director

Figure 9.9 A sample letter (written at a low reading level) given to patients who demonstrate nonadherent behavior, and who may be candidates for legal action.



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

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.

.....
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.
.....

Criteria for Determining the Need for Involuntary Confinement

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 are considered:

- # Laboratory results (acid-fast bacilli smears and cultures)
- # Clinical signs and symptoms of infectious TB
- # An abnormal chest radiograph, especially if cavities are present
- # A history of nonadherence (not caused by factors outside patient's control)
- # The opportunity to infect others



.
An order to confine a patient
should require that he or she
be isolated until no longer a
public health threat.
.

An order to confine a patient should require that he or she be isolated until no longer a public health threat. This decision should be based on

- # The patient becoming asymptomatic, with documentation of at least three negative sputum smears taken on different days
- # The local health officer's decision that the person has completed therapy according to the most recent American Thoracic Society/CDC treatment recommendations

The patient should be ordered to receive treatment in a proper facility until cured, unless it is certain that the person will voluntarily complete therapy at home once noninfectious. If the patient refuses the ordered treatment, the health officer should have the authority to extend the confinement order as needed.



Study Questions 9.33-9.35

9.33. Give four examples of nonadherent behavior.

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

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

Answers on pages 108-109.



Case Study 9.10

Walter, a 50-year-old single, unemployed male, was diagnosed with smear and culture positive, pulmonary tuberculosis one month before he was released from prison. The prison doctor telephoned 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 2 weeks after his release, Walter adhered to treatment. He then began missing appointments at the arranged DOT site and at the clinic, stating he felt "okay." For the next few weeks Walter's visits to the clinic became rare. On Walter's latest clinic visit, his sputum smear was positive for AFB. The health care worker assessed Walter's problems and tried everything he could think of to get Walter to adhere to his treatment — gave DOT at Walter's house or his favorite hang out, offered incentives, changed health care workers, and threatened legal action. When the health care worker mentioned legal action, Walter got very upset and threatened the health care worker. He stated that he felt "okay" and he was tired of 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 on pages 121-122.



SUMMARY

Adherence to treatment means that a patient is following the recommended course of treatment by taking all the prescribed medications for the entire length of time necessary. TB is nearly always curable if patients adhere to their TB treatment regimen. Adherence is important because nonadherence is the patient's inability or refusal to take TB drugs consistently as prescribed. This behavior is one of the biggest problems in TB control.

There are many reasons why a person might have trouble completing a regimen of TB drugs. One of the best predictors of adherence is a patient's past adherence. However, it is important to keep in mind that any patient can have barriers to adherence. Patients and health care workers are both responsible for ensuring patients' adherence. Patients must decide every day or week whether or not to take their medicine. What they decide often depends on how much help they get from the health care workers they see.

There are many strategies that may be used to ensure that patients complete treatment. One strategy that may be used is case management. There are three elements in any case management system: (1) assignment of primary responsibility for the patient, (2) systematic regular review of patient progress, and (3) a plan to address any barriers to adherence. A health department employee (case manager) is assigned primary responsibility and is held accountable for ensuring that each patient is assessed and a treatment plan is established, that each patient is educated about TB and its treatment, that therapy is continuous, and that contacts are examined.

The health care worker will need to learn as much as possible about the patient in order to assess potential adherence problems. Doing an assessment means talking to a patient to get information on the patient's medical history, current health problems, and other personal information, with a particular emphasis on identifying the problems most important to the patient as treatment begins. Unless special efforts are made to identify their needs, some patients may be lost to follow-up care.

The health care worker or other program staff should visit the patient to begin the assessment as soon as possible. When the health care worker begins to work with a patient, it is important to ask what the patient believes about TB disease and treatment. The health care worker should identify differences between what he or she believes and what the patient believes early in treatment. One way to do this is to ask several open-ended questions. When a patient's ideas are different from the health care worker's, the health care worker should accept that the patient has different views, and then make sure the patient knows the health care worker's point of view about TB.



Health information must be right for each patient's knowledge and awareness of the problem. Patients are more likely to pay attention to information that is relevant to their needs and does not require abrupt changes in their normal daily activities. In general, patients may be more likely to follow the treatment plan if they understand their illness and the benefits of treatment. In presenting health information, effective communication techniques should be used.

The health care worker and the patient can have serious problems understanding each other if they do not speak the same language. It is best to use trained medical interpreters, but there may not be any in the health care worker's area. Other persons who are used as interpreters are other health care workers who speak the patient's language, the patient's family members, or people from the patient's community. After the health care worker has identified an interpreter, appropriate guidelines should be followed to make the best use of the interview.

There are many ways to encourage patients to adhere to treatment. Giving directly observed therapy (DOT) is the most effective strategy for making sure patients take their medicines. DOT means that a health care worker or other designated individual watches the patient swallow every dose of the prescribed drugs. DOT should be considered for all patients because it is difficult to reliably 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 ensures that the patient completes an adequate regimen, lets 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, and helps the patient become noninfectious sooner.

Incentives and enablers may help patients agree to participate in a DOT program and stay with it. Incentives are small rewards given to patients to encourage them to either take their own medicines or keep their clinic or field DOT appointments. Enablers are those things that make it possible or easier for the patients to receive treatment by overcoming barriers such as transportation difficulties. Incentives and enablers should be chosen according to the patient's special needs and interests, or the patients may not care if they receive them.

To improve adherence in children and adolescents, the health care worker should work with the parents or caregivers. The health care worker cannot assume that parents will give medications to their children as prescribed; sometimes they do not. The health care worker should do everything possible to make sure that parents support their children's TB treatment. For example, the health care worker can educate parents, warn parents of possible problems, give DOT, use incentives and enablers, and give TB drugs in easy-to-take preparations.

To help patients complete treatment, the health care worker will need to assess the extent to which various problems present barriers to adherence. A "behavioral diagnosis" can be used to develop strategies to improve each patient's treatment plan. The purpose of doing a behavioral



diagnosis is to identify the specific reasons why a patient is not being adherent. At the start of treatment the patient should be told about nonadherence and how it causes treatment failure and further TB transmission. The health care worker should listen to the patient's response and identify and resolve any barriers to adherence. It is crucial that the health care worker and the patient come to an agreement about taking TB medication.

There are many ways to help patients adhere to TB treatment. The support of family, friends, and health care workers can be important to patients trying to complete treatment. The patients should be asked to identify persons who support their TB treatment and can help them remember to take medications or keep their DOT appointments. In addition, the medication regimen should be tailored to the patient. If possible, the regimen should be simplified and changed within acceptable therapeutic limits to match the patient's lifestyle. For some patients, a formal adherence agreement — a written understanding between the health care worker and a patient — may be useful.

Different types of reminders can help patients keep appointments. When a patient fails to keep an appointment, a health care worker should call right away to schedule a new appointment. If the patient repeatedly breaks appointments, a conference should be held with all members of the health care team (physician, nurses, health care workers, and other staff) so that the problem can be discussed and resolved with help from the entire staff.

As a general rule, individuals have the right to ignore a doctor's advice or refuse treatment if they wish. However, persons with infectious TB may lose that right if health officials believe these persons risk infecting others by not taking their prescribed medicine. Patients who are unwilling or unable to adhere to treatment may be required to do so by law. If the patient does not adhere to DOT voluntarily, the next step may be DOT that is ordered by a public health official or a court. 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.



Additional Reading

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ANSWERS TO STUDY QUESTIONS

9.1. What is adherence to treatment? (page 6)

Adherence to treatment means that a patient is following the recommended course of treatment by taking all the prescribed medications for the entire length of time necessary.

9.2. Why is adherence to TB treatment important? (page 6)

Adherence is important because TB is nearly always curable if patients adhere to their TB treatment regimen.

9.3. What are four serious consequences that can result when a patient with TB disease is nonadherent? (page 6)

Nonadherence is the patient's inability or refusal to take TB drugs as prescribed. When medical treatment is complicated or lasts for a long time, as in the treatment for TB disease, patients often do not take their medication as instructed. This behavior is one of the biggest problems in TB control and can lead to serious consequences. A nonadherent patient with TB disease may

Remain sick longer or have more severe illness

Spread TB to others

Develop and spread drug-resistant TB

Die as the result of interrupted treatment

9.4. Give eight reasons why a patient might be nonadherent. (pages 7-8)

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

Once **patients no longer feel sick**, they often think it is all right to discontinue taking their TB drugs. TB symptoms can improve dramatically during the initial phase of treatment (the first 8 weeks). 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-resistant organisms.



- # 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 a regimen.
- # Some patients have strong **personal or cultural beliefs** about TB disease, how it should be treated, and who they can turn to for help. When TB treatment conflicts with these beliefs, patients can become fearful, anxious, or alienated from their health care workers (a person who provides health care or health services to patients, such as physicians, physician's assistants, nurse practitioners, nurses, and outreach workers).
- # Certain patients **lack skills** necessary for following a health care worker's instructions and adhering to a prescribed regimen. Elderly patients with limited mobility or manual dexterity, patients with substance abuse or mental health problems, and young children are particularly at risk for problems with adherence.
- # **Lack of access to health care** can also be a significant barrier to successfully completing a TB regimen. Special efforts must be made to reach and provide care to patients without a permanent address or a means of transportation. Patients with jobs may have work schedules that conflict with clinic hours. Immigrants and refugees, as well as persons who inject illicit drugs, may need reassurance that their TB disease and treatment will be kept confidential and should not cause them legal problems.
- # Some patients, especially recent immigrants, may not be able to find a health care worker who speaks their language. When a patient speaks little or no English, this **language barrier** can present significant problems for adherence, as patient education and support services can have little effect. Unless a good interpreter is found, such patients may be unable to continue treatment.
- # Some patients have **poor relationships with health care workers**. When patients and health care workers fail to establish a trusting relationship, this lack of relationship can influence patient adherence. If a patient trusts or has confidence in his or her health care worker, he or she is more likely to follow instructions and advice and to cooperate with the health care worker. Patients may also be more likely to bring questions and concerns regarding adherence to the health care worker's attention.
- # Finally, some patients may have a **lack of motivation** to adhere to a TB regimen. If patients have many competing priorities in their lives such as substance abuse, homelessness, sickness from other diseases (e.g., HIV), taking TB medication may not be considered a priority by the patient.



9.5. Explain why a patient's adherence to a TB treatment regimen is difficult to predict. (page 9)

Each patient is unique and may have his or her own reasons for nonadherence. One of the best predictors of adherence is a patient's past adherence. If a patient was nonadherent in the past, it is likely that he or she will encounter similar problems with the current treatment regimen. However, it is important to keep in mind that any patient can have problems with adherence. Barriers are anything that can prevent a patient from being able to adhere to a TB treatment regimen. Many health care workers think they can tell which patients will be adherent, but research shows they are correct only about half the time (that is, their predictions are no better than flipping a coin). Although adherence is hard to predict, 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 problems.

9.6 Whose responsibility is it to ensure adherence? (page 9)

Patients and health care workers are both responsible for ensuring patients' adherence. Patients must decide every day or week whether or not to take their medicine. What they decide often depends on how much help they get from the health care workers they see.

9.7 Describe a case management system. (page 12)

There are many strategies that may be used to ensure that patients complete treatment. One strategy that may be used is case management. There are three elements in a case management system:

- # Assignment of primary responsibility for the patient
- # Systematic regular review of patient progress
- # Plan to address any barriers to adherence

A health department employee (case manager) is assigned primary responsibility and is held accountable for ensuring

- # Each patient is assessed and a treatment plan is established
- # Each patient is educated about TB and its treatment
- # Therapy is continuous
- # Contacts are examined



9.8. To address the patient’s specific needs, what kind of things does the health care worker need to learn about the patient? (page 14)

The health care worker will need to learn as much as possible about the patient in order to assess potential adherence problems. The health care worker will need to learn about the patient’s

- # Medical history and current health problems
- # Knowledge, beliefs, and attitudes about TB
- # Ability to take responsibility for following the TB treatment plan
- # Resources (family, other social support, finances)
- # Barriers to treatment
- # History of adherence to previous TB regimens or other medication

9.9. How soon should the health care worker talk with the patient to begin the assessment? (page 15)

The health care worker or other program staff should visit the patient to begin the assessment as soon as possible. If the health care worker is assigned to work with a hospitalized TB patient, he or she should visit before the patient leaves the hospital. If the patient leaves the hospital before the health care worker can get there, he or she should visit the patient at home as soon as possible. During the first meeting, the health care worker should learn at the very least the names of the patient’s close contacts so a contact investigation can begin. The information the health care worker finds out in these meetings is confidential; he or she should follow the agency’s or clinic’s rules for keeping patient information confidential.

9.10. What is an open-ended question and what can it help the health care worker learn about a patient? (page 16)

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 like “What,” “Why,” “Who,” “When,” and “How” that demand an explanation. In addition, phrases that begin with “Tell me about” or “Explain to me” may be helpful in eliciting information from the patient. Such questions are used when a health care worker needs to explore complex issues that do not have a finite or predetermined set of responses.



9.11. In the list below there are close-ended and open-ended questions. Mark an X for each open-ended question that the health care worker can ask the patient to find out his or her ideas and feelings about TB. (page 17)

- 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?

9.12. Why is it important to assess the patient’s knowledge, beliefs, and attitudes regarding TB and adherence to TB medicine? (pages 17-18)

Assessing TB patients’ knowledge, beliefs, and attitudes regarding TB and adherence to TB medicine may help the health care worker better understand the patient’s views and suggest areas in which the patient needs education. They may also give the health care worker some idea of the patient’s ability to adhere to a treatment regimen. For example, asking a patient what problems the illness has caused him or her can help the health care worker assess the strength of family and social support; potential job-related problems; and, to some extent, the problem-solving skills of the patient.

Throughout treatment, the health care worker should ask the patient about his or her concerns about TB and success with adherence to the regimen. Whenever possible, the health care worker should adapt such questions according to the patient’s age, family situation, education level, and cultural background. Remember that the more the health care worker is aware of the patient’s ideas and concerns about TB and its treatment, the better prepared the health care worker will be to anticipate and resolve problems that can arise.



9.13. List eight effective communication techniques that can help the health care worker to present new information to patients. (pages 27-29)

Use simple, nonmedical terms in explanations, and **be specific** about the behaviors that are expected. For example, it is much more helpful to say, “This pill will help 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 very basic materials. Highly educated patients may prefer more detailed information. If a patient does not read or write, health care workers should give instructions orally and leave visual cues or reminders, such as a snapshot of each medication, with the time the patient should take it written in large numbers.

Limit the amount of information given at any one time. If too much information is given, the patient may not remember any of it. To avoid overwhelming the patient, the topics to be discussed should be organized in the order of their 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 capsules every day.” This information should be reviewed before leaving the patient.

Repeat important information. Some data indicate that 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 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 two-way. This means that the health care worker should listen to feedback and questions from the patient to be sure they received and understood the message. The health care worker should use open-ended questions to assess the patient’s knowledge and beliefs.

Use concrete 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 patients do every morning, such as brushing their 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’s not only *what* is said and done, but *how* it is said or done, that will help the patient adhere to treatment. The health care worker should be encouraging and supportive. The health care worker’s warm, concerned, and respectful attitude toward the patient will make the experience more pleasant for both and will render the treatment more effective.

9.14. **If the health care worker uses an interpreter, what are four problems the health care worker may encounter?** (pages 32-33)

The health care worker and the patient can have serious problems understanding each other if they do not speak the same language. If an interpreter is used, the health care worker can still have problems getting accurate, unbiased information and protecting the patient’s confidentiality. For example,

- # Interpreters may not state accurately what the health care worker and the patient have said
- # Interpreters sometimes add their own ideas of what has been said
- # The patient may be uncomfortable talking about personal information that he does not want a third person, the interpreter, to know
- # Interpreters may have difficulty finding equivalent words or translating medical terms into the patient’s language

It is best to use trained medical interpreters whenever possible. If a trained interpreter is not available, other persons who are sometimes used as interpreters are other health care workers who speak the patient’s language, the patient’s family members, or people from the patient’s community. If an interpreter is unavailable when the health care worker makes a home visit, the health care worker should call back to the office or clinic if see if someone there could translate for them over the telephone. If family members must be used to interpret, **children should not be used**; they will hear personal information and may be asked to translate things that the family feels children should not discuss, and this can be upsetting.



9.15 List at least six guidelines for working with an interpreter that can help the health care worker make the best of the interview. (pages 34-35)

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 as exactly as possible
- # Give the patient time to answer questions

9.16 What is DOT? (page 38)

A component of case management that helps to ensure that patients adhere to treatment is directly observed therapy (DOT). DOT is the most effective strategy for making sure patients take their medicines. DOT means that a health care worker or other designated individual watches the patient swallow every dose of the prescribed drugs. DOT should be considered for all patients because it is difficult to reliably predict which patients will be adherent. Even patients who intend to take their medicine might have trouble remembering to take their pills every time. All DOT visits should be documented. In many health departments, DOT is the standard of care.



9.17 Who should be considered for DOT? (page 40)

All patients should be considered for DOT. However, there are certain groups of patients for whom DOT is often the best option, regardless of local treatment completion rates. These groups include

- # Patients with drug-resistant TB
- # Patients receiving intermittent therapy
- # Persons at high risk for nonadherence, such as
 - 9 Homeless or unstably housed persons
 - 9 Persons who abuse alcohol or illicit drugs
 - 9 Persons who are unable to take pills on their own due to mental, emotional, or physical disabilities
 - 9 Children and adolescents
 - 9 Persons with a history of nonadherence

9.18 List and explain four tasks that are part of the DOT encounter. (pages 41-42)

Delivering DOT means that the health care worker should

- # **Check for side effects.** At each visit, before the drugs are given, the health care worker should ask if the patient is having any adverse side effects. Patients being treated for TB should be educated about symptoms indicating adverse reactions to the drugs they are taking, whether minor or serious. 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 supervisor should be told that the drugs were not given, and the prescribing clinician should be notified about the adverse reaction. The health care worker should arrange for the patient to see the clinician as soon as possible
- # **Verify the 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 the pills.** Medication should not be left for the patient to take on his or her own. 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

- # **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.

9.19 Name at least five places where DOT can be given. (page 44)

DOT can be given anywhere the patient and health care worker agree upon, provided the time and location are convenient and safe. **Clinic-based DOT** is delivered in a TB clinic or comparable health care facility (Figure 9.3). For some patients, DOT must not interfere with the patient's work schedule, so DOT can be provided in a nonclinical setting or during nonbusiness hours. 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 health care facility is called **field-based DOT** (Figure 9.4 and Figure 9.5). Field DOT can be given at almost any site:

- # The patient's home
- # The patient's workplace
- # A public park or other agreed-upon public location
- # A school
- # A restaurant

Sometimes staff at other health care settings, such as outpatient treatment centers, can be asked to give DOT to a patient who can get to the alternative health care setting more easily than the TB clinic.

9.20 What are four advantages of DOT? (page 48)

When used as a collaborative effort with the patient, DOT has many advantages over self-administered therapy:

- # It ensures that the patient completes an adequate regimen
- # It lets the health care worker monitor the patient regularly for side effects and response to therapy
- # It 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

Often patients who have successfully completed DOT are willing to describe their experience or share it with new patients. If this can be arranged, former patients may help encourage new patients to participate in the DOT program.

9.21 What are incentives and enablers, and what are their purposes? (page 54)

Just offering a DOT program is not enough. Patients must agree to participate in taking their medicine and stick with it. Incentives and enablers may help them do this.

Incentives are small rewards given to patients to encourage them to either take their own medicines or keep their clinic or field DOT appointments. **Enablers** are those things that make it possible or easier for the patients to receive treatment by overcoming barriers such as transportation difficulties. Incentives and enablers are widely used in facilities providing TB services; they help patients stay with and complete treatment.

9.22 How does a health care worker determine which incentives and enablers to use for each patient? (page 54)

Incentives and enablers should be chosen according to the patients' special needs and interests, or the patients may not care if they receive them. 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. If transportation is not a problem, then he or she should offer something that is needed. Learning as much as possible about patients will help to identify their needs and interests and better motivate them to complete treatment. The best time to begin using incentives is after a good relationship has been established with a patient. Enablers, however, may be vital to the initiation of treatment and should be provided as soon as treatment starts.

9.23 What are some sources of incentives and enablers? (page 56)

Programs can obtain incentives and enablers from many different sources. Possible resources 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
- # 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



9.24 What are five ways the health care worker can help parents improve adherence in children? (pages 60-61)

The health care worker should do everything that can be done to make sure that parents support their children's TB treatment, including

Educate parents of children and adolescents with TB disease. By assessing their knowledge and beliefs about TB, the health care worker can address concerns and needs, correct misconceptions, and help parents understand their child's disease. If both the patient and his or her parents are knowledgeable about TB, the patient is more likely to successfully complete a regimen.

Warn parents about the possible problems their children might have during TB treatment. Children may resist taking medications, may have adverse reactions to the medications, and may have problems swallowing pills and capsules (the common form of TB medications). When parents know in advance about problems that can come up during their child's treatment, they can cope with and help solve problems as they arise.

Give DOT to children with TB when parents' or caregivers' compliance with giving medications as prescribed cannot be ensured.

Use incentives and enablers, such as coloring books and toys, to encourage a child to take medicine. Giving incentives to parents and caregivers should be considered, too; this will encourage and reward their participation.

Give TB drugs in easy-to-take preparations. Rifampin can be made into a liquid suspension. Isoniazid can also be prepared as a suspension, although its stability varies. The health care worker can discuss the use of liquid medications with the patient's clinician. Isoniazid and pyrazinamide pills can be crushed and given with small amounts of food.

9.25 Why are adolescents at high risk for nonadherence? (page 61)

Although adolescents can be responsible for taking their own medications, they are also frequently nonadherent. They may be embarrassed about having to take TB medications because they are concerned about what their friends think. Also, they may not feel threatened by TB and may not take the condition seriously. For these reasons, adolescents are a high priority group for DOT.



9.26 If a health care worker conducts a behavioral diagnosis, what methods can the health care worker use to help a patient whose adherence problem is:

a. Forgetfulness? (page 64)

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, or use DOT.

b. Lack of motivation? (page 64)

Point out the dangers of nonadherence and benefits of therapy, increase the frequency of visits, provide incentives and set short-term goals, use DOT

c. A complex regimen? (page 64)

Simplify the regimen, associate the regimen with other activities, use combined capsules, or use DOT.

d. Poor relationship with the health care worker? (page 64)

Develop communication skills, be accessible throughout care, work on attitudes about patients and DOT, change health care workers, provide social services

9.27. Describe how cultural, religious, or other personal beliefs can affect the treatment for TB. (pages 66-67)

Sometimes cultural, religious, or other personal beliefs affect a patient's TB treatment. It is important for the health care worker to sincerely respect the beliefs of the patient. Sometimes patients seek medical advice from folk healers or alternative practitioners. The health care worker may encounter patients who use folk remedies along with their prescribed medications. For example, in some Asian cultures, TB medicines are considered "hot" and need to be countered with something "cold," such as green leafy vegetables.

Take the time to learn about the patient's cultural beliefs. If the patient thinks that the health care worker does not respect his or her beliefs, it could cause the patient to distrust the health care worker. If the patient comes from a background that includes the use of alternative medicine or folk medicine, find out if there are barriers to the acceptance of conventional medical practices. A discussion about the patient's beliefs and health practices may help the health care worker to individualize treatment so that it is acceptable to the patient.



When folk or alternative practices are safe, health care workers should consider including them in the treatment plan. For example, some people believe in the healing power of prayer. These persons may be more willing to take medications after saying a brief prayer, so accepting their belief in prayer is an important aspect of treatment. If a patient is taking an herbal remedy, the health care worker should check with the patient's physician or pharmacist to be sure it will not cause side effects or interact adversely with the patient's TB drugs. He or she should ask patients who have concerns about nutrition supplements or interactions with TB drugs to discuss this with their 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 TB drugs for a full course of treatment. 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.

9.28. Name eight specific things the health care worker can do to form an effective partnership with his or her patient. (page 68)

Patients make independent decisions every day about whether they will take medication or show up for DOT. The health care worker must recognize the important role of the patient in making decisions about treatment. For this reason, the health care worker should develop a partnership with the patient. Effective partnerships call for specific behaviors from the health care worker:

- # Listen and try to understand the patient's knowledge, beliefs, and feelings about TB disease and treatment
- # Be open minded about the patient's beliefs and cultural expectations
- # Recognize and address the patient's fears about the illness
- # Understand and fulfill the patient's expectations about treatment, when possible
- # Communicate clearly so that the patient can understand the messages
- # Avoid criticizing the patient's adherence behavior; suggest behavior changes respectfully
- # Treat the patient with dignity and respect
- # Be consistent in what is done and told to the patient



9.29. Who can provide support to a patient and help the patient remember to take medications? (page 69)

The support of family, friends, and health care workers can be important to patients trying to complete 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. Such persons might include

- # Family members
- # Friends
- # Teachers
- # Social workers
- # Landlords
- # Clergy
- # Neighbors

9.30. What are two things the health care worker can do to tailor the regimen to the patient's lifestyle? (page 70)

To improve adherence, the medication regimen should be tailored to the patient. If possible, the regimen should be simplified and changed within acceptable therapeutic limits to match the patient's lifestyle. For example, the patient's physician can prescribe

- # An **intermittent regimen** for a patient whose schedule doesn't permit daily DOT appointments
- # A **combined pill**, which is a fixed-dose combination capsule or tablet that may enhance patient adherence, for patients with difficulty swallowing. In the United States, the Food and Drug Administration has licensed fixed-dose combinations of isoniazid and rifampin (Rifamate) and of isoniazid, rifampin, and pyrazinamide (Rifater).

Patients who are not on DOT sometimes find it useful to monitor their pill-taking by checking off doses on a daily calendar. A calendar can help patients remember the days they need to take medicine and engage them in determining their own schedule. A weekly pill box may also help patients monitor their pill-taking.



9.31 What is a formal adherence agreement? (page 71)

For some patients, a formal **adherence agreement** — a written understanding between the health care worker and a patient — may be useful. A sample adherence agreement is presented in Figure 9.7. A patient should dictate or 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 next to the health care worker’s signature and be given a copy to keep. The health care worker should review the agreement with his or her patient periodically to assess how well both are doing and to make changes as needed.

9.32. What three methods can be used to help patients keep their appointments? (pages 73-74)

There are three methods to help patients keep their appointments:

- # Remind patient of appointment
- # Contact no-shows and make another appointment
- # Use other alternatives for patients who repeatedly break appointments

Examples of Methods to Help Patients Keep Appointments

Remind patient of appointment	Contact the no-shows and make another appointment	Use other alternatives for patients who repeatedly break appointments
<ul style="list-style-type: none"> # Send a post card # Call the patient by phone (opportunity to counsel) # Give an appointment card # Give an appointment calendar 	<ul style="list-style-type: none"> # Call the same day as the appointment # Visit the patient at home 	<ul style="list-style-type: none"> # Hold a conference with all members of the health care team # Possibly include the patient in the conference # Consider legal alternatives



9.33. Give four examples of nonadherent behavior. (page 80)

The Advisory Council for the Elimination of Tuberculosis (ACET) defines nonadherent behavior as an inability or unwillingness to follow a prescribed treatment regimen. Examples of nonadherent behavior include

- # Taking medication inconsistently
- # Missing clinic appointments
- # Consistently failing to report for DOT
- # Refusing medications

9.34. Describe the progressive interventions that should be attempted before a court orders involuntary confinement. (page 81)

ACET recommends that 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 orally 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, which 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. 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. However, when a patient with infectious TB refuses treatment and voluntary isolation, emergency detention to isolate the person is appropriate. Confinement can be either in a hospital or in some other institution with TB isolation facilities.



9.35. List the criteria for deciding if a patient should be confined. (pages 84-85)

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 are considered:

- # Laboratory results (acid-fast bacilli smears and cultures)
- # Clinical signs and symptoms of infectious TB
- # An abnormal chest radiograph, especially if cavities are present
- # A history of nonadherence (not caused by factors outside patient's control)
- # The opportunity to infect others

An order to confine a patient should require that he or she be isolated until no longer a public health threat. This decision should be based on

- # The patient becoming asymptomatic, with documentation of at least three negative sputum smears taken on different days
- # The local health officer's decision that the person has completed therapy according to the most recent American Thoracic Society/CDC treatment recommendations

The patient should be ordered to receive treatment in a proper facility until cured, unless it is certain that the person will voluntarily complete therapy at home once noninfectious. If the patient refuses the ordered treatment, the health officer should have the authority to extend the confinement order as needed.



ANSWERS TO CASE STUDIES

- 9.1. Mr. Howard is unemployed and homeless. The homeless shelter Mr. Howard frequents recently sent him to the hospital because he had TB symptoms. He was diagnosed with TB and admitted to the hospital for TB treatment. The hospital's infection control nurse immediately telephoned a TB case report to the health department TB clinic.**

Mr. Howard remained in the hospital for 5 days. On the day he was discharged, a nurse instructed Mr. Howard to go to the TB clinic the following morning for an evaluation and a supply of medicine. He failed to keep the appointment.

A health care worker had been assigned to find Mr. Howard when his case was reported. When Mr. Howard missed his appointment, she set out to locate him and persuade him to come to the clinic. She eventually found him in a crowded bar, where she scolded him for his careless behavior and ordered him to return with her to the clinic.

What should the health care worker have done differently?

The health care worker should have visited Mr. Howard to begin the assessment as soon as possible (before Mr. Howard left the hospital). If he had left the hospital before she got there, she should have located him and spoken to him privately. By approaching Mr. Howard in a public place, she has failed to maintain confidentiality. After approaching him in this way, the health care worker will have a difficult time establishing a trusting relationship with Mr. Howard. It is important he feel comfortable sharing his thoughts.

How can the health care worker get to know Mr. Howard better in order to assess potential adherence problems?

The health care worker will need to learn as much as possible about Mr. Howard in order to assess potential adherence problems. The health care worker will need to learn the following about Mr. Howard:

- # Medical history and current health problems
- # Knowledge, beliefs, and attitudes about TB



- # Ability to take responsibility for following the TB treatment plan
- # Resources (family, other social support, finances)
- # Barriers to treatment
- # History of adherence to previous TB regimens or other medication

Also, assessing TB patients' knowledge, beliefs, and attitudes regarding TB and adherence to TB medicine may help the health care worker better understand the patient's views and suggest areas in which the patient needs education. They may also give the health care worker some idea of the patient's ability to adhere to a treatment regimen. For example, asking a patient what problems the illness has caused him or her can help the health care worker assess the strength of family and social support; potential job-related problems; and, to some extent, the problem-solving skills of the patient.

Throughout treatment, the health care worker should ask the patient about his or her concerns about TB and success with adherence to the regimen. Whenever possible, the health care worker should adapt such questions according to the patient's age, family situation, education level, and cultural background. Remember that the more the health care worker is aware of the patient's ideas and concerns about TB and its treatment, the better prepared the health care worker will be to anticipate and resolve problems that can arise.

- 9.2. Michael, 45 years old, is a cook at a local fast food restaurant. He went to see his physician because he was feeling fatigued, was unable to sleep, had lost his appetite, and had been coughing for several weeks. His physician suspected tuberculosis and admitted Michael to the hospital for further tests.**

His sputum smears were positive for AFB and he was started on appropriate therapy. The physician called the local health department to report the diagnosis. A case manager was assigned and asked a health care worker to visit Michael in the hospital. The health care worker visited Michael in the hospital the next day.

- # **How would you assess Michael's knowledge, beliefs, and feelings about TB disease and treatment?**

One way to learn about the differences between Michael's beliefs and the medical understanding of TB 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



like “What,” “Why,” “Who,” “When,” and “How” that demand an explanation. In addition, phrases that begin with “Tell me about” or “Explain to me” may be helpful in eliciting information. Such questions are very useful in assessing a patient’s ability and willingness to adhere to treatment.

For example, the health care worker could ask Michael

- # What do you know about TB?
- # What causes TB?
- # What do you think TB does to your body?
- # How severe do you think your illness is?
- # What problems has your illness caused for you?
- # Why do you think you got sick when you did?
- # What treatment do you think you should receive for TB?
- # What are the most important results you hope to get from this treatment?
- # What do you fear about your illness?
- # How do your family members or close friends feel about your TB?

Why is it important to assess Michael’s knowledge, beliefs, and feelings about TB disease and treatment?

It is important to assess Michael’s knowledge, beliefs, and feelings about TB disease and its treatment because the more the health care worker is aware of the Michael’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 Michael’s views and will help determine areas in which he needs education. If Michael’s ideas are different from the health care worker’s, he or she should accept that he has different views, and then make sure that he knows the health care worker’s point of view about TB. The health care worker can make it clear that even if he or she does not share Michael’s views, the health care worker should respect them. Knowing and respecting Michael’s views will improve the working relationship and make Michael more likely to be adherent.

An assessment may also give the health care worker some idea of Michael’s ability to adhere to a treatment regimen. For example, asking Michael what problems the illness has caused him can help the health care worker assess the strength of his family and



social support; potential job-related problems; and, to some extent, Michael's problem-solving skills.

- 9.3. Willie, a 40-year-old construction worker, was just diagnosed with TB. The health care worker has completed her initial assessment and learned that Willie is very upset because he thinks he is going to die. He knows very little about TB, except he remembers his grandfather "wasting away" and dying from TB when he was young. He has a 2-year-old son at home who he is afraid will also die from TB. Willie did not complete school beyond the 8th grade. He is worried that he will lose his job once his employer learns he has TB.**

The health care worker needs to educate Willie about TB and its treatment.

What should the health care worker do to effectively communicate with Willie?

Since Willie has little knowledge about TB the health care worker should begin by confirming the accurate information and correct any misconceptions he may have. To be certain that Willie has an accurate understanding, the health care worker should ask Willie what has just been explained and what is understood. Since Willie is very upset, the health care worker may have to spend extra time reexplaining important information. The health care worker should tell Willie that TB is curable if he adheres to prescribed therapy. The health care worker should also assure Willie that his son and other family members and close contacts will be evaluated for TB infection and disease and will be given appropriate therapy if needed.

When presenting this information to Willie the health care worker should remember to use the following techniques:

Use simple, nonmedical terms in explanations, and be specific about the behaviors that are expected. Try using words that are familiar to Willie.

Use the appropriate language level. Since Willie's education doesn't go beyond the 8th grade, written information should be at a lower reading level. Willie may only be able to understand very basic materials.

Limit the amount of information given at any one time. Willie was just diagnosed with TB and is very upset and afraid. Giving him too much information at this time may be too overwhelming and he may not remember any of it. To avoid overwhelming Willie, the topics to be discussed should be organized in the order of their importance.

Discuss the most important topics first and last. Remember, Willie is very upset. You may want to present important information at the beginning and at the end of the session.



Willie will have an easier time remembering information that is presented first and last. The health care worker should tell Willie what is expected of him before explaining test results, the expected outcome of a procedure, or treatment.

Repeat important information. Again, since Willie is very upset, you may want to repeat key messages throughout the session, have Willie repeat the information, then in later sessions review previously presented material first.

Listen to feedback and questions. Communication with Willie should always be two-way. This means that the health care worker should listen to feedback and questions from Willie to be sure he received and understood the message.

Use concrete examples to make information easy to remember. This is very important. You may also want to use visuals to help get your messages across to Willie.

Make the interaction with the patient a positive experience. The first interview is key to establishing a trusting relationship with Willie. It's not only *what* is said and done, but *how* it is said or done, that will help Willie adhere to treatment. Since Willie is very upset and has concerns about his child's health, the health care worker should be encouraging and supportive. The health care worker's warm, concerned, and respectful attitude toward Willie will make the experience more pleasant for both and will render the treatment more effective.

9.4 Angelina, a 35-year-old Hispanic migrant farm worker, was referred to the health department by a local community college. The college conducted a health fair for the migrant farm workers at a farm in the area. Angelina's skin test was positive at 25 mm of induration. When asked about her health, she told the health fair staff that she had been coughing for a couple of weeks, felt tired, and had lost some weight.

After much coaxing by the health fair staff, Angelina, who speaks very little English, arrives at the health department for further tests. With her are her two 11-year-old twins. The twins speak English. No one in the TB program at the health department speaks Spanish, but the health care worker remembers that a nurse in the Maternal and Child Health program speaks Spanish.

Who would you ask to interpret?

The health care worker should ask the nurse to translate. Angelina's twins are young and they may hear personal information about their mother that may be inappropriate and it may be difficult to make sure that the information will be kept confidential. In addition, her twins are probably unfamiliar with medical terms.



The nurse in the Maternal and Child Health program agrees to help the health care worker translate. He says he only has 5 minutes to spare. The nurse and the health care worker rush into the room where Angelina and her twins are waiting. Without any introduction or prompting by the health care worker, the nurse begins to speak to Angelina. Angelina looks startled and is reluctant to answer any questions. When Angelina does answer questions, the nurse doesn't seem to be listening to Angelina completely. He keeps cutting her off.

What should the health care worker have done differently?

After the health care worker identified the nurse as an interpreter, she should have

- # Asked for Angelina's permission to use an interpreter
- # Planned the interview and decided what key points to talk about with Angelina
- # Met with the nurse before the interview to talk about the goals for the interview

Since the nurse did not have adequate time to serve as an interpreter, the health care worker should have looked for another interpreter.

What are some instructions the health care worker could have given to the nurse before the interview?

Before the interview, the health care worker should have set aside some time to speak to the nurse. The health care worker should have given the following instructions to the nurse:

- # Remind him that all information in the interview is confidential
- # Ask the nurse to refrain from adding his own comments
- # Ask the nurse to explain questions or answers that are not clear
- # Give him time to translate each phrase before continuing
- # Ask the nurse to translate the patient's and the health care worker's own words as exactly as possible

9.5 You are assigned to deliver DOT to Mrs. Wilson, a 76-year-old woman who lives alone in the house 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 her home to help her take her medication. Mrs. Wilson is elated to have some company. She happily offers you cookies and wants to “talk awhile” before she takes her medication.

What are the tasks you complete when you deliver DOT to Mrs. Wilson?

Check for side effects. At each visit, before the drugs are given, the health care worker should ask Mrs. Wilson if she is having any problems with the medications. Mrs. Wilson should be educated about symptoms indicating adverse reactions to the drugs she is taking, whether minor or serious. If Mrs. Wilson has symptoms of serious adverse reactions, a new drug supply should not be given; Mrs. Wilson should stop taking medication immediately. The supervisor should be told that the drugs were not given, and the prescribing clinician should be notified about the adverse reaction. The health care worker should arrange for Mrs. Wilson to see the clinician as soon as possible.

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

Watch Mrs. Wilson take the pills. Medication should not be left for Mrs. Wilson to take on her own. The health care worker or Mrs. Wilson should get a glass of water or other beverage before she is given the pills. The health care worker should watch Mrs. Wilson continuously from the time each pill is given to the time she swallows it.

Document the visit. The health care worker should document each visit with Mrs. Wilson 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.



9.6 Nick is a 27-year-old single unemployed male. He has been in and out of rehabilitation clinics for crack use. He picks up odd jobs in the warehouses and diners on the waterfront. He lives in a single room occupancy hotel.

Four weeks ago he was brought by the police to the emergency room of General Hospital for treatment of stab wounds to the right arm resulting from a drug deal gone bad. Upon admission he was intoxicated, appeared poorly nourished and underweight, and had a productive cough. His smears were positive for AFB and he was started on appropriate therapy. He remained in the hospital for 5 days. Against medical advice, Nick then insisted on leaving the hospital. On the day of discharge, the infection control nurse telephoned a report to the health department, and instructed Nick to go to the health department the next morning for evaluation and a supply of medicine. He failed to keep his appointment. The next week a health care worker was assigned to locate Nick and persuade him to come to the clinic. The health care worker found him lying on a park bench near the hotel where he lives. The health care worker convinced Nick to go to the clinic for follow-up tests. At the clinic, Nick reluctantly agrees to take his medication, although he does not want DOT. He says he is not a “baby” and can take the medication on his own.

How would the health care worker help Nick adhere to his treatment regimen?

When the health care worker begins to work with Nick, it is important that he asks Nick what he believes about TB disease and treatment. Nick doesn't seem to understand the importance of finishing treatment. Therefore, adherence may be very difficult.

Next, the health care worker should educate Nick about TB and its treatment. As part of patient education, Nick should be told that some people have trouble staying on the medication schedule. The health care worker should help Nick find ways to identify and deal with potential adherence problems. Nick is more likely to be adherent if he helps make the decisions and chooses the solutions rather than being told what to do. In addition, Nick is more likely to pay attention to information that is relevant to him and does not require abrupt changes in his behavior. In general, Nick may be more likely to follow the treatment plan if he understands his illness and the benefits of treatment. After the health care worker assesses Nick and establishes a relationship with him, incentives and/or enablers could be offered to help Nick adhere to treatment.



What can the health care worker say about DOT to convince Nick of its importance?

It is important to explain the benefits of DOT to Nick and to stress the fact that DOT is not punitive. The health care worker could explain that DOT is more than watching Nick swallow each pill. DOT will

- # Help him keep appointments
- # Provide education when needed
- # Offer incentives and enablers to encourage adherence

It is also important to point out that DOT will help the health care worker monitor Nick for any side effects and help him complete an adequate regimen.

9.7 Mrs. Chan has active pulmonary TB and is very reluctant to participate in the DOT program. She is afraid she will die from her disease, and is very anxious. Because of difficulties she had when she immigrated 5 years ago, Mrs. Chan doesn't trust health department staff or any other government employee.

A health care worker is assigned Mrs. Chan's case while she is hospitalized. During a visit to the hospital, the health care worker explains to Mrs. Chan that she is being offered DOT so that she will never forget to take her medicine. If she follows all the health care worker's instructions, Mrs. Chan will receive a supply of dietary supplements at each meeting and \$100 at the end of treatment. Mrs. Chan smiles and nods.

The health care worker is very surprised when Mrs. Chan doesn't show up for her first DOT appointment.

What can happen if a health care worker offers Mrs. Chan incentives before gaining the patient's trust?

Incentives and enablers should be chosen according to the patients' special needs and interests, or the patients may not care if they receive them. For example, if this health care worker had known that transportation is a problem for Mrs. Chan, he could have offered bus tokens, bus fare, or taxi fare. If transportation was not her problem, then something else that she needs or would appreciate could have been offered. The health care worker didn't take the time to learn as much as he could about Mrs. Chan to identify her needs and interests and better motivate her to complete treatment. More importantly, he offered Mrs. Chan incentives before he had established a good



relationship with the patient. Because Mrs. Chan doesn't trust the health care worker, she may see the incentives as a bribe and may feel insulted by his offer.

How might the health care worker have done a better assessment interview with Mrs. Chan?

The health care worker could have begun by using open-ended questions to ask Mrs. Chan her concerns about TB. The more he can become aware of her ideas and concerns about TB and its treatment, the better prepared he would be to anticipate and resolve problems that can arise. Mrs. Chan might be able to trust the health care worker and feel more comfortable sharing her thoughts if he would

- # Listen carefully to the patient and pay attention to hesitations, inconsistencies, or strong emotions
- # Speak openly, honestly, and politely about differences in ideas. Correct Mrs. Chan's misconceptions tactfully and allow time for questions if she doesn't understand fully
- # Show Mrs. Chan proof of what he is saying, such as chest x-rays or laboratory reports, whenever possible
- # Involve Mrs. Chan in the development of the treatment plan and be flexible in meeting her needs

9.8 Ms. Johnson is a 68-year-old widow with active TB disease. She has several other health problems, including obesity, osteoarthritis, and poorly controlled diabetes. She needs a cane to help her walk and often becomes anxious when she leaves her apartment. She lives in a low-income housing block 3 miles from the TB clinic. Ms. Johnson's two children live outside the state and visit infrequently.

Conduct a behavioral diagnosis of Ms. Johnson's potential barriers to completing her TB treatment and the methods that can be used to overcome the barriers.

Ms. Johnson has several barriers to adherence that may prevent her from successfully completing a TB regimen which include

- # Complex medication regime
- # Complex health problems
- # Physical limitations



- # Lack of support from family
- # Low income, possible lack of money to pay for health care

Her other health problems, with the addition of the TB drugs, will make pill-taking very complex. Consideration should be given to simplifying her TB regimen as much as possible and to using DOT. Ms. Johnson has a problem getting around easily, so DOT delivered in her home would enable her to take her medication consistently.

Ms. Johnson lacks support because her family is not nearby. DOT will provide her with some social support and can help her to resolve problems that may arise. Because Ms. Johnson's income is low, it may help to facilitate third-party payment for her health services or a referral to a social worker who can make sure she gets any benefits to which she is entitled. If there is a home health nursing program in the area for which Ms. Johnson qualifies, consideration may be given to assigning her DOT care to a nurse who is able to manage all of Ms. Johnson's health care problems in a coordinated manner.

9.9. 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.

Why might Mr. Sivaraman be nonadherent?

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 no-shows, either with a telephone 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 therapy?

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 the patient 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 health care team (physician, nurses, other health care workers, and other staff) 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.

For some patients, a formal **adherence agreement** — a written understanding between the health care worker and a patient — may be useful. A patient should dictate or 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 next to the health care worker's signature and be given a copy to keep. The health care worker should review the agreement with his or her patient 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.

- 9.10. Walter, a 50-year-old single, unemployed male, was diagnosed with smear and culture positive, pulmonary tuberculosis one month before he was released from prison. The prison doctor telephoned 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 2 weeks after his release, Walter adhered to treatment. He then began missing appointments at the arranged DOT site and at the clinic, stating he felt "okay." For the next few weeks Walter's visits to the clinic became rare. On Walter's latest clinic visit, his sputum smear was positive for AFB. The health care worker assessed Walter's problems and tried everything he could think of to get Walter to adhere to his treatment — gave DOT at Walter's house or his favorite hang out, offered incentives, changed health care workers, and threatened legal action. When the health care worker mentioned legal action, Walter got very upset and threatened the health care worker. He stated that he felt "okay" and he was tired of 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.

