

## SESSION 2: Essential elements of dot — part 1

#### **INTRODUCTION**

In this 3-hour session, participants will discuss the many barriers that can interfere with a patient's successful completion of therapy and explore ways to address them. The trainer will review methods for building rapport and communicating effectively with patients, and participants will practice the skill of asking open-ended questions. The topic of ensuring that the patient actually swallows the dose, one of the most important tasks involved in DOT, will also be covered. The session will conclude with an overview of common adverse reactions to TB medications and their signs and symptoms.

MATERIALS SUPPLIED FOR THIS

SESSION

- Outline for trainers
- Participant's Workbook (1 reproducible master copy)
- PowerPoint slides or masters for overhead transparencies:
  - Risks for Nonadherence
  - How Can DOT Staff Build Rapport and Trust?
  - Skills that Contribute to Good Communication
  - Common Adverse Reactions to TB Drugs
  - Review Questions
- Handout: Adherence Case Studies (1 reproducible master copy)
- Video Segment: Teresa Rollins case study (3 min)

MATERIALS
YOU NEED
TO SUPPLY

- Duplicate Participant's Workbook for each participant
- Duplicate handouts: Adherence Case Studies (optional)
- Poster paper, chalkboard, or dry-erase board
- Overhead projector or laptop and LCD projector
- VCR and monitor (if you choose to use the optional video segment)
- · Poster pens, chalk, or dry-erase markers
- Participant handout: Your program's DOT form
- PowerPoint slide or overhead transparency: Your program's DOT Form

## Material in this session is adapted from:

- Core Curriculum on Tuberculosis, 4th ed. Atlanta: Centers for Disease Control and Prevention; 2000.
- Improving Patient Adherence to Tuberculosis Treatment. Atlanta: Centers for Disease Control and Prevention; 1994.
- Self-Study Modules on Tuberculosis: Module 4, Treatment of Tuberculosis Infection and Disease. Atlanta: Centers for Disease Control and Prevention; 1995.
- Self-Study Modules on Tuberculosis: Module 9, Patient Adherence to Tuberculosis Treatment. Atlanta: Centers for Disease Control and Prevention; 1999.
- TB Frontline: Satellite Primer Continued, Modules 6 9, "Patient Adherence," broadcast on February 10, 2000.
- 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.

#### SESSION OUTLINE FOR TRAINERS

#### 5 MIN LEARNING OBJECTIVES

Review with participants.

Upon completion of this training session, participants will be able to:

- 1. Explain why patient adherence is important to successful TB control outcomes
- 2. Identify at least five reasons why a patient might be nonadherent
- 3. List five techniques to build trust and communicate effectively with TB patients
- 4. List two ways to ensure that a dose is actually swallowed by a patient
- 5. State three commonly observed side effects to anti-TB medications and their signs and symptoms

## 20 MIN I. RISKS FOR NONADHERENCE (OHs/PowerPoint slides)



Review the definition of adherence, found on page 1-7 of this Trainer's Guide.

## A. Why is patient adherence critical to successful TB control outcomes?

Discuss with participants.

When patients adhere to their complete course of TB treatment:

- 1. The risk for developing drug-resistant TB is decreased
- 2. The risk of TB spreading to others is decreased
- 3. Prolonged illness, disability, and possible death from TB are avoided

#### B. Who is at risk for nonadherence?

Discuss with participants.

- 1. Can we reliably predict who will be nonadherent to their treatment? No! Anyone can be nonadherent, regardless of social class, educational background, age group, gender, or ethnicity
- 2. Which persons are at especially high risk for nonadherence?
  - a. Homeless or people who don't have permanent housing
  - b. Persons who use alcohol and/or other substances
  - c. Persons who are unable to take pills on their own because of mental, emotional, or physical disabilities
  - d. Children and teenagers
  - e. Persons who previously did not adhere to their TB treatment

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#### Risks for Nonadherence-Part 1

## C. Why would a patient not adhere to his/her treatment?

Refer participants to page 2-3 of their workbooks. Brainstorm answers to this question and record the answers along the left-hand column of the following form on a chalkboard, poster sheet, or overhead transparency. When participants have no more ideas, fill in missing items as needed. Use the right column to record answers for the next question.

- 1. Patient no longer feels sick
- 2. Lack of knowledge about TB
- 3. Personal or cultural beliefs about TB
- 4. Forgetfulness
- 5. Lack of access to health care
- 6. Language barriers
- 7. Poor relationship(s) with health worker(s)
- 8. Lack of motivation
- 9. Medication side effects
- 10. Complex regimen
- 11. Competing priorities (e.g., need to find housing, access drugs, etc.)
- 12.
- 13.

Why would a patient not adhere to his/her treatment? (List challenges)	What are ways to address each challenge?
1	1
2	2
3	3
4	4
5	5
6	6
7	7

8	8
9	9
10	10

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## Risks for Nonadherence-Part 2

## D. What are some ways to address each of these challenges?

For each barrier that you generated in the previous exercise, ask participants for ideas of how to address the barrier. Record participants' strategies in the right column of the chalkboard, poster sheet, or overhead transparency. When participants have no more ideas, fill in missing items as needed.

Challenges	Ways to Deal with Challenges
Patient no longer feels sick Lack of knowledge about TB Personal or cultural beliefs about TB	Assess patient's knowledge, beliefs, and feelings about TB; provide health education through discussion, or through written or A/V materials, or repeat key concepts especially about transmission.
Forgetfulness	Telephone reminders; provide calendar, bookmark or other visual reminders; daily pill pack dispenser; associate pill-taking with patient's other regular activities
Lack of access to health care	Use DOT; assist with transportation; refer to social worker (when available)
Language barriers	Use interpreter; request assistance from other staff; learn key phrases in patient's language; use commercial telephone translation service
Poor relationship with health worker(s)	Develop communication skills; be accessi- ble throughout care; work on attitudes about patients; change health workers; provide or refer to social services

Lack of motivation Reinforce dangers of nonadherence and

benefits of therapy; increase frequency of visits; provide incentives and/or enablers; set short-term goals; emphasize patient's ability/responsibility to protect others

from TB

Medication side effects

Take medication before or after meals as

indicated; notify case manager so that medication/dosage can be altered if

needed

Complex regimen Notify case manager so that combined

capsules can be used, if possible, or medication/dosage altered; associate pill-taking with patient's other regular activities

Competing priorities (e.g., need to find housing, access drugs, etc.)

Provide or refer to social services, including drug treatment programs; schedule DOT around substance-using times

20 MIN

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## Option #1



### **Adherence Case Studies**

See reproducible master of 2-page handout: Adherence Case Studies (pages 2-18 and 2-19). Distribute one copy to each participant.

#### 1 – 5 participants:

Ask group members to read Case Study #1. Debrief and discuss using the questions that follow the case study. Repeat with Case Study #2.

#### 6+ participants:

Break large group into small groups of 3 – 4 participants. Divide the two case studies between the groups. Ask each group to assign one person to serve as recorder/reporter. Ask each small group to read their assigned case and discuss it using the questions that follow. The recorder/reporter will record the group's responses. If time allows, reassemble the small groups into the larger group. Ask each small group's recorder/reporter to summarize the group's case study and their responses to the questions. If time allows, ask participants outside of the responding group for other responses.

### Case Study #1: Mario

1. What are the challenges to Mario's adherence to his six months of TB treatment?

Substance (heroin) use; complicated, multi-pill regimen; Mario is undocumented so he may avoid the health system for fear of being deported; Mario is feeling better so he may not think he needs ongoing medication.

2. What factors in Mario's life might help him to remain adherent to his TB treatment?

Mario speaks English fairly well; Mario is married and has a family, which might motivate him to stay well and noninfectious; Mario has access to health care and has a job.

3. How could a DOT program help Mario to stay adherent to his treatment?

A DOT program could 1) help connect Mario with a treatment program for substance use; 2) assure Mario that his immigration status is not an issue for them; 3) arrange a convenient place for Mario to receive his medications or assist him in getting to the clinic; 4) educate Mario and his wife about TB; 5) investigate ways to simplify his medication regimen.

## Case Study #2: Louis

1. What are the challenges to Louis' adherence to the rest of his LTBI treatment?

Mental health and hearing problems; substance (alcohol) use; adverse reactions to INH; unstable employment and housing; Louis is single and may lack a family support system.

2. How could a DOT program help Louis to stay adherent to his treatment?

A DOT program could 1) help connect Louis with other agencies to address his mental health and substance use problems; 2) work with Louis' parole officer to help Louis find a job and housing; 3) find a time and place convenient to Louis to deliver his LTBI medication to him; 4) educate Louis about the importance of completing his LTBI regimen; and 5) help find ways to ensure that Louis can hear and understand what the DOT staff tell him.

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### Option #2



## **Adherence Case Study Video**

View the Teresa Rollins case study video (3 minutes). Discuss the following questions:

1. What challenges to adherence does Mrs. Rollins face?

Lacks knowledge about TB; admits to being forgetful; lives alone; has limited support; lacks physical mobility.

2. How did the DOT staff person in the video work to lessen her challenges?

Shared correct information about TB, while still respecting her religious beliefs; linked pill-taking to her daily Bible reading; provided home-based DOT; enlisted aid of daughter.

#### 15 MIN II. BUILDING RAPPORT AND COMMUNICATION SKILLS



### A. Why is building rapport with a TB patient so important?

Discuss with participants:

If a patient trusts and feels comfortable with a health care worker, he/she is more likely to participate in his/her own care, follow instructions, and adhere to his/her TB treatment. Rapport between the patient and the health care worker is not built in one visit, but must be developed and nurtured over time. However, first impressions are important; the quality of the interaction at the first meeting between patient and health worker can set the tone for the relationship to follow.

## B. How can DOT staff build rapport and trust? (OHs/PowerPoint slides)

Discuss with participants, using overheads/PowerPoint slides, How Can DOT Staff Build Rapport and Trust?

- 1. "Start where the patient is." Listen and try to understand the patient's knowledge, beliefs, and feelings about TB disease and treatment. Recognize and address the patient's fears.
- 2. Explain to the patient that you will do everything in your power to protect his/her confidentiality. Respect the patient's right to make decisions about his/her life and care.

- 3. Communicate clearly. Freely provide complete and accurate information. If you don't know the answer to a patient's question, admit it, then investigate the answer and provide a response to the patient as soon as possible.
- 4. Avoid criticizing the patient's adherence behavior; suggest behavior changes respectfully. Involve the patient in identifying possible solutions to adherence problems.
- 5. Be on time and be consistent in what you do and say with a patient.
- 6. Adopt and reflect a nonjudgmental attitude about behaviors that the patient may participate in that you may not be comfortable with (e.g., drug use, homosexuality, and preferring to sleep on the street rather than in a shelter).

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## **Guest Speaker: Building Patient Rapport**

Invite an experienced staff member who is skilled at building patient rapport to speak to the participants about his/her perspectives, style, and methods. Ideally, a staff member from your TB program will be available to fill this role; however, staff from another health program can also be called upon. Help the speaker to prepare his/her presentation by asking him/her to address the following questions:

- How do you establish trust and rapport with your patients?
- Under what circumstances is it most challenging to establish rapport with a patient? How do you address these challenging circumstances?
- Describe a situation in which establishing trust/rapport was particularly slow or difficult. Which strategies worked well with this person?
   Which didn't? What lessons did you learn from working with this person?

15 MIN

# C. Skills that contribute to good communication (OHs/PowerPoint slides)



Consider brainstorming and recording participants' ideas first; then fill in missing items as needed.

1. Listen attentively and respectfully to the patient; use open, relaxed body language

- 2. Assure the patient of privacy and confidentiality
- 3. Avoid being judgmental or accusatory, and never show frustration
- 4. Use simple, nonmedical terms
- 5. Use the appropriate language level for the patient
- 6. Limit the amount of information given
- 7. Discuss the most important topics first and last
- 8. Repeat important information
- 9. Listen to feedback and questions from the patient
- 10. Use concrete examples
- 11. Ask open-ended questions

## D. What is an open-ended question?



Discuss with participants:

- 1. A question that cannot be answered with a simple "yes" or "no"
- 2. Questions that begin with words and phrases such as: Who? What? When? Where? Why? How? Tell me about... Explain to me...

## E. Why are open-ended questions useful?

Discuss with participants:

Open-ended questions are useful because they are more engaging and can provide one with more information than questions that ask for "yes" or "no" answers; they help the health care worker get a clearer and fuller understanding of the patient's situation and needs.

#### 15 MIN

#### ACTIVITY



#### **Open-Ended Questions**

What are some examples of open-ended questions that you might ask a patient to assess his/her knowledge or beliefs about TB?

Brainstorm answers to this question and record the answers on a chalkboard, poster sheet, or overhead transparency. Examples:

- What causes TB?
- How do you think you got TB?
- What problems has your illness caused for you?
- When did you first start to feel sick / start coughing?
- How do your family members or close friends feel about your TB?
- Explain to me what TB does to your body.
- <u>Tell</u> me about any difficulties you have taking medicine.
- What side effects are you experiencing from your medicine?

- Where would be a good place for me to deliver your medicine to you?
- What symptoms are you experiencing?

#### III. OBSERVING AND DOCUMENTING THE DOSE



## A. How can I make sure that a patient is actually swallowing the dose?

1. What are some of the ways you've seen patients avoid swallowing their doses?

Explore ways that patients in your program have avoided swallowing their pills. Examples might include:

- 1. "Cheeking" the pills or hiding under the tongue
- 2. Keeping the pills in their hands
- 3. Hiding pills in furniture or clothing
- 4. Promising to take pills later
- 5. Going to another room to "get a glass of water" or otherwise taking the pills out of your sight with a variety of excuses
- 6. Answering the telephone
- 7. Picking up a crying child
- 2. Why is it important for the patient to take all the medications at once, while the DOT worker is there?

Family members may offer to give the medications or partial doses to the child or adult TB patient "later."

Explain the importance of the patient taking all of the medications at once, while you are with him/her.

3. What are some of the ways you can prevent patients from doing these types of things?

For each example, explore ways to ensure that pills are actually swallowed:

- Observe closely for signs of actual swallowing
- Provide beverage to accompany the pills
- Respectfully ask patient not to turn away or leave the room during swallowing
- Deliver dose away from furniture

If you have a strong suspicion that the patient is not swallowing the medication, more intrusive measures may be useful in rare situations, such as when language barriers exist or when the patient has mental health problems that might interfere with adherence to swallowing. Consider asking the patient to open his/her mouth wide to show you.

#### B. How do I document the dose?

Review your program's forms and procedures for documenting a successfully delivered or a missed dose. Use an overhead transparency or PowerPoint slide to show your DOT form; include a copy of the DOT form in the participants' handouts. Highlight the most important areas of the form that must be completed after each DOT visit.

The DOT worker is responsible for documenting all medications taken by each client. It is recommended that this be recorded on a TB DOT Log (for a sample see page 2-13 in this *Trainer's Guide* and page 2-9 in the *Participant's Workbook*), and on the medical record when returning to the clinic. The form should provide complete client identification, a medication schedule, a list of medications the client is receiving, and space for recording 1) each time medication is observed to be taken, 2) possible side effects, and 3) other relevant information

Adapted from a San Francisco, Department of Public Health, TB Division form

	Daily D	Patie Address (o		8	က	4
	Daily DOT Log	Patient's name Address (or regular hangout)	:			
Place your clinic identifying information here	,	Medications & Schedule				
		Observed				
		Delivered Not observed				
	Date:	Not available	·			
		Time				
		HW Initial				
		Side Effects/ Other Comments				

## 15 MIN IV. ADVERSE REACTIONS TO TB MEDICATIONS



While DOT workers are not the providers overseeing the patient's clinical care, they are the people who often have the most frequent contact with patients and therefore are the ones who are most likely to hear about or notice any side effects the patient may be experiencing. The DOT worker should always ask each patient if he/she is experiencing any side effects. Therefore it is critical that DOT workers be familiar with typical adverse reactions to TB medications.

#### A. What are the four main TB medications?

Review with participants:

- 1. Isoniazid (INH)
- 2. Rifampin (RIF)
- 3. Ethambutol (EMB)
- 4. Pyrazinamide (PZA)

If possible, show samples of each of the above medications as well as combination drugs.

## B. What are the most common adverse reactions? (OHs/PowerPoint slides) What are the signs and symptoms of these adverse reactions?

Review information with participants, using the overheads/PowerPoint slides: Common Adverse Reactions to TB Drugs. Refer participants to page 2-10 in their workbooks. For more detailed information about doses and adverse reactions to first-line TB medications, see Core Curriculum on Tuberculosis, 4th ed. Atlanta: Centers for Disease Control and Prevention; 2000, pp. 120 – 121.

### C. How should adverse reactions be reported?

Review your program's procedures for how a DOT worker should report a patient's side effects to the case manager or other appropriate staff. Important points to address are:

- 1. Importance of the DOT worker reporting side effects quickly (provide specific timeframe)
- 2. Identifying who should receive the report
- 3. Identifying how the report should be made (telephone, written form, etc.)
- 4. How the report will be handled within the TB program
- 5. What the DOT worker should tell the patient regarding next steps

#### ► ACTIVITY



## Finding Out If a Patient Is Having Adverse Reactions

Ask participants to divide into pairs. One person will start by playing the role of a TB patient, the other will be a DOT staff person. Ask the person playing the DOT staff person to use open-ended questions to find out if the patient is experiencing any adverse reactions. Remind participants that open-ended questions begin with words and phrases like Who? What? When? Where? Why? How? Tell me about... Explain to me...

Example: "How has your stomach been feeling, Mrs. Jones?"

Avoid: "Have you been nauseous, Mrs. Jones?"

Example: "I notice you have some redness on your hands today, Mr. Smith.

When did it first appear?"

Avoid: "Is that redness on your hands something new?"

After 5 minutes, instruct the members of each pair to switch roles. After five more minutes of practice, reassemble the group and lead a brief discussion with the following questions:

- What are some examples of open-ended questions that were posed to the patients?
- How effective were the questions at getting information?
   What adverse reactions did the patients reveal?

Participants can record their notes about this activity on page 2-11 of their workbooks.

## <sup>10 MIN</sup> REVIEW QUESTIONS



The following questions can be used for a group discussion to review the session's main points (use overhead/PowerPoint slide, Review Questions), or they can be utilized as a written post-test for individuals (see page 2-12 in Participant's Workbook).

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What are two negative consequences that can result if a TB patient does not adhere to the treatment regimen?
Give five reasons that a patient might be nonadherent. Give a possible way to deal with each reason.
Name five techniques to build trust and communicate effectively with TB patients.
What are two ways you can be sure that a dose is actually swallowed by a patient?

5) What are three commonly observed adverse reactions to anti-TB medications?

## <sup>5 MIN</sup> **EVALUATION**

Ask participants to share their feedback about this training session on the evaluation form (see page 2–14 in Participant's Workbook).

#### **ADDITIONAL RESOURCES**

- Core Curriculum on Tuberculosis, 4th ed. Atlanta: Centers for Disease Control and Prevention; 2000.
- Facilitating TB Outreach: Community Workers and Hard-To-Reach TB Populations.
   Video available from the Francis J. Curry National Tuberculosis Center.
   http://www.nationaltbcenter.edu
- Improving Tuberculosis Treatment and Control: An Agenda for Behavioral, Social and Health Services Research. Proceedings of Tuberculosis and Behavior: National Workshop on Research for the 21st Century: 1994, Aug 28 – 30; Bethesda, MD. Atlanta: Centers for Disease Control and Prevention; 1995.
- *Self-Study Modules on Tuberculosis: 1 5.* Atlanta: Centers for Disease Control and Prevention; 1995.
- Self-Study Modules on Tuberculosis: 6 9. Atlanta: Centers for Disease Control and Prevention; 1999.
- Social Support Services for Tuberculosis Clients. New York: Charles P. Felton National Tuberculosis Center; 1999.
- Sumartojo E. Adherence to the tuberculosis treatment plan. In: Cohen FL, Durham JD, eds. *Tuberculosis: A Sourcebook for Nursing Practice*. New York: Springer Publishing Co.; 1995, chap 7.
- http://www.harlemtbcenter.org
   Charles P. Felton National Tuberculosis Center at Harlem Hospital
- http://www.cdc.gov/nchstp/tb
   Division of TB Elimination, Centers for Disease Control and Prevention
- http://www.nationaltbcenter.edu
   Francis J. Curry National Tuberculosis Center
- http://www.umdnj.edu/ntbcweb
   New Jersey Medical School National TB Center

#### **ADHERENCE CASE STUDIES**

## Case Study #1

Mario is a 22-year-old married man, born in Mexico, who has lived in the U.S. for the past two years as an undocumented worker. He is a waiter in a restaurant and speaks English fairly well. Mario has been injecting heroin about two times a month for the past year. He was recently released from the hospital where he was treated for INH-resistant active pulmonary TB. Mario's sputum is negative and he is feeling much better and is anxious to return to work. His doctor has prescribed a complicated, multi-pill regimen for Mario to follow for the next six months. Mario's wife, who speaks no English, recently arrived from Mexico with their 3-year-old son. They live with Mario in a small two-room flat.

	n. They live with Mario in a small two-room flat.
1.	What are the challenges to Mario's adherence to his six months of TB treatment?
2.	What factors in Mario's life might help him remain adherent to his TB treatment?

## **ADHERENCE CASE STUDIES**

## Case Study #2

Louis is a 31-year-old single man who was recently paroled from prison and has returned to his small, rural hometown. He has been involved with the criminal-judicial system since age 14. A Department of Corrections psychiatrist diagnosed him as being mildly schizophrenic. He is also partially hearing impaired. While in prison, Louis began treatment for LTBI; he still has three months of his treatment to finish. Louis is a heavy drinker and experiences stomach upset while taking the INH. Louis has not been able to find work and has been sleeping in the park and in abandoned barns.

1.	What are the challenge	s to Louis	s' adherence	to the re	st of his LT	Bl treatment?

2. How could a DOT program help Louis to stay adherent to his treatment?