

TUBERCULOSIS CASE MANAGEMENT FOR NURSES

THE PEDIATRIC PATIENT

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INTRODUCTION

This module discusses why children with latent TB infection (LTBI), especially young children under the age of 5, have a greater risk than adults for developing TB disease. Opportunities to prevent TB from occurring are typically present but are often missed as a result of fragmented healthcare services. The nurse case manager must take advantage of every opportunity to prevent the progression from latent infection to active disease.

Attempting to treat a child, especially a healthy one, for an extended time is a challenge to health-care providers. Certain aspects of the TB nurse case management process are altered when the patient is a child. Many of these issues were introduced in Module 2. This module addresses some of the issues in greater depth.

LEARNING OBJECTIVES

- 1) Describe why young children who are infected with tuberculosis are more likely than adults to develop TB disease.
- 2) Describe the ways in which symptom manifestation and early detection of TB disease are different in children than in adults.
- 3) Identify commonly missed opportunities for prevention of TB disease in children who have latent infection.
- 4) Identify common barriers to adherence in pediatric populations.
- 5) Provide examples of age-appropriate strategies to improve adherence in children.

OVERVIEW OF TUBERCULOSIS IN THE PEDIATRIC POPULATION

TB infection in children is most often the result of contact with an adult household member or other close person who has active, infectious tuberculosis. Therefore, infants and children at greatest risk for infection are those in contact with adults who have TB disease of the respiratory tract or those with latent TB infection who are at high risk for developing TB disease (CDC, 1995).

Tuberculosis is a disease that progresses rapidly in children, and because of their immature immune systems, infected children are more likely than infected adults to develop TB disease, and are likely to develop it more rapidly. In fact, the younger the child, the greater the risk this progression will occur. (See Table 1) (Stark, Jacobs, Jereb 1992)

Table 1 Progression from TB Infection to TB Disease

AGE	% THAT PROGRESS TO DISEASE
Infants <1 year	Up to 43%
1-5 years	24%
11-15 years	15%
Adults with normal immunity	10%

TB disease most often presents as pulmonary disease in both adults and children. In adults this disease usually manifests itself in a specific set of respiratory symptoms. In children, however, pulmonary TB disease is more difficult to detect because it is often asymptomatic. When symptoms are present, they are generally nonspecific, and can easily be mistaken for other conditions. The differences between adults and children with pulmonary TB disease are summarized in Table 2.

Table 2 Comparison of Pulmonary TB Disease in Adults and Children

	ADULTS	CHILDREN
Tuberculin skin test reaction	Usually positive	Usually positive
Sputum	Smear and culture positive	Under 12 years old, it is likely that child will be unable to produce sputum
Symptoms	Respiratory: coughing, pain in chest on inhalation or coughing, hemoptysis General: fever, chills, night sweats, weight loss, malaise, fatigue	Respiratory: Usually asymptomatic (cough is rare with little or no sputum) May have recent history of pneumonia General: failure to gain weight
Infectiousness	Often infectious before treatment due to large numbers of tubercle bacilli and ability to forcefully expel them when coughing	Under 12 years old, rarely infectious due to fewer numbers of bacilli in pulmonary lesions and inability to forcefully expel them

The diagnosis of pulmonary tuberculosis in children is most commonly made during the contact investigation of an adult with active TB, or as a result of routine tuberculin skin testing. Although extra-pulmonary TB comprises only 15% of all adult cases of tuberculosis, in children 25% of TB cases are extra-pulmonary. One of the most common forms of extra-pulmonary TB in children is cervical lymphadenitis. Other common sites of TB disease include bone, joint, central nervous system (usually meningeal) and the abdomen (Waagner, 1993).

Many times the contact investigation fails to identify affected children promptly. Reasons for contact investigation failures include:

- Index case not reported promptly
- Index case interview not done in a timely manner
- Children not identified in the contact interview

Other reasons why opportunities to treat TB in children are missed include failure to:

- Recommend medication to a pediatric contact of a suspected infectious TB case
- Closely follow the infectious source case
- Obtain information about the source case regarding the period of infectiousness, site of TB disease, sputum, smear and culture results, including sensitivities, treatment plan, and adherence rates

NURSE CASE MANAGEMENT OF THE PEDIATRIC TB PATIENT

The nurse case management model involves intense interaction between the patient/family and the nurse. At each encounter, the nurse assesses the child and identifies existing or potential problems in the treatment plan, recommends changes, and provides the family with an explanation of any treatment modifications. If the child is a contact of a person with TB or is being evaluated to determine TB infection, the level of anxiety within the family may be very high. A brief explanation of the assessment process will help allay caregivers' fears.

The nurse case manager should be knowledgeable about the treatment protocols for TB disease and LTBI. The physician or nurse practitioner will prescribe medications and order laboratory tests and x-rays however, the nurse case manager should be able to answer questions about the length of treatment and medication side effects.

TB Education and Knowledge Review

The nurse case manager is responsible for providing the patient and family with information and knowledge about TB and its treatment. The overall goal of patient education is sufficient knowledge so the family can make wise choices and adhere to the regimen until treatment is completed. The following techniques can be employed by the TB nurse case manager:

- Question child and family regarding their knowledge of why medications are needed for treatment
- Provide written information about TB in language that child and parent can understand
- Keep explanations simple and focused
- Provide the nurse case manager's phone number and advise family to call if child experiences any problems. Establishing and maintaining communication is critical to the treatment process
- Instruct caregiver to seek medical evaluation if the child experiences adverse side effects from the medication, such as persistent vomiting, severe headache, or rash
- Discuss directly observed therapy (DOT) plan

Directly Observed Therapy vs Self-Administered Therapy

Once the diagnosis of TB disease or TB infection has been made and the child and family understand the need for anti-TB medication, the method by which the medication will be administered becomes of paramount importance.

As with the adult TB patient, the only way the nurse case manager can be assured that the child is taking the medication as prescribed is by using DOT. Unlike treatment for chronic illnesses such as seizure disorders, where serum drug levels are monitored regularly, there is no effective laboratory measurement that confirms adherence to the treatment regimen in TB. Therefore, DOT is the method of choice. When proposing this method to the parents or guardian, the nurse must assure the family that DOT is designed to ensure the most positive treatment outcomes while allowing as much control as possible. In the case of young children, DOT is generally provided in the home or at school/daycare center.

School is an ideal setting for treatment of tuberculosis disease and infection. The school nurse can observe, document, and assess the child for medication side effects. *Tuberculosis School Nurse Handbook* (NJMS National TB Center, 2001) and *Guidelines for Initiating a School-Based Directly Observed Therapy Program* (NJMS National TB Center, 1999) describe in detail the essential components of the DOT concept and methods of implementation.

When school DOT is not appropriate or is not an option, the child can receive DOT at home or at daycare. Generally, DOT is given at school on weekdays and the parent or guardian gives the medication on weekends. The nurse case manager should assess the parent or guardian's understanding of the treatment plan and instruct them to notify the nurse if there are any problems or concerns. When developing a plan, several factors must be considered:

- Age of the child (Table 3 lists age-specific strategies)
- Location (where does child spend most of the day)
- Frequency of administration (daily or intermittent therapy)
- Family's cultural beliefs
- Family's willingness to have healthcare personnel visit the home regularly
- Caregiver's understanding of the disease
- Family's concern about the need for long-term medication therapy and possible side effects

Although DOT is the ideal method of assuring the best medical outcome, not all clinics or schools can provide DOT, particularly for treatment of latent TB infection. In these cases a plan for self-administered medication must be devised to meet the needs of the child and family.

The nurse case manager should discuss with the child and family how to administer the medication, including a demonstration of how to crush pills and mix with food if necessary. Taking medication may be associated with daily rituals such as meals, brushing teeth, bedtime (medication at bedtime can decrease side effects). In addition, reminder notes taped on mirrors or the refrigerator are helpful, as are wrist watches that function as alarm clocks. Frequent monitoring is essential if medication is self-administered. If problems develop, the child should be placed on DOT.

Adherence Strategies

Optimal adherence to treatment is based on an effective collaborative alliance among the child, family, and healthcare team. A proactive approach and interventions that convey respect, realism, and hope are all critical components to adherence. Success in adherence requires consideration of the cognitive, psychological, cultural, political, and economic factors.

The following are activities to enhance adherence:

- Decorate the medication cup
- Use decorative/crazy straws
- Make a game of taking medication
- Make a poster, indicating treatment progress
- Give rewards for taking medications

Incentives for a child receiving treatment for TB can be obtained from local area merchants. Examples of incentives include tangible rewards, such as stickers, books, toys, movie passes, telephone calling cards, videos, or certificates to local shops or food merchants.

Assessing Adherence and Addressing Barriers

The evaluation of adherence requires the nurse case manager to consider:

- Adherence standards such as monthly adherence rate
- Child or family self-reporting
- Behavioral measures, such as keeping clinic appointments
- Measurable clinical outcomes, including improvement of symptoms or radiologic findings

In pediatrics, it is important to monitor adherence rates regularly. Early identification and resolution of problems is critical. Problem resolution requires identification of obstacles to adherence such as:

- Unpalatable medication
- Stigma associated with TB
- Family dynamics
- Lack of support system
- Denial of illness by child and family
- Parental attitude toward child's treatment
- Previous history of nonadherence
- Language barriers impeding understanding
- Cultural beliefs about interpretation of tuberculin skin tests when there is a history of BCG vaccine

To establish adherence to treatment, there must be open communication between the child and family, achieved by listening actively, giving feedback, and resolving conflict. An assessment of family beliefs and values is important to increase the provider's cultural sensitivity to issues as they occur. The child and family should be educated regarding TB. The child's support person within the family should be identified. Keep in mind that this person may not always be the parent; a grandparent or older sibling may be the major source of support. If the family is involved with other community agencies, they may be good resources in establishing improved adherence.

The nurse case manager must develop individualized strategies to resolve problems with adherence. A child's reaction to treatment is affected by his/her developmental characteristics, such as physical and cognitive capabilities. Problems should be addressed based on the child's developmental stage, age group, and social behavior. Some solutions may be as simple as:

- Mixing the medication with a food the child likes
- Rearranging the time medication is administered
- Shifting personnel to align with the child's personality preference

The key predictor for successful treatment outcomes is education. The child and his/her family must understand both the need for treatment and the proper method of medication administration. While taking into account universally recognized sequences and activities that facilitate learning, it is also important to acknowledge different styles of learning. Table 3 gives examples of age-appropriate adherence strategies that may be used at various ages and developmental milestones.

Table 3 Adherence Strategies at Various Ages

AGE	MAJOR MILESTONE	IMPORTANT EVENT	ADHERENCE STRATEGY
Infant birth-1 year	Trust	Feeding, bonding	Mothers and caregivers must comprehend need for treatment. To promote compliance, offer medication when baby is hungry. Mix with approximately 10 cc of breast milk or formula. Pill can be crushed and dissolved in small amount of warm water, then mixed with milk. INH liquid contains sorbitol, which can cause diarrhea. Therefore, it is not recommended. INH can be mixed with baby food such as cereal or fruit and given by spoon.
Toddler 1-3 years	Autonomy	Develops own identity	Use distraction. Disguise taste with vehicle of child's choice—jelly, pudding, honey, chocolate syrup, applesauce, and ice cream. Expect difficulty but be persistent. Give simple explanations. Use incentives for each daily dose if needed.
Preschooler 3-5 years	Independence	Independent in toileting. Has fears of bodily damage; employs fantasy thinking, storytelling; makes friends; separates from parent	Give simple explanations. Allow some negotiation for time of medication administration or vehicle used. Offer rewards and verbal praise, but be consistent and assertive.
School age 5-12 years	Identification of social role with same sex parent, sibling conflict	School	Discuss treatment plan with child. Provide simple and accurate information. Child may be able to swallow pills whole. Child should receive DOT if possible. School DOT 2 or 3x/week may be an option. May be indicated to reduce dose-related side effects.
Adolescent 12- 18 years	Puberty. Sex role identification. Feelings of vulnerability and rebellion against authority	Peer relationships	Involve adolescent in decision making. Potential for poor adherence. School DOT is an excellent option.

Problem-Solving Techniques to Resolve Nonadherence

- Talk to the child and family concerning any problems. (e.g., inability to pick up monthly medication)
- Overcome barriers (e.g., in high school, medication may be given during morning homeroom to avoid tracking students during the day)
- Plan medication adherence to coincide with performance of daily habits or rituals
- Simplify treatments by recommending intermittent DOT
- Elicit the support of family and friends

Discharge Planning

At the completion of treatment for TB, the nurse case manager should review the child's diagnosis and treatment. The parent should be instructed regarding future skin testing and chest x-rays. Inform the family that the child's tuberculin skin test will remain positive and retesting is not necessary; nor is there an indication for regular follow-up chest x-rays, unless the child is being evaluated for a respiratory illness and the healthcare provider orders it as part of the evaluation.

A treatment completion letter or card should be provided, emphasizing the importance of keeping this document throughout the child's life. The nurse case manager should also verify that the child has a link with a primary care provider, and that information regarding the child's TB treatment has been communicated to the proper office. Verification of treatment may be needed for clearance and/or entrance into college, military service, or certain types of employment.

For the treatment of TB or LTBI to be most effective, it is essential that the child and family have a full understanding of the significance of treatment. The final visit is an opportunity for the nurse case manager to ask the child and/or parent if they have any questions regarding the TB treatment process and to correct any misconceptions by filling in any gaps in their knowledge. The nurse case manager can then be assured that the discharge plan has prepared the child and family for the impact of TB treatment on their lives both now and in the future.

REVIEW QUESTIONS

SECTION REVIEW – OVERVIEW OF TB IN THE PEDIATRIC POPULATION

- 1) Describe the difference between tuberculosis in a child and an adult.
- 2) How are children with TB usually identified?
- 3) Discuss “missed opportunities” for treatment.

SECTION REVIEW – NURSE CASE MANAGEMENT OF THE PEDIATRIC TB PATIENT

- 1) What elements of the patient’s TB knowledge must the nurse review?
- 2) Describe the purpose of DOT in the treatment of TB.
- 3) How is adherence to TB medication measured?
- 4) Name three barriers to adherence.
- 5) Identify age-specific strategies for improving adherence rates.
- 6) Discuss the importance of discharge planning and the final office visit.

APPENDIX

TARGETED SKIN TESTING SCHEDULE

Only those children who are at increased risk of exposure to someone with tuberculosis need to be targeted for tuberculin skin testing. The American Academy of Pediatrics (AAP) guidelines for skin testing of children specify which categories of at-risk children should be tested and at what ages and intervals (AAP, 2000).

Recommended Tuberculosis Skin Testing of Children (AAP)			
IMMEDIATE TESTING	ANNUAL TESTING	TEST EVERY 2-3 YEARS	TEST AT 4-6 YEARS OLD AND AGAIN BETWEEN 11-16 YEARS OLD
Contacts of persons confirmed or suspected of infectious TB	HIV infected	Exposed to people who are: HIV+, homeless, residents of nursing homes, users of illicit drugs, institutionalized adolescents or adults, migrant farm workers. Continued potential exposure by travel to endemic areas and/or household contact of persons from endemic areas with unknown TST status	Parents immigrated (with unknown TST status) from regions of the world with high-prevalence rates
Radiographic or clinical findings suggesting TB	Living in household with person(s) infected with HIV	Foster children with exposure to adults in the preceding high-risk groups	Have no specific risk factors but live in high-prevalence areas
Immigrating from endemic areas of the world in the last 5 years (e.g., Asia, Middle East, Latin America, Africa)	Incarcerated or institutionalized adolescents		
Travel history to endemic country			
Significant contact with indigenous people from endemic country			

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