

## **TUBERCULOSIS CONTROL IN AN ADOLESCENT POPULATION: TRAINING MANUAL FOR AN INNOVATIVE EDUCATIONAL PROGRAM**

### **Introduction**

Adherence. Defining the term is fairly simple. In the clinical setting it refers to patients taking medication as prescribed by a health care provider for the prevention or cure of a disease.<sup>1</sup> Although the definition may come easily, achieving adherence proves to be the more difficult task. For centuries clinicians have attempted to discover methods to encourage patients to take the medication that will improve their health and possibly save their lives. Still, large portions of medication remain unconsumed and illnesses that could have been avoided become manifest. Tuberculosis (TB), the primary killer among infectious diseases worldwide, can be prevented with six months of anti-tuberculosis medication when infection is detected. However, it is estimated that 20 to 50 percent of patients receiving preventive treatment fail to complete the treatment regimen.<sup>2</sup> Although the TB case rate in the U.S. has decreased since its height in 1992, the current rate (6.8 cases per 100,000 people in 1998) is still above the national goal for the year 2000 of 3.5 per 100,000.<sup>3</sup> Furthermore, despite decreases in the total number of cases, the proportion of foreign-born TB cases in the United States is increasing.<sup>4,5,6</sup> In 1998, the TB rate in foreign-born persons was approximately four to six times higher than for those born in the U.S.<sup>7</sup> As TB, a treatable and curable disease, continues to be a health problem in the U.S., it is apparent that strategies to increase adherence to TB treatment need to be identified and implemented.

Adherence to anti-TB medication is a particular concern for geographical areas and populations that have a high prevalence of TB. California ranks number one among states nationwide with the highest annual number of reported TB cases, and the city of Los Angeles ranks second after New York among cities with the highest number of TB cases.<sup>7</sup> Los Angeles County TB rates more than doubled the national rate from 1989 through 1996, and continued to be well above the national rate in 1998 (11.8 versus 6.8). The majority of the cases in Los Angeles County are among those born in foreign countries (71%). In 1997, among TB cases with foreign-born persons, the birth countries with the highest percentage of cases were Mexico with 26% and the Philippines with 12%.<sup>8</sup>

Although only active TB cases are reported in the statistics, TB control involves both active and latent cases. For those with tuberculosis infection not receiving preventive treatment, approximately 1 in 10 persons will develop active tuberculosis disease at some point in their lives.<sup>9</sup> In particular, adolescents are more susceptible to the development of active TB due to hormonal changes and altered protein and calcium metabolism associated with adolescent growth.<sup>10,11</sup> Researchers have identified the possibility that adolescents are at increased risk for the disease due to an endocrinological effect upon the capacity of the immune system to control dormant tuberculosis bacilli. This endocrinological effect also appears to change the nature of the disease process so that TB in adolescents becomes characteristically that of adult-type pulmonary tuberculosis,<sup>12,13</sup> and adolescent "patients who acquire TB during adolescence are more likely to develop cavitory disease---either progressive primary pulmonary TB of chronic (re-infection) pulmonary TB---than are younger children."<sup>14,15</sup> Also, the time interval between initial infection and the development of active disease is shorter for adolescents than for those in older age groups.<sup>11</sup> Despite this increase in risk for disease, many adolescents who are prescribed

preventive therapy to avoid TB disease fail to complete it. Among adolescents who initiated preventive treatment between 1992 and 1996 in Los Angeles County, only 55.4% of the adolescents completed care. Low compliance to medical treatment of tuberculosis infection is a factor leading to treatment failure and the increase in new cases of tuberculosis. Patients with TB who fail to complete a standard course of therapy are at increased risk for treatment failure and may play a role in the emergence of drug-resistant strains of TB and further spread of TB.<sup>16</sup>

Research literature addressing patient adherence issues for TB treatment has identified several factors that influence adherence among adults. Patients requiring preventive treatment do not experience symptoms of the disease, but may experience the toxicity of the medication immediately and may require additional patient education to convince the patient of the importance of medication adherence.<sup>17</sup> Factors that may influence an individual's level of adherence include competing demands on time, knowledge of tuberculosis and preventive therapy, intention to take medication, importance of treatment relative to other social issues, and social support.<sup>17</sup> Patients on TB treatment have identified features related to their TB treatment, such as transportation to the clinic, waiting time to see the clinician, and clinic hours, as factors that influence adherence.<sup>18</sup> In addition, culture may play an important role in adherence. For example, among Latinos in California, tuberculosis was found to be stigmatized disease, and patients with the disease feared social rejection from friends and family should they learn about their condition.<sup>17,19</sup> The stigma surrounding TB may induce social pressure to hide even preventive treatment and avoid it if possible.<sup>20</sup> In contrast, among undocumented Mexican workers in Orange County, California, patients undergoing treatment for active TB were found to be highly adherent to the treatment regimen, although they continued to deny their TB diagnosis.<sup>21</sup> Interventions designed to increase adherence to TB treatment should be culturally sensitive, taking into consideration the beliefs and needs of the patient population.

In addition to the adherence problems facing adults, adolescent patients experience issues unique to this age period. For many adolescents receiving preventive TB treatment, TB may be their first experience with a chronic illness and their first time to receive long-term care in the healthcare setting. Because they no longer receive pediatric care, adolescents are now required to transition into adult health care. Whereas pediatric health care tends to involve the family in the management of the child's health issues, adult care focuses more on the individual receiving care and shifts the responsibility to the teen.<sup>22</sup> The transition from family-centered, pediatric care to individual-centered adult care may require more attention in order to assist adolescents in the management of their health care issues and allow them to accept more responsibility of it. Other factors that impact adolescent adherence to the prescribed treatment include the individual's cognitive development, motivation, stresses on the adolescent's life and methods of coping, and relationships with others including family, peers, and health care providers.<sup>23</sup> Psychosocial factors, such as self-esteem, locus of control, and self-efficacy, have also been found to influence adolescent compliance among various chronic diseases.<sup>24,25,26</sup> For instance, high self-esteem has been associated with improved adherence in conditions such as renal failure and diabetes. In addition, a positive correlation was identified between the level of perceived susceptibility and adherence to treatment for rheumatic fever.<sup>27</sup> However, in a study on adherence to treatment for iron deficiency, another asymptomatic condition, there was no significant correlation between self-esteem or locus of control and level of patient adherence.<sup>28</sup>

Given the unique circumstances that adolescents with TB face, it is apparent that prevention

approaches tailored to the adolescent experience are necessary. In particular, efforts are needed to address TB infections not only to protect infected individuals from the onset of the TB disease, but also to shield the general public from its spread. A recent analysis of health care expenditures for TB in the US revealed that the majority of cost is spent on inpatient treatment. Concentrating efforts on outpatient and prevention will dramatically decrease the amount spent on TB treatment.<sup>29</sup> Essential in the effort to protect adolescents and the general public from the spread of TB are effective prevention interventions that promote adherence to treatment. These interventions should appropriately meet the needs of patients according to age level, as well as cultures and beliefs.

In the effort to increase adherence to TB treatment, several programs have employed incentives and enablers to encourage patients to return to clinics for medication and to complete treatment. The health departments of almost every state in the U.S. use incentives and enablers, such as meals, clothing, transportation, and cash, to increase adherence with TB drug regimens.<sup>30</sup> The use of incentives for TB treatment is recommended by the Scientific Assembly on Microbial Tuberculosis and Pulmonary Infection, and has been thought to have contributed to the decrease in TB cases in the U.S. In a previous study conducted by Morisky et al., adult patients with both active and latent TB were more likely to remain in care and adhere to the medical regimen when they received incentives and health education.<sup>31</sup> Another TB program demonstrated that incentives that were chosen by the patients were related to the completion of TB prophylaxis.<sup>32</sup> Both monetary and non-monetary incentives were successful in increasing the rates of returns for TB skin test readings among intravenous drug and crack cocaine users when compared with motivational education alone and the usual encouragement to return. Rice and Lutzker found that while the incentive conditions were more expensive, they were more cost effective and were successful in increasing appointment keeping.<sup>33</sup> Although the use of incentives for TB treatment among adolescents has not been previously examined, incentives have been effective in other programs for adolescents, such as attendance in repeat pregnancy prevention programs<sup>34</sup> and participation in interventions to reduce intercourse rates and improve condom use.<sup>35</sup> As demonstrated by these examples, incentives have been effective in increasing attendance in various programs. Consistent attendance is particularly important in TB treatment programs, as patients are often required to attend monthly visits in order to refill their monthly supply of medication.

Programs attempting to increase adherence to treatment among youth have recognized the importance of parental involvement. Parents provide social support in chronic care activities. While the responsibility of treatment management will shift to the adolescent, parents can act as “adherence observers” and can provide support for an adolescent who is learning new skills of treatment management and adherence.<sup>36</sup> A program that was designed to increase youth's self-management of their chronic health conditions, involved both the children and their parents in a training intervention. The youth in the intervention group experienced significantly higher rates of therapeutic adherence and more self-responsibility in the management of their health condition.<sup>37</sup> Another study conducted in Cape Town, South Africa, found a significant increase in treatment adherence for youth with active TB when the patients' parents participated in a parent-centered interview and were given a patient education booklet.<sup>38</sup> These examples support the argument that health care providers serving adolescents should involve parents in the treatment process.

Peer counselors have also been effective in influencing positive health behaviors. Peer counselors can be described as someone of "equal standing or similar age to the recipient".<sup>39</sup> At the University of Iowa, peer counselors were successful in increasing adherence to TB treatment among students receiving care with the Student Health Services. Prior to the implementation of the peer counselor program, completion of treatment ranged from 5-14%. Following its implementation, completion rates increased to 62-79%.<sup>40</sup> Peer support is particularly important for adolescents, as it has been recognized that peers have a significant and perhaps greater influence on a young person's health than do parents or health personnel.<sup>41,42</sup> When counseling female teens on the use of oral contraceptives, peer counselors significantly increased adolescent adherence when compared with nurses.<sup>43</sup> Peer counselors have successfully influenced the outcomes of other adolescent programs focused on HIV risk-reduction, asthma education, anabolic androgenic steroids, tobacco, alcohol, and other drug use.<sup>44,45,46,47</sup> Many of these programs have used peer counselors to conduct health education sessions in group or classroom settings. Other programs have employed peers on a telephone hotline.<sup>48,49</sup> One telephone service provided emotional support for people with Lupus or for people with family members with Lupus. When asked to evaluate the telephone hotline, 92% of the individuals who used the service were at least moderately satisfied with it, and 60% reported a change in feeling as a result of the emotional support provided by the peer counselors. Changes in behavior were attributed to the hotline when they occurred.<sup>46</sup>

### **Purpose of this Training Manual**

From 1995 through 1998, the California State University in Long Beach and the UCLA School of Public Health conducted a joint research project in order to test the effectiveness of two interventions, peer counseling and contingency contracting (incentives), on adolescent adherence to preventive TB treatment. A three year study was conducted in two Los Angeles County health clinics which compared the adherence of adolescents who were divided into four groups and assigned different interventions: 1) peer counselor, 2) incentive contract, 3) combined use of peer counselors and incentives, and 4) usual care. By involving the parents of the teen clients and peer counselors whom reflect the age and background of the client population, the peer counselor and contingency contracting components were designed to meet the needs of teens with TB infection through social support and positive reinforcement.

This training manual was designed to be a tool for health care providers to increase TB treatment compliance among adolescents in their care settings. Based on research data collected during the three-year Adolescent TB prevention study, this manual provides recommendations for TB programs that serve adolescent populations of diverse backgrounds. The components of the intervention that demonstrate promise for increasing treatment adherence will also be highlighted. The activities described in this training manual can be incorporated into the usual activities of health clinics that serve TB infected adolescents and can be implemented by the clinic staff. Based on the experiences of the UCLA/CSULB Adolescent TB Project staff, specific suggestions have been included to facilitate the care of in the clinics. In addition, Sections B and C of the training packet provide guidance on the implementation of two innovative interventions that were implemented during this study: one using peer counselors and the other utilizing contingency contracts.

### **Overview of the Research Study**

This study was conducted at the Curtis Tucker Health Center in Inglewood and the Long Beach Health Department. The purpose of the study was to examine the effects of two interventions, peer counseling and contingency contracting, on the treatment adherence of adolescents undergoing preventative TB treatment. In order to test these approaches, adolescents who agreed to participate in the study were randomly assigned into one of three educational intervention groups or the usual care group. The first intervention group received the Educational Peer Counseling, the second group participated in the Parent-Adolescent Contingency Contracting Incentive Intervention, and the third intervention group received a combination of the Educational Peer Counseling and Parent-Participant Contingency Contracting Incentive Intervention. Finally, a fourth group did not receive an intervention, but received the usual clinic care.

All eligible adolescents who were been recommended for chemoprophylaxis were invited to participate in the research study. The adolescents were referred to each of the two clinics after being screened for tuberculosis and receiving a positive diagnosis for a non-active case of TB. The majority of the adolescents were screened for TB as a requirement prior to attending school. The adolescents were recruited after their first clinic appointment and prior to receiving treatment. Prospective participants and their parent/guardian(s) were informed of the study and were requested to sign an informed consent form which explained the nature, purpose, and procedures of the study. This consent form apprized the teens and their parents/guardians of the following: that participants would be assigned to group randomly, that participants assigned to the peer education group would be contacted by telephone by a peer who may have be known to them, and that participants assigned to the parent-participant contingency contract or combined groups would be expected to develop contingency contracts between the parent/guardian and participant with the reward to be provided by the parent/guardian. To compensate the participant for his/her time, a \$15 payment was made for completion of a baseline interview and an additional \$15 was paid for completion of a final interview. A baseline interview was administered to the adolescents during the first appointment when the adolescent was prescribed preventive TB treatment. The adult who accompanied the patient during this visit was also interviewed. Approximately one month after the initiation of TB drug treatment, a second interview was conducted with the adolescent, and an exit interview was administered around the time of the patient's final visit for preventive TB treatment. The follow-up assessment was conducted with a one-month window prior to or after the six month period. The adult was also given an exit interview at the time of the adolescent's exit interview. Treatment adherence was measured through the completion of care, treatment time in weeks, and the percentage of appointments kept compared to appointment made while in treatment.

The four intervention groups are described below:

**Peer Counseling Intervention:** Adolescents who are as similar as possible to the study participants were recruited as peer counselors. When possible, these peer counselors were adolescents who had completed tuberculosis preventive therapy. All peer counselors were extensively trained in their roles and responsibilities (including the necessity for strict confidentiality) and followed a standardized protocol. Under the supervision of the site coordinator, peer educators contacted all participants assigned to them by telephone during the first week following randomization. Subsequent contacts took place at least every two weeks. The initial contact was introductory, and was designed to establish rapport, address the role of the peer educator, and stress the importance of clinic attendance and medication taking. Later telephone contacts addressed the information collected on the baseline interview such as behavioral and normative beliefs, and addressed any problems or concerns identified by the participant during any subsequent contacts.

Parent-Participant Contingency Contract Intervention. In the Contingency Contract component for the Adolescent TB treatment program, the parent and teen signed a contract in agreement that if the adolescent adhered to the prescribed TB treatment, the parent would give the teen an incentive of his/her choice. Adherence to TB treatment included keeping appointments with the TB clinic and taking the TB medication everyday. The program staff presented the contract agreement to the parent and child, and helped them to negotiate an incentive and the terms of the agreement. Since research indicates that patients tend to drop out of TB treatment in the early stages in the treatment regimen, two incentives were usually given within the first few months of treatment, and one at the completion of treatment. Parents and teens were asked to set a schedule for when incentives were to be awarded. They chose to give the incentives monthly; at the end of the entire treatment, a "You did it!" reward; or any schedule they chose together. Examples of suggested incentives are listed in Table W.

*Incentive Suggestions*

Special meal at home  
 Going out to eat  
 Clothes  
 Going to the movies / renting a tape  
 Special gift  
 Staying up later  
 Doing less chores  
 Being driven somewhere  
 Doing something with parents  
 Having a special party  
 Money  
 Anything agreeable to both the parent and the teen

Combined Intervention. Participants in this group received a combination of the peer counseling and parental contingency contracting interventions, as described above.

Usual Care. Participants in this group received all of the treatment and educational services customarily provided by the clinic. Included in the usual care are health education from TB clinic staff and an assessment of the teen's physical health in response to the TB medication.

*Performance Sites*

The sites selected for this research study are the Inglewood Health District located in the southwest area of Los Angeles County, and the Long Beach Department of Health and Human Service located at the southern portion of Los Angeles County. These health centers have among the highest number of adolescents (12-18 years of age) on chemoprophylaxis in the County. The health centers serve populations with similar but not completely comparable sociodemographic characteristics.

The Inglewood Health District has a population of approximately 394,659 (LA County Population Projections -- 1994). Nearly 17% of the residents of Inglewood have a college degree, while 28% did not finish high school. It is estimated from 1990 census statistics that the median family

income is \$37,751, with 14% of the population living at or below the poverty level. The racial composition in the District consists of approximately 21% non-Hispanic White, 36% Hispanic, 32% Black and 11% Asian or Pacific Islander residents. In 1992, the incidence rate of tuberculosis for Inglewood was 40.7 per 100,000, over four times the national rate.

Long Beach is located on the Pacific coast and lies 25 miles south of the City of Los Angeles. Although a part of the Los Angeles megalopolis, Long Beach has a population of 424,276 (LA County Population Projections -- 1995), ranking it as the fifth largest city in California, immediately after San Francisco. Long Beach is a fairly large city geographically, covering 51 square miles. As is typical of large cities in California, Long Beach is diverse in terms of socioeconomic status, education, and ethnicity of its residents. Nearly 25% of all Long Beach adults hold at least a college degree, but approximately the same percentage did not finish high school. According to 1990 census figures, the median household income is \$31,938, with 28% of households earning \$50,000 or more and 17% of the population living below the poverty level. Fifty percent of Long Beach residents are white (non-Hispanic), 24% are Hispanic, 13% are African American, 13% are Asian/Pacific Islander, and less than 1% are Native American. The incidence rate of tuberculosis for Long Beach was 25.8 per 100,000 in 1992, and 33.8 per 100,000 in 1993.

During 1993, preventive treatment was initiated on approximately 229 patients 12-18 years of age at the Inglewood Health Center. Compliance rates for this group of patients have been quite low, with only approximately 45% of patients completing the entire 6 month regimen. The compliance rate for 1995 was comparable; of the 145 teenagers initiated on INH treatment, 85(59%) completed the regimen. During 1993, 233 Long Beach adolescents were started on tuberculosis preventive therapy. Most of these adolescents were Hispanic/Latino or Asian/Pacific Islander. Therapy for eight of these adolescents was halted for medical reasons. Of the 225 remaining adolescents, 140 (62%) completed therapy, and 85 (38%) stopped therapy against medical advice or were lost to follow-up.

For this study, adolescents between the ages of 11-19 ( $M=14.87$ ) were recruited from the two public health clinics ( $N=794$ , 48.6% female). Active consent was obtained from the parents prior to the adolescents' participation with a refusal rate of 22%. The sample consisted of 77.8% Latinos, 9.4% Asian Americans, 8.1% African Americans, 4.7% White/other (including Biracial and unspecified). Forty-eight percent of the participants requested that their interview be conducted in Spanish.

## **RESULTS OF THE STUDY**

### **Treatment Group**

The purpose of the study was to test the effectiveness of the peer counseling and contingency contracting interventions of the adherence to preventive TB treatment among adolescents. The study hypothesized that the combined intervention group would experience higher adherence than each individual intervention, and usual clinic care would have the lowest rates of adherence when compared to the intervention groups. In terms of the completion of treatment, while the overall completion rate for the study sample was 79.8%, 84.8% of the participants in the combined intervention group completed their treatment, followed by 80.3% in the peer counseling group, 77.8% of those receiving usual care, and 76.4% in the incentive group. Although the differences in these results were not statistically significant, the combined intervention saw a slightly higher number of participants who completed their treatment. In

terms of the participants' appointment keeping behavior, the overall percent of appointment kept was 72.3%. The percent of appointments kept were slightly higher in the peer counseling group (73.6%), followed by the combined intervention group (73.0%), the usual care group (72.0%), and the contingency contracting group (70.8%). However, the differences were not statistically significant. The average length of treatment time for those patients who completed treatment was 23.6 weeks. For those who did not complete treatment, the average length of treatment was 11.0 weeks. Predictors for completion of care were ethnicity, site of treatment, and person with whom the patient lives. Some reasons given for not completing treatment were that individual forgot to take the medication, had problems with transportation to the clinic, was worried about other things, ran out of medicine, had side effects from the medication, or moved from the area.

### **Ethnicity, Immigrant Status, Acculturation**

Because TB is high among persons of various ethnicities and among persons born in foreign countries, it is important to examine differences in adherence to TB treatment in order to better understand and serve appropriately the patient population. When examining differences in appointment keeping behavior in terms of ethnicity, Asians had the highest percentage of appointments kept (73.4%), followed by Latinos (73.3%). Asians had the highest rates of treatment completion (87.8%), followed by Latinos (80.7%). In contrast, African American patients experienced the lowest rates in both appointment keeping (62.7%,  $p=0.007$ ) and completion of treatment (63.3%,  $p=0.003$ ).

Rates of treatment completion also differed by country of birth. Participants born in Asia had the highest rates of completion (90.6%,  $p=0.002$ ), followed by Mexico (81.6%) and Central America (80.9%). Those born in Africa had the lowest rates (45.5%). In terms of the number of years in the U.S., participants in their second year of immigration had the highest rates of treatment completion (86.6%,  $p=0.032$ ), followed by those who have been in the US for five or more years (83.5%). Participants who were born in the U.S. had the lowest rates of completion (74.1%).

### **Age and Person Live With**

Differences in treatment behaviors also occurred with respect to age. A factor which interplayed with age was the person with whom the adolescent patient lived. An analysis of the data revealed that younger participants, ages 12-14 years, had a higher percentage of appointments kept (75.1%,  $p=0.000$ ) than participants ages 15-16 years (73.1%) and 17-18 years (66.19%). Younger participants also had the highest rates of completion of care (84.7%,  $p=0.003$ ), while participants ages 17-18 years had the lowest rates (72.1%). Similarly, those living with both parents had the highest percentage of appointments kept and experienced the highest rates of completion of treatment, while those living with others, such as another relative or boyfriend/girlfriend, had the lowest appointment keeping and completion rates ( $p=0.000$  for both). These findings are related since those who were younger tended to live with both patients. It appears that living with both parents has a positive influence on the completion of TB treatment and on appointment keeping. To demonstrate this point further, for participants ages 17-18 years, those living with both parents had the highest appointment keeping percentage, and those living with "others" had the lowest ( $p=0.027$ ).

### **Responsibility and Support in Treatment**

Adolescent patients took the sole responsibility for taking their medication in 39.0% of the cases.

Parents were responsible for remembering medication in 41.9% of the cases, and the responsibility was shared between the patient and another party in 8.1% of the cases. When the responsibility was shared, it was usually between the patient and a parent, generally the mother. Differences in the persons responsible for medication taking occurred with respect to ethnicity, age, person live with, and site. African American and Asian patients were more likely to report that they alone were responsible for remembering to take their medication, while Latino patients were most likely to report that the responsibility lay with their parents. Among the different age groups, as age increased, patients took more responsibility for their medication; patients ages 12-14 years were more likely to report that parents were in charge of the medication. Parental responsibility was highest when the patient lived with both parents or one parent alone. However, when the patients did not live with any parents, they tended to rely on themselves or other relatives, particularly aunts and uncles. Finally, those who received treatment in Long Beach were more likely to report that their parents were responsible for their medication. Similar trends in ethnicity, age, person live with, and site exist with regard to who is responsible for remembering clinic appointments.

When asked if there was someone close to them who helped remind them to take their medication, approximately 72% of those who completed treatment had someone to help them. Of those who had someone to remind them of their medication, 72.1% had a parent/guardian/foster parent remind them, 17.8% had a sibling, 9.6% were reminded by another relative, and 5.2% had a friend remind them.

African Americans were least likely to report needing help in taking medication at baseline ( $p=0.000$ ) and at exit ( $p=0.011$ ). Younger participants (ages 12-16 years) were more likely to report needing help in taking medication at time 2 ( $p=0.009$ ) and at exit ( $p=0.0005$ ). Low acculturated participants were more likely to report needing help in taking TB medication, while high acculturated were least likely to report needing help at baseline ( $p=0.004$ ) and at time 2 ( $p=0.040$ ).

#### **Site, Satisfaction with Care, Access to the Clinic (Clinic Hours, Issues with School, Transportation)**

Long Beach had higher rate of completion than Inglewood (85.9% vs. 73.9%,  $p=0.006$ ). The percent of appointments kept was higher in Inglewood than in Long Beach (73.4% vs. 71.2%,  $p=0.201$ ).

Satisfaction with care (nurse, program, interventions) was high. A weak relationship found between satisfaction with the program and completion of treatment. Patients in Long Beach were more satisfied with program than those in Inglewood. Inglewood patients were most likely to report waiting time at clinic as a barrier to treatment. Patients in the White/other category were most satisfied with nurse, while African Americans were least satisfied. African American patients more likely to report that the clinic hours and waiting time at the clinic were barriers to care. Those patients in the combined peer counseling and contingency contract group were less satisfied with peer counselor than those in peer counseling group.

*Difficulty in getting to the clinic:* Patients appear to experience more difficulties in getting to the clinic earlier in their treatment, and the difficulty lessens towards the end of treatment. It was

more difficult for participants in Long Beach to get to the clinic, particularly at time 2 ( $p=0.010$ ). It was more difficult for female participants to get to the clinic at time 2 than for male participants ( $p=0.008$ ). Older participants (ages 17-18 years) had more difficulties in getting to the clinic at time 2 than younger ones ( $p=0.009$ ).

*Taking time off from school:* More teens reported taking time off from school at baseline and exit. Participants in Inglewood reported taking more time off from school for clinic appointments at time 2 ( $p=0.001$ ) and at exit ( $p=0.0005$ ) than those at Long Beach. African Americans took time off from school more often at time 2 ( $p=0.035$ ) and exit ( $p=0.000$ ) than teens from other ethnic groups.

Throughout the study, participants in Inglewood fell behind in class more than those in Long Beach (baseline  $p=0.0005$ , time 2  $p=0.004$ , exit  $p=0.0005$ ). At time 2, Latinos reported falling behind in class the most, followed by whites/other, Asians, and African Americans ( $p=0.009$ ). Teens living with "others" were more likely to report falling behind in class at exit than the rest ( $p=0.031$ ). Participants with low acculturation fell behind more in class at time 2 ( $p=0.001$ ) and at exit ( $p=0.001$ ). Participants with low acculturation were most likely to report falling behind in class, while high acculturated were least like to report falling behind at time 2 ( $p=0.003$ ) and exit ( $p=0.001$ ).

## **DISCUSSION AND SUGGESTIONS**

### **Addressing issues specific to your client population**

Based on the findings from the study, this section includes suggestions for TB control programs. In addition to the information gathered through the analysis of the research data, many lessons were learned during the implementation of the study while working with a diverse adolescent population in the clinic setting.

The research data presented on the Adolescent TB Project includes findings based on the patients' demographic characteristics, such as ethnicity and age. Although no intervention will change patient demographics, it is important to take into consideration and recognize these differences.<sup>17</sup> Demographic characteristics may be markers for other causal factors, such as access to care and level of knowledge about of the disease. Furthermore, the differences in compliance by ethnicity and age group support the argument that a TB prevention program should consist of various strategies and should be tailored to the patient population.

One method of tailoring interventions and determining what approach will be most effective is to conduct a brief interview with the adolescent. The interview should be conducted alone with the teen, without the presence of parents, in order to ensure confidentiality and privacy. During the first visit in which the adolescent is prescribed preventive TB treatment, providers should interview the patient briefly in order to assess the patient's knowledge, attitudes, and intentions towards adherence to the treatment; to evaluate his/her level of social support for the treatment; and to identify any possible barriers towards adherence. Questions should address with whom the patient lives and the quality of these relationships.<sup>50</sup> Previous studies have found that the adolescent patient's estimation of his/her future adherence is a good predictor of what will be the actual level of adherence.<sup>28,51</sup> Asking the patient about his/her intentions to take the medication may help health care providers to assess the patient's adherence to medication. By identifying those patients who may have difficulties taking medications regularly, health care providers can

recognize which patients may require additional attention and follow-up. Also, as questions are asked regarding relationships with parents, health care providers may recognize that the teen is attempting to gain greater independence from parents; therefore, the more effective strategy would be to encourage more responsibility of care with the teen.

*Age Differences:* Care providers should take into consideration the patient's age at the initiation of treatment. Some researchers have found that although they may have higher problem-solving skills and cognitive development, older adolescents (ages 17-18) have lower rates of adherence than do younger ones (ages 12-14).<sup>52</sup> This difference in adherence may be due to the fact that older adolescents have different social and emotional needs, and are concerned with different issues, such as the acceptance of peers. Because adolescents are now shifting away from pediatric care to adult care, the responsibility of therapy also shifts from the parents to the adolescent. However, the readiness to accept this responsibility may vary between different teens. In addition, parents may not be prepared to surrender completely the responsibility to their children. Studies revealed that the agreement between the parent and adolescent regarding who is responsible for care is associated with adherence.<sup>53</sup> Our data reveals that younger patients tended to live with both parents and had more support in remembering medications and appointments. Younger patients were more likely to have their parents remind them to take their medication, whereas older patients tended to be solely responsible for remembering their medication. Consequently, younger patients experienced higher rates of adherence. In addition, older patients were more likely to report having events that got in the way of taking TB medication. In the initial interview with the patient, health care providers should assess the adolescent patient's ability or readiness to take responsibility for his/her treatment. The results of this study demonstrate that parental support in medication taking can positively influence adolescent adherence. In situations where patient and parent relationships are intact, health care providers should enlist the assistance of parents to help remind patients to take their medication. A discussion should take place between the patient, parent, and health care provider in which together they define what is to be expected for successful treatment, who is to be in charge of remembering to take medication, and what each person's role will be during the treatment period. The adolescent patient should have a sense of autonomy and freedom in their treatment, while still receiving support from parents and other family members.<sup>54</sup> Where a parent is not available or desired, the health care provider should help the patient to identify another person who will support the patient in their treatment regimen and can act as "adherence observers." This support can come from another family member, a friend, or a peer counselor.

*Ethnic Differences:* Our data demonstrates definite differences in rates of treatment completion and appointment keeping with regard to ethnicity. Among the ethnic groups examined in the study, African Americans experienced the lowest rates in both categories. In another study conducted in New York City, non-adherence with TB treatment was also highest among African Americans compared to other ethnicities.<sup>55</sup> In addition, studies on other health issues, such as asthma management and glycemic control, have also found lower rates of adherence among African Americans.<sup>56, 57, 58</sup> In our study, African American patients were more likely to take the sole responsibility of remembering their appointments and their medication, and were least likely to ask for help in these activities. However, they were more likely to report having trouble remembering to take their medication. They were also less satisfied with the care they received, particularly the peer counseling. However, our peer counselors tended to be of different

backgrounds than the African American patients, primarily Latino/a. Peer counseling may be a more effective invention to increase adherence among African Americans if the peer counselors that are recruited have more similar backgrounds as the patients. Because African American patients are less likely to ask for help in medication taking from their parents or other family members, peers may have a greater influence on these patients, particularly if these peers have had the similar experience of undergoing preventive TB treatment. Not only will this peer be a positive role model for treatment adherence, but he/she can provide social support and acceptance that teens desire from other teens who are their age.

*Immigrant Status:* The majority of the patients in our study were born outside of the U.S. and 50% of those who were foreign-born immigrated within the last five years. Several issues require attention regarding health care among immigrants. Many patients may be unfamiliar with the local health care system and the services that are available, which can become a barrier to adherence. Additional education may be necessary in order to orient immigrant patients on the care offered at the clinic. Patients may also come from cultures that have different beliefs and attitudes regarding TB and its treatment. Health care providers should be aware of these beliefs and should be sensitive in addressing them and their relation to treatment. For instance, for cultures in which TB is stigmatized and in which the knowledge of infection may cause shame, social reinforcement and incentives may be given to the patient.<sup>17</sup> The patient should be praised for taking the responsibility of protecting himself and his family from the disease, and incentives can be given in a manner which provides positive reinforcement for adherence to the treatment regimen. In addition, education can be given to family members to encourage social support and to improve adherence. Some of the patients may be undocumented immigrants and may fear that continuous care at a clinic will jeopardize their residency in the country. Health care providers should be aware of this sensitive issue when serving immigrant populations.

*Language Barriers:* From our study sample, 32.5% of the adolescents spoke Spanish only and 41.1% spoke a mixture of both Spanish and English. In addition, 48.5% of our sample population requested the Spanish version of the questionnaire during the baseline interview. With this high percentage of the patient population who will best understand treatment information when it is presented in Spanish, clinics should take the appropriate steps to ensure that there are enough clinic staff who are fluent in Spanish. Clinics should have a standard method of assessing staff competency in the language. In addition, as is true with all patients, providers should ensure that patients understand completely the importance of the prescribed treatment and what is expected of them. Once the patient has been given information regarding TB and TB treatment, he should be asked to repeat the information back to the health care provider and should be asked if he has any questions about the treatment.

*Locator Information:* Due to the transient nature of some members of the patient population, accurate contact information is essential for adequate follow-up and monitoring of patients. In addition to obtaining the patients' most current home phone numbers and addresses, the home phone numbers and addresses of relatives and friends should also be collected. It should be stressed to the patient that the friends and relatives identified must be those who would be most likely to know where the patients can be located. Health clinics should confirm the patient's most accurate locator information with the patient at each appointment.

*Clinic Hours:* Often times, clinics offering treatment for TB are open only during times when adolescents are in school, thereby creating a barrier to the adolescents' appointment keeping behavior. In addition to missing classes, patients may rely on others for transportation to the clinic. Those providing transportation to the adolescents may also need to miss work in order to meet the clinic time. The extension of clinic hours, such as more after school hours and hours after 5:00 p.m., would help to alleviate this problem. Clinics may choose to extend hours past 5:00 p.m. on one or two days a week in order to accommodate patients. Also, according to our data, patients appear to experience more difficulties in getting to the clinic earlier in their treatment, and the difficulty lessens towards the end of treatment. Therefore, health care providers may increase appointment keeping by helping adolescents identify a regular plan for getting to the clinic for each monthly appointment early on in treatment.

*Clinic Waiting Time:* Patient satisfaction with health care has been identified as one of the most important determinant of compliance with appointment keeping and medication.<sup>59</sup> Clinic wait time has often been cited as a factor contributing to patient satisfaction with care, and a long wait time has been identified as a barrier to appointment keeping. Wait times can be curtailed by scheduling patients by individual appointments, rather than by block appointment times. Physician lateness, patient lateness, and patient “no shows” also contribute to the long wait times. The problems of patient lateness and “no shows” can be addressed by the use of reminder telephone calls or letters.<sup>60</sup>

*Reminder Calls:* Because TB clinic appointments are generally scheduled one month ahead of time, they can be easily overlooked. A single call to the patient a day before the scheduled appointment increases the likelihood that the patient will keep the appointment and will decrease the amount of time and labor lost due to missed clinic appointments. In a study conducted among patients of an adolescent clinic, telephone call reminders increased attendance rates by 26.1% regardless of whether the patient was successfully contacted or messages were left with a family member or an answering machine. When patients were contacted, attendance increased by 47.8%.<sup>61</sup> Upcoming appointment lists should be generated a few days prior to the appointment date in order to notify the patients with ample time.

*Continuity of Health Care Provider:* Research indicates that patient satisfaction with care is related to trust with the provider that is established through continuous care.<sup>62</sup> When possible, clinics should identify the health care provider who was last seen by the patient and should attempt to schedule an appointment with the same health care provider for subsequent appointments. Clinic staff who are responsible for the care of teens in TB treatment can help to enhance compliance through interactions with the patient and through the communication of information regarding TB and its treatment.

*Medical Charts:* In order to conduct adequate follow-up activities with the patients, clinics should make certain that medical charts can easily be located by nurses or other health care staff who are responsible for following the progress of the patients' treatment and adherence. Efforts should be made to ensure that medical charts are returned quickly to the medical chart filing area so that they will be accessible when appointment reminders need to be made or when follow-up needs to occur for a missed appointments.

*Assessing Adherence:* Several measures have been employed as methods by which to monitor or assess adherence. The measures used for this study included the monitoring of appointments kept, the number of bottles of pills that were given to the patient, the total number of weeks in treatment, and the completion of treatment. Other studies and programs have assessed adherence through physician or parent estimation of adherence,<sup>63</sup> the detection of isoniazid in urine samples,<sup>64,65</sup> pill counts,<sup>66</sup> patient self-report,<sup>67</sup> and electronic tablet dispensers.<sup>66</sup> None of these measures is completely accurate in assessing adherence, and some are more accurate than others. Self-reports tend to over-estimate adherence due to patient forgetfulness or desire to please the health care provider, and patients may dispose unconsumed pills prior to pill counts. The most reliable measure of adherence is directly observed therapy,<sup>68</sup> since adherence is witnessed by the provider. Health providers should use a combination of methods when attempting to measure patient adherence to preventive therapy.

### **Limitations of the Study**

Several limitations of the study have been identified. One of these limitations includes the effect of the questionnaires on the patients. All participants in the study were interviewed three times within their six months of treatment, including those in the usual care group. Their participation in the interviews and the monetary incentives provided to them may have heightened their awareness of their treatment and may have encouraged them to complete treatment. Therefore, the interviews might also be viewed as an intervention that influenced behavior toward treatment adherence. A limitation concerning the contingency contracts was the lack of assurance that the adolescents in the study actually received the incentives that their parents agreed to provide. It was left up to the adolescent and parent to determine a time in which the incentive was to be given. Patients were only asked to self-report when an incentive was given, but no physical proof was ever required. This may have been problematic particularly if the family was low income and the family members were ashamed to admit that they could not afford to provide an incentive, although it was not required that incentives be something purchased. Finally, limitations occurred with the Spanish translations of the questionnaires in which patients had difficulty understanding some items on the questionnaires. For instance, several of those interviewed with the Spanish translations had difficulty understanding the response scales which, in English, ranged from Strongly Agree to Strong Disagree. Therefore, the validity of those data may have been compromised.

### **IMPLEMENTING THE INTERVENTIONS INTO YOUR CLINIC**

The interventions that were implemented during this study can be easily incorporated into the usual care procedures of health clinics serving adolescents. Clinics intending to implement these components should identify a staff member who will be responsible for the coordination of the peer counseling and contingency contract programs. This individual can be a health educator, a nurse, or another health care worker who is familiar with working with adolescent patients with TB infection and their families. He/She will be responsible for negotiating contingency contracts with teens and their parents and for the recruitment, training, and supervision of peer counselors. This individual will focus on the adolescent patient population, keeping track of when adolescents have appointments with the clinic. The coordinator can work with other TB health care staff who will interview the patients to determine what intervention will be most appropriate, based on the patient's assessment of the his/her prospective adherence and ability to take responsibility for the treatment. Once the appropriate intervention(s) has been chosen, the

coordinator can begin to implement it. Sections B and C of this training packet provide guidelines for the implementation of the peer counselor and contingency contract interventions.

The contingency contract component should add a minimal amount of cost to the clinic. The cost of furnishing the incentive should not be incurred by the clinic, as the parents of the patient will be responsible for providing the incentive. Again, the incentive need not be purchased by the parent, but can be a reward such as an extension of curfew hours. Therefore, the costs that will be added to the clinic are the time that the coordinator of the program will need to organize the activities, the time needed to negotiate the contract with the patient and adult, and the cost for photocopying contingency contracts. For the peer counselor component, the added cost will again come from the time needed for the coordination of the program and photocopying materials. In addition, the peer counselors may be paid for the time they spend contacting the patients and attending meetings for the clinic. However, if the clinic is not able to provide monetary compensation, peer counselors can also be recruited as volunteers to the program and can receive credit for school.

**Table 3. Socio-Demographic Characteristics of the Adolescent Population (N= 794)**

<b>Variable</b>	<b>Combined Sites (N= 794)</b>	<b>Site 1 (N=408)</b>	<b>Site 2(N=386)</b>
	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>
<b>Gender:</b> female (percent)	386(48.6%)	189 (46.3%)	122 (52.1%)
<b>Ethnicity</b>	<b>N=794</b>	<b>N=408</b>	<b>N=386</b>
Hispanic/Latino	618 (77.8%)	345 (84.6%)	273 (70.7%)
Black/African Amer.	64 ( 8.1%)	35 (8.6%)	29 (7.5%)
Asian	75 (9.4%)	8 (2.0%)	67 (17.4%)
White/Other	37 (4.7%)	20 (4.9%)	17 (4.4%)
<b>Age at start of treatment</b> (mean, SD)	15.38, 1.87	15.43, 1.88	15.33, 1.85
12-14	344 (43.3%)	166 (40.7%)	178 (46.1%)
15-16	263 (33.1%)	145 (35.5%)	118 (30.6%)
17-18	187 (23.6%)	97 (23.8%)	90 (23.3%)
<b>Birthplace</b>	<b>N=792*</b>	<b>N=408*</b>	<b>N=384*</b>
U.S. Born	164 (20.7%)	91 (22.3%)	73 (19.0%)
Mexico	384 (48.5%)	189 (46.3%)	195 (50.8%)
Central America	137 ( 17.3%)	98 ( 24.0%)	39 ( 10.2%)
Philippines/Thailand	53 ( 6.7%)	4 ( 1.0%)	49 (12.8%)
Asia	23 (2.9%)	4 (1.0%)	19 (4.9%)
South America	14 ( 1.8%)	10 (2.5%)	4 (1.0%)
Africa	12 (1.5%)	9 (2.2%)	3 (0.8%)
Other	5 (0.6%)	3 (0.7%)	2 (0.5%)
<b>Language Used in General</b>	<b>N=794</b>	<b>N=408</b>	<b>N=386</b>
English	122 (15.4%)	43 (10.5%)	79 (20.5%)
English and Spanish	326 (41.1%)	189 (46.3%)	137 (35.5%)
English and Ethnic Language	88 (11.1%)	20 (4.9%)	68 (17.6%)
Spanish Only	258 (32.5%)	156 (38.2%)	102 (26.4%)
<b>Began TB Preventive Treatment within:</b>	<b>N= 618*</b>	<b>N=311*</b>	<b>N=307*</b>
First year of immigration	123 (19.9%)	86 (27.7%)	37 (12.1%)
Second year of immigration	103 (16.7%)	56 (18.0%)	47 (15.3%)
3 <sup>rd</sup> -5 <sup>th</sup> year of immigration	84 (13.6%)	50 (16.1%)	34 (11.1%)
More than 5 years	308 (49.8%)	119 (38.3%)	189 (61.6%)
<b>School as Referral Source</b>	339 (74.0%)	176 (73.9%)	163 (74.1%)

\* The N varies due to missing values.

**Table 5. Comparison of Selected Demographic Variables: Completed versus Not Completed Treatment (N = 767) #**

<b>Variable</b>	<b>Completed Treatment</b>	<b>Did Not Complete Treatment</b>
<b>Total</b>	612(79.8%)	155 (20.2%)
<b>Gender:</b>		
Male	315 (80.2%)	78 (19.8%)
Female	297 (79.4%)	77 (20.6%)
<b>Age (mean, SD)</b>	15.25 (1.83)	15.86 (1.92)**
<b>Center</b>		
Site 1	289 (73.9%)	102 (26.1%) **
Site 2	323 (85.9%)	53 (14.1%)
<b>US Born (N=423)</b>		
YES	112 (71.8%)	44 (28.2%)**
NO	499 (81.8%)	111 (18.2%)
<b>Ethnicity (N=475)</b>		
Hispanic/Latino	482 (80.7%)	115 (19.3%)**
Black/African Amer.	38 (63.3%)	22 (36.7%)
Asian	65 (87.8%)	9 (12.2%)
White/Other	27 (75.0%)	9 (25.0%)

# The N varies due to missing values.

\*p <.05

\*\*p < .01

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