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# Factors Associated with Institutionalization for Treatment of Active Tuberculosis: A Synopsis from In-depth Patient Interviews

**Robert J. McDermott, PhD, Carol A. Bryant, PhD, Jeannine Coreil, PhD, Aimee R. Eden, MA, Lori K. Buhi, MPH**

## ABSTRACT

*To increase the effectiveness of therapeutic regimens for tuberculosis (TB) and to reduce the societal risks for both infected and uninfected individuals, it is beneficial to be able to predict factors associated with non-adherence to treatment. The purpose of this study was to acquire detailed case histories of TB patients admitted to a hospital setting and to gain a better understanding of how patients explain the life events leading up to their admission for treatment. Twenty-one patients with active TB were interviewed concerning their knowledge of TB, diagnosis and treatment history, recent history prior to hospitalization, reactions to and life changes associated with having TB, and future life intentions following treatment. Three situations were identified that contributed to institutionalization: inability to carry out self-care; need for specialized care to address conditions beyond the patient's control; and failure to follow the therapeutic regimen. Results confirmed known risk factors for acquisition of TB, situations that delay diagnosis and treatment, and variables that influence adherence and defaulting. Coordinated case management of multiple problems co-occurring with TB treatment may contribute to improved adherence. Consideration of psychosocial and economic needs is important to patient care. Improved communication between health care personnel and patients may enhance the likelihood of successful directly observed therapy (DOT) outside of an institutionalized setting. Some circumstances may preclude non-institutionalized care. These findings bring a dimensional richness to understanding of the patient's view of the disease and institutionalized care.*

*Florida Public Health Review, 2010; 7, 39-49.*

## Background

In 2006 there were 13,767 tuberculosis (TB) cases (~ 4.6 per 100,000 population) reported in the United States (U.S.), a 3.2% decline from 2005 (Centers for Disease Control and Prevention [CDC], 2007). The 2006 TB rate was the lowest since surveillance started in 1953. However, the rate of decline has leveled off since 2000 (CDC, 2007). In the U.S., TB disproportionately affects foreign-born persons and members of racial/ethnic minority groups (Kong, Calixto, Burman, Reves, Yang, & Cave, 2002). For example, the 2006 TB rate among foreign-born persons in the U.S. was 9.5 times that of U.S.-born persons, and rates among blacks, Asians, and Hispanics respectively were 8.4, 21.2, and 7.6 times higher than rates among whites (CDC, 2007).

During the early 1990s, just 29.1% of U.S. TB cases were among foreign-born persons. By 2005, that total increased to 50.1% of all cases (Sackoff, Pfeiffer, Driver, Streett, Munsiff, & Dehovita, 2006). Most cases for foreign-born individuals appear to be reactivation of latent tuberculosis infections (LTBI) rather than new cases (Sackoff et al., 2006). For

U.S.-born persons, the decline in TB cases continued in 2006 (2.3 per 100,000 population, a 7.0% decline since 2005 and a 68.6% decline since 1993). However, for foreign-born persons, whereas TB cases increased in 2006, the overall rate declined, albeit less steeply than among U.S.-born persons (21.9 per 100,000 population, representing a 0.5% decrease since 2005 and a 35.8% decline since 1993).

Among women, TB is the leading infectious disease cause of death. However, in developing countries, twice as many cases of TB occur among men (Jimenez-Corona, Garcia-Garcia, DeRiemer, Ferreyra-Reyes, Bobadilla-del-Valle, Cano-Arellano et al., 2006) and men also have a higher probability of death from infection (Navin, McNabb, & Crawford, 2002). In 2006, over half (55.6%) of TB cases among foreign-born persons in the U.S. were reported in persons from five countries -- Mexico, the Philippines, Vietnam, India, and China (CDC, 2007). Therefore, eliminating TB in the U.S. may become increasingly difficult because most foreign-born persons who progress from LTBI to active TB

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disease first became infected outside the U.S. (CDC, 2007).

The national health objectives set forth in *Healthy People 2010* acknowledge the TB problem and have set a goal to decrease the number of new cases to 1.0 per 100,000 population during the first decade of the 21<sup>st</sup> century (U.S. Department of Health and Human Services, 2000). However, other strategic plans for the elimination of TB in the U.S., predating the *Healthy People 2010* goal, have had mixed success (CDC, 1989). In 2006, TB incidence in the 50 states plus the District of Columbia (DC) ranged from 0.8 (Wyoming) to 10.4 (Alaska) and 12.6 (DC) cases per 100,000 population. Seven states (California, Florida, Georgia, Illinois, New Jersey, New York, and Texas) reported more than 500 cases each in 2006, with rates as high as 7.6 per 100,000 population (CDC, 2007).

#### *Risk Factors for TB Infection*

Immunocompromised individuals, such as persons with HIV (CDC, 2007), and hospitals have become the “breeding grounds” for many re-emerging infectious diseases, including TB (Stephens, Moxon, Adams, Altizer, Antonovics, Aral et al., 1998). Immunocompromised individuals are exposed in hospitals to medical treatments that create antimicrobial selection pressures that can lead to resistant strains (Stephens et al., 1998). Such unintentional exposure is increasingly problematic. Immunocompromised patients provide the opportunity for the adaptation of pathogens that otherwise might not be viable in healthy individuals (Stephens et al., 1998).

HIV (Stephens et al., 1998) and immigration (Sackoff et al., 2006) are two popularly cited risk factors contributing to TB in the U.S., but the literature identifies numerous other risks, including poverty and homelessness (Haddad, Wilson, Ijaz, Marks, & Moore, 2005). Among persons from low income households, there is a decreased likelihood of seeking diagnosis, treatment, and follow-up care (Theobald, Tolhurst, & Squire, 2006). Homeless individuals also are more likely to have longer hospitalizations.

Other identified risk factors include urbanicity (Heldal, Dahle, Sandven, Caugant, Brattaas, Waaler, et al. 2003), attendance at night clubs (presumably as a result of close contact in a crowded environment) and vegetarianism/low vitamin D levels (Grange, Story, & Zumla, 2001), and other social issues and medical problems (Hansel, Wu, Chang, & Diette, 2004).

Certain behaviors place individuals at higher risk of TB. For example, abuse of alcohol (Heldal et al., 2003), use of injection drugs (Durante, Selwyn, &

O’Conner, 1998), and use of marijuana (Grange et al., 2001) increase personal risk.

Moreover, TB susceptibility may differ for men and women. Men are more likely than women to report certain risk factors such as a history of imprisonment, residence in homeless shelters, and frequent use of alcohol and tobacco, any or all of which may influence TB susceptibility (Jimenez-Corona et al., 2006). Women often care for the sick or dying, thereby increasing their risk of exposure to TB. High-risk occupations, such as prostitution, increase the probability of contracting both HIV and TB infections (Grange et al., 2001; Theobald et al., 2006). Men and women are also affected differently by TB infection. Diagnosis and treatment for women may affect their likelihood of marriage, inspire isolation from family and the community, and increase the probability of unemployment. Some research has concluded that men’s concerns focus mainly on the potential for lost wages (Theobald et al., 2006).

#### *Factors that Delay Diagnosis and Treatment*

Gender also may influence diagnosis and treatment, as differences exist with respect to how men and women seek health care. Whereas women readily use health care services, men are more likely to remain symptomatic for longer periods of time before accessing health services (Jimenez-Corona et al., 2006). Provider bias also has been identified as an issue. One study found that women were less likely to be examined for TB, and that disease criteria were more likely to be applied for male patients (Theobald et al., 2006).

Various perceptions and reactions to TB affect patients’ motives to seek treatment, delay treatment, or adhere to prescribed therapeutic regimens. Fear is the most common emotion experienced by patients, in particular, fear of diagnosis, symptoms, and treatment (Hansel et al., 2004). These strong emotions are associated with the perceptions of, and experiences with, isolation, rejection, and loss of income (Hansel et al., 2004; Marra, Marra, Cox, Palepu, & Fitzgerald, 2004). In addition, there are several misunderstandings about TB that contribute to treatment delays. Misconceptions regarding the bacille Calmette-Guérin (BCG) vaccine abound, sometimes resulting in treatment refusal, because persons who are “vaccinated” mistakenly believe they are immune to TB (Shukla, Warren, Woeltje, Gruber, & Fraser, 2002). Public knowledge about TB is poor relative to some other infectious diseases, and consequently, people perceive themselves to have low risk of contracting the disease. Education, age, and income are associated with knowledge of tuberculosis (Ailinger, Lasus, & Dear, 2003). Other reasons for non-adherence or defaulting from

treatment exist. Some persons believe that they can treat themselves, and ignore the actual gravity of illness. Others fail to understand the importance of continuing and completing treatment after they begin to feel better following initial therapy (Ailinger et al., 2003; Shukla et al., 2002). Additional reasons why patients fail to adhere to therapy may stem from boredom, frustration, depression, and anxiety (Hansel et al., 2004; Marra et al., 2004). In extreme instances, such reactions may contribute to a loss of hope or desire to live, ultimately leading to refusal of treatment (Koana, Tuba, Siziya, & Sikaona, 2004). Treatment outcomes may be affected adversely when patients fail to keep appointments, perhaps due to their limited monetary, transportation, or other personal resources (Sackoff et al., 2006). Consequently, health care providers have no opportunity for direct observation of therapy (DOT).

Factors that may influence whether a patient is able to adhere with treatment can be attributed to the rigorous treatment process and uncomfortable side effects that are experienced by some patients. Most important of these is the risk of complications related to liver function, and therefore, treatment protocols require regular monitoring of liver function through blood tests. Other side effects include gastrointestinal disturbances, itchiness, rashes, sexual dysfunction, fatigue, decreased level of feminizing hormones, and increased appetite (Heldal et al., 2003). TB patients also have noted the large sizes of the pills, the amount of pills, the strength of the medication, and the medication's unpleasant aftertaste (Heldal et al., 2003). The treatment can affect other lifestyle habits such as alcohol use and drug use (Heldal et al., 2003; Jimenez-Corona et al., 2006). Unfortunately for some, the unanticipated effects of the TB treatment outweigh the benefits, and they fail to complete therapy.

Social and political issues also affect reasons for TB therapy adherence. Many undocumented foreign-born TB patients fear being reported to immigration. Thus, they delay treatment, and disease progresses to a more severe state (Hansel et al., 2004). Tuberculosis is also a "public" disease in the sense that public health departments must conduct a complete investigation and test persons in contact with an affected individual. This process can be embarrassing and lead to avoidance of diagnosis and treatment (Hansel et al., 2004). After diagnosis, a person may be labeled by his or her community as a societal misfit or menace, sometimes contributing to being isolated or stigmatized as mentioned above (Koana et al., 2004).

A meta-analysis of qualitative research on tuberculosis treatment adherence identified eight major themes considered important by patients and

providers: organization of services, concepts of illness and wellness, financial burdens of therapy, knowledge, attitudes and beliefs about treatment, law and immigration issues, personal characteristics, side effects, and social support (Munro, Lewin, Smith, Engel, Frethelm, & Volmink, 2007). These variables were further analyzed into four categories: structural factors (e.g., poverty), social context, health service factors, and personal factors. A review of interventions to improve adherence to tuberculosis management identified several factors associated with increased adherence: reminder systems, monetary incentives, health education, and better supervision of tuberculosis staff (Volmink & Garner, 2000). Few studies have focused on precursors to institutionalization, whether voluntary or legally mandated, to ensure completion of tuberculosis therapy. A review of incarcerated TB cases in Colorado identified homelessness and alcohol abuse as important factors associated with therapeutic detention (Burman, Cohn, Rietmeijer, Judson, Sbarbaro, & Reves, 1997). A state-wide review of institutionalized TB patients in California determined that 46% of patients were homeless, 81% had substance abuse problems, and 28% had mental illness (Oscherwitz, Tulskey, Roger, Sciortino, Alpers, Royce, et al. 1997).

#### *Treatment Adherence versus Defaulting*

Whereas there appear to be multiple reasons for delay of, and non-adherence with therapeutic regimens, the motivation *for* adherence is more singular. The main reason for adhering with the rigorous treatment process and for withstanding any negative social consequences that coincide is the fear of dying (Hansel et al., 2004). However, patients do occasionally report other benefits that emanate from treatment: enhanced spirituality, and the sense of having received a "wake-up call" with respect to their lifestyle (Hansel et al., 2004). Sackoff et al. (2006) reported that newly diagnosed persons were more likely to adhere with therapeutic regimens than were patients with LTBI. Knowing which groups may be more or less likely to be adherent with treatment, and defining these predispositions, continues to be a challenge for public health practitioners.

A particular challenge is the issue of persistent non-adherence with tuberculosis therapy. The literature is somewhat lacking in studies about common risk factors for persistent non-adherence. Actions by the court sometimes have placed TB patients who have defaulted on their treatment in hospitals for DOT. Specialized hospitals, such as sanatoriums that focus on TB, were effective instruments of the past. However, during the 1970s, several TB sanatoriums were closed or converted to other facilities (Meyer, 1991). By 1980, such

specialized hospitals existed in just 15 states (Dandoy, 1982). Today, the only U.S. tuberculosis sanatorium is the A.G. Holly State Hospital in Lantana, Florida.

There is little current literature available that describes case histories of individuals who are court-ordered to a sanatorium setting or become temporary residents there as a last resort for completion of treatment. Moreover, multiple gaps exist in the literature pertaining to TB, including its precursors and sequelae. Most of the literature concentrates on the male population and lacks distinctions by gender, age group, and socioeconomic status. Whereas there are differences in the distribution of TB by gender and race/ethnicity, understanding of specific risk behaviors for disease acquisition and defaulting from therapy are imprecise. New studies may illuminate selected commonalities among non-adherent cases as well as the positive environments or characteristics that influence a patient's favorable decision to complete therapy. Therein, public health officials and health care providers can be better equipped to offer the necessary support for persons undergoing TB therapy that can optimize outcomes.

### **Purpose**

To increase the effectiveness of TB therapeutic regimens and to reduce the societal risks for both infected and uninfected individuals, it is beneficial to understand the factors associated with defaulting from treatment. Such knowledge may aid in identifying patients who are most likely to default and creating interventions to motivate patients under treatment to complete their regimens. These efforts would help minimize new TB infections and their transmission. With the re-emergence in importance of infectious diseases and the rise in multi-drug resistant (MDR) strains, TB could become an even more serious problem in the U.S. in the future. Thus, the purpose of this study was to acquire detailed case histories of selected TB patients who had been admitted to a sanatorium setting as a last resort for treatment, and to identify factors ascribed by patients themselves as contributing to their institutionalization.

### **Methods**

The priority audience for this study consisted of patients with active TB who were in temporary residence at the A.G. Holley State Hospital, the only remaining freestanding TB sanatorium in the U.S. The TB patient census at A.G. Holley State Hospital fluctuates but ranges between 30 and 45 at any given time (Dr. David Ashkin, personal communication, February 2006). To be eligible for inclusion in the study, a patient had to be between 18 and 70 years of

age, English-speaking, undergoing treatment for active TB, and in residence at the sanatorium during the period of this study.

Four interviewers (holding or pursuing university graduate degrees) were trained to carry out in-depth interviews with TB patients. Training points emphasized building rapport and trust with patients, as well as identifying cues for probing to enrich the responses of less verbal interviewees. In all, 22 interviews took place between October 2006 and May 2007. Most interviews lasted about one hour each although some patients broke off the interview prior to its being completed. Subsequent inspection of interview results gave rise to a recommendation that just 21 interviews be used for compilation and interpretation.

Interviewers followed an interview guide developed especially for this project. The guide was based on the published literature with anecdotal input from TB care providers. Questions were targeted to a middle school grade reading and comprehension level. The guide was reviewed for content validity by a team of tuberculosis care experts and deemed appropriate for the intended audience. Specific content domains included demographics, knowledge of TB (including transmission modes), diagnosis and treatment history, immediate life history prior to coming to the sanatorium, experience with institutionalization, feelings and reactions to having TB, life changes as a result of TB, and future intentions upon completion of treatment.

Recruitment of interviewees occurred based on inclusion criteria and through consultation with a designated administrator at A.G. Holley State Hospital. Patients were told that the purpose of the interview was to improve understanding of the experiences of individuals with TB undergoing hospital-based TB treatment, that their comments would be important to the research team, and that they would be useful for others experiencing TB and undergoing similar treatment. Individuals were informed that their participation in the study was voluntary and they could stop participation at any time. An informed consent document requiring signature was included. No financial remuneration or other incentives were provided to patients. Interviews were tape recorded and transcribed verbatim. References to patient names were eliminated or fictionalized. The research protocol for the study was reviewed and approved separately by institutional review boards of the University of South Florida (Social and Behavioral Science Division) and the Florida Department of Health.

The analytic approach of the study consisted of developing individual profiles or case histories from the patients' perspectives, that is, based on their own



understanding of the life events that figured importantly in their acquisition of the disease, treatment and adherence experience, and subsequent institutionalization. Individual illness narratives were constructed from the 21 interview transcripts, with particular attention to relevant background information, experience with treatment and adherence, and expectations for the future. Key themes were identified for each narrative and illustrated by selected quotes to highlight principal ideas. Systematic comparison across cases allowed the identification of cross-cutting themes, patterns and recurrent situations associated with the illness and treatment experience.

## Results

The interviewees ranged in age from 21 to 56 years. Whereas 7 patients were in their 20s or 30s, 13 were in their 40s or 50s. Of the original 22 interviewees, 16 were male and 6 were female. Presented with categories of race/ethnicity, 9 self-identified as African American, 4 as white, 2 as American Indian/Alaskan native, 1 as Hispanic and 1 as Asian. Four others did not report ethnicity (1 of these interviews was not analyzed), and one selected "other."

Of the 21 interviewees, 10 were homeless, 13 were drug users, and 7 were both. Eight had been in jail or prison, and 10 were HIV-positive. A few lived with family but had drug problems, HIV co-infection, mental illness, and/or could not properly care for themselves. Only four of the patients interviewed were independent, functional adults. Two of those were foreign-born persons who worked and supported their families; the third was a young Hispanic male who worked and lived alone in an apartment; the fourth was a single African American male who worked and also lived alone in an apartment. The first three persons required in-patient treatment for extraordinary reasons (e.g., MDR strain, brain affected by TB, and liver function affected by medication), and the fourth could not balance work with the treatment regimen. What follows in the text below is a summary of factors contributing to the admission of these patients at the sanatorium.

### *Unable to Care for Self*

The majority of patients interviewed were admitted to the sanatorium because they were so sick they could no longer care for themselves and required in-patient treatment. In addition to TB, many were co-infected with HIV or had other illnesses, such as hepatitis C, pneumonia, and/or emphysema. Two patients were so ill they collapsed prior to admission and others reported being unable to walk.

*With HIV I wasn't taking my medication. I had stopped taking my medication so I was getting so, so sick. My immune system was so low; I couldn't walk.* (African American woman in her 40s)

*Sometimes when the nurse come [to observe therapy], I be too weak to get up and answer the door to let her in.* (African American woman in her 20s)

Many patients were hospitalized in community settings before being referred to the sanatorium. Some were hospitalized after collapsing in a public setting or presenting in an emergency room. Others were persuaded to go to the hospital by their case worker. Several individuals said they weighed less than 100 pounds by the time they were admitted. In some instances these patients remained in a community hospital for several months before being sent to the sanatorium. A few patients went to the sanatorium voluntarily, but for most, they only consented when threatened with a court-ordered mandate.

*I signed a contract saying that I would like to come here.... He [the doctor] explained it to me, he communicated with me real good. He was telling me about this hospital, and I did want to come. I said yes, I would love to go. And here I am at A.G. Holley Hospital doing real good.* (African American woman in her 40s)

*This man came to my room, asked me did I want to go to a hospital in Lantana, Florida. And I say, yeah, I go. So I wined up here. ... Well, the man...explained to me about what all, how the hospital is. It's real good nurses and doctors. You take your medication every day. You go out on smoke breaks. You go shopping. I say, well, I want to go. So here I am!* (African American woman in her 40s)

A man refused to cooperate on multiple occasions, reporting difficulty in balancing survival with the demands of the TB treatment. After being discharged from a local hospital for pneumonia and TB

treatment, he received treatments at the local health department. He was incarcerated “on three different occasions” for missing DOT appointments before being court-ordered to receive care at A.G. Holley State Hospital.

*I'm just here taking meds because I'm obligated to by law. So they making me do it. It not something I'm voluntarily doing.* (African American man in his 50s)

Several factors – drug use, homelessness, and mental illness – contributed to the severity of several patients’ health problems and their need for in-patient treatment. Whereas patients were not asked directly about these factors, 13 patients reported that they had used drugs and/or alcohol, and many of these believed drug use had contributed to the onset of TB as well as other health problems.

*I was a real crack addict. I lost my children due to crack. I kept falling out on the streets and I wasn't eating and I was wondering why I was losing so much weight.* (African American woman in her 40s)

*My ex-wife's just real scared that I'm going to be a bad influence on my son, the alcohol and drugs, you know? I did have a real bad drinking problem, which mind you the only drugs I really used was marijuana. Up until recently, I got into cocaine.* (White man in his 30s)

*...I was heavy into crack. Very heavy. Two-hundred bucks a day heavy. Well, thank God I'm here...they saved me.... They gave me a second chance. But like I said to you, the drugs had me out of it. He showed me the x-rays and said I had TB everywhere but in my brain. I'm a lucky man.* (African American man in his 40s)

At least 10 patients were homeless immediately prior to their admission to the sanatorium and a few others reported living in homeless shelters at other points in their lives. As with drug use, many patients believed they acquired TB while homeless.

*I was living in the homeless shelter. They say that's where it spreads easy. That's how you get a lot of infectious diseases. But they took me to the hospital.* (African American woman in her 40s)

*Well, I was basically homeless. I mean, not really; I get disability so I live in, but I prefer to live in shelters, you know, Salvation Army and what have you. I think that's pretty much where I got this TB from.* (White man in his 30s)

Homelessness was a motivator for at least one man to go to the sanatorium voluntarily.

*So, I was trying to go along with the program in the hospital because I wanted treatment, and I didn't want to get back outdoors and get stuck again. ... When I left [the] hospital, I went to a motel room for a month. I think the state paid for the motel room for a month. So I was there by myself, and they would bring me my medicine every day. ... I would sit up and look out the window and wait for them. If they was 5 minutes late, I was looking out the window wondering. We had no problem about the medicine because I was glad to get it. ... I asked twice to come here [to A.G. Holley]. About when the time run out for me at the motel room, I asked about A.G. Holley. They had told me about AG Holley, but they said it was, A.G. Holley, was for people that ran away and wouldn't take their medicine. So they knew I was homeless when I left the motel room. I didn't have anywhere to go. So I asked my counselor about A.G. Holley and he said, 'don't worry about it; I'll get with you on that and you won't be outside.'* (African American man in his 50s)

A third contributing factor, mental illness, was reported by three patients.

*...they diagnosed me as manic depressive/suicidal, because I've*

*tried to kill myself a couple of times. I took a whole box of D-Con rat poison. (African American woman in her 40s)*

*I'm a paranoid schizophrenic. (White man in his 30s)*

### *Need for Specialized Care*

A smaller group of patients interviewed said they were sent to the sanatorium because they needed specialized in-patient care. One person required special care for a MDR strain of TB that was being treated intravenously through a port placed in his arm.

*Right now I am here at the hospital because I have multi-drug resistance. ... I have this different type of disease that 50 percent only survive. I'm having this port...for the medication injection...into a vein. ("Other" ethnic group man in his 20s)*

Other patients could not tolerate the medications used in the DOT program because of poor liver function and required careful monitoring while trying different pharmaceutical alternatives. Whereas nine patients discussed side effects from their DOT, one attributed his need for specialized in-patient care to the medication's negative affect on his liver.

*See, the problem I have is that my liver, okay, when I take the meds, at the beginning it was like 11 meds, I think. Then they jumped out to 22. When they gave it to me 22 meds like twice a week I think, that's when my liver went bad. So my enzymes were high, everything else were doing like wrong in my stomach. Everything stopped working I think. And they told me that I should stop the medication. So I stopped it and I came back again and I got sick again and they told me that the best thing is to come to the hospital and see what's going on with my liver so they can continue the treatment. (Hispanic man in his 20s)*

*There were side effects with a lot of the meds that they had me on. And they kept switching me around to*

*different ones. (White man in his 30s)*

One patient needed to be monitored closely because the TB had affected his brain. He described going to the doctor for constant headaches for three months, and finally, he was diagnosed with TB. A CT scan revealed that the TB was in his brain.

*They needed me at the hospital because at the hospital, I can find better technician look at me every time. ... It is not a problem for me, take medication. ... [The health care worker] tell me she is going to send me somewhere in a hospital if they accept me. ("Other" ethnic group man in his 40s)*

### *Failure to Follow Therapeutic Regimen*

Some patients were well enough to care for themselves but failed to keep their appointments with case workers assigned to observe them taking their TB medications. They offered several reasons for their inability to meet the DOT requirements: (1) the medication side effects made it impossible to work and meet financial obligations; (2) case workers were chronically late, acted impatient, or provided incorrect information that made them miss appointments, and (3) they simply did not realize the severity of the situation or did not believe they could be incarcerated for failure to complete the regimen.

*...Well, I took the meds for a day or so, but I would do it a day and I would miss a day or miss a week, and then go back. And that wasn't fixing it right because I couldn't take the medicine and live at the same time. I had to work to survive. And on this medication it draws you and makes you sleepy. It's impossible to work. So I either had a choice, I live or don't live. Either work and eat, or you take the medicine and don't eat. So after that I refused that. So they picked me up and put me in jail. At least there I was getting the meds and eating at the same time so I didn't have to worry about anything. So they let me out of jail and I went right back to the same thing. I wouldn't take the meds because I couldn't do both. They put me back in jail. I been to jail so many times for this stuff. I been to jail on 3 different occasions*



... My mind was made up that I wasn't going to take the meds. I had to live regardless of what I had inside ... I had to survive. (African American man in his 50s)

I'm scheduled to go by the health department every day to pick up my meds and I went there one day and the lady, the clerk who give me my meds wasn't there and I asked them, hey, what am I supposed to do? Oh, just go home and come back tomorrow. Okay, well that's fine with me. I didn't have to take 20 pills that day, you know? So I went home. The next day when I went back they said, oh, I'll go get your medicine, just sit here for a minute. And wow, here come the police. Why do I gotta go to jail? (White man in his 30s)

They [the health providers] should have been more clear about stuff.... Like the day she wanted me to go up there for blood work. She should have been clear you know, hey, if you're not here, this and this and this is going to happen. If I would have knew that, that would have made me take this more seriously. (Woman, race/ethnicity unspecified in her 20s)

Finally, a man reported that he was sent to the sanatorium involuntarily because he endangered others by going out into public without the protective mask required during the first month of treatment. He also admitted that he argued with the public health worker who came to his home to warn him about exposing others and refused to promise to comply with the DOT regulations.

I had it where you could spread it. ... anyhow, they caught me off my [house] boat. But I wasn't jeopardizing nobody. ... She [the caseworker] came out and she was saying you know, you can't do this and you can't...I said, I got perturbed, you know, and I told her, 'look, lady, you don't run my life, and you don't tell me where I can go and what I can't do and who I can't have on my boat or nothing.' I said, 'I'll just go catch me a damn plane and go to Las

Vegas, how about that?' Anyhow, well, the next lady made sure I didn't go to Las Vegas, because they had the police down there when I went to take my medicine.... (White man in his 50s)

## Discussion

These results confirmed a number of the known risk factors for acquisition of TB, the situations that contribute to delays in diagnosis and treatment of disease, and the variables that influence adherence versus non-adherence (i.e., defaulting) to therapeutic regimens. Poor adherence by patients to TB treatment confounds initiatives to eliminate the disease in the U.S. and elsewhere and can contribute to the emergence of multi-drug resistance (Thiam, LeFevre, Hane, Ndiaye, Ba, Fielding, et al., 2007). Explanations for poor adherence to treatment regimens have been described as complex and multifaceted and involving factors beyond the personal traits and attitudes of patients (Sumartojo, 1993; Munro et al., 2007; Thiam et al., 2007). The complexity of understanding TB treatment adherence may be analogous to understanding adherence to treatment of other chronic diseases, such as cancer, in that its efficacy is dependent on the provider-patient relationship, the extensive therapeutic regimen, certain psychological and physical characteristics of patients, interactions of these factors, and even one's definition of what constitutes adherence (Basch, Gold, McDermott, & Richardson, 1983). TB's chronic nature if untreated, its socio-cultural association with poverty and homelessness, and the nature of its required interactions with physicians, nurses, and other health care workers affect access to and adherence with therapeutic regimens (Hill, Stevens, Hill, et al., 2005; Snider, 1982; Thiam et al., 2007).

In the current study, three precursor situations could be identified that contributed to patients having to complete their TB treatment at a sanatorium facility. The first of these (inability for self-care) was comprised of a complex set of confounding circumstances involving co-morbid conditions, substance abuse and mental illness, and poverty. It accounted for the largest number of patients interviewed and may be the most difficult situation to address. When extenuating circumstances co-exist and can be identified, practitioners should assume that there will be interference with normal TB treatment and that additional steps may be necessary to ensure a favorable therapeutic outcome (completion of treatment and cure). Adherence is profoundly challenging for socially marginalized individuals coping with personal and societal

stressors related to poverty, homelessness, mental illness and substance abuse. Applied research with such populations has led to recommendations for coordinated treatment programs that address contextual issues and psychosocial needs along with implementation of therapeutic regimens. The results of the current study lend support to such recommendations.

Thiam et al. (2007) devised a program to increase treatment adherence that may have relevance to patients at high risk of defaulting. They based the program on recognition of the existence of five issues: (1) patient difficulty in accessing treatment; (2) poor communication between health care personnel and patients; (3) poorly applied DOT; (4) lack of a strategy to search for defaulting patients; and (5) limited supervision of outreach case workers. As part of a training program health workers improved counseling and communication with patients through acquisition of better interpersonal and negotiation skills, thereby enhancing their relationships with patients.

A second situation that emerged from the interviews was a clear need for specialized care to address conditions beyond the patient's control (e.g., MDR TB strains, inability to tolerate typical therapeutic regimens, including toxic effects on the liver, perhaps exacerbating pre-existing liver disease). Consequently, supervision of care for these confounding conditions in conjunction with specific treatment for TB may require services of facilities such as a sanatorium.

A third group of individuals fell under the description of failing to adhere to the therapeutic regimen, including maintaining DOT appointments. Some evidence emerged from the interviews that the side effects of the therapeutic regimen were disabling with respect to employment and meeting financial obligations. Thus, defaulting may not have been a consequence of ignorance or deliberate sabotage of the treatment by the patient, but rather, legitimate hardships placed upon patients by the therapy. Health care providers may need to explore different pharmaceutical options with such patients in an attempt to find the drug that the patient can tolerate and that is responsive to the disease state. Health care providers may need to be careful to avoid a "one size fits all" philosophy concerning therapy, and understand that just because the patient defaults initially, he or she may still desire to be a partner in care.

At least a partial explanation for defaulting revealed by the interviews was the perception that case workers often were late for DOT, acted impatiently (possibly, judgmentally), or provided incorrect information that contributed to their missing

appointments. Whereas this explanation may require further confirmatory investigation, the approach offered by Thiam et al. (2007) to involve the patient in selection of the DOT treatment supporter may strengthen the DOT, minimize missed appointments, and reduce overall defaulting. Supervision of and regular reminders given to case workers may enhance the success of provider-patient relationships and contribute to more favorable treatment outcomes.

The special situation of the patient that appeared to act without social conscience, thereby exposing others to his TB, highlights a rare but nevertheless important consideration. For such individuals, whether or not there are other mitigating circumstances, the only sound public health solution may be institutionalization for completion of the therapeutic regimen. Thus, public health authorities must develop strategies for identifying, locating, and apprehending persons whose disease state, lack of social conscience, and refusal to address their DOT needs pose a threat to others.

The development of a health care provider mindset for comprehensive and multi-modality approaches to augment TB treatment is essential in response to poor adherence by some patients. Research on adherence to tuberculosis therapy has underscored the importance of taking into consideration the patient's psychosocial and economic environment, and the need for patient-centered care that holistically addresses co-morbid conditions and social needs (Munro et al., 2007). Particularly with regard to patients needing institutionalized treatment, the impact of co-occurring problems such as homelessness, mental illness and drug abuse, coordinated care approaches offer important advantages (Oscherwitz et al., 1997; Hwang et al., 2005). A large proportion of the patients in the sample were homeless, mentally ill or substance abusers, highlighting the need for coordinated care within case management by well-trained medical staff. For the homeless population in particular, monetary incentives have been found to improve adherence with tuberculosis therapy (Hwang et al., 2005). Assistance with housing arrangements may also contribute to improved adherence. None of the interviewees reported the involvement of social service agencies for homelessness, mental illness or substance abuse in their illness narratives. Training of tuberculosis control personnel in the incorporation of broader case management approaches is encouraged.

Although Thiam et al. (2007) conducted their study in the West African country of Senegal, some of their key findings may nevertheless be useful to a U.S. population that has a significant proportion of treatment defaulters. The acquisition and

improvement of counseling and communication skills by case workers and other health care providers, the introduction of flexibility in the choice of DOT supporter (where the patient plays a role), the enhanced supervision of case workers seeking patients in their indigenous neighborhoods, and other tactics significantly decreased defaulters compared to usual TB control procedures.

The present study had several notable limitations. First, only 21 people completed interviews. Whereas these participants comprised approximately half of the typical patient census at A.G. Holley State Hospital, no conclusion can be drawn concerning the representativeness of this sample compared to all patients who reside or have resided temporarily at this facility. Although these interviewees had some diversity in age, gender, ethnicity, and nation of origin, the overall profile of this sample did not necessarily match that of persons who acquire TB or are treated for it in the U.S. Moreover, these TB patients may be unlike patients who receive treatment at non-specialty hospitals around the country. In addition, patients at this facility reside there typically for between three and six months. Whereas persons interviewed showed a range of time in residence, no judgment can be made concerning the effect that time in residence may have had on their responses. Four different interviewers (all females between the ages of 25 and 35, 1 Hispanic, 3 white non-Hispanic) collected data in this study. The quality and depth of the information obtained from patients may have been influenced by interviewer biases, differences in their communication skills and divergent knowledge of the subject matter, their specific and idiosyncratic interactions with the patients and the setting, and other factors. Because interviewers' contact with patients was limited to the period of time in which the interview was completed, it was not possible to establish the type of trust and openness needed to explore contributing factors in great depth or to verify the veracity of patient reports. Moreover, these data are limited to patient reports and were not verified through provider consultation or medical records.

These limitations notwithstanding, this study brought some richness to the understanding of the patient's view of the disease and his/her institutionalization that is not typically captured when investigating TB and its sequelae. System changes beyond the scope of services carried out at A.G. Holley State Hospital and other facilities that offer specialized treatment for persons with TB may be necessary to reduce the overall impact of this disease in the U.S. Moreover, whereas gaps in understanding of the patient's perspective may continue to exist,

deployment of certain mechanisms can enhance the provider-patient relationship, improve provider and institutional quality of care, and perhaps, reduce overall the need for extended institutional stays by persons with active TB.

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