TB & CULTURAL COMPETENCY

Notes from the Field

Northeastern Regional Training and Medical Consultation Consortium Issue #5, Winter 2007

SPECIAL ISSUE: TB and the Subculture of Methamphetamine Users

Previous issues of this newsletter highlighted the challenges of working with TB patients from Pakistan, Ecuador, Mali, and China. This issue looks at a TB outbreak among patients born in the US, but whose lifestyle places them in a "subculture" of illegal substance users. Many health workers face challenges when working with substance users due to a lack of familiarity with a drug user's day-to-day reality, priorities, and decision-making process. Regardless of the culture in which they have been raised, substance users may be seen as part of a different "subculture" or "reference group" of peers who validate the behavior of group members. Let's see how this team of health workers coped with the culture of a group of clients who are actively using drugs.

by Jenny Donovan, BA and Susan Robinson, RN

Introduction

Program Manager Donna Allis describes the situation: "Our local Tuberculosis Control Program is in a medium incidence state in the Pacific Northwest. Traditionally, the major risk factor for tuberculosis in our county is being foreign-born. This past year, however, we have been working on an outbreak among US-born individuals whose main risk factor is using methamphetamines (meth). The clients in this group are as diverse as those in any cultural group; however, we have learned some important lessons about meeting the needs of this drug using subculture as a whole."

Meet Joe, Our Index Client

When we received the referral from the local hospital Joe, our index client, had described symptoms of a productive cough, hoarseness, chest pain, dyspnea, fever, night sweats, fatigue, anorexia, and a fifty-pound weight loss. This five foot, eleven inch tall man weighed only 111 pounds and he was 4+ sputum smear positive. His chest X-ray showed extensive pulmonary TB, and he was short of breath at rest. Although he did not have chronic medical risk factors like diabetes, Joe suffered from severe dental decay, a history of alcohol abuse and meth use, a 20 year, 1-2 pack per day cigarette habit and chronic mental health problems. He lived in his truck and reported a limited social network. On initial interview, he named only two contacts.

Certain social and clinical factors meant that our health department had to make special efforts to be sure he completed treatment. His housing situation was unstable, so we rented him a motel room, provided food, directly observed therapy (DOT), and close supervision – that is the standard of care in our county for a homeless, infectious TB patient. We even agreed to do his laundry. He was severely ill and did not protest these arrangements. Still, he remained infectious for a prolonged period as we focused our efforts on maintaining him in isolation in the motel room for several months.

Although this clinical picture represents classic symptoms of tuberculosis, often individuals using methamphetamines have many of the same symptoms — but do not have TB.

During this time we advised him to stay in his room, eat the meals we had delivered, and take his medications by DOT. He was advised to not have visitors stay for long periods of time. As his health improved, he strayed from these recommendations and went out to dinner with his father, visited a casino, and had friends sleep over in his room – all during the period when he was likely still infectious. He complained that he had 'cabin fever' and could not stand being cooped up all the time. What could

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we do about this? First, we let Joe 'vent' his frustrations. Then, we reacted by not being punitive, but by appealing to his human side and re-educating him about the potential harm he could be doing others by infecting them with *M.tb* organisms. A doctor visited his room to discuss infection control procedures and work out ways to protect visitors as best as possible. Other creative solutions were to provide for his entertainment needs by getting him a video cassette recorder (VCR) so he could watch movies, getting him free books or movies from the library, buying him a deck of playing cards, and suggesting that he go for outdoor walks or picnics with his family. As difficult as it was managing Joe throughout his course of treatment, we suspected the contact investigation would prove even more challenging!

The Contact Investigation

At first, Joe was not talkative at all; he was in bed, short of breath, and severely ill. Furthermore, he was reluctant to name people engaged in illegal activities. He stated that his father and niece were his only contacts in the past months. Both of them were tuberculin skin test (TST) positive and started treatment for latent TB infection (LTBI); however, the niece soon decided to stop treatment when she became pregnant. It actually was easier to get information from Joe in the course of general conversation than by asking direct questions. So while we were in his motel room providing DOT, delivering groceries, drawing blood, or handling his laundry, we would talk to him about his life, slowly learning where he went, what he did, for how long, and who else was there. We had to keep an open mind about his anti-social tendencies and build trust with him.

As we proceeded with Joe's treatment and the contact investigation, our TB control staff faced some difficult individual behaviors and challenging characteristics of meth users as a group. A universal trait was an inherent distrust of systems – the health care system, the legal system, any system. This is especially true of any system perceived to be connected with government. Many drug users feel as though the 'system' has let them down or they have been 'burned' by the establishment. They have great difficulty trusting anyone involved in those systems and are often reminded by their circle of meth-using peers of past events, real or perceived, that perpetuate this cycle of distrust. The repercussions of being caught by authorities would make their already precarious livelihoods even more difficult.

We found out in conversation that Joe had five siblings – all meth users – and decided that they probably were contacts. He said they were all homeless, without phones, so we were at a dead end. After we again explained the importance of testing his contacts so their health could be protected, Joe agreed to tell his siblings to come to the health department, but he would not tell us where they were. When his family members started coming in to the health department, we quickly identified two more active TB cases, who were put on treatment. These individuals too, were reluctant to name any more contacts.

Most of the potential contacts did not have permanent housing; they would rent a motel room for a while when the weather was cold or live in a tent city in the summer. They tended to survive by engaging in petty theft or stealing cars. A few were more mainstream, with jobs and rented housing. These two groups, daily users and weekend users, would mingle to buy and use meth, and then drift apart. Money was a problem for both groups. They would not use medical services unless they were severely ill, since they felt they could not afford it. This lifestyle is common among the meth users in our county, but may be different among meth users in other locations – or among users of other kinds of street drugs.

METHAMPHETAMINE'S EFFECTS ON THE USER

In addition to being physically addictive, methamphetamine can be very psychologically addictive as well. Under the influence of methamphetamine, users experience bursts of energy, talkativeness, and excitement. Users are able to go for hours or even days without sleep or food. High doses or chronic use have been associated with increased nervousness, irritability, paranoia, and occasionally violent behavior, while withdrawal from high doses generally leads to severe depression. Chronic abuse produces a psychosis similar to schizophrenia and is characterized by paranoia, picking at the skin, self-absorption, auditory and visual hallucinations, and sometimes episodes of violence.

Center for Substance Abuse Research (CESAR), University of Maryland, 2005

Again, the contact investigation stalled because it was difficult to identify additional contacts for medical evaluation. Most of the meth users in our town hang out as a group at one place, to buy and use meth and spend time together. They are suspicious of outsiders and we were trying to think of how best to reach them and get them in for testing and medical evaluations. "A girlfriend of one of the secondary cases grew to understand the importance of stopping TB, and decided to help us. She suggested that we just try a simple informational flyer," said Susan Robison, RN. "She said that her friends were forgetful and needed to know a specific time and place where they could be tested. And she knew where everyone was hanging out." One

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member of the health department staff, Maggie Osborne, had just come back from a TB Education and Training Network Conference and was full of ideas of how to make a flyer that would be the right reading level and contain only the essential information. We were thinking of using a neutral site for the testing, like a church mission or homeless shelter, but the alley next to a "meth house" seemed more convenient for the people we were trying to reach. So we designed a flyer that stated "If you hang out at X address, two nurses will be giving free TB testing nearby on such and such date." As we weighed the pros and cons of 'doing what you have to do to get the job done' vs. the danger of being a stranger walking in on people actively using meth, the patient's girlfriend, our ambassador, volunteered to hand out the flyers herself because she was known to the group.

The meth house was in a 'normal' neighborhood, but the yard was full of junk, all the window blinds were shut, and there was a pile of furniture blocking the front door. Ventilation inside was probably not very good. We could see two surveillance cameras on the property. Signs were posted saying "You are being videotaped" and guard dogs could be heard inside the house. It was the home of a meth dealer and several of Joe's potential contacts were living there temporarily. Most of the action was in the garage, where people went to buy and use meth.

Before the planned date, we informed the police department that we would be using needles and requested they not show up during our testing session. We were somewhat concerned about our own safety, so we took some precautions. First, we told everyone at the office where we were going and what we would be doing. We dressed down for work that day and took cell phones with us. We parked in the alley outside the meth house, in a way that would allow a fast exit, if needed. Then we set up a little table next to our car, with the medical supplies in the open trunk. We could then leave quickly if the situation ever seemed unsafe. We felt uncomfortable and foolish, just sitting there, but we waited. People inside the house were initially suspicious, expecting a trick. First, one person came to be tested, then another, and it snowballed. We relaxed and chatted with people about their lives and taught them about TB. Seventeen people were tested that day, and sputum samples were collected from those who were coughing and looked sick. A $5.00 incentive was offered for those who would come back in two days to have their TST read. We brought cookies and juice that day, and sixteen people came back. We found one person with active TB and five with LTBI – all with direct links to Joe. After that, our contact investigation took off: we knew what people looked like, they knew us, and we had established that law enforcement would not intervene.

With so many positive test results, we knew there were more contacts that needed testing. These are other strategies and opportunities we took advantage of:

A family event: Joe's niece was in the hospital having her baby which prompted a new strategy: Only let people in to visit mom and baby if they had been screened for TB by the health department. The new mother lobbied all of her friends and family to be screened so they could come to visit. This helped us find the baby's father and grandmother, both of whom had active TB disease, as well as many more people with LTBI.

The right question: The question that was most effective at eliciting names of new contacts was "Do you know anyone else who is sick and coughing?"

The walk-in informant: One Friday afternoon a man walked in to our office and said he "knew a lot about those people." It turned out to be a mixed blessing, because this man was mad at the meth user group and gave us a list of names and addresses of people he wanted out of his neighborhood. Still, it was an opportunity to expand the investigation and the few other contacts we tested were all TST positive.

Case Management and Completion of Treatment

The next challenges consisted of following up regularly with all of the people on treatment for active disease and LTBI. Sometimes our clients were friendly, talkative, and outgoing. At other times they could be elusive, disappearing for a few days at a time. This might have been due to their pattern of bingeing on meth for a few days, and then 'crashing' or sleeping it off for a few more days. It was often very difficult to find people with no fixed address, to wake them when they were in a deep sleep, and to encourage their cooperation when they were confused and anti-social upon waking up. At times like these it was sometimes better to try again another day.

This extensive outbreak eventually required an Epi Aid (Centers for Disease Control and Prevention support of a TB outbreak team and financial assistance) and involved 11 cases of TB disease. All persons with active TB disease completed treatment. Several were so severely ill that they, too, required prolonged isolation in a motel room with all of the support services mentioned previously, although we no longer agreed to do laundry! Contact investigation efforts identified a total of 393 contacts (229 from the community, 92 jail inmates, 47 jail staff, 8 court house staff, and 17 health care workers). The first round of TST comprised 337 persons; the second round 161. Of 92 persons who were TST positive, 72 were started on treatment for LTBI. Many are still on treatment. Fortunately, there was no HIV infection found in any of these high-risk clients.

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WORKING WITH PARTNER ORGANIZATIONS IS WORTHWHILE

We found that partnering with outside organizations that work with active substance users was significant in helping us locate and motivate individuals for testing and follow-up. We knew some of these partners from 'cross training' activities – and we built on these earlier relationships. Partners included other health department units, the needle exchange program, local jail, hospital emergency department, shelters – and of course the CDC.

- **Health department units**, such as programs for STDs and substance use, provided us with extra staff when we needed more people to handle the increased demands of TB screening and DOT activities. Our environmental health program had already worked with many of these partner organizations in the clean-up of meth houses, and they helped us organize a staff safety in-service training provided by a local drug abuse specialist and police. We learned to move slowly, keep our hands visible and open without making a fist, maintain a 3-5 foot physical distance from clients, as well as de-escalation techniques.
- **The needle exchange program** was a significant partner because their staff was very supportive of our TB work and the meth-using clients felt comfortable there. The staff has a long history of trust with the clients, know them by their first names, and understand the details of their lives. We would just go there to spend time, be seen in a trusted environment, and build up our credibility as people the meth users could trust, too. Needle exchange staff then introduced us to new contacts, and helped us in locating and eliciting responses from contacts.
- **The jail** was very useful when our clients were booked; we would just check the roster every day and see if anyone we were looking to find was on the list. Then we visited clients in jail and had plenty of time to just sit and talk with them, making it easier to elicit more commitment for follow-up. It also enabled us to work with the jail's medical staff in providing DOPT (directly observed preventive therapy) to clients who would otherwise not have received it.
- **The hospital's emergency department** saw about half of our clients during the time we investigated this outbreak. We also worked closely with the infectious disease (ID) nurse and other providers. It was important to get them ***"thinking TB"*** when they faced a US-born patient with TB symptoms.
- **Shelters and missions** can also be useful partners in this kind of situation. We were able to provide testing at the shelter where we located and identified new contacts.
- **The Centers for Disease Control and Prevention** can provide technical expertise and financial assistance to hire more staff temporarily. This is invaluable when an extensive outbreak overwhelms a local health department.

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During this period, all of these clients continued to use meth, although some have tried to slow down. Working with substance-using TB patients is challenging in many ways. These patients are difficult to identify initially and may not seek medical care. Once they are in the health care system, their providers may not suspect tuberculosis if the patients are US-born. It takes time, effort and a nonjudgmental attitude on the part of health care professionals to develop trusting patient-provider relationships. We found it useful to not make a big deal of their apparent drug use, to not react when it was mentioned, and to not bring it up all the time. We tried to be relaxed, but attentive to them, and to not give away feelings through disrespectful facial expressions or body language. It was more effective to demonstrate concern for the person (and not their behavior), and to not take on a 'parental' role and lecture them that they should do 'X, Y, or Z.' If we sensed that the client felt we were being too pushy, we backed off. Personal attitudes about substance abuse may make this more challenging for some staff than others. Safety issues, always present, are elevated in working with this population.

Effective care and treatment for tuberculosis with a hard-to-reach group requires an enormous amount of work; however, the outcomes of our continued efforts have been substantial. We have not had an additional active client in this outbreak for eight months. We have made new friends and colleagues at the Centers for Disease Control and Prevention who helped us make these interventions realistic to implement. We learned we can't do it alone – we needed partners all the way through the process and it was important to ask for help. TB control involves multiple strategies of prevention and care. The reward is the public's health- which is, in part, entrusted to us.

LESSONS LEARNED

LESSON #1: BUILD A FOUNDATION WITH TRUST

- **Emphasize confidentiality, trust and consistency.** "We found it best to mention confidentiality first," agreed the staff from the Snohomish Health District. "You have to be forthright and give complete information. That way you demonstrate that you trust the client." Many clients have been lied to all their lives and are just waiting for you to do it, too. Take care to not promise more than you can deliver or knowingly deceive them at any time.
- **Limit the number of staff involved in the contact investigation.** Allow clients to trust one or two staff before becoming overwhelmed by too many. One or two staff can begin to make connections, link people together, figure out how the group functions, who has power, who are caretakers or risk takers, etc. This will help in finding contacts and getting people to follow-up.
- **Meet clients where they feel comfortable.** Often, it was difficult to get the clients to come to the clinic. The clinic is not familiar territory for them and is not a place they feel comfortable when they are high. It was more effective to meet them where they could be found routinely in the field. Sometimes they seem stunned and appreciative that the health worker made the effort.
- **Help clients navigate the health system.** Clients really appreciate help with navigating the system in the TB clinic, as well as other health facilities. Do not take chances on clients getting lost or frustrated with a complicated voicemail system. Some days if they are too high, or perhaps not high enough, one small perceived barrier may turn them away forever. It is more effective to have one definite contact person who is expecting the client and who will be available immediately if the need arises. Meth is a stimulant and causes the brain to release high doses of adrenaline, the body's 'fight or flight' mechanism. This induces anxiety, wakefulness, and intensely focused attention – called "tweaking." Clients in this state may not have much patience. Five minutes can seem too long for most meth users. They may just leave and you may never get an opportunity to interview, test, or educate that particular client again.
- **Be open-minded about appointments.** The appointment system can be a barrier. A 'scheduling' mentality is generally not helpful with this group. Most of the time they will show up when they are able. If you stick to a 'scheduled' appointment time, they may not make it and then may not come at all because they feel bad about missing the appointment and may be afraid you will be angry with them. **Act happy when they show up!**
- **React to the person, not the behavior.** Do not judge the client's lifestyle, that is not our job. If you are judgmental, clients will pick up on this. Be honest with yourself. Be cheerful and warm. Listen to client's stories, they will soften your heart. Some of these clients may have faced extremely difficult circumstances in their lives. Treating them with empathy and respect will both benefit them as people as well as the overall TB control effort.

INTRA-STAFF ISSUES

During the course of this outbreak, staff discovered they had different levels of comfort and approaches to working with this new client group. Difficulties arose when other units were recruited to help as the outbreak grew, and these newcomers were not familiar with TB and drug users. Clients sometimes 'pushed their buttons' to see if they could get a reaction. One nurse felt that colleagues were stereotyping the clients as "meth users" instead of making the effort to recognize them as people who are addicted to methamphetamines. She saw them as individuals who were poor, struggling to get by day-to-day, having to steal for a living. Others felt that the new clients had brought their problems on themselves by using illegal drugs and acting irresponsibly.

Staff meetings were held to sensitize staff, build competency in dealing with substance using clients, and develop effective strategies for working toward completion of treatments for both disease and LTBI. We discovered that it was important to honor differences and acknowledge staff boundaries. In the end, we could agree to disagree and continue working as a team. Not everyone was equally effective or comfortable at providing DOT to room-bound patients or tracking down elusive contacts to make sure they completed treatment for LTBI. Management was fortunate to have a large enough pool of staff to be able to assign the more interested and culturally proficient staff to manage the patients involved in this outbreak.

LESSON #2: TAKE STEPS TO COPE WITH MANIPULATION

Manipulation is a survival skill among meth users on the street, a game and a skill to be proud of. How can

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health workers cope with it and keep their eyes on the prize of treatment completion?

- **Do not let manipulative behavior put you off.** Know what it is and let it roll off. Sometimes you can use it to your advantage with the art of compromise.
- **Negotiate incentives for cooperation:** Two food coupons for the chest X-ray, gift cards for addresses and phone numbers where child contacts can be found, or a ride somewhere for coming in for TST reading. Don't be held hostage, use your judgment. Even if the client skips out the door thinking they 'won' – you won too!
- **Know your personal limits.** Then you can let yourself be manipulated, knowing that it is being done within your rules. If it helps the client feel 'one up' on you and it gives them back a sense of power, but you achieve the desired health outcome, that is OK. Staff with 'control issues' may be well-served to not work with this group. Remember that we are here to protect the public's health and our goals are TB elimination. Changing a substance user's personal behavior is not what we expect to do. If you can do both, great, but remember the primary goal: get the TST, the CXR, the sputum sample, or the medication regimen completed.

LESSON #3: MAKE EFFECTIVE USE OF INCENTIVES AND ENABLERS

In this particular outbreak among individuals who use methamphetamines, we were challenged to modify our use of incentives. In this situation, we wanted to provide our clients with incentives for a variety of behaviors. We developed written guidelines listing what behavior(s) earned an incentive or enabler. It was very important that the guidelines were written and the entire TB team bought into the guidelines, as the clients would use a variety of strategies to manipulate the system. Having a consistent system limited some of those behaviors.

- **Incentives need to be flexible and immediate.** When we changed the incentive structure to reward clients only when they came the *second* time in a given week, we lost some of our clients who were functioning very much in the minute or the day, not two days in advance. If a particular incentive is not working, ask about client preferences to find out what will work.
- **Remember, a strong provider-patient relationship can be an incentive.** Regardless of the client behaviors, we learned we must make each client feel warmly welcomed, and create an environment of excitement when they come for DOT. Simply say something like: "Hey … here's my man! How great to see you today!"

Lesson #4: Ensure Staff Safety

In this outbreak among individuals who use methamphetamines, we made a variety of individual and program changes to address safety needs of TB control staff. The likelihood of violence was heightened due to our clients possible involvement with illegal activities, and their unpredictable, potentially violent and paranoid behaviors. We also experienced first-hand threats of domestic violence among clients in our waiting room and verbally abusive behaviors to staff. The incidences were not limited to the TB control program staff, but included other program staff as well. Thus, safety became a Health District issue and led to a temporary modified incident command structure.

Further, we requested that our local police department visit our health district and tuberculosis control clinic to make recommendations to enhance safety. Although our

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WAYS TO USE INCENTIVES EFFECTIVELY

- ***Incentives must be tailored to meet the needs of the group.***
- ***Write the incentive/enabler policy down to decrease attempts to manipulate TB staff.***
- ***If an incentive process isn't working, ask the group why and consider modifications.***
- ***If you have an incentive/enabler program in place, don't drop the ball. Always have the gas card, for example, available. Clients may depend on it.***
- ***Spend time helping staff to appreciate that incentives/enablers are cost-effective in the long run – so they do not harbor feelings of ill will toward clients who come in not to get well but to get a food coupon.***
- ***Not all incentives cost money – the value of a smile can be immeasurable.***

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clinic is equipped with cyber-locks, we learned to take sharp items such as scissors and extra pens out of exam rooms, be firm in not allowing clients into our protected space if aggression was observed or suspected, and to readily back each other up if an incident was unfolding. We installed doorbells in exam rooms and provided cell phones for staff to carry in the event they needed to call for help. And finally, because our field staff often does not see each other during the day, we developed a Staff Safety notebook. If an incident occurred, staff was encouraged to document it briefly in the log for all others to see prior to walking into a difficult situation the next day.

Jenny Donavan and Susan Robison

CONTRIBUTORS:

TB Control Program, Snohomish Health District, Everett, Washington:

- **Donna Allis, RN, PhD** TB Program Manager
- **Jenny Donovan, BA** Disease Investigator
- **Gloria Fiedler, MSW** Program Manager, HIV/AIDS
- **Susan Robison, RN** Public Health Nurse

Charles P Felton National TB Center at Harlem Hospital:

- **Bill Bower, MPH** Director of Education and Training
- **Paul Colson, PhD** Program Director
- **Julie Franks, PhD** Health Educator

New Jersey Medical School Global Tuberculosis Institute:

- **Lauren Moschetta-Gilbert, MA** Training and Consultation Specialist

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1. Did you find this newsletter easy to read? ❑ yes ❑ no

   Why?_____

   _____

2. Was the newsletter's length: ❑ too long ❑ too short ❑ just right

3. Will you apply anything from this newsletter to your current practice? ❑ yes ❑ no

   If yes, what specifically _____

   _____

4. What **cultural competency** topics would you like to see in future newsletters?

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We need cases to highlight!

Many of you are out in the field doing great work with people from a variety of cultural backgrounds.

Would you be willing to contribute or be interviewed for a case study or article? If so, please provide your contact information. Fax this page to 973-972-1064

Many of the photos in this newsletter are courtesy of the Stop TB image library at: http://stoptblpipserver.com/

NEW JERSEY MEDICAL SCHOOL
GLOBAL TUBERCULOSIS INSTITUTE

225 Warren Street, Newark, NJ 07101-1709
(973) 972-3270
www.umdnj.edu/globaltb