

## Factors associated with identifying tuberculosis contacts

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### SUMMARY

**SETTING:** Little is known about why some tuberculosis (TB) patients identify few or even no contacts.

**OBJECTIVES:** To describe patient perceptions of the contact investigation interview and determine potential factors associated with identifying TB contacts.

**DESIGN:** A total of 13 focus groups were conducted: 10 groups with previously smear-positive pulmonary TB patients born in the United States or Mexico, and three with program staff to discuss attitudes toward and perceptions of the contact investigation interview. Patients were recruited into separate groups by country of birth and number of contacts identified.

**RESULTS:** The data indicated that patients—even those who identified few contacts—overwhelmingly reported identifying contacts easily and willingly. Understanding the purpose of the contact investigation and seriousness

of TB facilitated naming contacts, while miscommunication and misconceptions about TB hindered the process. Patients felt strongly about informing their contacts before the health department contacted them. Staff respondents reported that education and effective communication were critical during contact investigation interviewing.

**CONCLUSION:** Data indicated that patients, including those identifying few contacts, reported wanting to name their contacts. However, misconceptions may affect their understanding of who their contacts are, and hence the quantity and quality of the contacts identified. These findings underscore the need for effective communication and education.

**KEY WORDS:** contact investigation; tuberculosis; focus groups

IN THE UNITED STATES, tuberculosis (TB) control programs conduct contact investigations—also known as contact tracing—to identify persons exposed to infectious TB patients and evaluate them for active TB disease and latent TB infection (LTBI). Because infected contacts are at high risk of progression to active disease and are important candidates for treatment of LTBI,<sup>1</sup> prompt identification of contacts is a high priority in TB control.<sup>2</sup>

A critical first step in the TB contact investigation process, the contact investigation interview is inherently an inquiry into social networks.<sup>3–5</sup> Patients suspected of or diagnosed with TB are typically asked to identify persons with whom they have spent a prolonged period of time and describe the frequency, duration, and proximity of the contact. It is unknown how many contacts a contact investigation is expected to yield, as the literature indicates wide variation.<sup>6–10</sup> Furthermore, no known studies have examined the appropriateness of the contacts that are identified.

The specific factors that may influence contact investigation outcomes are not well characterized. However, a variety of health, socio-economic, and cultural factors have been shown to affect a patient's ability to seek health care and adhere to treatment

recommendations.<sup>11,12</sup> For example, patients who are non-adherent to treatment recommendations are likely to be substance abusers, mentally ill, homeless, or associated with congregate settings.<sup>13–16</sup> Social stigma attached to TB, as well as cultural beliefs about TB, are also known to affect health-seeking behavior, willingness to disclose TB status, and treatment outcomes, especially among foreign-born persons,<sup>11,12,17–20</sup> who comprised half of the new TB cases in the US in 2001.<sup>21</sup> These same factors may indeed impact contact investigation outcomes. A study conducted by the Centers for Disease Control and Prevention (CDC) found that homeless persons identified fewer close contacts, while substance abuse and homelessness were risk factors for non-adherence to LTBI treatment.<sup>10</sup> Another CDC study evaluating contact investigations found that only 50% of TB patients who resided in homeless shelters identified any contacts.<sup>9</sup>

Contact investigations may not be achieving optimal outcomes.<sup>9,10</sup> A study reviewing contact investigation policies and procedures in 11 TB control programs indicated wide variations in both policies and practices, including the amount and type of data collected on contacts.<sup>22</sup> Investigations involving persons both at high risk for TB and difficult to reach present

particular challenges. An investigation of an outbreak among transgender persons demonstrated how relying on traditional contact investigation procedures would have caused investigators to overlook the important social networks that played a major role in transmission.<sup>23</sup> Ineffective contact investigations that fail to identify the most at-risk contacts result in missed opportunities for prevention.<sup>6,24</sup> Furthermore, the contact investigation interview, the first step of the contact investigation process, has the potential to exert a critical influence on contact investigation outcomes. Namely, fewer contacts are identified and evaluated if the quality of the contact investigation interview—influenced by the interviewer's skills, the patient's willingness to share information, and a range of other factors—is suboptimal. To date, no known scientific studies have examined patients' perceptions of the contact investigation interview to determine how patients view the contact investigation interview and their expected role in the contact investigation process.

Given that TB disproportionately affects certain sub-populations in the US, including foreign-born persons from TB-endemic regions, substance abusers, and the homeless, this study aimed to explore the factors that influence the identification of contacts. Do patients understand the purpose of the contact investigation interview? Do patients see the benefit and importance of disclosing their contacts? What qualities or skills do contact investigation staff believe contribute to effective contact investigation interviews? These types of inquiries led to the present study.

## STUDY POPULATION AND METHODS

The primary objectives of this study were to describe TB patients' perceptions of the contact investigation interview and to determine potential factors associated with identifying contacts. The study focused on non-Hispanic, US-born pulmonary TB patients and Mexico-born TB patients. The study design included both patients who identified 'few' (0–3) contacts and those who identified 'many' (8+) contacts to ascertain potential differences in perceptions between the two groups. Patients with a history of substance use and homelessness were also included. Foreign-born patients from Mexico were targeted, largely because Mexico contributes the largest proportion (about one quarter) of foreign-born TB cases to the US,<sup>21</sup> and because the literature on TB attitudes and beliefs is limited.<sup>25,26</sup> Furthermore, focus group discussions were conducted with contact investigation staff to produce a comprehensive picture of the range of perspectives and to further validate the findings.

Since we knew of no published studies examining perceptions of the contact investigation interview, this study was exploratory in nature. Focus group methodology was incorporated for its flexibility and effectiveness in obtaining information about attitudes,

perceptions, and motivations for behavior. Focus groups have been used extensively to help program managers design new interventions.<sup>27</sup>

The study was conducted in three cities—San Francisco and San Diego, CA, and Dallas, TX. These sites were selected on the basis of: 1) availability and willingness to participate; 2) geographic diversity; 3) total number of reported TB cases; 4) number of verified foreign-born TB cases; 5) per cent of TB cases born in Mexico; and 6) per cent of substance abusers (alcohol, non-intravenous/intravenous drug use) among TB cases.

TB patients and staff convened in separate focus groups to discuss their perceptions of the contact investigation interview. All participating patients were at least 18 years old, non-infectious, initially sputum acid-fast bacilli (AFB) smear-positive, and receiving treatment for active pulmonary TB. All patients meeting one of the following criteria were invited to participate: 1) US-born/non-Hispanic identifying zero to three contacts ('few'), 2) US-born/non-Hispanic identifying eight or more contacts ('many'); or 3) Mexico-born patients. Information on sex, age, race, history of substance abuse, history of homelessness, and number of contacts identified was abstracted from medical charts; length of time in the US for the Mexico-born patients was also abstracted. All participants received a \$25 remuneration for their participation.

All eligible TB program staff at each site were encouraged to participate in staff-only focus groups. Participating staff had at least 6 months' experience conducting contact investigations. Information on sex, age, race, position, length of experience, contact investigation training, and languages spoken fluently was self-reported by staff participants.

To ensure consistency and standardization, one moderator facilitated all of the staff and patient focus groups that were conducted in English, while a second, bilingual moderator led the discussions in Spanish with the groups from Mexico. The use of a focus group guide ensured consistent data collection across groups and provided flexibility to obtain clarification.<sup>27</sup> The guide for the patient groups consisted of a series of open-ended questions. Constructs from the Health Belief Model<sup>28</sup> were used to develop core discussion topics, such as perceived seriousness of TB, perceived benefits of identifying contacts, and perceived barriers to identifying contacts. Focus groups with contact investigation staff highlighted skills, training, and perceptions of the factors that facilitate and hinder the elicitation of contacts. To minimize 'social desirability',\* participants were reminded that

\* 'Social desirability' refers to the inclination to produce socially acceptable answers or responses that the questioner might expect (or wish) to hear. (For example, if patients are asked if they are having difficulty with the medicines, they may feel obligated to answer 'no' whether or not they were having difficulties because they believe that it's what the nurse wants to hear.)

the facilitators had no association with the health department.

Focus groups were audio recorded and transcribed verbatim for analysis using the computer-based qualitative software program, Atlas-ti 4.1.<sup>29</sup> Spanish transcripts were translated into English by trained professional translators and spot back-translated to ensure accuracy. Content analysis was performed by examining the major themes and patterns that emerged from the data, using 'grounded theory', an inductive approach for constructing and confirming theory through systematic data coding.<sup>30</sup> To control for subjectivity during analysis and ensure inter-coder agreement, two trained researchers independently and systematically coded the data and compared the results. Inconsistencies and disagreements in coding were discussed and resolved before final analysis commenced. The study was determined to be exempt under 45 CFR 46 by the CDC's Human Subjects Research Committee.

## FINDINGS

Ten patient focus groups were conducted with 54 patients in the winter of 1998, and grouped according to number of contacts identified. In addition, three staff focus groups were conducted with 18 staff members. Participants were evenly distributed across the three sites. Demographics of participants are shown in Tables 1 and 2.

One major theme that emerged across all 10 patient focus groups was that patients, regardless of whether they had identified 'few' or 'many' contacts or had a history of substance abuse, reported providing contacts easily and willingly. This finding appeared to be facilitated by several factors and hindered by others. Patients' overwhelming understanding of the purpose of the contact investigation and seriousness of TB appeared to facilitate the identification of contacts. Another facilitating factor was patients' strong moral and personal obligations to family and friends. One

**Table 2** Demographics of focus group staff participants

Staff demographics (n = 18)	%
Female	83
Median age (years)	48
White, non-Hispanic	44
African American	33
Hispanic	11
Asian	11
Median length of contact investigation experience (years)	6.5
Received contact investigation training	78
Spanish-speaking	11

comment from a homeless male substance abuser typified responses. 'I mean, you know, I do have an infectious disease. I don't want to see nobody get sick.'

Another theme that emerged across all 10 patient groups was that patients felt strongly about being able to inform their contacts before the health department reached them. 'It'd be a whole lot easier for you to get the news from me than to hear somebody you don't know on the phone . . . it's a lot easier to take from somebody you know,' summarized one female patient. In fact, the vast majority of patients in all 10 patient groups reported informing their contacts. One patient vividly recalled how she felt when her friends were contacted before she had a chance to reach them: 'It made me feel like I wasn't trusted enough. . . . Why wouldn't I tell them? Why would I want everybody that I'm around to get sick, you know?'

Trust in the contact investigation staff reportedly facilitated patients' willingness to name their contacts. Patients in all 10 groups felt assured that the information they were providing 'doesn't go any further. It's all confidential.' Both trust and good rapport were also identified in each of the three staff groups as essential to a successful contact investigation interview.

Across all patient and staff groups, communication emerged as either a key facilitator or a key challenge to the contact investigation interview process. Patients frequently reported feeling 'listened to' and 'cared for' by the staff. While staff also emphasized the importance of good communication, both patients and staff recalled communication challenges. Among the most frequently cited barriers was communication with non-English speaking patients, which was further complicated by a lack of interpreters. Several staff noted that even with an interpreter they were often uncertain about the quality of the information being communicated. Staff remarked that training on cultural sensitivity and working effectively with interpreters would be valuable.

Another challenge emerging across all 13 patient and staff focus groups was the wide variance in how a 'contact' was perceived and used. Some patients reported being asked to name only household members, while others reported being asked for a comprehensive list: 'Make a list of all the people that you've had

**Table 1** Demographics of focus group patient participants

Patient demographics	US-born		Mexico-born (n = 23)
	'few' (n = 19)	'many' (n = 12)	
Male (%)	90	58	74
Age range (years)	27–63	22–63	21–71
Median age (years)	51	46	39
African American (%)	53	67	NA
History of substance abuse (%)*	79	42	17
History of homelessness (%)	42	25	13
Mean length of time in US (years)	NA	NA	14
Median no. of contacts identified per case	2	12	6

\* Includes abuse of alcohol, non-injecting, and/or injecting substances.  
NA = not applicable.

contact with, wherever it was, in a car, or people that you lived with for some time, talked with, who were there while you coughed, who you laughed with, sang with.' Several patients claimed to have given many names to the contact investigation worker, yet their charts noted only three or fewer contacts. Staff acknowledged having difficulty conveying the meaning of an 'at-risk' contact, and reported that the lack of clear, standardized definitions magnified the problem. As one nurse conceded, 'There's so many shades of gray.'

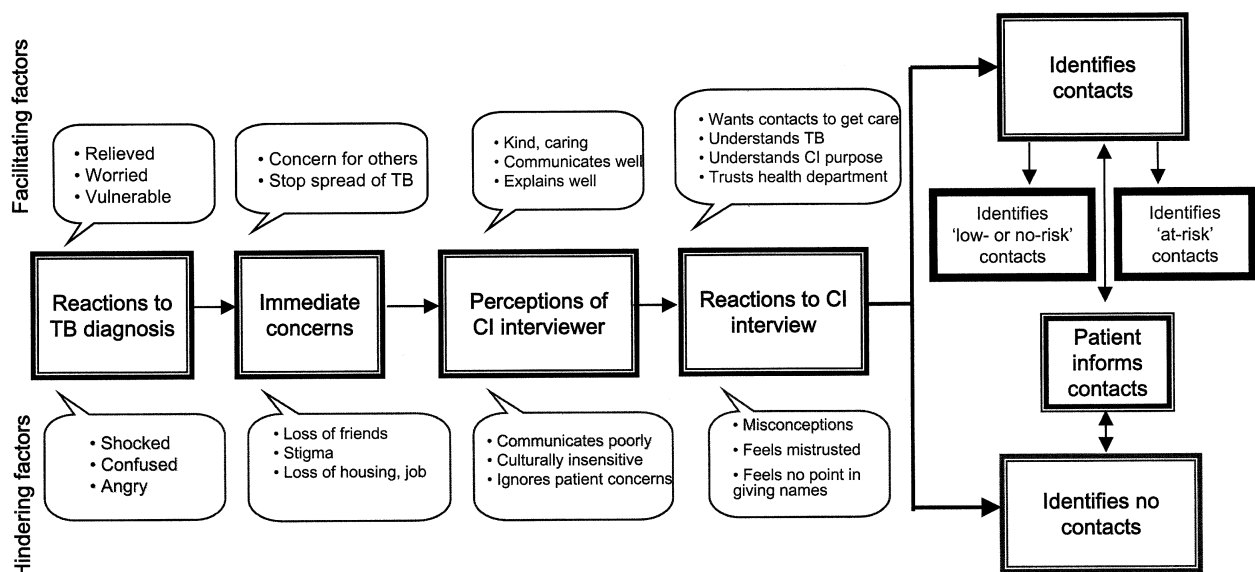
Staff acknowledged the challenge of communicating the need to obtain personal information. Likewise, some patients, unclear about the connection between the contact investigation questions and the disease control process, perceived the contact investigation interviewer as prying into their personal lives. Others reported being confused initially until they realized the purpose of the questioning. One shrewd patient articulated precisely the key issue, '(He) doesn't need the names of the people. He needs the people that have been infected to come in.'

Emerging across all 10 patient group segments was the finding that patients, even those nearing completion of therapy, lacked accurate knowledge about TB and how it was transmitted. Some patients reported believing that TB could be spread by sharing eating utensils, drinking from the same bottle, or shaking hands with a person with TB. 'I coulda got it from a donut. I coulda got it from a beer can.' Others asked questions during the focus groups about risk factors, treatment implications, and even their own diagnosis, indicating their need and desire for clarification and additional information. In contrast, staff emphasized the importance they placed on educating patients.

Both patients and staff cited patients' fears of alienation or abandonment as challenges to the contact investigation interview process: 'Friends will run away from you.' or 'They point to you with a finger and say that you have something ugly. They don't get close to you.' Fear of stigma emerged in all of the patient focus groups, particularly among Mexico-born patients. In addition, loss of employment and loss of housing were common fears that for some patients became a reality. Staff reported that their training did not adequately address social and economic issues. Fear of legal authorities was raised only occasionally by substance abusers, who expressed particular concern for their contacts.

Furthermore, patient fears were often magnified by the timing of the contact investigation process. The contact investigation interview is typically conducted immediately upon suspicion or diagnosis of active TB disease, at a time when patients are feeling sick and often afraid and confused by all the people involved, and sometimes provided contradictory information. 'There were so many residents, doctors, whatever!' Many patients recounted experiences tantamount to 'information overload.' Also recognizing this problem, staff reported making efforts to re-interview patients at a later, less stressful time. Several staff suggested the need for additional training in counseling. They also suggested the need for a better system of coordinating information among health care providers.

The Figure illustrates the major factors that emerged from the data that appeared to affect patient perceptions of the contact investigation interview. As can be seen, patients' overwhelming understanding of the purpose of the contact investigation and seriousness of TB, as well as their strongly felt moral and personal obligations to family and friends, facilitated the



**Figure** Model of patient perceptions of contact investigation (CI) interview process.

identification of contacts. On the other hand, shock and confusion due to the timing and personal nature of the questions, accompanied by fears associated with the stigma carried by TB, negative perceptions of the interview process, and misconceptions of TB transmission were among the factors that hindered the identification of contacts.

## DISCUSSION AND CONCLUSIONS

The findings from this study indicate similar perceptions and attitudes toward the contact investigation across the group segments of persons who identified 'few' contacts and those who identified 'many' contacts. Patients who identified few contacts did not do so out of lack of cooperation; on the contrary, the majority of patients in all 10 patient groups reported wanting to cooperate and stop the spread of TB to their family and friends. Patients clearly understood the seriousness of TB and saw the benefits of identifying contacts. They felt it was their personal responsibility to inform their family and friends, and that they, not the health workers, could best express the need to be tested and possibly treated. The few patients who reported a reluctance to provide names were substance abusers, who hesitated primarily out of fear that their privacy and that of their contacts would be invaded. Others noted concern about stigma and fear of alienation.

Communication appears challenging, as indicated by patients' misconceptions and unanswered questions, and may be further hindered by the timing of the contact investigation interview within the TB treatment process. Being subjected to the contact investigation interview before patients are able to digest and understand their diagnosis and its implications would seem to explain their reports of fear and confusion surrounding the whole process. Furthermore, staff reportedly do not regularly assess patients' emotional readiness or level of understanding, and do not feel prepared to address patients' personal concerns, such as stigma, social alienation, and fears of losing income and housing. Programs may yield improved contact investigation outcomes with provision of sufficient staff training in listening, culturally appropriate interviewing techniques, and a consistent practice of re-interviewing patients after initial fears and confusion subside—a practice reported by some staff but not uniformly recommended by TB program policy.<sup>22</sup>

The findings from the three staff groups demonstrate considerable convergence regarding the issues that influence contact investigation interview outcomes; specifically, staff highlighted patients' concern for others and non-judgmental attitudes of staff whom they trusted to protect their confidentiality as facilitating factors, while cultural and linguistic barriers, stigma, and other urgent patient priorities reportedly hindered elicitation of contacts.

The study findings raise a question about the qual-

ity of the names identified during contact investigations. The lack of uniformity of approach between and within TB control programs—consistent with the literature<sup>22</sup>—was evident by the varying methods used by staff to elicit names, making it difficult to get patients to focus on and identify contacts truly at risk for TB infection and/or disease. The discordance between patients' claims of providing many names and the actual records raises further questions. For example, could misconceptions about TB transmission, as indicated in the data, lead patients to identify many but not necessarily appropriate contacts? Alternatively, were some identified contacts simply not recorded by staff? This may be particularly relevant to contact investigations of homeless persons, as several homeless respondents reported that, while they were willing to cooperate in providing contacts' names, they only knew the street names of their friends. 'How you gonna go find a guy whose name is Gonzo? I mean, how you gonna find these guys?' They and others acknowledged being even less helpful in providing locating information. 'I didn't see no problem about cooperating. I told them, well, if you can find these people . . . these people ain't got no place to live, I mean, you just can't go up to their house and dial them on the phone. These people wander all over the county. . . .' Similarly, staff reported frustration at not knowing how to work under these circumstances. It is possible that such 'street names' were simply not recorded as contacts, reflecting the perceived futility of following up with these contacts. Further investigation is needed to explain the discrepancies between the number of contacts patients reported identifying and that shown in their records.

Interpretations of these findings are subject to several methodological and study limitations. First, while useful for its flexibility to explore unknown issues, focus group methodology is inherently limited in its generalizability to broader populations. Thus, the conclusions drawn from this study apply only to the participating sites. Second, the focus group method does not allow specific attribution of responses to specific respondents, thus barring quantification of information. Third, the recruitment of patients favored the selection of those who were cooperative and willing to participate in the study. In recognition of this potential selection bias, this study was designed to recruit patients who were by definition 'less adherent' to the contact investigation interview (i.e., identified zero to three contacts); these persons indeed comprised over half (61%) of the 31 US-born study participants. Finally, patients from Mexico were the only foreign-born population represented. The median number of years they had resided in the US was 14 years, much longer than had been anticipated, and their legal status was unknown. It is likely that such participants were indeed legal immigrants, a factor that could explain the apparent willingness to provide contacts'

names. Caution should be used in projecting the study findings to wider audiences that include patients without legal residence status.

In spite of these limitations, the findings suggest several programmatic and training areas that may enhance the quality and effectiveness of contact investigations. Program policies can be developed to promote more effective communication to ensure that patients understand the purpose of the contact investigation and the meaning and importance of identifying a 'true' contact. The consistent use of standardized definitions should further improve the contact investigation interview process and outcomes.<sup>7</sup> Maintaining a systematic practice of re-interviewing patients is likely to produce an enhanced yield of contacts, in terms of both quantity and quality. In addition, ensuring that staff are sufficiently trained to address issues commonly faced by TB patients, such as substance abuse and homelessness, and appropriately matched whenever possible with patients' cultural and linguistic needs, may alleviate some of the communication challenges identified by both patients and staff, as well as the obstacles staff reported in locating many of the 'hard-to-reach' contacts.

Policies and procedures should offer sufficient flexibility to incorporate patients' strong desire to inform their contacts before the health department does. Furthermore, providers need to communicate and coordinate care to ensure consistency in the information provided to 'true' contacts and hence the quality of names identified. Finally, periodic monitoring would ensure the quality of contact investigation interviews and consistency of names and information recorded.

In addition, programs should ensure that contact investigation staff needs are met by developing a comprehensive training plan that includes: 1) using effective listening and communication skills during the contact investigation interview to ascertain patients' understanding and beliefs about TB and their attitudes toward treatment, 2) tailoring culturally sensitive education to persons of diverse backgrounds, 3) enhancing effectiveness with interpreters, and 4) ascertaining and appropriately addressing housing, employment, and other personal concerns.

Finally, while these findings contribute valuable information for the improvement of contact investigation interview outcomes, further research encompassing a wider and more diverse group of patients and programs may be useful to determine the extent to which these findings hold true across a broader range of programs.

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