The Effect of Tuberculosis and Tuberculosis Contact Tracing on School Function: An Exploratory Focus Group Study

R.E.G. Upshur, MA, MD, MSc, FRCPC,[1] L. Deadman, RN, BScN,[2] P. Howorth, RN, BScN,[2] L. Shortt, RN, BScN, BA, MEd[3]

ABSTRACT

Setting: Selected schools in East York, an ethnically diverse municipality of 110,000 people within Toronto.

Objective: To explore school staff's attitudes and beliefs about the nature of tuberculosis and its possible effect on the function and culture of schools.

Design: Four focus groups of 6-8 school staff, lasting from 1 to 1.5 hours, were held in the spring of 1997 at four different schools deemed to be at high risk for tuberculosis contact tracing.

Results: The study identified the following dominant themes: fear of tuberculosis and its impact on school, lack of knowledge and the need for education concerning tuberculosis, and issues in multiculturalism.

Conclusion: Tuberculosis was perceived by staff of East York schools to be a source of fear. Lack of accurate and reliable information concerning tuberculosis contributes to this situation. Staff identified age-specific and culturally relevant, educational initiatives as means to reduce this fear.

ABRÉGÉ

Milieu : plusieurs écoles sélectionnées de East York, une municipalité de la ville de Toronto dont la population de 110 000 personnes regroupe des ethnies diverses.

Objectif : essayer de déterminer l'attitude et les croyances du personnel au sujet de la tuberculose et de ses effets possibles sur le fonctionnement et la culture en milieu scolaire.

Méthodologie : quatre groupes de consultation composés de membres du personnel de 6 à 8 écoles, que l'on a réuni de une heure à une heure et demie au cours du printemps 1997, dans quatre écoles différentes considérées comme présentant des risques élevés de contact avec la tuberculose.

Résultats : l'étude a identifié les grandes questions suivantes : la peur de la tuberculose et de ses retombées en milieu scolaire, l'absence de connaissances et le besoin d'expliquer la tuberculose, ainsi que la problématique du multiculturalisme.

Conclusion : le personnel de East York considère que la tuberculose fait peur. Le manque d'informations exactes et fiables au sujet de la tuberculose explique cette situation. Le personnel a proposé des mesures éducatives, adaptées aux cultures et aux catégories d'âge, comme moyen pour atténuer la peur.

Tuberculosis contact tracing is an integral aspect of tuberculosis control and an important function of most public health units in Canada. Increasingly tuberculosis is becoming an issue in school environments. As a consequence, public health units find themselves involved in contact tracing investigations in school populations.

School contact tracing poses special challenges. Depending on the nature of the case and the estimated extent of exposure, it may be necessary to perform skin tests on the entire school. This can create considerable anxiety for the staff, students and parents of the school, requiring a skilled and sensitive response from health unit staff. Information needs will vary depending on the age range of the school and the demographic make-up of the school population. Multicultural communities are increasingly the norm in urban Canada.

Contemporary research emphasizes the importance of socio-cultural factors in understanding tuberculosis,[1-3] foremost among these being the health culture of the community. Understanding this context is indispensable to the development of educational strategies to enhance knowledge of disease transmission, improve compliance with treatment and reduce the social harm associated with the stigmatization of illness.

Canadian data exist on the likelihood of transmission of tuberculosis in schools.[4-6] Qualitative research on the social impact of tuberculosis and the impact of contact tracing on school function and culture is scarce. To our knowledge, there are no published qualitative studies on the attitudes and beliefs of Canadian school employees concerning tuberculosis.

In 1996, the East York Health Unit conducted contact tracing for two cases of active pulmonary tuberculosis in two schools. In both cases health unit staff were struck by the degree of anxiety among staff, students and parents. Media interest in one school increased the perception of the risks and dangers associated with a case of tuberculosis. The process of contact tracing was traumatic for many involved, particularly for young children found to have positive tuberculosis tests.

These experiences indicated that research was required to characterize the attitudes and perceptions held by school staff concerning tuberculosis. It was hypothesized that qualitative methods could gain insights into the culture and belief structure of school staff that a survey instrument would be unable to adequately detect and measure. Consequently, a focus group study was conducted among school staff in schools to explore their knowledge and attitudes towards tuberculosis. Focus groups are a recognized research methodology designed to use group process to facilitate the discussion of attitudes and beliefs towards health issues.[7]

1. Departments of Family and Community Medicine, Public Health Sciences and The Joint Centre for Bioethics, University of Toronto
2. Community Health Nurse, East York Office, City of Toronto Department of Public Health
3. East York Office, City of Toronto Department of Public Health

Correspondence: Dr. Ross Upshur, Primary Care Research Unit, Room E349B, 2075 Bayview Avenue, Toronto, ON, M4N 3M5, Tel: 416-480-4753, Fax: 416-480-4536, E-mail: rupshur@idirect.com

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MATERIALS AND METHODS

The Borough of East York is a densely populated, urban municipality located in Metropolitan Toronto. It has a population of just over 100,000 people. The community is home to an ethnically diverse population with over 70 home languages represented in its school population. The rate of tuberculosis was 18/100,000 persons in 1996 compared to a national average of 7 cases per 100,000.

Recruitment and sampling

Participants for focus groups were drawn from the staff of four schools in East York: one high school, one middle school (Grades 6-8) and two elementary schools (Kindergarten-Grade 5). All staff were eligible. Principals at each school were approached to recruit participants. The research was given ethics approval by the Research Committee of the East York Board of Education and the East York Health Unit.

Focus group format

Focus groups were conducted at four different schools in East York in 1997. Each focus group lasted from 45-90 minutes. One focus group occurred in a school that had undergone a contact tracing episode in the previous year. All participants gave informed consent. Each focus group was facilitated by either a community health nurse or community medicine resident. The questions are listed in Appendix 1.

Analysis

The audiotapes for each focus group were transcribed verbatim. The transcripts averaged 21 pages in length. Inaudible comments were indicated in the transcript and considered lost data. Each transcript was analyzed by three independent readers for common themes by the examination of key phrases and recurrent concepts of concern. Agreement on the final set of themes was achieved by consensus among the readers. Specific quotations and phrases from the text were selected as being particularly representative of the major themes.

The analytic technique used was the editing analysis style.[8] In this technique, dominant themes emerge from the analysis of the transcripts rather than imposing an *a priori* set of categories on the data.

Appendix 1
List of Questions Asked in Focus Groups

1. What experience have you had with tuberculosis and in what setting?
2. In your school community, what do you think are the issues of concern around tuberculosis disease and the process of contact tracing?
3. How would the diagnosis of a case of tuberculosis in your school affect you or others?
4. What would make your school community more comfortable with tuberculosis?
5. What role can the Health Unit play to reduce anxiety and support the school community that is going through contact tracing?

RESULTS

Each focus group had 9 participants, the majority of whom were teachers. At each focus group, all members participated. The atmosphere at each group was largely collegial and cordial.

Three dominant themes emerged from the focus groups concerning the impact of tuberculosis on school function: fear of the disease and its impact on the school, lack of knowledge and the need for education to overcome both fear and lack of knowledge, and multicultural issues.

Fear of tuberculosis

In all focus groups, tuberculosis was regarded as something to be feared. Tuberculosis was referred to as "unknown", "feared"," virulent" and "fatal". It was thought that a person with tuberculosis would be viewed as "dangerous", "dirty" and "disgusting". It was also expressed that tuberculosis was a disease of the past, and had largely been conquered by modern medicine.

The discovery of a case of tuberculosis in a school and the need for contact tracing in the school was universally thought to be a serious problem. In all focus groups, words such as "panic", "nervousness", "uneasiness", "fear", "anger", "anxiety" and "alarm" were used to describe the likely situation in the school. Reflecting on the contact tracing episode from the previous year, one respondent stated:

> *I found that when the incident happened, students came up to you in absolute panic. It wasn't the immigrant students. It was the ones who were aware of what TB was or what they thought it was and they really had no information on it. They really didn't know what it was but they knew it was something terrible and it was How do I know I don't have it? and they were just really panic stricken.*

Another respondent commented on the effect on parents:

> *It would scare a lot of parents cause I think a lot of them have come from countries where TB is rampant, and if they suddenly found out we were testing for it they would assume it was rampant here. Certainly that would be one of my fears.*

In some focus groups, it was thought that the consequences of the discovery of a case would be grave: parents might withdraw their children, and the school image would be tarnished.

Knowledge of tuberculosis

It was evident in all focus groups that general knowledge concerning tuberculosis was poor. This was quickly recognized and commented upon by the focus group participants themselves:

> *That highlights the real problem is we don't know anything. We don't know how we would get it so automatically there would be a panic amongst ourselves as well.*

There was uncertainty expressed as to whether tuberculosis was caused by a virus or bacteria. Most did not know the mode of transmission and lacked information concerning the signs and symptoms of disease. Questions were raised about whether

the disease was preventable by a vaccine or not, whether it was treatable or not, and what a positive tuberculosis skin test meant.

In all focus groups, the central role of education and communication emerged as the preferred method to overcome the fear associated with tuberculosis. This was succinctly phrased by one respondent: "Educate. Inform. Disclose." It was believed that having a trusted external agency such as the health unit co-ordinating communications would help. HIV/AIDS education was viewed as a successful model.

Several education strategies were offered. For teachers, staff meetings, assemblies and meeting in class with health care professionals were believed to be helpful. The possibility of including communicable disease issues in schools in teacher education was mentioned. Student understanding could be facilitated by the provision of age-appropriate information. The integration of communicable disease knowledge with basic science and health education emerged as a valuable tool in several groups. Internet resources, videos, health fairs and plays were also mentioned as possible avenues to increase understanding. Community understanding was discussed as well: using key community leaders, the shopping mall, the community centre, daycares and places of religious devotion to reach out to the community was considered important. It was also agreed that more information on specific attitudes towards tuberculosis in ethnic communities was needed.

Multiculturalism and immigration

Most participants believed their schools to be at high risk for having a case of tuberculosis. This belief was linked to an intuition that rates of tuberculosis are higher in immigrant populations. The issue of screening immigrants to Canada was a recurrent theme. Some participants expressed opinions about the laxness of immigration procedures and expressed concern that not enough was being done to ensure that those recently immigrated were free from communicable disease. One response summarizes this theme:

One of the reasons I wanted to participate is I feel that of all the schools in Toronto, this one in particular could be considered a risk for the possibility of it. [tuberculosis] This school could be one of the high risk schools because of the nature of the student body and because we have kids coming in from every part of the world imaginable and especially now since they're coming in from war-ravaged parts which I also seem to think that coming in they don't screen the immigrants as carefully as they should.

The presence of a large ethnically diverse population increases both the risk of tuberculosis and the complexity of risk communication. Information would need to be accessible and presented in culturally appropriate ways:

Also too, this is a very multicultural community here and they would all have different ideas about health and illness and how to look after children or how they deal with illness and sickness and so you'd have to really be very specific and very clear. You'd probably need interpreters.

DISCUSSION

This study has identified several areas of concern with respect to tuberculosis. It is evident that lack of knowledge and fear of the disease form a potent combination. This is exacerbated by the presence of a large immigrant population perceived to be at high risk by school staff. Concerns over the perceived laxness of immigration rules may also indicate a problematic set of normative beliefs.

It was universally believed that the panic and fear associated with tuberculosis can be allayed through the use of educational interventions. Many potential strategies were identified as useful for the transmission of knowledge. No focus group considered it desirable that harm arise in schools or in communities due to tuberculosis. Any interventions and educational initiatives would involve a partnership between staff in schools and health units.

Issues of multiculturalism and immigration figured prominently in discussions. In each focus group, it was posited that different ethnic groups may have different perceptions of tuberculosis. There is some empirical evidence to support this hypothesis.[1,9] It is unclear to what extent immigration changes those perceptions, and whether the cultural significance of tuberculosis retains the same structure in the adopted country. This is a question that is amenable to future empirical study.

Focus groups are limited by not being generalizable.[7,10] It may be that the opinions and beliefs expressed at the focus groups do not reflect the views held by the staff at large. A form of selection bias could account for the views expressed in that only those who had strong feelings about tuberculosis volunteered for the focus groups. In these focus groups, no effort was made to ensure that participants were unknown to each other. Consequently there is a possibility that group dynamics may have suppressed the expression of certain beliefs. However, the discussions appeared to be candid, and participants were not afraid to admit their fears and lack of knowledge in front of colleagues and health care professionals. This would argue against any suppressive influence of group dynamics.

REFERENCES

1. Liefooghe R, Michiels N, Habib S, et al. Perception and social consequences of tuberculosis: A focus group study of tuberculosis patients in Sialkot, Pakistan. *Soc Sci Med* 1995;41(12):1685-92.
2. White GL, Henthorne BH, Barnes SE, Segarra JT. Tuberculosis: A health education imperative returns. *J Commun Health* 1995;20:29-57.
3. Rubel A, Garro LC. Social and cultural factors in the successful control of tuberculosis. *Public Health Reports* 1992;107:626-36.
4. Yuan L, Richardson E, Kendall P. Evaluation of a tuberculosis screening program for high-risk students in Toronto schools. *Can Med Assoc J* 1995;153:925-32.
5. Rothman L, Dubeski G. School contact tracing following a cluster of tuberculosis cases in two Scarborough schools. *Can J Public Health* 1993;84:297-302.
6. Herrick T, Davison Z. School contact tracing for tuberculosis using two-step Mantoux testing. *Can J Public Health* 1995;86:321-24.
7. Kitzinger J. Introducing focus groups. *Br Med J* 1995;311:299-302.
8. Crabtree B, Miller W. *Doing Qualitative Research*. London: Sage Publications Inc., 1992.
9. Johannson E, Diwan V, Huong N, et al. Staff and patient attitudes to tuberculosis and compliance with treatment: An exploratory study in a district in Vietnam. *Tuber Lung Dis* 1996;77:177-83.
10. Mays N, Pope C. Rigour and qualitative research. *Br Med J* 1995;311:109-12.

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