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Socio-cultural factors influencing prevention and treatment of tuberculosis in immigrant and Aboriginal communities in Canada

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Abstract

This multi-method study used a participatory action research approach to examine the complex net of socio-cultural factors that influenced behaviour related to tuberculosis (TB) prevention and treatment in the 10 highest risk cultural groups consisting of immigrant and Aboriginal populations in the province of Alberta, Canada. Trained community research associates collected qualitative interview data and helped with interpretation and evaluation. A community advisory committee established foundation principles and monitored the ethical and cultural appropriateness of the research process. A key finding is that although patients with active disease learn about TB from health professionals, people in high-risk populations need to learn more about TB transmission and prevention prior to contact. This is particularly important given that lack of knowledge of TB was strongly associated with negative attitudes towards TB and a worse experience of the disease. The study results underline the need for accessible and culturally appropriate health education about TB in the high risk groups. This can be accomplished in collaboration with lay people, particularly those who have recovered from active TB, their family members and health workers from the community.

Keywords: Tuberculosis; Immigrants; Aboriginal; Health education; Participatory action research; Canada

Introduction

This study is an experiment in collaborative research, guided by an action research framework (Lewis–Beck, Bryman, & Liao, 2004; Reason & Bradbury, 2001). Advisers and researchers were drawn from the cultural groups with the highest incidence of tuberculosis (TB) in the province of Alberta, Canada. The goal of the study was to identify better practices for prevention and treatment in these cultural groups. In Canada there is a high prevalence of TB in immigrant and Aboriginal populations (Grzybowski & Allen, 1999). Among cases, the proportion of foreign-born residents of Canada has increased from 35% (1980) to 57% (1994), and that of Aboriginal people from 14% to 19% in the same time period, while in the non-Aboriginal population in Canada, the proportion of cases decreased from 49% to 21% (Rivest, Tannenbaum, & Bédard, 1998). The increasing

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proportion of foreign-born TB cases in Canada is consistent with the shift in immigration patterns over the past 30–40 years. In the 1950s and 60s immigration was mainly from countries whose TB rates were similar to Canada's; now it is from countries in Africa and Asia, where the prevalence rate can be 50% or higher (Schwartzman & Menzies, 2000; Long, Sutherland, Kunimoto, Cowie, & Manfreda, 2002). Many migrants to Canada test positive for TB infection because of exposure to TB even though they have not developed active disease. Tuberculosis is five times more common among Aboriginal people than among most other Canadians, according to Fitzgerald, Wang, and Elwood (2000), while Fanning (1991) suggests the rate of TB in the Aboriginal population may be 10 times the Canadian norm. On the global scene, TB is one of the three infectious disease priorities identified by the G8 in its July 2001 summit agreement to which Canada was a signatory. TB remains a key priority for the World Health Organization.

Following an epidemiological review of patient medical records at the Capital Health TB Clinic in Edmonton (the TB Clinic), the project was expanded to include the collection of qualitative interview data by lay research associates selected from among the most affected ethnic populations. Since the epidemiological review showed that rates of completion of prophylaxis for TB in Canada varied among immigrant and Aboriginal populations, an obvious question was whether there are cultural barriers to TB prevention. Consequently, this study's primary objective was to identify and understand sociocultural factors surrounding the prevention and treatment of TB among the participating communities. Such understanding could then inform program delivery and training programs for health professionals and within those cultural communities. Related objectives discussed elsewhere were: to build research capacity within the participating communities by orienting members of these communities to research methods, providing them with an experiential base and a network of partners to collaborate with on future health research issues (O'Connor & Gibson, 2003); to gain experience as a research team in collaborative health research on sensitive health issues in diverse communities; and to heighten awareness within these communities of the prevalence, prevention and treatment of TB (Hibbard, Gibson, Marquez-Ortiz, Doering, & Cave, 2004). This article addresses the first two objectives primarily. The other objectives were met experientially, and outcomes of this qualitative research exercise have not been measured quantitatively as it is inappropriate.

The study included new Canadians from the following countries: China, Hong Kong, East India, Vietnam, The Philippines, and Eastern Europe as well as four rural Aboriginal communities. Ethics approval was provided by the University of Alberta Faculty of Medicine, and permission was obtained from community leaders.

Theoretical framework

As early assumptions by the research team anticipated considerable differences in health beliefs and practices among the cultural groups being studied, the Health Belief Model (Strecher & Rosenstock, 1997) was originally envisioned as a theoretical framework. People's behaviour regarding TB was not primarily determined by their ethnicity; rather, other factors emerged as more influential than ethnic heritage, such as age and length of time in Canada. Furthermore, there was clearly more intercultural and cross-cultural community diversity than anticipated. The population categories used in the provincial clinical files, from which data were first drawn, such as "India," included people from places as diverse as Afghanistan and Pakistan. Thus, early in the project it became apparent that the Health Belief Model could not be applied for the following reasons:

- the small size of the sample;
- the interpersonal differences within the communities used for this study; and
- the study design, which employed lay colleagues as interviewers.

However, Kleinman's (1981) approach to understanding individual behaviour combines well with Triandis's (1994) approach to understanding sociocultural context, since explanatory models can identify overlapping personal and sociocultural factors that inhibit or enhance health behaviours. These concepts guided the research design. The study was also framed by a participatory action research (PAR) approach (Ortiz, 2003) involving an advisory committee and community research associates. The two-pronged approach of this research—the examination of factors influencing TB and the socio-cultural component—dictated a participatory design whereby learnings could be developed within the affected communities, maximizing opportunities for health promotion as a concurrent benefit of the research. With the PAR approach, experience and feedback influenced the reflexive design of the study throughout (Gibson, Gibson, & Macaulay, 2001).

The experiment fell between traditional public health research paradigms and ethnography. The dual commitments to maximize community involvement and capacity-building introduced a second theoretical consideration in which ethics became paramount, driving revisions in study design as a result of formal and informal evaluations and day-to-day experiences with the community research associates in an iterative process. (Huxham (1996) describes this process as transformational collaboration.) Consequently, the theoretical framework was consistently influenced by the