REVIEW

Adherence to tuberculosis care in Canadian Aboriginal populations
Part 1: definition, measurement, responsibility, barriers

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ABSTRACT

Objectives. In a 2-part series, the current literature with respect to adherence to tuberculosis care among Canadian Aboriginal populations is reviewed. In the current paper, which comprises part 1 of this review, adherence is defined, and methods of measurement, issues of responsibility and potential barriers to adherence are explored.

Study design. Literature review.

Methods. A systematic search and analytic review of relevant studies was undertaken, including an online search of electronic databases (PubMed, PsychINFO, MEDLINE, Native Health Database, Scopus, Social Science Citation Index) and publications by governmental and non-governmental agencies.

Results. Poor adherence to therapy for TB disease is the most common cause of initial treatment failure and of disease relapse worldwide. Adherence to care for TB disease is necessary for the health of both the affected individual and society as a whole. Adherence is a task-specific behaviour that is not inherent to ethnic identity. The term applies only when common agreement over a care plan has been reached between patient and provider. The International Standards for Tuberculosis Care and the Patients Charter outline the responsibilities for adherence on the part of both patients and providers. For Canadian Aboriginals, barriers to adherence may derive from a complex interaction between the health system, personal factors and social factors, which may include dysfunctional acute and public health systems, dissonant (between health care provider and patient) belief systems, concurrent co-morbidities and life stressors, poverty and social stigma.

Conclusions. Adherence is a task-specific behaviour, not a personality trait. It is influenced by the interaction of systemic, personal and societal factors. These factors must be understood within the historical experience of TB and the cultural meaning of health and illness among Indigenous Canadians.

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INTRODUCTION

Indigenous peoples, who number more than 370 million globally, suffer a disproportionate burden of illness due to tuberculosis (TB) (1). In Canada in 2008, the incidence of TB was 28.2 cases per 100,000 in the Aboriginal (defined as First Nations persons of treaty or non-treaty status, Métis and Inuit) population, compared to 0.8 cases per 100,000 in the Canadian-born non-Aboriginal population (2). Programs in selected regions of the country are failing to contain and/or diminish TB infection and disease in the Indigenous population.

Adherence to the diagnosis and treatment (or “care”) of TB infection and disease is only one requirement for an efficient program. However, poor adherence to TB therapy is the most common cause of initial treatment failure and disease relapse, which in turn contribute to patient morbidity, mortality, the transmission of the disease to others and the development of drug resistance (3).

There are few published studies that have specifically focused on TB adherence in Canadian Aboriginal patients. There are no published studies that compare rates of adherence to TB care among ethnic or racial groups in Canada. Adherence or non-adherence to TB treatment and care are not behaviours inherent to a person’s ethnicity or race (4). Adherence is a general concern for TB programs in all populations, both in Canada and worldwide. In order to understand the barriers to adherence and potential interventions that would improve adherence, we must appreciate the health service, personal and social determinants of adherence behaviour (5). These determinants share common characteristics across national, ethnic and cultural boundaries, yet also display unique characteristics within the Aboriginal Canadian context.

In a 2-part review, adherence to the care of TB infection and disease in Canadian Aboriginal populations is examined. Adherence issues are similar for both conditions, although treatment of TB disease is of greater importance within control programs than treatment of TB infection. In this current paper (part 1), adherence is defined, issues of measurement and responsibility are explored and barriers to care are described. In part 2 of this series, strategies to improve adherence to TB care are reviewed.

It must be recognized that Aboriginal communities and people are not all the same. Heterogeneous values, beliefs, behaviours, health systems and social structures exist within and between Canadian Indigenous (and non-Indigenous) populations. However, through an exploration of the medical and social literature on adherence to TB care specifically (and to medical care more generally) within both Indigenous and non-Indigenous populations, we are challenged to re-evaluate our approach to this complex issue.

How do we define TB adherence and why is it important?

The word “adherence” has replaced “compliance” in much of the medical literature due to concerns about the connotation of submissive obedience which is sometimes ascribed to the latter term (6). Patient adherence has been defined by the World Health Organization (WHO) as the extent to which a person’s behaviour (e.g., taking medication, attending follow-up appointments) corresponds with recommendations from a health care provider which have been agreed upon by that individual (7). An important component of therapy for TB infection or disease, which requires a long duration, is that a “tailored consensual regimen” (8) is established at the beginning. If agreement is not established at the outset,
another term should likely be used, such as “non-concordance” (6). Establishing informed agreement between the patient and health care workers (HCWs) regarding the goals and methods of the care plan is a necessity, and requires time, skilful communication, cultural safety and documentation. The attributes of successful health communication processes are described in a rich and widely available body of literature, of which only a few references are indicated here (9–14).

Anderson and Funnell (15) have suggested that for a chronic disease such as diabetes, the concepts of compliance or adherence are dysfunctional and should be dropped in favour of an approach of empowerment and collaboration that supports patient self-management. They note that “It’s not that people are unwilling to change, it’s that people are unwilling to be changed. Patients often resist efforts to get them to change as a way of preserving and expressing their own autonomy…Eliminating the concepts of adherence and compliance makes it possible for our patients to discover and actualize their personal responsibility for their diabetes self-management” (15). However, the issue of adherence to TB care is different from that of other chronic diseases, as the goal of care is not only to cure the individual patient, but also to prevent the transmission of infection (and subsequent development of disease) to other individuals. Therefore adherence to TB treatment and care is a necessity for the health of both the individual patient and his or her community or society.

TB control is not the same as control for most other infections. Although the health care system plays a role in protecting members of society from many communicable diseases, the transmission characteristics of Mycobacterium tuberculosis pose particular challenges and call for heightened responsibility and accountability from health providers and patients alike. In the case of some infectious agents, such as those that are transmitted sexually, or through fecal-oral or food-borne routes, individuals within a society may take several measures to reduce their risk of exposure. However, individual options for protection against infection due to Mycobacterium tuberculosis are limited; installation of ultraviolet lights in a high-risk environment may be one of the few preventive options available to individuals.

For TB programs, adherence applies to a patient’s behavioural conformity with an agreed-upon care plan. This plan includes diagnostic and therapeutic monitoring, disclosure of contacts, infection control, measures which may include home or facility isolation, medications (varied in type, dose, duration, method of delivery) and contact with the health system (e.g., clinic visits) (16). With regard to medication, adherence has been defined in some jurisdictions as taking every dose of medication as prescribed for the entire duration of an appropriate treatment regimen (17). There have been attempts to determine “clinically relevant” definitions of medication adherence for TB, reflecting the minimum number and appropriate timing of doses necessary to reliably cure TB (6,18,19). However, no consensus has been established regarding a standardized definition of clinically relevant non-adherence (19). It should be noted that definitions of non-adherence that are used for research studies are designed for a different purpose (evaluation) than those designed for programmatic intervention (tertiary prevention).

Adherence to the taking of TB medication may be considered a continuous “variable” which in turn is continuously monitored by a control program in “real time.” Ideally, interventions would occur with even a single missed dose. However, programs may pragmatically decide on a particular number of missed doses that
will “trigger” intervention at all levels to enhance or enforce adherence. Examples of criteria that trigger “problem solving initiatives” on the part of various TB programs may be found in Table I (19–22). The Canadian Tuberculosis Standards do not define prospective adherence criteria to be used by programs, but they do set performance targets that apply to the taking of medication for TB disease and latent tuberculosis infection (LTBI) for individual patients and programs (Table II) (5).

Programs that use twice-weekly directly observed therapy (DOT) have looked to the pharmacokinetics of TB medications for answers regarding “biologically relevant” adherence criteria. In early studies, rapid INH inactivation (acetylation) was seen in 95–100% of Inuit individuals tested, 63% of First Nations persons, and 30% of the general Canadian population (23). Clinical studies have confirmed that when the interval between INH doses is extended to 1 week or greater, intermittent TB therapy is not effective, due to rapid INH inactivation in some patients and due to the limitations in the INH dosage that can be used without incurring additional toxicity (24). Although we know that once-weekly INH therapy would be insufficiently curative over the duration of therapy, it is unclear how many individual doses may be missed within a twice-weekly DOT regimen (essentially creating a once-weekly program) before cure is compromised.

### Table I. Criteria that trigger closer supervision of patients with active TB disease (19-22).

**For self-administered therapy**

1. Guidelines for Tuberculosis Control in New Zealand, 2003
   a. One missed clinic visit, and/or
   b. One pre-arranged Public Health Nurse visit, and/or
   c. Health Care Worker concerned about adherence, and/or
   d. More than 15% of daily medication missed at any pill count.

2. Tuberculosis Control Program for the Cree Region 2003, James Bay Cree Territory, Quebec
   a. Surplus of pills detected on inspection of pill container at clinic visit, and/or
   b. Missed clinic visit, and/or
   c. Negative urine INH test, and/or
   d. Taking <80% of medication prescribed, as determined at any interval.

**For enhanced DOTS**

1. Denver Metropolitan TB Program, USA, 1984–1994
   a. >2 consecutive weeks of DOT therapy missed, and/or
   b. Prolongation of therapy >30 days due to sporadic missed doses.

2. Alberta Tuberculosis Control Program, 2008
   a. >2 missed consecutive doses of medication.

### Table II. Canadian tuberculosis standard recommendations regarding performance targets that apply to the taking of medication for TB disease and LTBI, for patients and programs (3).

**Within treatment programs for TB disease**

1. A minimum of 80% of prescribed doses taken by the patient.
2. Less than 5% of patients discontinue or modify therapy because of adverse effects.
3. Programs achieve 90% cure or treatment completion within 12 months of starting treatment for patients who did not die or transfer to other jurisdictional programs during treatment.

**Within treatment programs for LTBI**

1. A minimum of 80% acceptance of treatment among persons with LTBI at high risk for progressing to TB disease and without contraindication to therapy.
2. A minimum of 80% of patients complete the required number of doses.
3. Less than 5% of patients discontinue therapy due to adverse effects.
How do we measure adherence?

Adherence to follow-up may be measured by counting the number of scheduled (and unscheduled) health care encounters that occur. Adherence to TB medication may be measured in the following ways (25):

- counting the doses given through directly observed therapy (DOT) or directly observed preventive therapy (DOPT)
- patient self-report
- scheduled and/or unscheduled pill counts
- records of medication refills
- use of medication bottles that record electronically when the container is opened
- patient use of devices (telephone, text messaging, computer) to communicate with HCW when pills are taken
- urine assay for the presence of INH
- visualization of urine for the red-orange colouration associated with the use of Rifampin

The ability of HCWs to predict adherence or non-adherence to TB therapy is poor (7,21,25,26). One of the few consistently identified predictive markers for non-adherence is a previous history of TB (21,27).

The use of directly observed programs provides the most reliable and accurate information about adherence, provided that the treatment is indeed observed (28). Patient self-report of adherence is not consistently reliable (25). Urine testing is dependent on the patient's drug metabolism and may give a positive result even if the medication is taken irregularly (25). Microelectronic devices within pill containers are expensive, are subject to manipulation by the patient, are difficult to use for some patients and do not actually record medication ingestion (25,29).

For programs that do not use direct observation of therapy, multiple measures of adherence should be used as each one alone is problematic. Adherence behaviour may also vary within a therapeutic plan; for instance, patients may adhere to taking their medication, but not to being monitored in a clinic (25).

Who is responsible for adherence?

The medical literature describes a spectrum of opinion regarding who or what “owns” the ultimate responsibility for adherence to TB care – the health system, which should respond and cater to patient needs, or the TB patient himself/herself, in accordance with public health demands (28). Canadian practice has been to steer a middle path that requires a patient-centred approach while recognizing individual responsibility within society. The International Standards for Tuberculosis Care (ISTC) (30) and the companion document “Patients’ Charter” (31) have been endorsed by WHO, the Stop TB Partnership and the International Union against Tuberculosis and Lung Disease (IUATLD). Passages relevant to adherence are shown in Tables III and IV. The documents are designed to promote adherence through the establishment of a collaborative partnership between patient and caregiver.

In Canada, the health system that is responsible for TB adherence includes both clinical and public health workers. Health care workers (HCWs) who do not have the capability or means to assess adherence must examine their involvement in care for patients with TB infection or disease using the professional standards set by the ISTC. Success in meeting the ISTC requires knowledge, skill and wisdom in both clinical and public health care, close collaboration and communication and primary allegiance.
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Table III. Extracts from the International Standards for TB Care which are relevant to the promotion of adherence to treatment within TB control (30).

**Standard 7.** Any practitioner treating a patient for tuberculosis is assuming an important public health responsibility. To fulfil this responsibility the practitioner must not only prescribe an appropriate regimen, but also be capable of assessing the adherence of the patient to the regimen and addressing poor adherence when it occurs. By so doing the provider will be able to ensure adherence to the regimen until treatment is completed.

**Standard 9.** To foster and assess adherence, a patient-centred approach to administration of drug treatment, based on the patient’s needs and mutual respect between the patient and the provider should be developed for all patients. Supervision and support should be gender-sensitive and age-specific and should draw on the full range of recommended interventions and available support services, including patient counselling and education. A central element of the patient-centred strategy is the use of measures to assess and promote adherence to the treatment regimen and to address poor adherence when it occurs. These measures should be tailored to the individual patient’s circumstances and be mutually acceptable to the patient and the provider. Such measures may include direct observation of medication ingestion (directly observed therapy) by a treatment supporter who is acceptable and accountable to the patient and to the health system.

**Standard 17.** All providers must report both new and retreatment cases and their treatment outcomes to local public-health authorities, in conformance with applicable legal requirements and policies.

Table IV. Extracts from the Patients’ Charter for TB Care which are relevant to the promotion of adherence to treatment within TB control (31).

**Patients’ rights**

1. Care
   - The right to free and equitable access to TB care, from diagnosis to completion of treatment regardless of resources, race, gender, age, language, legal status, religious beliefs, sexual orientation, culture or health status.
   - The right to receive medical advice and treatment fully meets the new International Standards for TB Care, centring on patients’ needs.

2. Dignity
   - The right to be treated with respect and dignity, including the delivery of services, without stigma, prejudice or discrimination by health-care providers and authorities.

3. Information
   - The right to information about the availability of health-care services for TB, and the responsibilities, engagements and direct or indirect costs involved.
   - The right to receive a timely, concise and clear description of the medical condition, with diagnosis, prognosis and treatment proposed, with communication of common risks and appropriate alternatives.
   - The right to know the names and dosages of any medications or interventions to be prescribed, its normal actions and potential side effects and its possible impact on other conditions or treatments.

4. Security
   - The right to nutritional security or food supplements if needed to meet treatment.

**Patients’ responsibilities**

1. Share information
   - The responsibility to provide as much information as possible to health-care providers about present health, past illnesses, any allergies and any other relevant details.
   - The responsibility to provide information to health-care providers about contacts with immediate family, friends and others who may be vulnerable to TB or who may have been infected.

2. Follow treatment
   - The responsibility to follow the prescribed and agreed treatment regimen and to conscientiously comply with the instructions given to protect the patient’s health and that of others.
   - The responsibility to inform health-care providers of any difficulties or problems in following if any part of the treatment is not clearly understood.
to the common goal of the health of the patient and community, as opposed to ends related to power, control or personality.

In the 3 Canadian territories (Northwest Territories, Nunavut and Yukon), TB control for Aboriginal populations is delivered through the respective territorial departments of health. In the provinces, however, TB care for Aboriginal persons is delivered through a variety of mechanisms, personnel and levels of government (32). The multiplicity and variability of health systems for Aboriginal TB care between and within provinces pose challenges to meeting the standards of the ISTC and the Patients’ Charter (32–34).

**What are the barriers to adherence?**

Factors that create barriers to adherence to the initiation and completion of therapy for LTBI and for TB disease are similar. They may be characterized as relating to the broad categories of health systems, personal factors and the social and family context (4).

Although there are few studies that have specifically examined adherence in the Canadian Aboriginal context, lessons may be learned from a critical appraisal of studies of Indigenous and non-Indigenous populations throughout the world. In the search for factors that will predict adherence or non-adherence, studies have at times shown contradictory results even within the same general populations, suggesting that “adherence behaviour is influenced by complex interactions among predictive factors, rather than resulting directly from the factors themselves” (35).

It is difficult to separate personal from social factors, given the view in Aboriginal and many other cultures that health and illness reflect the state of harmony or balance between the physical, spiritual and social aspects of self (36–40). While we can acknowledge prevalent cultural values, it is important to note that a heterogeneity of beliefs with respect to health exists within and between cultural, ethnic and racial groups. It is imperative for HCWs to understand the individual patient’s experiences, beliefs, values and attitudes at a personal level as well as within a wider social context.

**Health system factors**

Health systems that do not function in a manner designed to meet patient needs create barriers to adherence to TB care. Examples (4,25,28,33) of system barriers include the following:

- HCWs or systems which fail to adhere to recommended guidelines or standards cannot expect adherent behaviour from their patients. Control programs must embrace and consistently apply guidelines and standards, and must evaluate their work in a transparent manner, in order to engender the trust and credibility that is required to sustain adherence among individual patients, communities and populations.
- Long wait times for care.
- Health care facilities or mechanisms that actively or passively promote feelings of physical insecurity or rejection (e.g., unclean clinics).
- Lack of trust, respect and/or dignity in relationships between patients and HCWs, as well as between HCWs.
- Failure on the part of HCWs and the health system to provide continuity of care and consistent care.
- Care that is apparently available but in reality is not accessible due to an operational culture that does not accord with patient needs (e.g., hours of operation, lack of home care, inaccessibility to the disabled, transportation barriers, etc.).
• Care, particularly within in-patient settings, that engenders or fails to address feelings of isolation, stigmatization and fear (with ensuing depression, anger or anxiety).

• Staff that are insufficiently knowledgeable or skilled in the diagnosis, investigation and management of TB, particularly the potential side effects and toxicity of therapy. Such defects in quality of care fuel patient concerns about TB (e.g., medication side effects, fear of venipuncture, etc.). These factors have been commonly and consistently found to be negatively associated with TB adherence in many studies.

• TB programs that “lose” migratory patients due to “watershed” areas of jurisdiction and/or poor patient follow-up and tracking systems.

• Care that focuses on TB but obstructs, or fails to acknowledge and assist, the patient with regards to other perceived health or social priority needs or adherence barriers (e.g., co-morbidities including addiction, employment, securing concerns, homelessness, etc.). In particular, TB programs that “compete” with addictions will most likely fail.

Personal factors
Adherence to therapy for LTBI or TB disease has not been consistently shown to be related to patients’ age, sex or race. Adherence is a task-specific behaviour, not a personality trait (7). A variety of studies of adherence to care for tuberculosis and other conditions have implicated the following factors, which may be described as personal or relating primarily to the individual, in the formation and maintenance of barriers to adherence:

• Knowledge, attitudes and beliefs

Lack of knowledge about the causation and characteristics of TB infection, disease and therapy, particularly with regard to potential side effects of medication, duration of therapy and achievement of cure, have been associated with non-adherence. Recent studies in both rural and urban Canadian Aboriginal populations have revealed widespread misunderstanding of the causes, symptoms and risks associated with TB infection and disease (41–44). Although non-Indigenous populations are also poorly informed about TB (45), a knowledge deficit in the Aboriginal population is particularly troublesome given the high rates of infection and disease in this group. Studies show that health workers consistently underestimate the desire of patients for health information (7,46). Improved knowledge about TB has been associated with adherence to treatment of LTBI and TB disease (47–50).

It is necessary to understand the perceptions and beliefs of individual patients and their communities regarding specific illnesses, as this type of misunderstanding between health care workers and patients often results in non-adherence (51–53). Negative beliefs, attitudes and interpretations regarding tuberculosis are generated through internal and external (social) mechanisms and may lead to fear, hopelessness, anger and a sense of loss that is directed inwards (depression) or outwards (anger and aggression). All are associated with non-adherence to TB therapy. If illness is seen as a result of an imbalance between the physical, spiritual and social aspects of self, then the patient...
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and/or his/her community may regard tuberculosis (or other illnesses) as a moral failure, resulting in self- and community-driven stigmatization (11,36,39,54,55). The association of breath with spirit in many cultures may also imply, to the patient and/or others, a defect for which the patient may feel, or be held, responsible (11,54).

Greater effort is required in order to understand how Aboriginal patients and communities view the causation and meaning of TB infection and disease. McConnel notes that compliance measures the gap between the beliefs of patients and those of Western medicine:

“Strong compliance with Western medical advice occurs when there is strong cultural affinity between patient, or population, and the culture of Western medicine. From a Western perspective, strong compliance as healthy behaviour occurs when the scientific concepts of cause and effect, and statistical relationships including predictability, and shared. Poor compliance occurs when a culture (or subculture such as drug addicts) is dissonant with the treating Western medical culture. Unhealthy behaviours persist to a greater degree in sections of the community that do not share, or place low priority on, concepts of cause and effect, and statistical predictability” (13).

If adherence requires belief in the scientific culture and language that is prevalent in Western medicine, success as measured within this framework may be limited. However, McConnel suggests that it may be possible to promote adherence to a “shared understanding…which accommodates both cultures’ belief systems – a synthesis of knowledge systems derived from dissonant world views” (13). We need to develop such a shared understanding of the cause, treatment and meaning of TB if we are to make any sense of the word "adherence" in Aboriginal communities (56).

• Co-morbidities and life stressors

Co-morbidities, including alcohol/substance abuse, HIV, psychiatric illness and chronic diseases such as diabetes and renal failure, may impede the individual's ability to adhere to TB therapy in a variety of ways, including (but not limited to): increased risk and severity of medication side effects; severity of symptoms and/or complications of TB disease; pill burden; economic burden; competing “internal” (personal) and “external” (societal) priorities and demands; and interference with psychological and emotional survival and resiliency mechanisms.

Life stressors such as lack of resources (financial, shelter, time, available transportation), unemployment, instability in relationships, insecurity and fear are associated with decreased adherence to medical therapy (51). Such stressors compromise healthy coping mechanisms (e.g., adherence to medication) and promote unhealthy strategies that may be helpful in other ways, such as denial of illness, which may defuse anxiety, free up time and allow patients to focus on other concerns, such as their families (51).
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Studies of medication adherence point to the important role played by the patient’s sense of control over his or her illness, and over the treatment process. Patients who do not feel in control of their treatment, or who feel “left out” of their treatment, are more likely to be non-adherent (51,57). Studies suggest that some patients are non-adherent as a way to regain control within systems that are perceived as unresponsive to their concerns (51). Conversely, studies in which patients are taught how to gain a sense of control within the health care system have resulted in improved health outcomes (51,57).

The Health Belief Model developed by Rosenstock (58) and modified by Becker (59) uses the following components to predict adherence:
- the patient’s belief in his/her own susceptibility to illness
- belief regarding the severity of the illness and its consequences
- belief in the efficacy of therapy
- perception of the barriers to treatment
- presence of reminders that act as cues or stimuli

This model has been more helpful in retrospective as opposed to prospective prediction of adherence (51).

Recent literature on adherence to therapy for TB and other illnesses focuses on the concept of self-efficacy, which may be defined as the personal belief that one is primarily in control of one’s own health (60). If we apply behaviour theory that was originally developed in relation to alcohol addiction and recovery (61), patients may adhere to TB therapy to the extent that they
- believe that TB is hurting them
- wish to overcome it
- feel sufficient efficacy to adhere

Self-efficacy is related to a “sense of coherence” (SOC). Recent studies of adherence to therapy for other conditions including hypertension, diabetes and HIV suggest that a high SOC on the part of patients is associated with adherence, independent of other sociodemographic and behavioural factors (62). Individuals with a high SOC believe that what happens in life is understandable (comprehensibility); that resources are available to help when problems occur (manageability); and that difficulties encountered in life are challenges that are worthy of engagement (meaningfulness). A high SOC prompts patients to understand their illness and have the capacity and motivation to adhere to therapy; illness is seen as a challenge that can be met rather than an unbeatable threat.

Social factors
- Poverty

Poverty creates barriers to adherence to TB therapy. Poverty is characterized by disadvantage both in a material sense (money, shelter, food, physical security, material goods, etc.) as well as in less tangible but critical spheres of power, voice and esteem (3,28). A few of the many barriers to adherence that are created by poverty are as follows:
- inability to adhere to therapy if this entails temporary or permanent loss of employment (or other activity-generated) income, or income equivalent such as firewood, food, etc. A study in northern Quebec showed an association between non-adherence and time spent in traditional activities on the land (63).
- inability to pay for modalities that are
required for adherence (e.g., transportation, childcare, food, other medication to manage side effects, etc.). For Aboriginal people in Canada, there is insufficient recognition by health care providers that travel to community and regional clinics and hospitals brings patients monetary and non-monetary “costs” that are not covered by treaty health care provisions. Similarly, adequate nutrition for patients with TB may often be impossible for Aboriginal patients on current rates of social assistance (64).

• Social stigma

There is a prevalent negative stigma attached to TB in Canadian Aboriginal communities that has been amply documented as a barrier to adherence (43,44). The stigma acts at a personal level, as discussed previously, but also within families and communities, resulting in isolation and alienation of patients who are then more likely to be non-adherent.

The stigma associated with TB exists in many ethnic and cultural subpopulations in Canada, but it is useful to understand the historical context which may contribute to its existence in Aboriginal communities.

Mycobacterial disease due to either *Mycobacterium tuberculosis* or *Mycobacterium bovis* – or both – existed in North and South American populations prior to European contact (65). However, the epidemics that occurred post contact were fuelled by the interaction of risk factors that included relative genetic susceptibility; facilitated transmission in crowded circumstances within newly created reserve and non-reserve communities and institutions (residential schools, hospitals, sanatoria, etc.); malnutrition; and concomitant infections/diseases (29,66–70). Healthy children were taken away to residential schools only to be returned to their parents when they became ill, or in some instances they died of TB while attending school. Adults and children were taken, forcibly or otherwise, to sanatoria. For the families of those who died, notifications and burial records were often incomplete or non-existent. For those who were cured, re-integration into their communities was frequently difficult. Lives were saved through the implementation of medical interventions available in the early and mid-twentieth century, but the collective memory of loss and suffering has lead to fear of the disease in many Canadian Aboriginal communities.

• Self and community efficacy

The view that tuberculosis was not present prior to European contact is common, as is the view that Aboriginal people generally lived long, healthy lives prior to contact (39,55). The devastating morbidity and mortality experienced by generations of Aboriginal people due to this disease, which has been so closely linked to the colonizing experience, has given birth to a sense of vulnerability which in turn has influenced public health discourse (39). Aboriginal health programs and systems are sometimes caught up in a discourse of “blame and corrective demand” that undermines the motivation and self-empowerment of individuals and communities to achieve and maintain health (39). Approaches to the diagnosis and care of tuberculosis that carry messages of victimization or helplessness to patients, families and communities result in ambivalent states of dependency on, and anger with, ostensible

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“helpers.” Tuberculosis programs must build on the existing resilience and strengths of individuals, families and communities in order to promote self-efficacy – the confident belief in one’s own ability to make choices that will result in cure and good health. In collectivist cultures, a sense of shared efficacy, or communal mastery, is also important. A recent prospective study among Native American women suggests that a sense of shared or communal efficacy (i.e., “I am successful by virtue of my social attachments”) was more closely associated with resiliency in the face of stress than a sense of self-efficacy (i.e., “I am the key to my success”) (71).

The experience of colonization, institutionalization, alienation and marginalization has promoted the dissolution of traditional internal social control and norms of behaviour in some Aboriginal communities (39). This condition has been called “anomie.” Lack of employment and the failure of the traditional life of hunting and gathering to provide security in modern circumstances have led to an erosion of self-reliance. New local norms have emerged in some communities around dependency, marginalization and alienation. In such an environment, there are few internal or external obligations set by individuals or communities and little motivation to meet any that exist. Yet obligations and rights are essential to the structure and cohesion of communities (39).

Studies have shown that self-perceived health and adherence to therapy for a variety of conditions are both greater when patients perceive that they have sufficient levels of practical and emotional support from family and friends (51,72–74). In the context of Aboriginal communities, this may be achieved while respecting an individual’s right to autonomy in decision making. The principle of non-interference in the affairs of others was an important component of some pre-contact Aboriginal cultures (39,75) and likely provided an important social and survival benefit in the context of a hunter-gatherer society. Today the principle reinforces the need for individuals to take responsibility for their decisions, behaviours and attitudes. For family, friends and community members, it is possible to respect the autonomy of an individual who is non-adherent to medication while providing an environment of physical, emotional, psychological and spiritual support that nourishes change.

DISCUSSION

In the context of TB care among Canadian Aboriginal people, key messages regarding the definition of adherence and potential barriers to care include the following:

- Poverty
- Adherence or non-adherence is a task-specific behaviour, and is not inherent to any particular ethnic or racial group.
- The word “adherence” may only be applied when agreement to a care plan is initially established between patient and provider(s).
- Poor adherence to TB therapy is the most common cause of initial treatment failure and of disease relapse, which in turn contribute to patient morbidity, mortality, the transmission of the disease to others and the development of drug resistance. Adherence to care for TB disease is a necessity for the care of both the individual and society.
• Canadian practice endorses a patient-centred approach while recognizing individual responsibility within society, as outlined in both the International Standards for Tuberculosis Care (ISTC) and the Patients’ Charter.
• Adherence behaviour is influenced by complex interactions between health system, personal factors and societal factors, rather than directly from individual factors acting independently.

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