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Reducing Health Disparities in Canada

REVUE CANADIENNE DE

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PREFACE

Reducing Health Disparities

A Priority for Canada

Morton Beiser, MD, FRCP, CM[1]
Miriam Stewart, PhD[2]

Despite Canada's generally high standard of living and despite a system that promises universal access to high quality care, disparities in health remain a pressing national concern. These disparities are not randomly distributed. Specific subpopulations suffer a burden of illness and distress greater than other residents of Canada. For this reason, they can be characterized as "vulnerable populations". Aboriginal peoples, immigrants, refugees, the disabled, the poor, the homeless, people with stigmatizing conditions, the elderly, children and youth in disadvantaged circumstances, people with poor literacy skills, and women in precarious circumstances are vulnerable populations – more likely than others to become ill and less likely to receive appropriate care.

Despite our commitment to equity and access – in health and opportunity – 18% of Canadians live in deep poverty, and income inequality is increasing. The wealthy live longer than the poor, and experience fewer chronic illnesses, less obesity, and lower levels of mental distress. According to the 2001 census, at least 14,000 people in Canada are homeless. Homeless people are at risk for premature death, infectious diseases, mental illness and substance abuse. The middle-aged homeless – people in their 40s and 50s – often have health disabilities more commonly seen in individuals who are decades older.

Canada's Aboriginal population is just under 1 million, and its rate of growth is double that of the population as a whole. Although there has been progress – neonatal death rates in Aboriginal communities have dropped in recent years to a point where they now approximate the national average – equity in health for this population is still a distant goal. An Aboriginal baby, for example is almost three times more likely than a non-Aboriginal baby to die during the first year of life, and the rate of chronic illness among adult Aboriginal people is three times higher than the national average.

Canada's newest settlers, like indigenous peoples, are subject to inequities in health and health care. The 250,000 immigrants admitted each year are, on the whole, healthier than native-born Canadians. However, during their first decade in Canada, immigrants are far more likely than the native-born to develop tuberculosis. Over their total life span, some immigrant groups experience a particularly high risk for cardiovascular disorders, obesity, and cancer of the colon. Moreover, crisis and conflict create mental suffering for refugees, who constitute about 10% of the immigrant population.

People with physical and mental disabilities constitute another subpopulation vulnerable to assaults on health. They suffer a double disadvantage, having to cope not only with the disability itself, but with the added burdens of compromised health and inaccessible, inadequate health-related services. Stigma and public censure create additional distress and erect barriers to care for persons suffering from chronic mental disorders, such as schizophrenia, and from various forms of addiction.

Almost half of all Canadian adults lack the literacy skills necessary to participate fully in our knowledge-based economy. They face high levels of unemployment and are often forced to live in unstable environments. Families face direct health risks as a result of lack of literacy, having difficulty, for example, in reading instructions for baby formulae, medications, or educational materials about health and safety.

Women experience unique health risks because health research and the health system have not addressed the factors that influence their health status and health behaviours. To illustrate, the rate of smoking among certain groups of women is increasing at an alarming rate, as are its consequences, such as cancer, respiratory and cardiovascular disorders. Single parents (primarily women), unpaid caregivers, homosexuals, bisexuals, and transgendered people are also at risk for compromised health arising from gender influences and sex differences.

Under the joint leadership of the Institutes of Gender and Health and Population and Public Health, the Canadian Institutes of Health Research launched a cross-cutting initiative. This major initiative mobilized research focussed on understanding and reducing disparities and promoting the health of vulnerable populations. In the three years since the CIHR Reducing Health Disparities Initiative was created, partnerships have developed with Health Canada, the Social Sciences and Humanities Research Council, the Heart and Stroke Foundation, the National Secretariat on Homelessness, the Canadian Population Health Initiative, Citizenship and Immigration Canada and international agencies (e.g., NIH Fogarty International Centre and INS in Mexico). This Initiative has built research capacity through interdisciplinary teams; generated alliances between academic researchers, policymakers, practitioners and the public; and translated research knowledge into information that will inform programs, policies and practices in health and health-related sectors. As a result of two Requests for Applications (RFAs) in 2002 and 2003, 24 impressive teams have been funded. Each interdisciplinary team is focussing on one or more vulnerable populations. These teams include researchers from diverse disciplines and universities, community groups, service agencies, schools, hospitals, Native band councils, advocacy and self-help groups, and/or regional and international NGOs. Many teams have built on initial funding to apply for and receive further financial support for other relevant research. Others have engaged policymakers and practitioners in a process of knowledge transfer, and several teams have created their own Web sites. A new RFA

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1. Professor of Psychiatry, University of Toronto; Founding Director and Senior Scientist, Joint Centre of Excellence for Research on Immigration and Settlement (CERIS); National Scientific Coordinator, Reducing Health Disparities Initiative, Canadian Institutes of Health Research (CIHR).
2. Professor, University of Alberta, Faculties of Nursing and Medicine; AHFMR Health Senior Scholar; Scientific Director, CIHR - Institute of Gender and Health; CIHR Leader/Champion, Reducing Health Disparities Initiative

offering support for multi-year interdisciplinary teams was launched in December 2004.

An International Think Tank on Reducing Health Disparities, hosted by this Initiative on September 21-23, 2003, attracted 103 researchers from across Canada, the US, Mexico, Australia and New Zealand, as well as Canadian policy-makers and representatives from all partner agencies. The final report of this International Think Tank, which created international research priorities, can be accessed online at www.igh.ualberta.ca/rhd/finalreport.htm. In March 2004, many funded researchers participated in a Policy Forum on Health Disparities co-hosted by the Initiative partners and the Federal-Provincial-Territorial Task Group on Health Disparities. Over 50 policy influencers at federal, provincial and territorial levels examined the policy implications of health disparities research at this successful symposium.

The six articles that comprise this special *CJPH* supplement are based on synthesis papers originally commissioned for the 2003 International Think Tank. Together, they constitute thought-provoking overviews of research in health disparities and help to chart a future course. Although each author identifies topics and activities specific to his or her respective field, there are multiple points of convergence. First and foremost, Canada must support and expand its efforts to create a knowledge base that informs relevant policies and practices. Research is required to document inequities, to elucidate the mechanisms that produce health inequities, to design and test interventions that reduce inequities, and to evaluate programs already in effect.

Most research to date has been conducted within a social science framework. However, inequities are not the result of unfair social structures or misguided policy alone; genetics, human physiology and human development also play important roles in the creation of inequity. Research must, therefore, be multidisciplinary, and must involve international collaboration. For example, homelessness is universally associated with high rates of death. However, death rates among homeless men in Toronto are about one half that of homeless men in US cities. Comparative research can illuminate whether this is attributable to differential rates of homicide and HIV infection, Canada's system of universal health insurance, or some other combination of factors.

A recent *Lancet* article reviewed attempts by various European countries in the period between 1990 and 2001 to reduce socio-economic inequalities in health. The article concluded that countries vary widely with respect to their awareness of the problem, and their willingness to take action to address it. The authors also commented that policy-making in this area "is still largely intuitive and would benefit from incorporation of…rigorous evidence-based approaches."[1](p.1409).

Canada's commitments to social justice, universal health care and equity are sources of national pride. These principles challenge us to take our place among those countries willing to contribute knowledge about, confront and redress inequalities in health that are avoidable, unnecessary and unfair. Living up to our national ideals requires that we address this challenge collectively.

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PRÉFACE

Réduire les disparités sur le plan de la santé

Une priorité pour le Canada

Morton Beiser, M.D., FRCP, CM
Miriam Stewart, Ph.D.

En dépit d'un niveau de vie généralement élevé au Canada et d'un système qui se targue d'offrir un accès universel à des soins de haute qualité, les disparités en matière de santé demeurent un sujet pressant de préoccupation sur le plan national. Ces disparités ne se répartissent pas selon l'effet du hasard. Certaines sous-populations sont aux prises avec davantage de problèmes de maladie et une plus grande détresse que d'autres résidents au Canada et c'est la raison pour laquelle on les qualifie de « populations vulnérables ». Les Autochtones, les immigrants, les réfugiés, les personnes handicapées, les pauvres, les sans-abri, ceux qui sont stigmatisés, les personnes âgées, les enfants et les jeunes placés dans des situations désavantageuses, les gens faiblement alphabétisés et les femmes en situation précaire, constituent des populations vulnérables qui risquent plus souvent que d'autres de tomber malades et sont moins susceptibles de recevoir les soins appropriés.

En dépit de notre volonté d'assurer l'équité et l'accessibilité pour tous en matière de santé et de possibilités, 18 % des Canadiens et des Canadiennes vivent dans une grande pauvreté et les disparités du revenu ne cessent d'augmenter. Les personnes aisées vivent plus longtemps que les pauvres, sont moins souvent atteintes de maladies chroniques, moins sujettes à l'obésité, et leur niveau de détresse mentale est moins élevé. Selon les données du recensement de 2001, au moins 14 000 individus sont sans-abri. Ces gens sont à risque de décéder prématurément, de contracter des maladies infectieuses, des maladies mentales ou de tomber dans la dépendance de la drogue. Les sans-abri d'âge moyen, autrement dit ceux qui ont entre 40 et 50 ans, présentent souvent des problèmes médicaux que l'on retrouve généralement chez les gens ayant quelques décennies de plus.

La population autochtone du Canada compte un peu moins d'un million d'individus et son taux de croissance est le double de celui de l'ensemble de la population. Bien que l'on puisse noter des progrès et que le taux de décès néonatal dans les communautés autochtones ait diminué ces dernières années jusqu'à frôler maintenant la moyenne nationale, on est encore loin de l'objectif d'équité en matière de santé dans cette population. Par exemple, un bébé autochtone court presque trois fois plus de chances qu'un bébé non autochtone de mourir au cours de sa première année, tandis que le taux de maladies chroniques chez les adultes est trois fois plus élevé que la moyenne nationale.

Comme les peuples autochtones, les nouveaux arrivants au Canada sont en butte à des iniquités en matière de santé et de soins médicaux. Les 250 000 immigrants qui arrivent chaque année sont, dans l'ensemble, en meilleure santé que les Canadiens nés au pays. Cependant, au cours de leur première décennie de résidence, ils sont beaucoup plus susceptibles que les Canadiens de naissance de contracter la tuberculose. Au cours de leur vie, certains groupes d'immigrants présentent un niveau particulièrement élevé de risque d'accidents cardiovasculaires, d'obésité et de cancer du colon. De plus, les crises et les conflits imposent des souffrances mentales aux réfugiés, qui constituent près de 10 % de la population immigrante.

Les gens atteints de déficience physique ou mentale constituent une autre sous-population vulnérable aux problèmes de santé. Ils subissent un double désavantage du fait qu'ils doivent non seulement vivre avec leur incapacité, mais, d'autre part, composer avec le fardeau supplémentaire d'une santé compromise et de services de santé inaccessibles ou inadéquats. La stigmatisation et la censure imposée par le public occasionnent une détresse supplémentaire et créent des obstacles qui empêchent de soigner les personnes atteintes de troubles mentaux chroniques comme la schizophrénie ou certaines formes de dépendance.

Pratiquement la moitié des Canadiens et des Canadiennes adultes n'ont pas le niveau d'alphabétisation nécessaire pour pouvoir participer pleinement à notre économie basée sur le savoir. Ils subissent des taux élevés de chômage et sont souvent forcés de vivre dans un environnement instable. Les familles sont directement exposées à des risques sur le plan de la santé à cause de leur alphabétisme déficient et ont de la difficulté, par exemple, à lire les instructions des aliments pour bébé, les ordonnances médicales et le matériel d'éducation sur la santé et la sécurité.

Les femmes sont particulièrement vulnérables sur le plan de la santé parce que la recherche et le système de santé ne se sont pas penchés sur les facteurs qui ont une influence sur leur état et leurs comportements de santé. En guise d'illustration, disons que le taux de tabagisme dans certains groupes de femmes augmente à un rythme alarmant, avec toutes les conséquences que cela implique, comme le risque de contracter le cancer ou encore des maladies respiratoires ou cardiovasculaires. Les parents seuls (principalement des femmes), les prestatrices de soins non rémunérés, les personnes homosexuelles, bisexuelles et transsexuelles courent également le risque de compromettre leur état de santé pour des raisons liées à l'influence du genre et aux différences de sexe.

Sous la gouverne conjointe de l'Institut de la santé des femmes et des hommes et de l'Institut de la santé publique et des populations, les Instituts de recherche en santé du Canada ont lancé une grande initiative de portée générale consistant à mobiliser la recherche sur la compréhension et la réduction des disparités et la promotion de la santé des populations vul-

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1. Professeur de psychiatrie, Université de Toronto, Directeur fondateur et chercheur principal, Centre d'excellence conjoint pour la recherche en immigration et en intégration; Coordonnateur scientifique national, Initiative de réduction des disparités sur le plan de la santé, Instituts de recherche en santé du Canada
2. Professeure, Université de l'Alberta, Faculté des sciences infirmières et de médecine; Chercheure émérite en santé de la Alberta Heritage Foundation for Medical Research; Directrice scientifique, IRSC – Institut de la santé des femmes et des hommes; Chef de file/promotrice des IRSC, Initiative de réduction des disparités sur le plan de la santé

nérables. Au cours des trois ans qui se sont écoulés depuis le lancement de l'Initiative qui vise à réduire les disparités sur le plan de la santé des IRSC, des partenariats ont été mis sur pied avec Santé Canada, le Conseil de recherches en sciences humaines, la Fondation des maladies du coeur du Canada, le Secrétariat national pour les sans-abri, l'Initiative sur la santé de la population canadienne, Citoyenneté et immigration Canada et des organismes internationaux (p. ex., le NIH Fogarty International Centre et l'INS au Mexique). Cette initiative a permis de mettre sur pied une capacité de recherche avec des équipes multidisciplinaires, de constituer des alliances entre les chercheurs universitaires, les décideurs, les praticiens et le public, et de traduire les résultats de cette recherche en information qui permettra d'élaborer des programmes, des politiques et des pratiques dans le domaine de la santé et des secteurs connexes. Suite à deux appels de candidatures en 2002 et 2003, on a financé 24 équipes impressionnantes. Chacune de ces équipes interdisciplinaires se penche sur une ou plusieurs populations vulnérables. Les équipes comprennent des chercheurs de diverses disciplines et universités, des représentants de groupes communautaires, d'organismes de service, d'écoles, d'hôpitaux, de conseils de bandes autochtones, de groupes de revendication et de groupes d'entraide, et/ou d'ONG régionales et internationales. Un bon nombre d'entre elles ont tiré partie du financement initial, puis demandé et reçu un soutien financier supplémentaire pour faire d'autres recherches pertinentes. D'autres ont entraîné les décideurs et les praticiens dans un processus de transfert du savoir et plusieurs ont créé leur propre site Web. Un nouvel appel de candidatures pour des équipes multidisciplinaires dotées d'un soutien financier étalé sur plusieurs années a été lancé en décembre 2004.

Une conférence de réflexion internationale sur la réduction des disparités en matière de santé, organisée sous l'égide de cette initiative du 21 au 23 septembre 2003, a attiré 103 chercheurs du Canada, des É.-U., du Mexique, d'Australie et de Nouvelle-Zélande, ainsi que des décideurs canadiens et des représentants de tous les organismes partenaires. On peut consulter en ligne à l'adresse www.igh.ualberta.ca/rhd/finalreport.htm le rapport final de la Conférence, qui a établi des priorités internationales en matière de recherche. En mars 2004, un grand nombre de chercheurs subventionnés ont participé à un forum sur la politique relative aux disparités sur le plan de la santé accueilli conjointement par les partenaires de l'Initiative et le Groupe de travail fédéral-provincial-territorial sur les disparités en matière de santé. Plus de cinquante personnalités influentes du niveau fédéral, provincial et territorial ont examiné les implications politiques de la recherche sur ces disparités lors de ce symposium très productif.

Les six articles composant ce supplément spécial de la *RCSP* sont basés sur des documents de synthèse qui avaient été à l'origine demandés pour la Conférence de réflexion internationale de 2003. Pris ensemble, ils présentent un tableau qui donne à réfléchir sur la recherche sur les disparités en matière de santé et établissent des jalons pour une orientation future. Bien que chaque auteur ou auteure aborde des sujets et des activités qui sont propres à son domaine, on note de multiples points de convergence. D'abord et avant tout, le Canada doit soutenir et multiplier ses efforts pour créer une base de connaissances pouvant servir de référence dans l'élaboration de politiques et de pratiques pertinentes. Il est nécessaire de faire de la recherche afin de documenter les iniquités, d'élucider les mécanismes qui sont à l'origine des disparités en matière de santé, de concevoir et de tester des modes d'intervention permettant de les réduire et d'évaluer les programmes existants.

À ce jour, la plupart des recherches se sont faites dans le cadre des sciences sociales. Cependant, les disparités ne sont pas seulement la conséquence d'une structure sociale injuste ou de politiques malencontreuses; la génétique, la physiologie humaine et le développement humain jouent, eux aussi, un rôle important dans l'apparition de ces disparités. Par conséquent, la recherche doit revêtir un caractère multidisciplinaire et faire appel à la collaboration internationale. Par exemple, il est reconnu sur le plan international que le phénomène des sans-abri est associé à un taux de mortalité élevé; cependant, chez les sans-abri de sexe masculin de Toronto, ce taux atteint environ la moitié de celui que l'on retrouve dans les villes américaines. En faisant une recherche comparative, on pourrait déterminer si cela est dû à une différence des taux d'homicides et d'infection par le VIH, au régime universel d'assurance-santé canadien ou à quelqu'autre combinaison de facteurs.

Dans un récent article du *Lancet*, on examine les efforts entrepris par divers pays européens entre 1990 et 2001 pour réduire les inégalités socio-économiques sur le plan de la santé. Les auteurs de l'article concluent que ces pays sont très diversement sensibilisés au problème et que leur empressement à prendre les mesures qui s'imposent varie beaucoup. Les auteurs affirment également que, dans cette région, l'élaboration des politiques « est encore largement intuitive et gagnerait à adopter... des approches rigoureuses axées sur les données. »[1] (p. 1409)

L'engagement du Canada envers la justice sociale, l'universalité des soins de santé et l'équité est une source de fierté nationale. Ces principes nous mettent au défi de prendre notre place au rang des pays qui souhaitent contribuer à la connaissance des disparités en matière de santé, les combattre et les corriger quand on peut les éviter ou qu'elles sont inutiles et injustes. Pour réaliser nos idéaux nationaux, nous devons nous attaquer à ce défi collectivement.

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Addressing Health Disparities Through Promoting Equity for Individuals with Intellectual Disability

Hélène Ouellette-Kuntz, MSc[1]
Nathalie Garcin, PhD[2]
M.E. Suzanne Lewis, MD[3]
Patricia Minnes, PhD[4]
Carol Martin, MA[5]
Jeanette J.A. Holden, PhD[6]

ABSTRACT

Intellectual disabilities (ID) are conditions originating before the age of 18 that result in significant limitations in intellectual functioning and conceptual, social and practical adaptive skills. IDs affect 1 to 3% of the population. Persons with ID are more likely to have physical disabilities, mental health problems, hearing impairments, vision impairments and communication disorders. These co-existing disabilities, combined with the limitations in intellectual functioning and in adaptive behaviours, make this group of Canadians particularly vulnerable to health disparities. The purpose of this synthesis article is to explore potential contributory factors to health vulnerabilities faced by persons with ID, reveal the extent and nature of health disparities in this population, and examine initiatives to address such differences. The review indicates that persons with ID fare worse than the general population on a number of key health indicators. The factors leading to vulnerability are numerous and complex. They include the way society has viewed ID, the etiology of ID, health damaging behaviours, exposure to unhealthy environments, health-related mobility and inadequate access to essential health and other basic services. For persons with ID there are important disparities in access to care that are difficult to disentangle from discriminatory values and practice. Policy-makers in the United States, England and Scotland have recently begun to address these issues. It is recommended that a clear vision for health policy and strategies be created to address health disparities faced by persons with ID in Canada.

MeSH terms: Health; health care access; policy; disabled persons; mental retardation

La traduction du résumé se trouve à la fin de l'article.

> "Compared with other populations, adults, adolescents, and children with [*intellectual disability*] experience poorer health and more difficulty in finding, getting to, and paying for appropriate health care…many health care providers and institutional sources of care avoid patients with this condition. Without direct clinical experience, health care providers may feel incapable of providing adequate care. They may not value people with [*intellectual disability*] and their potential contributions to their own health and to their communities."[1]

These words, from the U.S. Secretary of Health and Human Services in "Closing the Gap, A National Blueprint to Improve the Health of Persons with Mental Retardation", echo the concerns of families of persons with intellectual disability (ID) and the clinicians, caregivers and researchers trying to serve this most vulnerable segment of our population here in Canada. Not only do individuals with ID have more health concerns than those without intellectual challenges, but differences in the causes of health problems, the presence of functional limitations, communication difficulties (by the individuals themselves, as well as interpretations by care providers), and barriers to access to care contribute to their vulnerability. This article will review issues related to the extent of health problems experienced by persons with ID, the pathways leading to vulnerability, as well as health policies and programs that have been put into place to address some of the factors contributing to vulnerability. The article will conclude with a discussion of what needs to be done to make opportunities for good health equitable for persons with ID. The challenges are great, but so are the possibilities for improving the health, well-being and quality of life for members of this highly vulnerable population.

Intellectual disability

An intellectual disability (ID) is defined as a significant limitation in both intellectual functioning and conceptual, social and practical adaptive skills, originating before the age of 18.[2,3] This disability manifests as a lowered ability to cope with common life demands and to meet the standards of per-

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1. Departments of Community Health & Epidemiology and Psychiatry, Queen's University & Ongwanada
2. Department of Psychiatry, Queen's University & PREM-TGC
3. Department of Medical Genetics, UBC and BC Children's and Women's Hospital
4. Departments of Psychology & Psychiatry, Queen's University
5. Department of Otolaryngology, Queen's University
6. Departments of Psychiatry & Physiology, Queen's University

HEIDI* Program Team
*Health Equity for Intellectually Disabled Individuals (CIHR grant #63054)

Correspondence and reprint requests: Hélène Ouellette-Kuntz, Department of Community Health & Epidemiology, Queen's University, 191 Portsmouth Ave., Kingston, ON K7M 8A6, Tel: 613-548-4417, ext. 1198, Fax: 613-548-8135, E-mail: oullette@post.queensu.ca

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sonal independence expected for the individual in at least two of the following domains: communication, self-care, domestic skills, social skills, self-direction, community, academic skills, work, leisure, and health and safety. The World Health Organization has estimated that almost 3% of the world population has some form of ID.[4] Individuals with ID make up 1-3% of the population in Canada (i.e., 300,000-900,000 individuals).[5-8] Since ID is a lifelong disability, the cost of care for this group is significant. In the Netherlands, ID accounts for 9% of the total disease-specific costs, making it the most costly diagnostic category.[9] Therefore, appropriate use of our health care resources to best meet the needs of individuals with ID and their families must be considered a priority.

Individuals with ID are more likely to have physical disabilities (~30%), mental health problems (~30%), hearing impairments (~10%), vision impairments (~20%), and communication disorders (~30%) than individuals in the general population. These co-existing disabilities, combined with the limitations in intellectual functioning and in adaptive behaviours, make this group of Canadians particularly vulnerable to health disparities.

Health disparities

Health disparities are simply population-specific differences in health indicators. Such differences may or may not be inequitable. While not all differences in health can be eliminated, health disparities can be reduced by promoting equity. Whitehead defined health inequities as "differences in health that are unnecessary, avoidable, unfair and unjust".[10] Health inequities can therefore be defined as the presence of disparities in health and in its key demographic, social, economic, and political determinants that are systematically associated with social advantage/disadvantage. The inclusion of social determinants of health in the concept of inequity emphasizes that equity in health means equal opportunity to be healthy for all population groups.[11] It is therefore important to examine not only differences in health but also the causes or determinants of such differences. Not all determinants of differences are indicative of health inequities. Specifically, differences in health due to natural, biological variations; health-damaging behaviours that are freely chosen; or a transient health advantage may not be avoidable and unjust. In contrast, differences in health due to (a) health-damaging behaviours in which the degree of choice of lifestyles is severely restricted; (b) exposure to unhealthy, stressful living and working conditions; (c) inadequate access to essential health services and other basic services; or (d) natural selection or health-related mobility* can be said to be avoidable and unjust and hence indicative of inequities.[10] These considerations are important in addressing health disparities by promoting equity for individuals with ID.[12]

The findings described in this article reflect an extensive review of the literature including peer-reviewed articles, textbooks and government documents. Much of the published research concerned with the health status of persons with ID and their utilization of health services has been conducted in the United States (US), the United Kingdom (UK), the Netherlands, Australia and New Zealand. Unpublished thesis manuscripts based on research conducted in Canada are included in the review to reflect the consistency of findings across jurisdictions. While the Canadian-based research is scant, the similarities noted across the various countries, together with our experiences working with individuals with ID and their families, lead us to suggest that much of the findings are relevant to Canada.

Health disparities and intellectual disabilities

Life Expectancy and Mortality

The life expectancy of people with intellectual disabilities is shorter than that of the general population, and this is especially true for persons with severe ID.[13,14] Studies have demonstrated that the increased mortality occurs in the earlier years (up to age 40 or 50).[15,16] However, life expectancy of the ID population is increasing in parallel with the general population. This is seen most dramatically in individuals with Down syndrome, where the mean age at death increased from 26 years in 1983 to 49 years in 1997.[17] A significant proportion of the excess mortality seen in the ID population is related to a combination of associated co-morbidities (severe mobility impairments, seizure disorders, vision impairments, hearing impairments and an inability to feed oneself resulting in reliance on enteral feeding) which together are indicative of medical fragility; that is, susceptibility to infection and other medical complications.[14-16,18-20] Another factor associated with increased mortality is race; or more precisely, the social and economic disadvantage commonly experienced by certain groups. A recent study of persons with Down syndrome found increased mortality among Blacks and other races compared to Caucasians with Down syndrome in the US.[17] In Australia, increased mortality was found among individuals with ID of Aboriginal descent.[13]

Morbidity

As a group, individuals with intellectual disabilities have a greater variety of health care needs compared to those of the same age and sex in the general population. Medical conditions that are found at higher rates in this population include psychiatric,[21-23] seizure and gastrointestinal disorders.[24,25] Some infectious diseases such as tuberculosis, hepatitis B and helicobacter pylori are also more common in this group.

In the Netherlands, adults with ID were found to be 2.5 times more likely to have diagnosed health problems than patients without ID.[24] An Australian study showed that 95% of adults with ID had health problems. Specialist care was considered necessary for 74% of these conditions (819 conditions among 202 adults studied).[25]

Both malnutrition[26] and obesity are common clinical problems for individuals with ID. Prevalence estimates for obesity in this population range from 29.5-50.5% or twice as high as that in non-ID populations.[27-31] As in other groups, obesity in persons with ID is related to serious medical conditions such as coronary heart disease, hypertension and diabetes.[32] Cardiovascular disease is one of the most common causes of death among individuals with ID.[27]

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* Health-related mobility refers to the advantages conferred by good health such as higher education and income. It contributes to health disparities in that the healthier one is, the more likely one is to remain healthy or be able to improve one's health through lifestyle choices, environmental protections, and access to health care.

Persons with ID have poor dental health.[33] There is an increased incidence of gum disease, with gingivitis being 1.2 to 1.9 times higher than in the general population.[27] In 2002, the International Association for the Scientific Study of Intellectual Disabilities (IASSID) reported that periodontal disease, oral mucosal pathology, and moderate to severe malocclusion occurred at rates seven times higher in the ID population than in the general population.[34] A recently published Canadian study revealed that dental procedures make up 40% of day surgery visits by people with ID in Ontario.[35]

Among individuals with ID, aging is associated with decreased mobility and higher levels of osteoporosis and fractures.[36,37] The prevalence of both hearing and visual loss, which are higher among individuals with ID than in the general population,[38-40] also increase significantly with age,[41,42] as does the risk of experiencing abuse. Major mental disorders are frequent in elderly persons with ID;[43] in particular, there is a higher prevalence of dementia.[36,44] Premature aging has also been reported in individuals with Down syndrome. Several women's health issues have yet to be studied thoroughly in an ID population, though some studies report that women with ID experience menopause three to five years earlier than women without ID.[45]

Health problems secondary to medication use are significant in persons with ID. Due to their propensity for co-morbid disorders and the common use of medications, the prevalence of polypharmacy is high.[46,47] More than 15% of individuals with ID take two or more psychotropic medications concurrently.[48,49] Polypharmacy increases the risk for drug interactions, leading to sedation, increased confusion, constipation, postural instability, falls,[50] incontinence, weight gain, sex steroid deregulation, endocrinologic or metabolic effects, impairments of epilepsy management, and movement disorders such as tardive dyskenisia.[43] For example, oral contraceptives are a common method of birth control for women with ID; however, psychoactive and anticonvulsant medications reduce the efficacy of such oral contraceptives and the fluid retention associated with their use can precipitate seizures.[51]

Psychotropic medications are often administered to persons with ID to treat behavioural, emotional or cognitive problems. Pyles reviewed the use of psychoactive medications and found that 26-40% of persons with ID in the community and 35-50% of those living in institutions had current prescriptions.[52] Branford examined medication use by 1,510 persons with ID and found that 23% were taking antipsychotics and 29% were taking antiepileptics.[49] Given the high use of psychotropic medications with their significant side effects – including effects on memory and learning – incorrect diagnoses and inappropriate treatments can have a devastating effect on health, well-being and quality of life in this population. The use of such medications among persons with ID can also result in serious complications including osteoporosis,[45] fractures, decreased mobility,[36] serious injuries,[50] primary gonadal dysfunction, and increased risk of polycystic ovarian syndrome.[45]

There is also a high risk for drug-nutrient interactions, since drugs can deplete nutrient or mineral absorption, cause gastrointestinal problems or affect the taste of food, thereby lessening the desire to eat.[26] Medications can increase the excretion of nutrients or the action of enzymes that break down vitamins, and they can even be life-threatening. In some cases, medications will have a longer half-life because of decreased lean body mass which is common in persons with ID.[26]

Uptake of Health Promotion/Disease Prevention Activities

Several studies have confirmed that individuals with intellectual disabilities do not engage in health promotion and disease prevention activities to the same extent as the non-ID population.[25,53-57] This is particularly notable in the areas of physical activity, oral health, screening and immunization.

Adults with ID tend to lead sedentary lives. Only about 24% participate in regular exercise 3 to 4 days per week, compared to 51% of the general population.[25,57-61] Knowledge about dental hygiene is often poor, with 22% reporting that they do not brush their teeth daily.[33] A New Zealand study found that 73% of individuals with ID needed follow-up interventions, with the majority being health promotion activities. The six most common activities that were neglected were: 1) health protection, such as vaccination, regular checks for existing conditions and smoking cessation; 2) referral to an optician for sight testing, glaucoma and cataracts; 3) hematological testing, medication levels, cholesterol, blood sugars and hepatitis testing; 4) weight, obesity or underweight management; 5) ENT services, such as hearing tests, aids, wax, speaking and swallowing aids/treatment and lumps behind the ear; and 6) gynecological and other women's health concerns, such as menstruation, cervical smears, mammography, breast lumps, and uterine tumors.[54]

One study reported that only 39.1% of women with ID had had a Pap smear within the past three years, a finding significantly lower than for the comparison group of women without ID.[47] Women with ID are also less likely to perform breast self-examinations.

It is recognized that uptake of health promotion and disease prevention activities is not a simple lifestyle choice. Mitigating factors include education, income, self-efficacy and physical limitations. For individuals with ID who rely on caregivers to assist in such activities, the caregivers' attitudes, knowledge and skills further influence the decision to participate in health promoting activities. These and other factors contributing to disparities in health are outlined below.

Pathways and mechanisms leading to vulnerability

For persons with intellectual disabilities, the factors leading to vulnerability are numerous and complex. They include, first and foremost, the way society has viewed ID; the etiology of ID; health damaging behaviour in which the degree of choice of lifestyles is severely restricted; exposure to unhealthy, stressful environments; health-related mobility; and inadequate access to essential health services and other basic services. The pathways are complex because the mechanisms are interrelated. For example, as will be shown, the value society has placed on persons with ID has contributed to disinterest in understanding the various etiologies of ID and their health consequences, which has led to inadequate access to needed care. The following section highlights some of the specific contributors to vulnerability in this population beginning with a review of the historical policy context.

Historical Policy Context

To be adequately understood, health differences and the mechanisms contributing to health disparities faced by persons with ID must be considered in light of the socio-cultural, historical and policy context in which they have developed and continue to exist.

> "Intellectual disability is primarily a socioculturally determined phenomenon that has been apparent since the dawn of man. The impact of disability, however, has varied with the needs of society, its expectancies and social consciousness."[62]

The nature of the environment of care for persons with ID in Canada is influenced by our common societal values, as translated into legislation and policy.[63] Public policy ultimately defines the environment in which service providers deliver their care to individuals with ID. This care includes services provided by both health and social services, and the education sector in the case of children.

In order to understand and appreciate the current realities for persons with ID and their families, including the practice of health care provision, it is necessary to consider how disability policy has developed over the past 150 years, and particularly in the last 50 years.

Prior to the 1870s, there were no systematic procedures for caring for persons with ID. Some were cared for at home by family members; others lived on their own, in insane asylums, or in prisons. The lack of access to medical care meant that life expectancy was short, with infant mortality being very high. Health care provision was generally minimal.

The need for specialized care for persons with ID (as opposed to the generic care given to individuals with ID in psychiatric hospitals and prisons) was eventually recognized. As a result, policy-makers in the US, Western Europe and Canada created special institutions for persons with ID, where there was more consistent medical care. This marked the beginning of the "asylum era".[64] Although the original intent was to provide care that led to rehabilitation, this rarely occurred. The asylums became permanent places of residence for these individuals, who usually received minimal care or education. This model of care continued into the 20th century.

The second half of the 20th century saw a major shift in the provision of services to individuals with ID. Institutions, which were previously seen as providing the best approach to care, became overcrowded and had lengthy waiting lists. Moreover, research began to indicate that community-based alternatives were associated with more positive outcomes.[65] During the 1950s and 1960s, parents and advocacy groups complained about the conditions in institutions for the "mentally retarded" and their voices began to be heard. As a result, in 1958 the Canadian Association for Community Living was founded by parents of children with ID who wanted support and services within the community instead of in institutions.

South of the border, President J.F. Kennedy, who had a sister with an ID, formed the President's Committee on Mental Retardation in October 1961. The President's Committee made 112 recommendations that created a wave of community-based services, deinstitutionalization and research in the field of ID. Moreover, specific federal funds were earmarked for the care of persons with ID. In Canada, a federal-provincial conference on mental retardation was held in 1964, and this led to the creation of the National Institute on Mental Retardation (NIMR) at York University in 1967. NIMR's role was to provide information and carry out research related to ID.

The transition from institutional settings toward a more community-based setting for persons with ID has been guided by the normalization principle, a Scandinavian concept introduced by Bengt Nirje, which argues that the lives of individuals with disabilities should be as normal as possible.[66] This principle was introduced to North America by Wolf Wolfensberger, and subsequently widely applied to services for persons with ID. Normalization, as defined by Wolfensberger, recommended the utilization of means which were as culturally normative as possible in order to establish and/or maintain personal behaviours and characteristics which were as close to the norm as possible.[67]

The philosophy of normalization was widely adopted across Canada throughout the 1980s. Its influence is reflected in the deinstitutionalization movement that led to the closure and downsizing of institutions, and the development of community-based accommodation and services for both children and adults with ID. Currently, increasing numbers of persons with ID are being integrated into the community, the educational mainstream and supported employment. It has been estimated that in 2000, 89% of all individuals with ID in the US were living in the community (i.e., not in private or public institutions); of these, 61% resided in settings for six or fewer individuals.[68]

A serious challenge throughout this evolution has been to provide appropriate health care to persons with ID. Prior to the normalization movement in the 1970s, IDs were considered medical conditions requiring constant professional care, much of which occurred in institutional settings. Normalization introduced a dramatic shift in the philosophy of care.[67] However, medical – and particularly specialized psychiatric – care became less of a priority and medical care for persons with ID became known as the "Cinderella of psychiatry" in Canada.[69] As institutions closed, individuals with co-existing ID and psychiatric disorders (referred to as having a dual diagnosis) were forced to access generic mental health services, but appropriate structures were not in place to allow them to do so easily. These systemic problems led to misdiagnoses, inappropriate treatments and over-reliance on psycho-pharmacological interventions. Researchers in the UK and the US have concluded that "attempts to provide for mental health needs of people with [intellectual disabilities] within generic psychiatric services, whether by design or default, have been obviously unsuccessful".[70]

Individuals with mental health problems and ID experience a "double stigma." The presence of mental disorders in people with ID is "one of the main reasons for the breakdown of community placements and retention in residential environments that are more restrictive than otherwise required".[71] Behaviours that were acceptable in institutional environments are not tolerated in community settings, posing a threat to community inclusion for these individuals. Persons with ID and mental health issues are often considered inappropriate for traditional ID community integrated services because of their psychiatric difficulties but are also considered inappropriate for usual mental health services because of their low IQ. Adding to this stigma is the lack of knowledge of mental health professionals with regard to this population because of deficiencies in training and the existing barriers to practice in this area.[72-74]

Prior to deinstitutionalization, in some institutions professionals with specialized knowledge of the medical and psychological needs of these individuals ensured proper care and contributed to the training of the next generation of health care practitioners.[75] Ironically, part of the evils of the institutional system – the rigidity of the medical model and social marginalization – can be viewed retrospectively as having had some positive effects on the provision of health care to persons with ID. For example, the dietary needs of individuals with phenylketonuria were easier to control in institutional settings where dietitians and nurses could closely monitor a person's progress. Furthermore, much of the research leading to advances in our understanding of the medical disorders and complications associated with specific ID-related syndromes was carried out in institutions around the world.

Canada has evolved dramatically in its philosophical values regarding the care of individuals with ID: "Canada has moved from seeing segregation and institutionalization of persons with disabilities as desirable outcomes to believing in the value and promise of a fully inclusive society."[76] While such changes in philosophical orientation have benefited persons with ID over the past 30 years, they have had major implications for families, on whom the burden of care is often placed.

Today, for many individuals with ID, family is the sole source of social support. As individuals with ID are frequently unable to access supports themselves, families, as their key social network, play a critical role in securing needed care. In an attempt to access adequate health care services parents often take on an advocacy role, becoming the spokesperson for their family member, regardless of the latter's age. In addition to their many other responsibilities, parents often become heavily involved in information seeking, problem solving and educating themselves and others, including health care professionals and politicians, about their child.[77] In the process, they spend significantly more time interacting with professionals than do parents of children without disabilities.[78] Parents provide the necessary transportation and are the source of information about health and behaviour concerns, providing assistance in the medical setting.

The burden of caring for a child with ID in the community has been the focus of many studies.[79-82] The results highlight the many challenges facing families across the life span. Stress varies according to the age of the child, the type of disability and the degree of disability.[79] It is generally agreed that families experience particularly stressful times during periods of transition. For example, when a child with ID enters school, parents are often faced with the difference between their child and other students without disabilities of the same age. In addition, parents often are forced to advocate in order to obtain an educational assistant or other supports for their child in the classroom.[77,83] Other concerns frequently arise in adolescence when individuals with ID may become interested in sexual activity. Sex education and social skills training geared to the needs of teens with ID are not always readily available and parents are often concerned that their child continues to be vulnerable to abuse despite such training.[84] After the ages of 18 or 21, employment or productive day activities may not be available for individuals with ID[77,83] and day-to-day care and supervision of adults with ID becomes increasingly stressful for many parents as they themselves age. Finding ongoing care, accommodation and meaningful activities for adults with ID, as well as setting up trusts and guardianships, are major concerns for many older parents.[85] In addition, there are often ongoing concerns regarding behavioural challenges, explaining the child's disability to others, meeting personal needs and those of other family members, and respite care.[77,86] In the US, it is estimated that 61% of individuals with ID live with a family caregiver, and 25% of these caregivers are aged 60 or older.[68]

While important steps have been taken in order to integrate persons with ID into the community, they have been regrettably segregated once again by a failure to address their specialized medical needs. Although the aspect of social marginalization is being addressed by a shift to community care, planners have largely overlooked the development of adequate medical care for this population in community settings.

The health disparities faced by persons with ID are indicative of a complex interplay of various factors, including policy. The following sections examine the contributions of: etiology of an ID; individual behaviours; environments; health-related mobility; and barriers to access in the creation and maintenance of the disparities in health in the current policy context of community living for persons with ID.

Etiologies of Intellectual Disabilities

The cause of intellectual disability is unknown in a large proportion of cases. Some common causes for ID include Down syndrome; Fragile X syndrome; TORCH infections; prenatal insult; structural brain anomalies; and single gene, metabolic or neuromuscular disorders. Less common causes include rare genetic disorders. Several clinical series suggest that a diagnosis or cause of ID can be identified in 40-60% of all patients undergoing neurodevelopmental evaluation.[87-89]

As we learn more about the etiologies of all common disorders, it is increasingly evident that genetic factors play a significant role in the etiology of ID at all IQ levels.[90,91] It is also clear that the current exponential growth in genetic information will ultimately lead to improved diagnosis and understanding of the causes, treatment and prevention of ID.[92] When a genetic cause is known and understood, it can facilitate medical care for the person with ID as related complications can be anticipated and even prevented. It is therefore critical to attempt to determine the cause of the ID.

The main genetic causes of ID are chromosome abnormalities, small chromosome deletions and duplications, and single gene mutations. The following review illustrates the potential contribution of genetic testing to reducing health disparities faced by persons with ID.

Chromosome abnormalities are the most common cause of congenital mental disability.[87] Data from 16 worldwide-published studies show that chromosomal abnormalities are found in 4-34.1% of individuals with ID.[93] The best-known example of a genetic imbalance compatible with life is Down syndrome, caused in the majority of cases by trisomy of chromosome 21, and present in 1 in 700 newborn children.

Relatively small chromosomal deletions or duplications can also result in ID. Well-known microdeletion syndromes include Williams-Beuren syndrome, Prader-Willi syndrome, Angelman syndrome, Wolf-Hirschhorm syndrome, and DiGeorge/Velocardiofacial syndrome. As shown in Table I, the manifestations of these and other syndromes associated with ID include specific health problems.

Standard cytogenetic analyses are often not sensitive enough to detect the small chromosome rearrangements causing these and other disorders.[94] In recent years, the development and application of various sophisticated methods that combine DNA technology with cytogenetics have led to the discovery of many chromosomal rearrangements involving the otherwise almost indistinguishable ends of chromosomes.[95] Recent reports suggest that such sub-microscopic abnormalities lead to gene-dosage imbalance and represent a significant cause of ID with or without congenital anomalies.[95-99] Since the ends of human chromosomes are thought to be the most gene-rich regions of the genome, such gene-dosage imbalance is expected to have a disproportionately greater clinical significance than similar abnormalities in other regions of the chromosomes.[100]

Many disorders associated with ID are due to single gene mutations. Classical examples include phenylketonuria and other inborn errors of metabolism, Smith-Lemli Opitz syndrome, Noonan syndrome, Sotos syndrome, as well as numerous forms of x-linked mental retardation including Fragile X syndrome (see Table I for a list of significant health problems associated with these syndromes).

Despite the frequency and tremendous impact of ID on society, there exist no generally accepted guidelines for clinical and laboratory investigations directed at understanding its causes. This is unfortunate, because having a diagnosis can lead to better managed care and cost savings because of reduced numbers of unnecessary tests.[87] One of the key needs of families living with ID is to understand the disorder's long-term impact on the affected individual's development and future health. Families are understandably anxious to know the cause of ID in their relative, as are referring physicians, social agencies and therapists. Families feel that a diagnosis brings relief from uncertainty, allows refinement of prognosis and recurrence of risks, assures identification with an appropriate support group, and enables funding of special services. However, an incorrect diagnosis can lead to inappropriate counselling, stigmatization and labelling that can continue for years even after a diagnosis is invalidated or changed.[87]

Moreover, genetic forms of ID often exhibit distinctive natural histories in which the evolution of symptoms and disabilities offers opportunities to develop prospective health management templates.[101] Therefore, it is possible to develop specific templates of anticipatory health guidance for different forms of ID that include a combination of active intervention (as in screening for visual impairment or hearing loss), comprehensive diagnostic screening tests (e.g., laboratory or neuroimaging studies), parent and/or physician alerts for particular signs or symptoms, and a consistent strategy of ongoing functional assessment that reflects potential variations in the expected natural history.

There are presently many examples of health supervision guidelines that have been developed for specific genetic syndromes of ID, with the best model for preventative management being devised for Down syndrome, such as the early checklist by Dr. Mary Coleman as adopted by Cohen and the American Academy of Pediatrics.[102,103] Guidelines for the management of other syndromes, including Fragile X syndrome, achondroplasia, neurofibromatosis-1 and Marfan syndrome have been devised by the American Academy of Pediatrics; there are now more than 30 checklists for common congenital

TABLE I

Well-known Syndromes Associated with Intellectual Disabilities

Genetic Cause	Syndrome	Clinical Features
Chromosome Trisomy	Down (Trisomy 21)	Characteristic facies, cardiac and gastrointestinal anomalies, growth retardation, conductive hearing loss, risk of leukemia and Alzheimer disease
Contiguous Gene Microdeletion	Williams-Beuren	Supravalvular aortic stenosis, multiple peripheral pulmonary arterial stenoses, unique facies, mental and statural deficiency, characteristic dental malformation, and infantile hypercalcemia
	Prader-Willi	Obesity, muscular hypotonia, mental retardation, short stature, hypogonadotropic hypogonadism, and small hands and feet
	Angelman	Severe motor and intellectual retardation, ataxia, hypotonia, epilepsy, absence of speech, and unusual facies
	Wolf-Hirschhorm	Severe growth retardation and mental defect, microcephaly, unusual facies, and closure defects such as cleft lip or palate, coloboma of the eye, and cardiac septal defects
	DiGeorge/ Velocardiofacial	Hypocalcemia arising from parathyroid hypoplasia, thymic hypoplasia, cleft palate, cardiac anomalies, typical facies
Single-gene mutation	Phenylketonuria	Deficiency of phenylalanine hydroxylase, unusual odour, light pigmentation, peculiarities of gait, stance and sitting posture, eczema and epilepsy
	Smith-Lemli Opitz	Deficiency of 7-dehydrocholesterol reductase with multiple congenital anomalies including microcephaly, ambiguous genitalia, genitourinary and cardiac anomalies, polydactyly and syndactyly
	Noonan	Hypertelorism, low-set posteriorly rotated ears, short stature, a short neck with webbing or redundancy of skin, cardiac anomalies, deafness, motor delay, and a bleeding diathesis
	Sotos	Excessively rapid growth, advanced bone age, acromegalic features, and a non-progressive cerebral disorder
X-linked (trinucleotide repeat)	Fragile X	Macroorchidism, large ears, long facies, prominent jaw, large stature, autism spectrum disorder and hyperactivity

anomalies or syndromes.[89,101,104-108] Such preventative management approaches and guidelines to genetic disorders of ID may offset the negative consequences that may be perceived to arise from diagnostic labels.[109,110]

The early detection of phenylketonuria through newborn screening, with the prevention of severe cognitive and developmental delay by early dietary restriction of phenylalanine, is one of the most successful programs aimed at reducing ID in individuals at risk.[111] Another example is Down syndrome, where adoption of the health checklist for children with Down syndrome by the American Academy of Pediatrics in 1994 has led to far better outcomes for children with this syndrome.[103,112] With the recognition of a substantial risk for Alzheimer's disease and heart and eye disease in older individuals with Down syndrome, these concerns can now be addressed in a timely manner.[87,108] Similar approaches are being developed for a large number of other genetic causes of ID.

Thus, while the differences in health related to a genetic cause of ID may at first seem unavoidable, with an accurate early diagnosis of such genetic disorders and the provision of appropriate anticipatory care, some health problems can be avoided or their consequences minimized.

Health-damaging Behaviours/Lifestyles

Individual behaviour as a health determinant for persons with intellectual disabilities is complicated by their inherent limitations in adaptive functioning in areas such as self-care, communication and literacy. Because of their disabilities, individuals with ID are frequently dependent on others (family members or paid caregivers) to assist them in making healthy choices. In many cases, health-damaging behaviours in this population may be best understood in the context of health-related mobility discussed in a later section.

In addition to poor nutrition and low levels of physical activity, smoking, alcohol and caffeine consumption are behaviours of concern. Smoking occurs at higher rates in the ID population than in the general population, with those living in the community generally having a higher use of cigarettes, alcohol and caffeine than those living in institutions.[27,36,44,59] In many instances, initiation of smoking and caffeine consumption are behaviours modeled after caregivers. Historically, cigarettes have been used as rewards for good behaviour in institutions.

While many benefits have come from the closure of institutions for persons with ID, movement into community life has generally been associated with an increased risk for poor diet.[44] A study examining lifestyle practices of adults with ID found that the participants from group and family homes had higher body weight, higher percentage body fat, and higher cholesterol levels than participants from institutions.[59]

Research aimed at identifying and reducing barriers to choosing a healthy lifestyle among persons with ID is scarce. Individuals with ID often do not participate in physical activities because they lack either motivation or the opportunities to become involved in fitness programs.[113] One study suggested these may require adaptation and specialized training for persons with ID, in order to achieve goals such as increased cardiovascular fitness.[114] A survey of caregivers concluded that physical exercise programs that are not adapted to the needs and abilities of individuals with ID, or that are not located in nearby facilities, bar people with ID from enjoying the benefits of these services.[61] Special Olympics offers a segregated competitive sports program for individuals with ID, meeting the physical fitness needs of those with greater athletic abilities. Much more research is needed to determine how to ensure that non-competitive, leisure, recreation and sporting activities, and fitness programs are equally accessible to individuals with ID.

Exposure to Unhealthy, Stressful Environments

Previous or current residence in large institutions places persons with intellectual disabilities at risk for past or present exposure to a number of infectious diseases including tuberculosis, hepatitis B and *Helicobacter pylori*.[46,115,116] This is exemplified by an Ontario-based study examining the prevalence and screening methods for *Helicobacter pylori* among adults with ID. It revealed that 80% of study participants who had formerly been institutionalized suffered from the infection – which, untreated, has been associated with peptic ulcers and gastric cancer deaths.[36,117] This rate was three to four times higher than in adults with ID who had never been institutionalized.[118] While few individuals continue to live in large institutions, many adults live and/or work in smaller congregate settings where exposure to infectious agents and stressful environments remains a concern.

Health-related Mobility

Health-related mobility refers to the advantages conferred by good health such as higher education and income. It contributes to health disparities in that the healthier one is, the more likely one is to remain healthy or be able to improve one's health through lifestyle choices, environmental protections and access to health care.

Several studies have demonstrated that persons with ID are more likely to experience poverty than the general population[119] and that they have among the highest poverty rates, lowest average incomes, and highest out-of-pocket expenses of all population groups.[120] In the US, households with an individual with ID are larger, more likely to subsist below the poverty line, and are more likely to be dependent on means-tested income support.[121] The financial instability of this group threatens their access to nutrition, medical care and other resources.[120,122,123] Multiple conditions requiring additional and more comprehensive services add to personal health care expenses and can strain economic resources.[124]

Adults with ID tend to have limited education and levels of literacy, thereby limiting their access to health promotion literature and a myriad of health promotion activities. The education and literacy levels achieved by individuals with ID reflect both limitations inherent in their disability and the inadequacies of the education they receive.

Large-scale health promotion campaigns (e.g., anti-smoking, healthy eating, regular physical activity, sun protection and health care screening messages) frequently require a level of literacy or abstract thinking that renders them inaccessible to many individuals with ID. Few resources are available for persons with ID that describe the dangers of excessive alcohol, tobacco and caffeine consumption in terms that enable them to make informed decisions about such use. Thus, research on how low literacy impacts indirectly on health by contributing to poverty, stress, unhealthy lifestyles, low self-esteem, dangerous work environments and inappropriate use of health services is needed for this population.

More direct impacts of low literacy on health have been noted by the National Literacy and Health Program.[125] That program cited the incorrect use and mixing of medications and increased safety risks, such as home and workplace accidents, as major contributors to poor health in individuals with low literacy. In addition, language used in pamphlets to explain various medical conditions is often incomprehensible to persons with ID.

The ability to know when and how to access health care is critical to ensuring one's health. Currently, systems of health care rely on an individual's ability to recognize the need for care, to seek care, and to coordinate the provision of care. However, self-referral for consultation is rare in this population[44,126] and, in general, persons with ID are less likely to voice psychological complaints.[43] Since people with ID often lack the ability to recognize health problems,[127] it is important for caregivers and health care professionals to recognize signs of distress.[46]

Inadequate Access to Essential Health Services and Other Basic Services

In general, health screening for persons with ID requires significant improvement.[47] Since this population experiences health-related problems at similar or higher rates than the general population, individuals with ID should receive the same array of preventative health practices throughout their lifespan.[32,46] When comprehensive assessments are undertaken, they often reveal high rates of concurrent treatable conditions.[32]

An Australian study of adults with ID revealed that an average of 2.3 conditions per person were unrecognized prior to a comprehensive assessment and an additional 2.7 conditions per person were considered unmanaged.[25] Other studies identified high rates of previously unrecognized or poorly managed co-morbidity in this population. Such conditions include hypertension, obesity, congenital heart disease, abdominal pain, respiratory disease, cancer, gastrointestinal disorders, diabetes, chronic urinary tract infections, oral diseases, musculoskeletal conditions and osteoporosis, thyroid disease, hypothermia, pneumonia, vision impairment and hearing impairment.[36,44,46,127-132] A recent study examining the hospitalization of persons with ID living in Ontario noted high rates of admission for ambulatory sensitive conditions.[133] These admissions, also known as "preventable admissions", are due to conditions such as diabetes, asthma and hypertension, which are expected to be managed by patients outside an in-patient setting. They are used as a marker of access to appropriate primary care.

Other barriers to receipt and use of appropriate health care include characteristics of the individual (e.g., communication disorders, motor impairments), and features of the health care system (e.g., poor physical accessibility, health-care provider ignorance and discontinuity in care).

Communication difficulties

Communication difficulties are a major problem for both persons with intellectual disabilities and their health-care providers, and are more common in individuals with ID than in the non-disabled population.[134-137] A study conducted in Ottawa, Ontario found that 27% of adults with ID were identified by caregivers as needing speech, language and audiology services.[138] There is a wide range of communication deficits in persons with ID: some have difficulty understanding spoken language; others are non-verbal with no intentional communication; others use a small number of single words or single manual signs in specified situations or augmentative communication systems (e.g., pictures, assistive devices); a smaller proportion have extensive vocabulary and are able to communicate using long sentences. Language is often socially inappropriate and/or contains speech or grammatical errors.

The inability or unwillingness of others to adapt appropriately to the poor communication skills of many individuals with ID results in maladaptive behaviours that pose additional challenges for health professionals and parents. Such behaviours contribute to diagnostic overshadowing, with symptoms related to physical problems being misinterpreted as being attributable to ID. The inability to effectively communicate one's distress or discomfort makes the recognition, diagnosis and treatment of health problems challenging for individuals with ID, caregivers and health-care providers.[36,43,44,46,126,139,140] Language and cultural differences compound this issue.[139] Recently, the English National Board for Nursing identified insufficient communication skills training for health care professionals dealing with person with ID as contributing to their poor health.[58] The need for communication skills training has been emphasized in both nursing and medicine, with effective communication between health care professionals and patients being an important variable in patient satisfaction and compliance.[141-145]

Communication difficulties also have an impact on the availability of research specific to the treatment of health problems among persons with ID. Research is often limited to individuals who are able to consent to participating in research. The purpose of this requirement is to avoid taking advantage of persons who are unable to consent but who might reject such participation if they understood the full consequences of participation. Unfortunately, however, this also means that individuals who are not able to consent (or are deemed unable to do so) do not benefit from participating in research that might lead to better treatments or cures. Since drug interactions are common, the assumption that what works in a non-ID population will work similarly in an ID population is not necessarily so.

Despite the increased prevalence of communication difficulties in individuals with ID and the implications of such difficulties, many do not have access to services needed to diagnosis and respond to these problems. An Ontario-based study reported that only 35% of adults with ID who were identified by caregivers as needing speech, language and audiology services were actually receiving these services.[138]

Motor impairments and poor accessibility

These are barriers to appropriate care, especially since physical access to clinics and treatment centres is a first step towards consultation.[46] With respect to women's health care needs, medical procedures, such as mammograms and cervical cancer screening, are not always possible because persons with ID often have musculoskeletal problems that prohibit them from using standard equipment and examination tables.[146,147]

Service delivery restrictions

In a review of the health care literature, Beange and Lennox identified poor compliance to treatment management plans, poor continuity of care, inadequate knowledge of services and resources, and little time for examination/consultation as posing limitations to adequate care provision.[36] Almost three quarters of general practitioners surveyed indicated that time restrictions during consultations limit the quality of care they are able to provide to people with ID.[36] In Canada, fee-for-service remuneration of physicians does not include allowances for the additional time required to adequately assess the needs and manage the care of individuals with ID. Some jurisdictions have developed remuneration schemes that take into account the increased time demands on physicians for meeting the health care needs of special populations such as the elderly.

Knowledge and attitudes of health-care providers

Many physicians do not recognize the health needs of this population and therefore overlook potential health complications. The Surgeon General's Report noted reluctance on the part of general practitioners to "get to the bottom" of the problem, investigate, review and refer.[1] In a survey of general practitioners in Australia, 80% said they found it harder to provide good quality health care to patients with ID than to non-disabled patients.[54]

Voelker explains that the lack of standards of care and best practices for the ID population, and information on differences in the manifestation of symptoms, can cause coexisting syndromes to be misdiagnosed or missed completely.[129,140] Although emotional, behavioural, and psychiatric disorders are three to four times more common in people with ID, these symptoms in persons with mild disabilities and rare conditions are often overlooked and assumptions regarding treatment are often made prematurely.[43,129] Alcohol, drug dependency and depression are likely to be regarded as behaviour problems and there is often a lack of differentiation between mental illness and ID.[43,45] Horwitz and colleagues identified two major challenges to diagnosing mental health conditions in persons with ID: 1) that providers are often reluctant to diagnose mental health conditions in persons with ID and 2) that there are often difficulties in identifying symptoms.[27] Symptoms are frequently attributed to the disability rather than evaluated as potentially separate conditions (i.e., "diagnostic overshadowing"). This is not limited to issues of mental illness. It is often wrongly assumed that women with disabilities are not at the same risk for developing breast and cervical cancers as the general population, and therefore few women in this population have access to screening for these conditions.[45,147]

Parents of individuals with ID often become frustrated with health-care professionals who they see as being uninformed about ID.[77,148] Parents often describe physicians as being aloof and insensitive when providing diagnostic information, or not wanting to take the time to listen to their concerns, or being unreceptive to their suggestions.[77,148] Many parents feel that they have had to educate first themselves and then their physicians and other health care professionals about ID. As a result, interactions between parents and professionals can become strained. Parent advocates and professionals who are also parents of individuals with ID have emphasized the need for more collaborative parent-professional relationships.[149] Although parents participating in an Ontario study indicated that attitudes and the general level of awareness among health professionals about ID had improved in recent years, they felt that more exposure to persons with ID, education around specific health concerns for persons with ID, acknowledgement of the special needs of such individuals, and more compassion in general would improve physicians' relationships with families.[77]

Two recent Canadian studies considered the adequacy of psychiatry training in ID in our country.[72,150] A survey of training programs revealed, "inadequate training opportunities exist in many of the residency programs, particularly those involving adults and adolescents"[72] (p.138). The authors concluded that: "[a]cross Canada, there have been insufficient advances in clinical training and service developments to meet the needs of individuals with [intellectual] disabilities and comorbid mental health disturbances."[72]

In a survey of 60 senior psychiatry residents from across Canada, only half indicated they had received training in ID in their undergraduate medical education and 85% of them felt that more training was needed. Almost 90% of residents who had not received undergraduate education on ID responded that they would have benefited from such information. Eighty-five percent of respondents reported that they had some education regarding dual diagnosis in their residency program but most (59%) felt that more information and training was needed. These concerns, reported by senior medical residents, support the need for curriculum enhancements that experts in ID have long recommended.

A recent study showed that general practitioners typically do not see themselves as the most appropriate professionals to provide health care to people with disabilities, and that their general lack of knowledge of health needs and specialized diagnostic procedures places them at a disadvantage when dealing with such patients.[126] This uneasiness stems from the fact that in most programs, disability issues represent only a small portion of medical education curricula, and that continuing medical education is usually not geared towards disability-related issues. Similarly, a survey of dental schools indicated that 47% of schools had 8 or fewer didactic hours on the treatment of individuals with ID, and 65% had 10 or fewer hours on clinical activities associated with this population.[151] This lack of training and experience likely influences providers' willingness to provide treatment to individuals with ID.[27]

Initiatives to reduce inequities

In Canada, public policy development is influenced by the constitutional division of powers and budgets between the federal and provincial levels of government.[63] The provinces have traditionally had jurisdiction over matters pertaining to education, health and social services. The federal government often assists in running various programs through cost-sharing arrangements and transfer payments to the provinces in order to promote its national policies. The federal government makes many of its commitments to Canadians through federal budget speeches and Speeches from the Throne. The most recent speeches have mentioned persons with disabilities specifically, and this group has been singled out as a key priority for the current government.

> "These federal commitments, however, do not fit easily within the structures of the federal government. They cut across departmental lines, they affect the operations of many agencies and they are intimately interwoven with the jurisdiction of the provinces and territories as well as the voluntary and private sectors. This means that no one jurisdiction – let alone one federal department – can control decisions, resources and activities. Success depends on developing and sustaining a common vision of outcomes, objectives and lines of accountability."[152]

Protection for persons with intellectual disabilities is also specifically included under the equality rights section of the *Charter of Rights and Freedoms* of the Canadian Constitution. It guarantees persons with ID the right to equality before the law and to equal protection and benefit of the law without discrimination.

The Canadian government has become increasingly concerned with the needs of Canadian citizens with disabilities, in part because of our aging population. Although the federal government does not yet have a national policy concerning the care of individuals with disabilities or, more specifically for persons with ID, it has been moving in this direction.

In the last 10 years, the Government of Canada has organized task forces, governmental subcommittees and reports looking at the needs of individuals with disabilities. In doing so, "Canada has gradually developed a framework of legislation to protect those rights of persons with disabilities that are within the Government of Canada's jurisdiction. As well, a number of important initiatives have helped bring a sharper focus to the Government's efforts to make progress on disability issues."[76]

For example, in 1999 the Government of Canada released its disability agenda, entitled *Future Directions to Address Disability Issues for the Government of Canada: Working Together for Full Citizenship.*[153] The *Future Directions* document built on the framework introduced in 1998 by *In Unison,* the federal, provincial and territorial vision of full inclusion for persons with disabilities.[154] Although not specifically speaking to the needs of individuals with ID (but disabilities in general), *Future Directions* identifies seven key actions needed to help people with disabilities achieve full inclusion:

1. increase accountability and improve policy and program coherence;
2. build a comprehensive base of knowledge;
3. build the capacity of the disability community;
4. address the acute needs of Aboriginal people with disabilities;
5. improve access and remove barriers to disability supports and income;
6. enhance employability of persons with disabilities; and
7. reduce injury and disability rates by prevention and health promotion.

In 2000, the Canadian government made another important step towards defining public policy for individuals with disabilities in general, with the publication of the report on the *In Unison* vision.[155] This report on *In Unison* aimed "to provide Canadians with a broad view of how adults with disabilities have been faring in comparison with those without disabilities, using both statistical indicators and examples of personal experiences".[155] The report built upon common identified objectives and proposed a "Canadian approach" based on the *In Unison* framework for the development of disability supports. It focussed primarily on issues of individual accessibility and portability.

In December 2002, the Canadian government released its first comprehensive report on disability in Canada, *Advancing the Inclusion of Persons with Disabilities.*[76] The report, issued by the Minister of Human Resources, describes where Canada had made progress, how the Government of Canada had contributed, and where work remained to be done. As part of this important effort, the Canadian government was concerned about the different definitions that various government departments were using to determine eligibility for provincial and federal programs. Consequently, the Standing Committee on Human Resources Development and the Status of Persons with Disabilities, specifically asked the Canadian government to study the harmonization of disability definitions in federally administered programs. The Office of Disability Issues was commissioned to study and unify existing definitions of disability, in order facilitate understanding of the notion of disability across programs.

The resulting report was published by the Office for Disability Issues, Human Resources Development Canada, in late 2003. The report thoroughly examined disability definitions in the various provinces and territories, and defined disability on a federal-program basis. Unfortunately, this was not done from an ID perspective. The report also studied definitions of disability that exist worldwide. Although it did not position itself on the adoption of any one definition, it concluded that "[d]isability is a multidimensional concept with both objective and subjective characteristics. A single harmonized 'operational' definition of disability across federal programs may not be desirable or achievable. And, the scope of solutions to address the broader issues identified go beyond definitions." The authors went on to suggest:[156]

> "This report is not an end in itself. It does not resolve the tensions mentioned earlier but provides, for the first time, a shared information base to allow Government of Canada departments to provide a more coherent picture of its disability policies and programs and to continue a dialogue with all stakeholders…. In addition to the actions identified above, the report confirms the need for further examination of the complexities associated with disability definitions and eligibility criteria." (p.48)

While great strides have been made in Canada in the area of disability policy, the health needs of persons with intellectual disabilities have been largely overshadowed by issues of accessibility, employment equity and income security for persons with disabilities, without recognition of the specific vulnerabilities to poor health faced by persons with ID. As a result, Canada does not have a national policy concerning the health needs of persons with ID; nor do we have national statistics that provide us with a portrait of their vulnerability to experience health disparities. The Canadian situation is in contrast to developments in other countries such as the US, England and Scotland where a commitment has been made by governments to adopt an agenda for change which promotes equity by addressing health disparities faced by persons with ID.

In the United States and the United Kingdom, separate budgets, governmental committees and research institutes have been established nationally in order to improve the health of individuals with ID. During the last few years, important documents were written which reflect the current state of health and health care for persons with ID in the US, England and Scotland. These reports describe the need for "closing the gap", "valuing people" and "promoting health, supporting inclusion".[1,157,158] The themes and conclusions in these reports are the same: persons with ID are a marginalized group in society, partly because of their dependence on others for their care, partly because we do not know how to appropriately assess their health care needs, and partly because most health care professionals are ill-equipped to communicate and treat persons with ID. The policy documents outline similar objectives in caring for persons with ID**.**

Closing the Gap summarizes the six goals and action steps that form the US' National Blueprint to improve the health of persons with ID, i.e., to ensure that:

1. health promotion is extended to individuals with ID;
2. information is gathered about the health needs of persons with ID;
3. the quality of health care is improved;
4. health-care providers are appropriately trained;
5. sufficient funding is available to meet the health-care needs of persons with ID; and
6. there are increased numbers of providers of care to persons with ID.

In England, where government spending on individuals with ID surpassed £3 billion in 1999-2000 (or roughly $6.7 billion Canadian), the government's priorities concerning individuals with ID include: "[t]o enable people with [intellectual] disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary", and "[t]o ensure that social and health care staff working with people with [intellectual] disabilities are appropriately skilled, trained and qualified, and to promote a better understanding of the needs of people with [intellectual] disabilities among the wider workforce."[157]

Priorities for Scotland are aimed at reducing inequities by targeting five areas for action. New developments and interventions are being undertaken relating to:

1. leadership and accountability;
2. infrastructure, including a program of research focused on health improvements for persons with ID and database development;
3. specific interventions, such as health screening program specifically for persons with ID;
4. information; and
5. education, including initiatives pre and post registration/graduation for health professionals.[158]

In the US and many parts of western Europe, there has been a long tradition of education in the field of ID. In the US, the aforementioned President's Committee on Mental Retardation made many recommendations that included (a) the importance of interdisciplinary training, (b) best-practice in services for individuals and their families, (c) advancement of scientific understanding, and (d) coordination between universities and state agencies to survey the personnel needs in the field. These recommendations led to the passing of an American public law specifying that

> "…grants were authorized to assist in the construction of public or nonprofit clinical facilities associated with a university that would both provide services and aid in clinical training. This idea was 'an active, reciprocal exchange of information and resources between communities and universities that would benefit persons with ID through improved systems of service and personnel preparation.'"[159,160]

The initiatives, which have been or are being implemented in the United Kingdom, the US and Scotland are urgently needed in Canada in order to improve the health and well-being of Canadians with ID.

In November 2000 and April 2002, researchers in the field of ID in Canada met in Kingston and Vancouver (respectively) because of the "urgent need to develop training programs for health professionals who care for people with [intellectual] disabilities."[65] For the first time in Canada, this effort constituted an opportunity for educators, practitioners and community leaders to convene at national symposia in order to strategically address gaps in current education on ID in Canada. From these meetings came clear priorities for Canadians that included:

1. the need to lobby for a federal point of responsibility within Health Canada;
2. the desirability of epidemiological data regarding ID collected consistently across all provinces and territories;
3. endorsement and publication of a consistent definition of intellectual disability across Canada, including standardization of the assessment description and measures;
4. establishment of focal points in universities and colleges for the coordination and collaboration in ID studies; and
5. the creation of a national association for intellectual disability.[161]

Since these meetings, two organizations have been formed to respond to these priorities. The first is the HEIDI program (Healthcare Equity for Intellectually Disabled Individuals); a group of researchers looking at addressing health disparities faced by individuals with ID (www.heidiresearch.ca). The second organization is CARE-ID (Canadian Association for Research and Education in Intellectual Disabilities); an association striving to increase the number of researchers and educators in the field of intellectual disabilities.

CONCLUSIONS

> "Good health is essential to quality of life, and the health and well-being of its people are essential to the strength of the Nation…. Yet there is a segment of our population that too often is left behind as we work to achieve better health for our citizens. Americans with [intellectual disability], and their families, face enormous obstacles in seeking the kind of basic health care that many of us take for granted."[1]

Our review suggests that for Canadians with ID, the situation may not be very different. Persons with ID do not receive the services that their health conditions require. Limitations in domains such as self-care, literacy and communication are important barriers to accessing preventative and restorative health care. Furthermore, the inadequate efforts by governments and communities to accommodate these limitations place individuals with ID at an increased risk for poverty, physical inactivity, poor nutrition and greater stress. Barriers to health for this population are evident at various levels, including inaccessible health promotion messages, undiagnosed and untreated medical problems, and the lack of access to knowledgeable and sensitive health-care providers. These issues deserve serious attention as persons with ID are at greater risk for health problems than the general population and receive less preventative care. Furthermore, for persons with ID there are important disparities in access to care that are difficult to disentangle from discriminatory values and practices (such as reliance on caregivers, lack of training of health-care professionals, undiagnosed conditions, and other institutional discriminations which make even the recognition of the need to access care problematic in this population).

Achieving health for all means that public health practice and research must not ignore this segment of the population. It is recommended that a clear vision for health policy and strategies to address health disparities faced by persons with ID in Canada be created. Such a vision should include attention to the following areas:

1. enhanced research in genetics, medicine and health services aimed at ensuring accurate diagnosis, dissemination of guidelines for clinical and laboratory investigations directed at understanding etiology, and the development of specific health care watches for management;
2. monitoring uptake of health services by persons with ID and reasons for discrepancies;
3. developing a greater understanding of differences in manifestation and treatment of health problems in persons with ID;
4. training professionals in the different and special needs of persons with ID, including how to communicate with persons with ID and their caregivers;
5. public awareness campaigns and health promotion activities that include persons with ID.

Canada does not currently have a policy document such as England's *Valuing People White Paper*,[157] the US Surgeon General's *Closing the Gap*,[1] and Scotland's *Promoting Health, Supporting Inclusion*,[158] which concern individuals with ID specifically. There is no major public policy document from a federal branch of government that promotes society's values and goals for Canadian citizens with intellectual disabilities. We need to follow the lead of these countries and develop a national agenda that addresses health equity for persons with ID. To facilitate this, we need a national voice, a forum where researchers, families, individuals with ID and support agencies can work together to ensure the best quality of care for persons with ID. It is through this forum that national policies can be developed to secure the rights of this vulnerable population to the excellence in health care expected for all citizens of Canada.

> "To be disabled does not mean to be sick. An individual may have a disability and be healthy; however, to be healthy, like other individuals, individuals with disabilities need information and options that are accessible and useable."[162]

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RÉSUMÉ

Les déficiences intellectuelles (DI) sont des affections qui apparaissent avant l'âge de 18 ans et dont la conséquence est une limitation significative du fonctionnement intellectuel ainsi que des capacités conceptuelles, sociales et d'adaptation. Les DI touchent entre 1 et 3 % de la population. Les personnes atteintes présentent généralement des déficiences physiques, des problèmes de santé mentale, des troubles de l'audition ou de la vue, et des problèmes de communication. Ces incapacités concomitantes, combinées aux limitations du fonctionnement intellectuel et du comportement adaptatif, rendent ce groupe d'individus particulièrement vulnérable à des disparités sur le plan de la santé. Le but de cet article de synthèse était d'examiner les facteurs qui contribuent éventuellement à rendre vulnérables sur le plan de la santé les individus atteints de DI, de préciser l'ampleur et la nature des disparités auxquelles est en butte cette population et d'analyser les initiatives qui permettraient de s'attaquer à ces différences. Selon cette revue, les personnes atteintes de DI s'en tirent moins bien que la population en général sous l'angle de certains indicateurs clés de la santé. Parmi les facteurs de vulnérabilité, nombreux et complexes, mentionnons l'attitude de la société devant les DI, l'étiologie de ces déficiences, les comportements dommageables sur le plan de la santé, l'exposition à des environnements malsains, les problèmes médicaux de mobilité, et l'accès inadéquat aux services essentiels de santé et autres services de base. Dans le cas des personnes atteintes de DI, on note d'importantes disparités quant à l'accès aux soins de santé, disparités qu'il est difficile de distinguer des valeurs et des pratiques discriminatoires. Aux États-Unis, en Angleterre et en Écosse, les décideurs ont récemment commencé à se pencher sur ces questions. On recommande de se doter d'une vision claire en matière de politique et de stratégies sur le plan de la santé afin de s'attaquer aux disparités que subissent les personnes atteintes de DI au Canada.

Homelessness and Health in Canada

Research Lessons and Priorities

C. James Frankish, PhD[1]
Stephen W. Hwang, MD, MPH[2]
Darryl Quantz, MSc[1]

ABSTRACT

This article was for prepared for an international think-tank on reducing health disparities and promoting equity for vulnerable populations. Its purposes are to provide an overview of homelessness research and to stimulate discussion on strategic directions for research. We identified studies on homelessness, with an emphasis on Canadian research. Studies were grouped by focus and design under the following topics: the scope of homelessness, the health status of homeless persons, interventions to reduce homelessness and improve health, and strategic directions for future research. Key issues include the definition of homelessness, the scope of homelessness, its heterogeneity, and competing explanations of homelessness. Homeless people suffer from higher levels of disease and the causal pathways linking homelessness and poor health are complex. Efforts to reduce homelessness and improve health have included biomedical, educational, environmental, and policy strategies. Significant research gaps and opportunities exist in these areas. Strategic research will require stakeholder and community engagement, and more rigorous methods. Priorities include achievement of consensus on measuring homelessness, health status of the homeless, development of research infrastructure, and ensuring that future initiatives can be evaluated for effectiveness.

MeSH terms: Homeless persons; vulnerable populations; poverty; health status; health behaviour; health services

La traduction du résumé se trouve à la fin de l'article.

Canada has long had an international reputation for high quality of life. For a growing number of Canadians, homelessness has become a grim reality and obtaining shelter part of a daily struggle.[1] Research on homelessness is essential for policy-makers, program planners, service providers, and community groups. This knowledge can play an important role in public education and awareness campaigns, policy decisions, resource allocation, program development, and program or policy evaluation.[2] The identification of needs and priorities for research on homelessness is, therefore, a valuable undertaking.

The two primary goals of this article are to provide an overview of previous research on homelessness and the relationship between homelessness and health (with a main focus on Canada), and to spur discussion regarding strategic directions for future research. The National Homelessness Initiative has called for a comprehensive Canadian research agenda to "lay the foundation for understanding the root causes of homelessness, support policy development and serve as a resource for accountability and reporting." Development of this agenda will require active engagement by a wide range of stakeholders, including homeless people, those at risk of becoming homeless, service providers and advocates for homeless people, government representatives, researchers and research funding agencies.

METHODS

A variety of strategies were used to identify literature on homelessness that reflected diversity in both geographical and topical focus. This was deemed essential considering that many important sources of information are found in reports from government and community agencies, in addition to the peer-reviewed academic literature. This article is not a comprehensive review of the literature on homelessness in Canada, but rather an effort to frame the different types and areas of research for the purpose of developing future work.

An initial search strategy involved the use of electronic databases, including major social sciences, health and humanities databases. A second strategy sought out examples of literature from government, community, advocacy and service

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1. Institute of Health Promotion Research, University of British Columbia
2. Centre for Research on Inner City Health, St. Michael's Hospital; Faculty of Medicine, University of Toronto
Correspondence: Dr. James Frankish, Associate Director, Institute of Health Promotion Research, Room 425, Library Processing Centre, 2206 East Mall, Vancouver, BC V6T 1Z3. Tel: 604-822-9205, Fax: 604-822-9210, E-mail: frankish@interchg.ubc.ca

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websites. Examples of homelessness research, program descriptions and policy documents were collected. Canadian literature was the primary target of these searches, but review papers from international sources were also included for comparison purposes and to provide additional examples of interventions. Only documents that identified homelessness as a major focus were collected. Papers and reports on housing policy and programs were only included if they focussed on homelessness. General reports on housing policy and programs were excluded. Only literature and reports published since 1990 in English were reviewed.

Collected documents were reviewed and categorized. Research was defined broadly to include the systematic generation of new knowledge through a variety of means, including descriptive reports. A more restrictive definition (for example, one based on specific methods such as controlled trials) would have excluded a large proportion of the literature on homelessness in Canada. Research within the following categories were included:

1. conceptual research (examining the definition/meaning of homelessness),
2. environmental scans (documenting the extent of homelessness and health and social issues related to homelessness),
3. methods research (focussing on the development of new tools for studying homelessness),
4. needs assessments (focussing on the needs of the homeless as expressed by the homeless and service providers),
5. evaluation research (describing the process and outcomes of programs and policies), and
6. intervention research (examining the effectiveness of programs and services).

The scope of homelessness in Canada

Many efforts have focussed on obtaining a clearer understanding of the nature and extent of homelessness in Canada. Canada's first efforts to provide an estimate of the homeless population began in 1987 through the work of the Canadian Council on Social Development.[1] Further efforts at measuring homelessness have been undertaken by Statistics Canada. Data from the 2001 Census indicated that over 14,000 individuals were homeless in this country.[3] Most advocates and researchers, however, believe that these numbers vastly under-represent the problem, and new strategies are necessary to accurately capture usable information. Other strategies include the development of the Homeless Individuals and Families Information System (HIFIS) that focusses on capturing more complete information on shelter users in cities across Canada.[4] Specific cities in Canada have also initiated local *homelessness counts* in an attempt to measure the numbers of homeless and at-risk persons in their jurisdictions.

Examples from large urban areas include a report on homeless and at-risk persons in the Greater Vancouver region,[5] the Toronto Report Card on Homelessness,[6] and the City of Calgary Homeless Count.[7] A number of smaller cities and regions have produced similar reports.

The challenges associated with obtaining a clear picture of the scope of homelessness in Canada included the lack of a consistent definition of homelessness, difficulty in identifying homeless persons, the transient nature of homelessness, difficulty in communicating with homeless persons, and lack of participation by local agencies.[1,8] The definition of homelessness is particularly important. Homelessness can be viewed along a continuum, with those living outdoors and in other places not intended for human habitation at the extreme, followed by those living in shelters. These individuals are referred to as being absolutely homeless. Homelessness also includes people who are staying with friends or family on a temporary basis, often referred to as "couch surfing" or being "doubled up". Those at risk of being homeless, include persons who are living in substandard or unsafe housing and persons who are spending a very large proportion of their monthly income on housing. The definition of homelessness is not trivial. It can have profound consequences for policy, resource allocation, and parameters used to evaluate the success of homelessness initiatives. This article focusses on research and interventions related to absolute homelessness. Much of this information has implications for those who are at risk.

Other important aspects of homelessness in Canada are the impact of urbanization, the heterogeneity of the homeless population, and the complexity of the causes of homelessness. Canada is experiencing a rapid and continuing trend towards urbanization, as indicated by the fact that almost 80% of Canadians now live in cities with populations of 10,000 or more (www.sustreport.org/signals/canpop_urb.html). Although homelessness is a problem in rural areas of Canada, it has become an obvious crisis in large urban areas, where availability of affordable housing is limited due to a loss of rental units and a shortage of social housing.[5]

Heterogeneity within the homeless population is important to recognize. Homelessness affects single men and women, street youth, families with children, people of all races and ethnicities, life-long Canadians, immigrants and refugees, and these groups often face different health issues.[9] For most individuals, homelessness represents a transient one-time crisis or an episodic problem; for a distinctly different subgroup of individuals, homelessness is a chronic condition.[10]

There is no single pathway to homelessness. Homelessness is the result of a complex interaction of factors at the individual level (such as adverse childhood experiences, low educational attainment, lack of job skills, family breakdown, mental illness and substance abuse)[11-13] and at the societal level (such as poverty, high housing costs, labour market conditions, decreased public benefits, and racism and discrimination) (see Figure 1).[14-16] Research on homelessness has often reflected disciplinary traditions, with health researchers focussing on individual risk factors and social scientists looking at marginalization, exclusion and economic forces. This is important because the formulation of the causes of homelessness can become highly politicized and can influence public perceptions and policies related to homelessness.[16]

The health status of homeless persons

Causal Pathways

Homelessness is clearly associated with poor health. In reviewing the research in this area, a schema of causal pathways underlying this association may be useful (Figure 1). Homelessness has a direct adverse impact on health (Figure 1, arrow C). Crowded shelter conditions can result in exposure to tuberculosis or infestations with scabies and lice, and long periods of

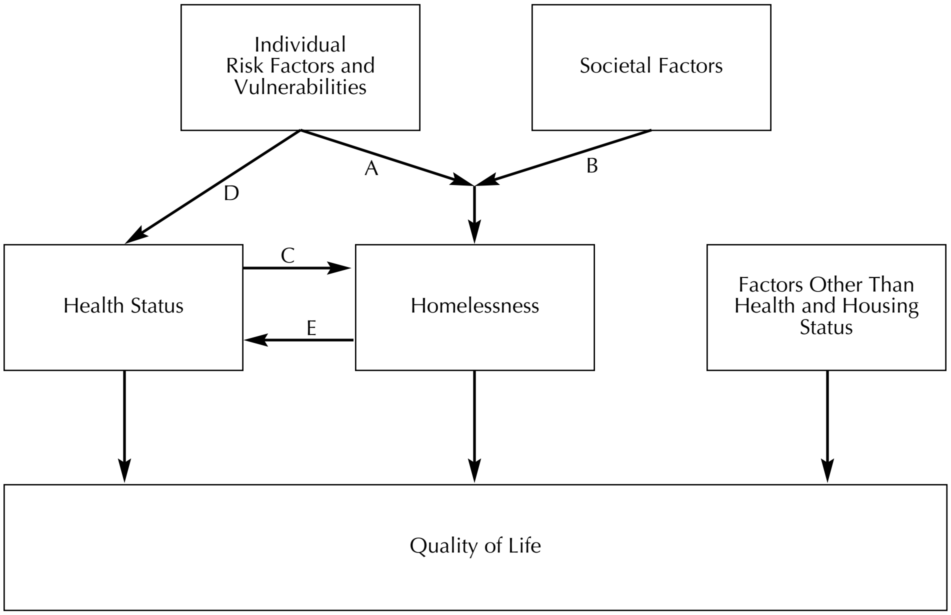

Figure 1. Causal pathways relating homelessness, health, and quality of life.

walking and standing and prolonged exposure of the feet to moisture and cold can lead to cellulitis, venous stasis and fungal infections.[17] However, the relationship between homelessness and ill health is far more complex.[18] Many risk factors for homelessness, such as poverty and substance use (Figure 1, arrow A), are also strong independent risk factors for ill health (Figure 1, arrow D). Many people who are homeless remain at risk for poor health even if they obtain stable housing.[19] In addition, certain health conditions (particularly mental illness) may contribute to the onset of homelessness and then in turn be exacerbated by the homeless state (Figure 1, arrows C and E). Finally, improved health and adequate housing are means of achieving the ultimate goal of improved quality of life. Researchers are now recognizing the need to understand and measure the impact of interventions on quality of life, in addition to housing and health outcomes.[20]

Specific Health Conditions

Homeless people are at greatly increased risk of death. Mortality rates among street youths in Montreal are 9 times higher for males and 31 times higher for females, compared to the general population.[21] Men using homeless shelters in Toronto are two to eight times more likely to die than their counterparts in the general population.[18,22]

The prevalence of mental illness and substance abuse is much higher among homeless adults than in the general population. Contrary to popular misconceptions, only a small proportion of the homeless population suffers from schizophrenia. The lifetime prevalence of schizophrenia is only 6% among Toronto's homeless.[23] Affective disorders are more common, with lifetime prevalence rates of 20-40%.[13,24] Alcohol use disorders are widespread, with lifetime prevalence rates of about 60% in homeless men.[24] Cocaine and marijuana are the illicit drugs most often used by homeless Canadians.[25] Patterns of substance abuse and mental illness vary across subgroups of homeless people: single women are more likely to have mental illness and less likely to have substance use disorders than single men.[24] Female heads of homeless families have far lower rates of both substance abuse and mental illness than other homeless people.[26]

Homeless people are at increased risk of tuberculosis (TB) due to alcoholism, poor nutritional status and AIDS.[27] In addition, the likelihood of exposure to TB is high in shelters due to crowding, large transient populations and inadequate ventilation.[28] Canadian data on the incidence and molecular epidemiology of TB among homeless people are lacking. In the US, more than half of TB cases among homeless people represent clusters of primary tuberculosis, rather than reactivation of old disease.[29] Treatment of active TB in the homeless is complicated by loss to follow-up, non-adherence to therapy, prolonged infectivity and drug resistance.[30] Directly observed therapy results in higher cure rates and fewer relapses.[27] Homeless persons with positive skin tests without active TB may be considered for directly observed prophylaxis.[31]

Among homeless youth in Canada, risk factors for HIV infection include survival sex, multiple sexual partners, inconsistent use of condoms and injection drug use.[32] Infection rates were 2.2% and 11.3% among homeless youths seeking HIV testing at two clinics in Vancouver in 1988.[33] In contrast, the prevalence of HIV infection was only 0.6% in a group of homeless youths surveyed in Toronto in 1990.[34] In a 1997 study of homeless adults in Toronto, the HIV infection rate was 1.8%, with increased risk observed among individuals with a history of using IV drugs or crack cocaine.[35] A study of homeless adults and runaway youth in 14 US cities in 1989-1992 found HIV infection rates ranging from 0 to 21% with a median of 3.3%.[36]

Sexual and reproductive health are major issues for street youth. Studies of street-involved youth in Montreal have documented high rates of involvement in survival sex, sexually transmitted diseases and unplanned pregnancy.[32,37,38] Anecdotal reports suggest that pregnancy is common among street youths in Canada; in the US, 10% of homeless female youths aged 14-17 years are currently pregnant.[39]

Injuries and assaults are a serious threat to the health of homeless people. In Toronto, 40% of homeless persons have been assaulted and 21% of homeless women have been raped in the past year.[40] Unintentional injuries due to falls or being struck by a vehicle, as well as drug overdoses, are leading causes of mortality among homeless men in Toronto.[21]

Homeless adults suffer from a wide range of chronic medical conditions, including seizures, chronic obstructive pulmonary disease and musculoskeletal disorders.[40] Hypertension and diabetes are often inadequately controlled.[41,42] Homeless people in their 40s and 50s often develop health disabilities that are commonly seen in persons who are decades older.[43] Oral and dental health is poor.[44-46]

Homeless people face many barriers that impair their access to health care, even under the Canadian system of universal health insurance.[1] Many homeless persons do not have a health card, are unable to make or keep appointments, or lack continuity of care due to their transience (i.e., no permanent address or telephone).[1] Homelessness entails a daily struggle for the essentials of life. Competing priorities may impede homeless people from obtaining needed health services.[47] Access to mental health care and substance abuse treatment remains a crucial issue.[48] Obtaining prescription medications can be problematic and adhering to medical recommendations regarding rest or dietary modification is often impossible.[41,49] Studies from the US have shown that homeless adults have high levels of health-care utilization and often obtain care in emergency departments.[50,51] Homeless people are hospitalized up to five times more often than the general public[52] and stay in the hospital longer than other low-income patients.[53]

Interventions to reduce homelessness and improve the health of homeless persons

This section provides an overview of the wide array of interventions reported within the literature that have attempted to decrease the prevalence of homelessness and improve the health of homeless people. We have classified these interventions into four clusters using a taxonomy derived from the literature, theory and past experience: (a) biomedical and health care strategies, (b) educational and behavioural strategies, (c) environmental strategies, and (d) policy and legislative strategies. For each cluster, we provide a brief description, examples of interventions of that type, and a summary of research gaps and opportunities within that cluster. These clusters are not mutually exclusive; some interventions may fit under more than one cluster.

Biomedical and Health Care Strategies

This cluster of strategies focusses on medical interventions to improve health status and includes primary health-care programs, clinical services through outreach programs, psychiatric treatment teams and substance abuse treatment. Interventions that are purely biomedical, however, may improve the health of homeless people but fail to address their homelessness. Thus, interventions that combine health care with housing and other social services need to be considered.

Only a small number of studies have examined the effectiveness of biomedical or health care interventions for homeless people using a rigorous controlled design. Most of these studies have focussed on homeless persons with mental illness or substance abuse. For example, studies have confirmed the effectiveness of the Assertive Community Treatment (ACT) model for homeless people with severe mental illness. ACT involves a team of psychiatrists, nurses and social workers that follows a small caseload of clients in the community and provides high-intensity treatment and case management.[48,54] Compared to usual care, patients receiving ACT have fewer psychiatric in-patient days, more days in community housing, and greater symptom improvement. A recent example of a combined housing and health service program is the New York City Housing Initiative.[55] This program made resources available to create 3,300 housing units and social services support for mentally ill homeless persons. Over two years, people in the program stayed in shelters an average of 128 days fewer than similar people in a control group. The treatment of substance abuse in homeless persons has been the subject of a number of studies; a recent review of the literature is available.[56]

Gaps in this area include a lack of research on interventions for homeless youth or families with children, limited research on interventions to address health problems other than mental illness or substance abuse, and little or no data on the effectiveness of various models of primary care delivery for the homeless. Opportunities for future research include a focus on “harm reduction” programs that seek to minimize adverse health impacts among homeless substance users rather than focussing exclusively on abstinence. Examples include “safe injection sites” for drug users and shelter-based controlled drinking programs in which residents are provided with alcohol on a metered schedule.

Educational and Behavioural Strategies

This cluster of strategies seeks to prevent homelessness or improve the health status of homeless persons through educational programs and behavioural change. Educational programs may focus on homeless people, individuals at risk of homelessness, or the general public. Efforts to promote behavioural change in the homeless include harm reduction programs, counselling, and referral services. Education of health-care workers, shelter workers and service providers is included in these strategies. For example, the Streethealth Coalition in Ottawa provides prevention and education on infectious diseases and health conditions often found in the homeless.[57] The Federation of Non-Profit Housing Organizations of Montreal promotes education on a range of basic life skills. Ontario’s Urban Aboriginal homelessness strategy includes culturally appropriate programs, such as cultural counselling and programs, and employment services.

Examples of programs targeting homeless or at-risk individuals include tenants’ rights organizations, eviction prevention services, and groups such as the Safe Homes for Youth in Ottawa, which provides education and support for high-risk youth.[57] Alternatively, educational initiatives may focus on increasing public and government awareness of homelessness issues. Examples include a public awareness campaign in Ontario to aid the public in assisting homeless persons[58] and efforts by advocacy groups such as the Canadian Housing and Renewal Association, the Centre for Equality Rights in Accommodation and the Housing and Homelessness Network in Ontario to promote changes in government policy related to homelessness.

Very little evaluation research has been undertaken on health education programs for the homeless.[59] This constitutes a major research gap. Reports of educational and behavioural interventions have often been limited to basic program information. More in-depth descriptions of development and implementation processes are needed; such information could provide a valuable resource for service providers seeking to begin similar initiatives. Opportunities for future research include a need for conceptual research on educational and behavioural interventions for homeless people, studies on how to make these interventions more accessible and appealing for the homeless population, and rigorous studies to evaluate the outcomes of such programs. Such efforts could benefit from attention to three key factors: motivation of individuals toward change through altered knowledge, attitudes, beliefs and values; enabling individuals to take action through skill building and availability and accessibility of supportive resources; and reward or reinforcement of positive action.[60]

Environmental Strategies

Environmental strategies are attempts to alter the social, economic or physical environment in a specific setting to create a supportive environment that enables and facilitates behaviour change. This approach recognizes that the environment or context in which homelessness occurs may be altered to enhance desired behaviours or limit undesirable actions. The environment or context may vary in scale from a single program (e.g., a supportive housing site or outreach program) to a specific neighbourhood to an entire city, province or country.

Examples of environmental strategies at the program level are Street City in Toronto, which provided services to homeless persons in an environment designed to engage individuals unaccustomed to living indoors,[57] and the Lookout Emergency Aid Society in Vancouver, which provided both short-term shelter as well as long-term supportive housing for adult men and women who were unable independently to meet basic daily needs.[4] A macro-level example is the federal government's Supporting Community Partnerships Initiative, which seeks to promote cooperation/coordination at a local level and to provide "communities with the tools and resources needed to set their own course of action" to respond to homelessness in their community.

Research undertaken in environmental strategies has largely taken the form of environmental scans and needs assessments. Two reviews have documented and categorized a number of Canadian programs/projects that included environmental strategies.[4,57] A number of projects have provided examples of community development processes in the homeless population. Researchers have outlined lessons learned while conducting community-based research on homelessness in Toronto.[61] Others have looked at factors that restrict or facilitate community participation by disadvantaged persons.[62] Opportunities for research include conceptual work to organize and frame these efforts, in-depth evaluations to ensure that programs have measurable outcomes, and translation of information into a form useful for planning.[2]

Policy and Legislative Strategies

This cluster includes efforts to reduce homelessness through policies and legislation related to poverty and its amelioration, social housing, public health, immigration and law enforcement. Recognizing that a variety of policy, regulatory, legislative and political factors create a climate that has an enormous impact on homelessness and its management, these strategies focus on the creation of "healthy public policies."

Examples of current initiatives include the government of Alberta's framework outlining policy responses to homelessness with respect to housing and support services, local capacity development and governmental coordination.[63] The 1999 Vancouver Agreement is an example of collaboration at the federal, provincial and municipal levels to focus on economic, social and community development in the Downtown Eastside neighbourhood, where homelessness is a major issue. Examples of public health policies that have been implemented or considered include safe-injection sites, needle exchange programs and other harm-reduction policies.

These strategies are foundational to all others, because the absence of a strong policy-legislative approach to homelessness will seriously limit and undermine efforts in other areas. There is a need for work to examine the impact of various health and social policies on the lives of homeless people. Particularly vital[64] areas include welfare policy as it affects adults and families with children, policies that impact young women,[65] and practices in the child welfare system that may contribute to youth homelessness.[66,67] Comparing policies in different jurisdictions and their impact on homelessness can provide important insights.[64,68] Government frameworks on homelessness call for efforts to ensure accountability in reaching specific targets and goals. But, there has been relatively little work on policy evaluation in this area. Future research has the potential to provide essential information to guide future policy-making.

STRATEGIC DIRECTIONS FOR FUTURE RESEARCH ON HOMELESSNESS

Based our review, we conclude that Canadian research in the area of homelessness and health faces important challenges. The complexity of the issue of homelessness requires the involvement of a wide range of stakeholders, including all levels of government, service providers, health professionals, biomedical/social science researchers, community groups and homeless people themselves. Both horizontal integration (across various sectors such as health, law, housing, social services) and vertical integration (across federal, provincial, territorial, and local governments, and within communities) are needed. Second, the diversity of values, beliefs and perspectives on homelessness must be acknowledged, and public discourse is needed on the causes of homelessness in Canada and the appropriate response to this problem. Third, consensus needs to reached on the definition of homelessness and the measures by which efforts to reduce homelessness or improve the quality of life of homeless people will be judged. Fourth, researchers need to design and conduct studies on homelessness that are policy-relevant and develop strategies to translate their research into policy and practice. There has been little research evaluating the effects of policy on homelessness or quality of life among the homeless and the vast majority of programs for homeless people have not been evaluated. Many of the evaluations that have been conducted are of modest quality, but at the present time, the resources and expertise that would allow for a robust evaluation are often not available at the local level.

These challenges should not deter or diminish current interests and efforts around research on homelessness and health in Canada. Rather, they call for renewed commitment, strategic planning and wise investment of human and fiscal resources. Within all six categories of research there is significant need for further development. Conceptual research on the definition and meaning of homelessness can provide greater clarity in ongoing discussions of homelessness among advocacy groups and policy-makers. Environmental scans that document the extent of homelessness and the health problems of homeless people are useful, but they remain primarily descriptive in nature. There is a need to move from this understanding to outcome measures and interventions. Methods research could make significant contributions through the development of valid/precise measures of quality of life in homeless people and individuals at risk. Needs assessment research needs to be systematically linked to objectives and interventions. Finally, more high-quality evaluation and intervention research is urgently needed.

Community involvement is vital in any work on homelessness and its conceptualization, measurement or change. While this may seem self-evident, the reality is that many groups often have limited capacity for engagement in these efforts. Concrete efforts are needed to ensure that communities are able to contribute to, and participate effectively in, the study of homelessness and use of research findings. The primary need is capacity-building to allow communities to initiate projects in equitable partnerships with government and academia. Resources must be made available to both promote research by various community groups and to teach research skills such as proposal writing and research design. Potential strategies include workshops, access to research courses at academic institutions, the development of easy-to-use research information, and financial support to allow community members to participate in these activities.

The issue of dissemination remains a key challenge in homelessness research. The question is how we can best communicate the lessons, experiences and best practices of dealing with homelessness. How can this information be communicated in a variety of forms and media that are appropriate to their target audiences? Significant barriers exist, including time, personnel, research capacity and resources.

We suggest three strategic priorities towards a better understanding of homelessness and the implementation and evaluation of efforts to reduce homelessness and improve the lives and quality of life among the homeless. The first priority is a nationwide effort to achieve a core, consensus definition and set of indicators related to the definition and extent of homelessness. Second, we need clear definitions and measures for a) the health status of homeless (and at-risk) groups; b) the use of the health and social services by homeless people; and c) relations between homelessness and broader, non-medical determinants of health (e.g., income, education, employment, social support, gender, culture, etc.). This effort to create a common dataset would not preclude communities from collecting additional data of local interest and value.

A third priority must be the development of research infrastructure. This effort would include the development of demonstration projects or surveillance systems that could reliably collect data on the indicators of homelessness. Government-funded projects that purport to address either the processes or outcomes of homelessness should be subjected to an "evaluability" assessment. Groups such as the Canadian Consortium for Health Promotion Research could assist all levels of government in determining whether current projects/programs are in fact, evaluable. We suspect that many projects and programs presently lack the necessary and sufficient conditions to be fairly evaluated. This effort could move research toward a model of program evaluation that sets realistic expectations in terms of measurement of focussed aspects of homelessness, and one that provides sufficient time and resources to allow for appropriate assessment of homelessness interventions and their effects.

We encourage investment of the needed resources toward the science and application of research on homelessness. Building on its traditions in health promotion and its strengths in population health research, Canada is well placed to be a world leader in intervention research on homelessness. This can be a vehicle for building community health. These efforts may generate additional benefits, including commitment to reducing health disparities, new partnerships across academic disciplines, and intersectoral work on the determinants of health.

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RÉSUMÉ

Cet article a été rédigé en vue d'une conférence de réflexion internationale sur la réduction des disparités en matière de santé et la promotion de l'équité dans les populations vulnérables. Son but était de donner un aperçu de la recherche sur le phénomène des sans abri et de stimuler la discussion sur les orientations stratégiques dans ce domaine. Nous avons retracé les recherches sur l'itinérance, avec un accent particulier sur celles qui ont été menées au Canada. Les études ont été regroupées selon leur sujet et leur cadre dans les catégories suivantes : ampleur du phénomène des sans abri, état de santé de ces personnes, interventions pour réduire le phénomène et améliorer la santé des individus, et orientations stratégiques pour la recherche future. Parmi les principaux problèmes étudiés, mentionnons la définition du phénomène des sans abri et son ampleur, son hétérogénéité et les explications contradictoires de la problématique. Les sans abris présentent un niveau élevé de maladie et le cheminement qui les amène à se retrouver sans-logis et en mauvaise santé est complexe. Parmi les efforts pour réduire le phénomène et améliorer la santé des individus, notons les stratégies de nature biomédicale, éducative, environnementale et politique, tous des domaines caractérisés par de nombreuses carences et possibilités en ce qui concerne la recherche. La recherche stratégique doit s'appuyer sur l'engagement des partenaires et de la collectivité et sur des méthodes plus rigoureuses. Les priorités doivent, entre autres choses, porter sur la création d'un consensus quant à la façon de mesurer le phénomène, l'état de santé des sans abri, le développement de l'infrastructure de recherche, et la volonté de s'assurer que l'on puisse mesurer l'efficacité des futures initiatives.

The Health of Immigrants and Refugees in Canada

Morton Beiser, MD, FRCP, CM

ABSTRACT

Canada admits between more than 200,000 immigrants every year. National policy emphasizes rigorous selection to ensure that Canada admits healthy immigrants. However, remarkably little policy is directed to ensuring that they stay healthy. This neglect is wrong-headed: keeping new settlers healthy is just, humane, and consistent with national self-interest.

By identifying personal vulnerabilities, salient resettlement stressors that act alone or interact with predisposition in order to create health risk, and the personal and social resources that reduce risk and promote well-being, health research can enlighten policy and practice. However, the paradigms that have dominated immigrant health research over the past 100 years – the "sick" and "healthy immigrant," respectively – have been inadequate. Part of the problem is that socio-political controversy has influenced the questions asked about immigrant health, and the manner of their investigation.

Beginning with a review of studies that point out the shortcomings of the sick immigrant and healthy immigrant paradigms, this article argues that an interaction model that takes into account both predisposition and socio-environmental factors, provides the best explanatory framework for extant findings, and the best guide for future research. Finally, the article argues that forging stronger links between research, policy and the delivery of services will not only help make resettlement a more humane process, it will help ensure that Canada benefits from the human capital that its newest settlers bring with them.

MeSH terms: Canada; immigrants; settlement and resettlement; migration policy

La traduction du résumé se trouve à la fin de l'article.

Professor of Psychiatry, University of Toronto; Senior Scientist, Joint Centre of Excellence for Research on Immigration and Settlement (CERIS); National Scientific Coordinator, Reducing Health Disparities Initiative, Canadian Institutes of Health Research (CIHR).

Correspondence and reprint requests: Dr. Morton Beiser, Joint Centre of Excellence for Research on Immigration and Settlement (CERIS), 246 Bloor Street West, 7th Floor, Toronto, ON, M5S 1V4, Tel: 416-946-5351, Fax: 416-921-7080, E-mail: mail@mortonbeiser.com.

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Identifying a category of people as vulnerable implies that they suffer a disproportionate burden of illness, lower than average life expectancy or compromised quality of life. As a group, immigrants fulfil none of these criteria. Immigrants are, on average, in better health than native-born Canadians, and have lower mortality rates. However, shortcomings in immigration and resettlement policy jeopardize immigrants' health advantage.

Canada selects immigrants on the basis of attributes such as education, job skills and youth, all of which are grouped under the rubric of human capital. Screening helps ensure that they are healthy as well.[1] After immigrants enter the country, responsibility for assuring they stay healthy devolves to the provinces. However, aside from defining a mandatory waiting period before becoming eligible for health-care coverage, and arranging surveillance for immigrants with a history of tuberculosis, provincial health policies have little to say about immigrants. Refugees, a sub-category of immigrants, have, by definition, suffered unusual stresses and assaults on their health prior to coming to Canada. In some ways, refugees are like other immigrants. For example, like immigrants in general, refugees have lower death rates than native-born Canadians. However, refugees are in less robust health than their immigrant counterparts, and they have a particular vulnerability to infectious and parasitic diseases.[2]

Expending a great deal of effort to select people to become part of Canada, and then more or less ignoring them is shortsighted. Resettlement experiences exert enormous influence on the eventual health of immigrants and refugees, and on the likelihood that their human capital will fulfil its promise.[3] A century or more of research concerning the health of immigrants and refugees has produced potentially useful findings that are, however, diverse, scattered and sometimes contradictory. This article advances an integrative framework to help make sense of an unwieldy literature. It proposes that the two paradigms that dominated 20th century research and practice – the sick and the healthy immigrant, respectively – were, at least in part, products of the socio-political context of the times, and that they fail to do justice to a complex issue. It further proposes that the current gap between research, policy and practice must be bridged to help ensure that the people who come to this country in apparent good health stay that way.

Background: Canada and immigration

Eighteen percent of the people living in Canada were born somewhere else.[2] In the expectation that immigration will help rejuvenate an aging society, provide both skilled labour where it is needed and unskilled labour for jobs Canadians do not want, and help to ensure present and future competitiveness in the global economy, Canada admits between 220,000 and 240,000 new settlers each year.[2] For reasons having nothing to do with economic benefit, or with compensating for the greying of a nation, about 10% of Canada's annual immigration quota consists of refugees, people deemed to be in need of refuge and protection. Canada is one of roughly 150 countries to have signed a UN Convention, signalling a commitment to protect the persecuted and stateless. Canada is also part of a much smaller group of these Convention signatories – about 20 – who offer not just temporary protection, but the option of permanent resettlement.

National discourse tends to focus on whether immigration fulfils the promise of net economic benefit and on the effects of immigration on social cohesion. The neglect of immigrant health is not only irresponsible, it is wrong-headed. Health is integral to immigrant human capital. If their health is compromised, immigrants cannot achieve their full economic and social potential. Moreover, immigration demands changes in social institutions, none more so than in health and health care; an effective response to this challenge requires information and the development of appropriate expertise.

As they have ever since Confederation, immigrants and refugees resettle in Canada, adjusting and changing their languages, habits, dress, foods and values in the process. They also reshape the language, habits, dress codes, foods and values of Canada.

Change brings challenges to new settlers and the resettlement country alike. However, nothing in the 100-year history of Canada prepared either the country or the immigrants and refugees it received for the diversification in migration flows that began in the 1970s. Before 1970, most immigrants (70% or more) came from Europe, with the United States a distant second (about 15%); Asia was the source region for 10% or fewer of all immigrants, and Africa, the Middle East and the Caribbean accounted for the remaining 5%.[1] Post-1970 figures document a startling reversal. By 2002, Europe and the UK accounted for only 17% of immigrant flows, the US for only 2%. South and Central America (9%), Africa and the Middle East (20%), and Asia and the Pacific (52%) have replaced so-called traditional sources of immigration.[4]

Although Canadian societal institutions – the economy, education, and health – have been slow to respond, the country's changing makeup can no longer be ignored. To adapt to change, the caregiving sector requires information about the health of immigrants and refugees, and about how this evolves over time; an understanding of health determinants, some of which may be similar to those in the majority culture population, others of which may be unique; an analysis of the match between health needs on the one hand, the use of health and related services on the other, and an appreciation of how socio-political context can affect research about and care for new settlers.

Models of immigrant and refugee health

Three somewhat conflicting paradigms have influenced the conduct of immigrant health research: nation states have always been cautious about admitting strangers who might be a menace to the health of the indigenous population, or a threat to its economic well-being. Consistent with these time-worn concerns, the sick immigrant paradigm proposes that it is the least healthy and well-adjusted people who choose to emigrate from their home countries of origin. Taking Canada's rigorous selection policies as its point of departure, the healthy immigrant paradigm portrays immigrants as the cream of the world's crop. According to this framework, if immigrants become ill as they resettle, it is likely due to convergence and/or resettlement stress. Convergence is a process through which, because immigrants are exposed to the health risks encountered by resident Canadians, their good health declines to the more mediocre Canadian average. The resettlement stress model proposes that declining health may be due to stresses inherent in the resettlement process. The interaction framework proposes that health is the outcome of interacting processes including predisposition – which may be genetic, or based on premigration exposures and experience – as well as post-migration stressors and individual and social resources.

The Sick Immigrant Paradigm

Until at least the middle of the 20th century, the idea that immigrants were sick and that the public needed to be protected from them dominated North American thinking. There was good reason for this, since it was immigrants from Europe who brought measles, smallpox, cholera and syphilis to the continent in the 16th and 17th centuries.[1] Protecting the public's health and economic well-being continues to guide federal policy. For example, Canada's *Immigration and Refugee Protection Act* refers to migrant health in only one place, s. 38.1, which mandates rejecting an applicant if he/she is (a) likely to be a danger to public health, or (b) to pose a danger to public safety, or (c) if he/she might reasonably be expected to cause excessive demand on health or social services. The last restriction does not apply to refugees or persons admitted to rejoin family. Regulations stemming from the Act call for continuing provincial surveillance of immigrants or refugees who have been granted permanent residence status, but who have evidence of inactive tuberculosis or who have been successfully treated for syphilis.

Refusing entry to people who might jeopardize public safety and/or empty the public purse seems reasonable. Politics can, however, all too easily use concern for the health of the public as a convenient smokescreen. Late 19th century Canada was ambivalent about immigrants who did not come from the "right" places, meaning Britain, northern Europe and the United States. The country needed cheap Asian and southern European labour to help build the railroads, cut down forests and work in mines, and it needed eastern European know-how to make central Canada's fields produce grain. But it was not at all sure that Canada wanted these people to stay.[5-9] Selection and settlement policies militating against non-white immigrants remained in effect until 1967, when they were replaced by a colour-blind system based on points assigned according to an applicant's human capital.

Rather than always supplying ballast for reasoned argument, science has been a sometimes naïve, sometimes complicit bedfellow of politics.

Until well after World War II, the sick immigrant paradigm fuelled anti-immigrant discourse. Psychiatry provides the most obvious example. G.F. Bodington, a powerful British Columbia mental hospital superintendent, inveighed against foreign governments for shipping off to Canada "weak-minded young persons…[to]…swell the ranks of the already too numerous lunatics…."[5] Toronto-based C.K. Clarke, a leader of pre-World War II Canadian psychiatry, wrote articles with titles such as "Keeping this young country sane," in which he cautioned that the influx of the genetically weak threatened to impair the quality of Canadian stock.[10] A popular explanation for migrants' putative mental fragility was that they were individuals who chose to leave home because they were the least well-integrated, and perhaps the least competent people in their respective societies.[11,12]

Statistics showing that mental hospitalization rates among immigrants were higher than among the native-born lent credence to the mentally sick immigrant paradigm.[13-15] However, hospital statistics confuse the amount of mental disorder a group suffers with the resources they can call upon to deal with problems. When mental illness strikes a member of a small, isolated or fragmented community, he or she may experience different treatment than someone suffering the same type of disorder who belongs to a community that can call on traditional healers, supportive family, or health-care professionals who understand the language and share the ethnocultural background of the patient. Hospitalization – usually the last resort in an episode of illness – may take place quickly in the first scenario, but take much longer, or even be avoided, in the second. A groundbreaking study by H.B.M. Murphy[16] illustrates this point. Murphy showed that mental hospitalization rates for immigrant groups in Canada increased as the size of the like-ethnic community decreased. Consistent with these findings, Bland and his colleagues[17] demonstrated that migrants as a whole were no more likely than members of the general public to be hospitalized for schizophrenia. Immigrants who were also members of ethnic minorities were, however, overrepresented on hospital rolls.

Undeterred by methodologically flawed studies, leading psychiatrists such as Bodington and Clarke argued in favour of psychiatric surveillance to make it tougher to get into Canada. Interestingly, although health officers during the early years of the 20th century could turn down a prospective immigrant if they found any evidence of insanity, neurosis or feeble-mindedness, psychiatric disorder accounted for less than 1% of all rejected applications.[5]

Psychiatry played a more significant role in a second method of crowd control – expulsion. Between 1900 and 1940, approximately 10,000 people were expelled from Canada every year, 10% of them – nearly 1,000 annually – for psychiatric reasons. Statistics from the one province, British Columbia, that recorded deportations by country of origin, suggest ethnic bias. Between 1921 and 1936, 6-7% of Canadian immigrants who had been born in the UK and admitted to a mental hospital were deported: comparative figures for Finns were 35%, for Hungarians 40%, and for Slovaks 65%.[5]

Nowadays, all immigrants, with the exception of refugee claimants, undergo comprehensive medical screening before entry. Perhaps partly as a result of these practices, newly resettling immigrants are, on average, healthier than resident Canadians.[2,18-23] Nevertheless, the idea that immigrants bring with them diseases such as syphilis, malaria and tuberculosis (TB) continues to be evoked as an argument against immigration.[24]

Screening and mandatory pre-entry treatment obviate the spread of syphilis by immigrants, and the mosquito vector necessary to infect humans with malaria is not found in Canada. However, TB is a more serious issue.

The major source countries for contemporary immigration are burdened with high rates of TB. For example, in the Philippines and China – currently the two major sources of Canadian immigration – the rates are 316 per 100,000 and 88 per 100,000 respectively. In Afghanistan, a major refugee-sending country, TB cases number 321 per 100,000.[25]

Tuberculosis rates fell in Canada throughout most of the 20th century, reaching an all-time low of 6.9 cases per 100,000 per year in 1987. However, rather than continuing to fall, the prevalence of the disease has since stabilized, and continues to hover within a range of 6.9 to 7.4 cases per 100,000 per year. Immigration helps account for TB's tenacity. Although the foreign born make up approximately 18% of Canada's population, they account for almost 60% of all cases of TB.[26] Most cases of active infection occur within five to seven years after initial resettlement.[27-33] Immigrant-receiving countries in Europe, Australia and the US have reported consistent findings: immigrants and refugees have a 4- to 10-fold greater risk of developing TB than non-Aboriginal native-born people.[27,31,34-38]

Do immigrants and refugees bring TB with them, as the sick immigrant paradigm suggests?

The rigorous health screening immigrants undergo as part of their entry requirements argues against this interpretation. Both Canada and the US require that immigrant applicants have a negative sputum culture and a normal chest X-ray. The system is not foolproof, however. People admitted under non-resident visa categories – a category that includes inland refugee claimants – do not receive pre-entry screening. Fraud is another possible explanation. Although plausible, and the subject of many anecdotes, the use of fraudulent X-rays is difficult to establish, its possible impact on the high rates of TB among new settlers probably impossible to determine.

For hundreds of years, countries have used quarantine to protect themselves against importing infectious illnesses. Although it does not quarantine prospective immigrants suspected of having TB, Canada disqualifies applicants who have X-ray abnormalities compatible with active TB until they have been successfully treated and found to be free from active disease.[1]

Modern-day quarantine has sometimes jeopardized health. During the winter of

1993-94, Dutch researchers studied the health of refugees who, while waiting to be officially processed, were housed in an offshore cruise ship. By the time health inspections took place, TB had spread not only among the refugees themselves, but also among the staff. The mini-epidemic was not the result of high initial rates of disease. Although there were a few carriers among the group placed under quarantine, disease spread resulted from inadequate living conditions and poor ventilation.[39]

In his book, *Silent Travellers: Germs, Genes, and the Immigrant Menace*, Kraut[40] describes late 19th century and early 20th century screening of immigrants on Ellis Island in New York. Charged with identifying carriers of dangerous or loathsome diseases, insanity and idiocy, medical officers examined thousands of would-be immigrants with a long list of conditions that could exclude entry. Despite rigorous screening, most immigrants proved to be healthy, and were admitted. Within a few years, however, the new settlers were suffering high rates of illness, including TB. In Kraut's view, immigrants had not brought TB with them, but, instead, contracted it after being admitted to the US where they faced overcrowded living conditions and poor diets, and were subjected to exploitative and physically hazardous work situations, all of which increased the likelihood of exposure and decreased their resistance to disease.

Explanations like Kraut's, which shifted the onus of disease from the individual and placed it in the lap of society, were consistent with the socio-political climate of the 1950s, 60s and 70s. The new optimism about human nature characteristic of these times prompted a new social construction of immigrants: perhaps they were not all sick or misfits, but strong, adventurous and healthy people. The "healthy immigrant,"[41-43] a popular construct consistent with post-1960s values, offers both good news and bad news. It proposes that immigrants are healthy when they arrive, but that they are fated to lose this advantage.

The Healthy Immigrant Paradigm

According to analyses of Canada's National Population Health Survey (NPHS) data,[19,22,23] short-stay immigrants (people present in Canada 10 years or less) have fewer chronic illnesses and less disability than either native-born Canadians or long-term immigrants. After 10 years, immigrant and native-born health patterns are similar. Using a different data set, the Canada Community Health Survey, Perez[42] describes a similar pattern. Immigrants present in Canada for less than 29 years have a lower risk of suffering a chronic health condition than their Canadian-born counterparts. However, the age- and sex-adjusted odds ratios for chronic illness among immigrants living in Canada 30 years and more equal those for non-immigrants.

There are conceptual and methodological issues that provide a basis for caution in inferring that resettlement makes people sick. First, studies that appear to support the concept have not been based on longitudinal follow-up of newly settled immigrants, but, instead on comparing the health of new settlers with those who came earlier. As already noted, in the years following 1970, immigrants began to come from very different parts of the world than the majority of their predecessors. Cross-sectional analyses run the very real risk of confounding time with cohort effects. Secondly, although the trends seem to apply to chronic conditions in the aggregate, specific conditions do not display a clear-cut pattern. For example, heart disease among men and cancer in women follows the trajectory predicted by the healthy immigrant effect. However, there is no demonstrable association between length of residence and increased risk of heart disease among women or cancer among men, or of diabetes or high blood pressure among either sex.[42]

Research reports supporting the healthy immigrant paradigm effect often fail to acknowledge that "immigrant" is far from a homogeneous category. For example, Chen et al.[19] and Newbold et al.,[22] both of whom affirm the healthy immigrant effect, also present data showing that immigrants from the Americas and Europe tend to be in worse health than immigrants from Asia and Africa. Asians and Africans tend to be more recent arrivals,[1] and have perhaps been subjected to more rigorous screening than people who came to this country earlier.

Aside from cohort effects, selective in- and out-migration could help explain the healthy immigrant effect. The subsample of immigrants coming to Canada whose ambitions go unrealised and who choose to leave, tends to be the most highly skilled[44] and may be the healthiest.[45] Selective out-migration of the healthiest people could account for the apparent decline in immigrant health.

Determining the extent to which the putative healthy immigrant effect applies to all or even any immigrants, and to all or any illnesses, and the extent to which it is a research artefact, constitutes an important research priority.

Two subcategories of the healthy immigrant model – convergence and resettlement stress – are based on proposed mechanisms explaining deterioration in immigrant health over time.

Convergence

According to the convergence premise,[20,46-48] exposure to the physical, social, cultural and environmental influences in a destination country sets in motion a process in which migrant patterns of morbidity and mortality shift so that they come to resemble the (usually worse) health norms of the resettlement country.

Part of the shift is passive, a product of immigrants' and their native-born counterparts' exposure to the same environmental toxins, stressors and pollutants. Part of the change may be due to more active processes such as adopting receiving society bad habits including smoking, drinking to excess, and eating junk foods,[49,50] and/or abandoning protective health behaviours that characterize many immigrant cultures.

Some research on cardiovascular disorders – conditions that account for one third of deaths worldwide[51] – is consistent with the convergence model. Marmot and Syme,[52] for example, found a higher prevalence of heart disease among Japanese male migrants to California and Hawaii than among their non-migrant counterparts in Japan. The authors also observed a dose-response relationship: coronary heart disease was three to five times more common among the most acculturated, as compared to the least-acculturated immigrants. First-generation Japanese immigrants in Hawaii had less cardiovascular disease than the second generation, whose health profiles approximated those found among native-born Hawaiians.

Obesity is becoming one of the industrialized world's major health concerns.[53] In

Canada, the prevalence of obesity rose from 5.6% in 1985 to 14.8% in 1998[54] and in the US obesity is a contributing cause of 280,000 deaths per year.[55]

China and Africa, two of Canada's leading source regions for immigration, boast the lowest rates of obesity (<5% of the population) in the world,[53] an observation suggesting that immigrants should be less prone to obesity than Canadians in general. Reports based on data from Canada's National Population Health Survey (NPHS) appear to bear this out.[56] The observation that the prevalence of overweight (Body Mass Index >25) seems to increase with increasing length of stay in Canada[57] implicates Canada's bad health habits as a possible risk factor. Unfortunately, immigrants are underrepresented in the NPHS, a limitation that obviates potentially informative analyses that could take into account factors such as age, gender, ethnicity, exercise and diet.

Obesity is linked with type 2, or non-insulin dependent diabetes, a condition affecting 177 million people around the world, and implicated in approximately 4 million global deaths per year.[53,58-60] Studies suggest that the prevalence of type 2 diabetes rises in concert with emigration from less affluent, to more affluent countries. After relatively diabetes-free immigrants resettle, their health apparently deteriorates. Immigrant rates of diabetes do not, however, converge with majority population norms, they overshoot them.[58] South Asian immigrants in Canada, for example, have higher rates of type 2 diabetes than native-born Canadians[61] and in the UK, South Asian immigrants have five times more type 2 diabetes than members of the indigenous British population.[62]

Some Canadian data about cancer among Italian migrants and their offspring[63] are more consistent with the convergence model. First-generation Italian immigrants have low rates of colon, lung and breast cancers – diseases with an etiology strongly embedded in environmental factors – while rates of illness among their offspring are midway between those of their immigrant parents and members of the receiving society. Balzi et al.[63] also report a dose-response effect: the risk that immigrants will develop colon cancer increases with increasing length of time in Canada.

Asians who migrate to the US have a higher risk of developing colorectal cancer than their counterparts who remain in Asia. Compared to US-born Caucasians, Chinese and Filipino immigrants have lower rates of colorectal cancer. However, Chinese and Filipinos born in the US have higher rates than US-resident members of the same ethnocultural communities who were born abroad. It is tempting to invoke the idea that, as Asians adopt western diets which are typically high in meat, sugar and alcohol – foods associated with increased risk for cancer[64] – the risk of developing the disease rises accordingly. Research demonstrating that descendants of Japanese immigrants are more likely than the first generation to eat western rather than Japanese-style meals,[65] and that, compared to their counterparts born abroad, US-born Japanese eat more sugar, drink more alcohol, and consume more calories per day[66] lends credence to this interpretation.

Immigrant men experience a greater risk of rectal cancer during resettlement than immigrant women, possibly because women change their dietary habits more slowly than men.[62,66] Women are, however, not immune to rectal cancer, nor apparently to the effects of resettlement. Compared to Asian women born in their home countries, US-born Asian women have a 60% increase in rates of cancer. In comparison with women born in Asia and whose four grandparents were also born there, women born in the US and who had one grandparent who had also been born in the west had a risk of cancer 1.4 times greater; for women with two western-born grandparents, the risk rose to 2.2, and for three grandparents, it rose to 2.9.[67]

The increase in risk for colorectal cancer coincident with immigration status is particularly dramatic among Japanese. Compared to Japanese born in Japan, US-born Japanese are twice as likely to develop cancer. Japanese born in the US not only have higher rates of cancer than their non-immigrant and foreign-born counterparts, but a 60% greater risk of developing the disease than US-born Caucasians.[68]

Countries routinely use infant and perinatal mortality rates to index economic and social development. According to Carballo, Divino and Zeric,[69] immigrant-sending countries tend to have high infant and perinatal mortality rates. In line with this observation, research has demonstrated that, compared to native-born women, immigrant women in France and Britain experienced higher risks of perinatal morbidity and mortality.[70-73]

Other research, however, qualifies interpretation of such results by demonstrating that perinatal mortality rates vary, not according to immigration levels in general, but according to the ethnicity and country of birth of immigrant mothers. For example, UK studies have demonstrated particularly high perinatal mortality among immigrants from Pakistan and the Caribbean.[69,73-75] Moroccan and Turkish women living in Belgium have higher than average perinatal and infant mortality rates. In Germany, rates of perinatal and neonatal mortality were higher in foreign-born groups, especially babies born to Turkish mothers.[69] Findings bearing on perinatal mortality might be explained by socio-economic disadvantage, a factor often overlooked in the analysis of research data pertaining to immigrants.

Ali[18] suggests that the healthy migrant effect applies to mental, as well as physical health. Using data from the Canadian Community Health Survey (CCHS), a study of 131,000 Canadians aged 12 or older, Ali demonstrated that all immigrants, with the exception of those who had been in the country 30 years or more, had lower rates of depression and alcohol dependence than the Canadian-born population. The risk of mental disorder among long-stay immigrants was, however, higher than that for the age-matched segment of the general Canadian population. Ali's claim that these data demonstrate the healthy immigrant effect is, however, far from compelling. First, the CCHS data are cross-sectional, not longitudinal. Inferring longitudinal trends from cross-sectional findings risks the confounding of time with cohort effects. Canadian immigration patterns have changed dramatically over a 30-year period. Immigrants taking part in the CCHS who had been living in Canada 30 or more years are highly likely to have come from Europe or North America. Immigrants who arrived in more recent years are more likely to have their origins in Asia and Africa, regions with low rates of depression and alcohol dependence.[14] Unfortunately, Ali's investigations of the effect of length of resettlement do not include country of origin or ethnicity. The evidence for convergence is, furthermore, compromised by the fact that rates of disorder among different length-of-stay cohorts is not linear, but, instead, highly irregular.

Ali's data provide a plausible basis for inferring that immigrants present in Canada 30 or more years are a group at high risk for mental disorder. It may be that more rigorous selection processes in recent years account for healthier immigrant cohorts. Alternatively, as Lai's[76] data suggest, aging may be a more risk-prone process for immigrants than for the Canadian-born.

By definition, the convergence model proposes that, as newly arriving immigrants become increasingly exposed to the environments their native-born counterparts have always known, the superior health of the former inevitably declines until it equals that of the latter. As research about cancer,[67] TB,[27,33-37] cardiovascular disorder,[77] overweight,[57] neonatal and perinatal mortality,[70-73] and mental illness[18,78] demonstrate, however, the average health of new immigrants does not always deteriorate to equal that of the receiving society: it can get worse.[22,66,79,80] This phenomenon, called immigrant overshoot, directs attention to risk factors unique to resettlement, as well as those which immigrants may share with members of the receiving society, but whose effect may be amplified by the resettlement experience.

Resettlement Stress

The resettlement stress paradigm provides an explanatory framework for immigrant overshoot. According to this model, stresses such as unemployment, poverty and lack of access to services have an adverse effect on everyone, but immigration and resettlement increase the probability of experiencing these stresses. For example, during their first 10 years in Canada, an immigrant is much more likely to live in poverty than a native-born Canadian.[81-83] Immigrant families with children are three times more likely to be poor than their native-born counterparts.[82] Poverty not only increases the likelihood of exposure to risk factors for diseases but also compromises access to treatment.[43,45]

In addition to increasing the risk of exposure to adversity, the immigrant situation can amplify the damaging health effects of adverse circumstance. Although unemployment jeopardizes the health of both immigrants and the native-born,[84] it seems to affect immigrants more powerfully,[22] perhaps because, during difficult times, immigrants have fewer resources to call upon than their native-born counterparts.

Age increases the probability of illness for everyone, but it may affect immigrants more profoundly than the native-born. The health status discrepancy between immigrants aged 50 and older and their younger counterparts is even more striking than it is between older and younger people in the general population.[18]

Marginal socio-economic status – an all too common experience for immigrants and refugees, particularly during the early years of resettlement – not only increases the likelihood of exposure to risk factors, but compromises survival rates in diseases such as cancer.[85] Inadequate access to screening and prevention programs may be part of the explanation.[45,46,84] A California study demonstrated that Asian women, with the possible exception of Japanese and Filipino, were far less likely than women in the general population to have received a Pap test for cervical cancer during the three years prior to the survey. The author of the study[86] raises the concern that differential rates of immigrant versus non-immigrant participation in screening programs may be in part the product of a "false sense of security," shared by health providers and immigrants themselves, that Asians are resistant to cancer. To counter this false sense of security, information such as the fact that Vietnamese women are five times more likely than white women to develop cervical cancer[85] should be widely disseminated. Limited English proficiency also creates barriers to preventive health care: although 63.8% of Korean women participating in a US study who were proficient in English reported having a mammogram within the previous two years, the figure dropped to 45% among women with limited linguistic proficiency.[87] Data from the province of Ontario demonstrate that most women do not follow breast screening guidelines suggested by their physicians. Economic disadvantage and health literacy are among the factors predicting non-adherence.[88] Since early detection has enormous impact on survival, Canadian research on immigrant's access to, and use of, cancer screening programs is urgently needed.[2]

Socio-economic and ethnocultural status affect not only access to service, but to quality of care. Blacks with diabetes have more amputations than whites and diabetes-related mortality is increasing more quickly among minorities than among majority culture populations.[89] Black, Puerto Rican, Japanese, Hawaiian and Filipino women in the US are more likely than women in the general population to deliver low birthweight infants. Low birthweight, defined as less than 2500g, has multiple causes, most of which, including caloric intake, smoking, alcohol consumption, lack of social support and stress, affect the mother and/or the developing fetus.[90-93] Inadequate prenatal care, a difficulty disproportionately experienced by socio-economically and culturally marginalized communities, also increases the risk of low-birthweight babies and infant deaths.[94-98] Since the putative causes of low birthweight – risk-inducing health habits and deficiencies in care – tend to heap at the bottom of the socio-economic ladder, they are considered part of the explanatory chain linking socio-economic disadvantage to infant deaths.

An "epidemiological paradox" challenges the explanatory power of socio-economic disadvantage as a sufficient explanation of low birthweight or of neonatal death. A team of US researchers[99] carried out a study of perinatal health among four groups: immigrant Asian, immigrant Mexican, US-born Black, and US-born Caucasian women. In comparison with their white counterparts, US-born Blacks and foreign-born Mexican mothers experienced more putative risk factors including inadequate prenatal care, teen births, a greater tendency to rely on public rather than private care, and lower levels of maternal and paternal education. Foreign-born Asian Indian mothers, on the other hand, were highly likely to enjoy good prenatal care, were rarely teenagers, and the average level of maternal and paternal education was higher than in the four comparison groups. As expected, the US-born Black women were highly likely to deliver low-birthweight babies, and to experience elevated neonatal mortality rates. Despite a comparably high-risk profile, however, Mexican rates for low birthweight and neonatal mortality were no higher than those found among US-born Caucasian women. Although socio-economically advantaged in comparison to the other three groups, Asian Indian women had higher levels of low-birthweight babies, higher levels of fetal mortality and infants who were more likely to demonstrate growth retardation.

Retention of traditional health behaviours offers a possible explanation for epidemiological paradox. Rumbaut and Weeks[100] analyzed birth records for a large US sample of foreign- and native-born women giving birth between 1989 and 1991. Despite the socio-economic advantage of the US-born mothers, immigrant women were, on the whole "superior health achievers" because they were more likely to enjoy social support during pregnancy, less likely to smoke, drink alcohol, or take drugs, and their diets, even if deficient in calories, tended to emphasize carbohydrates and vegetables rather than fats, oils and sweets. Canadian research offers some confirmation of the superior health achiever effect. Doucet et al.[101] found no difference in rates of low birthweight or prematurity among native-born and immigrant mothers in Quebec. A follow-up study[90,91] suggested that highly acculturated immigrant women delivered more low-birthweight babies than their less acculturated counterparts. Other research[102-104] suggests that the higher the level of cultural retention, the greater the tendency to breastfeed.

Although it supports some of the tenets of the resettlement stress paradigm, research in mental health also reveals its inadequacies. During the post-World War II era, when notions about the sick immigrant were being reconsidered, a particular variant of the resettlement stress paradigm, known as the disillusionment model, became very popular. Despite having been based on a very limited number of observations – primarily of World War II displaced persons under psychiatric care – the disillusionment model gained surprisingly widespread acceptance. According to the model, the psychological process of adapting to a new country followed predictable phases.[105-110] During an initial phase – sometimes called the euphoria of arrival – the mental health of immigrants was equal to, or even better than that of the host country population. The second phase, inevitably overtaking the first, was a phase of disillusionment and nostalgia for a lost past. During this phase people were at high risk for developing psychiatric disorders. Eventually, adaptation to the new environment took place; new settlers began to think and act more and more like people in the majority population and their mental health improved.

Community-based studies[109-112] tend to confirm that the period between 10 and 24 months after arrival is a time of high risk for the development of depressive disorder. However, other research[112] demonstrating that a time-specific period of elevated mental health risk is not universal, but appears only among immigrants lacking personal and social supports, points to the need for more complex explanations than either a convergence or resettlement stress model can supply. In addition, research among Southeast Asian "boat people" in Canada contradicts the purported healthy immigrant effect: the longer the refugees stayed in Canada, the better their mental health tended to be.[113,114] The Canadian Southeast Asian refugee study also demonstrated that the occurrence of mental disorder and exposure to putative mental health risk could be out of step with each other. The longer refugees stayed in Canada, the more likely they were to recognize and experience racially based discrimination. Despite the fact that discrimination jeopardizes mental health, the refugees' general level of well-being improved with length of stay.[114,115]

Another epidemiological paradox challenges conventional thinking. Poverty is one of the most powerful factors placing the mental health of children and youth in jeopardy. However, even though immigrant children are three times more likely than their non-immigrant counterparts to live in severe poverty, their rates of emotional and behavioural problems are significantly lower.[82]

The Interaction Paradigm

The unexpected and sometimes apparently contradictory results of research in immigrant health point up the inadequacies of both the sick and healthy immigrant paradigms. A need exists for a model that takes into account immigrant characteristics, pre- and post-migration stressors, and strategies adopted by individuals, their families and the larger society to cope with the immigration and resettlement experience. Such a model must take into consideration that immigrants differ by country of origin, entry class (e.g., immigrant versus refugee), previous exposure to illness, prior experience with the western health care system, levels of acculturation and of cultural retention, and previous health habits, each of which can affect health. Poverty and unemployment are universal health risks and immigration increases the likelihood of exposure to them, as well as the amplitude of their impact. The health effects of social exclusion and discrimination, all too commonly faced by immigrants, are just beginning to receive serious research attention. However, the story of resettlement is not all about predisposition and pain. Individuals, their families, the like-ethnic community, and the larger society develop coping strategies to maintain immigrant health and well-being. A comprehensive model of immigration and health must incorporate the supportive and stress-buffering effects of personal and social resources.

Neither the sick, nor the healthy immigrant paradigm offers an adequate framework to explain disease phenomena such as reactivation in the case of immigrant tuberculosis; predisposition, which may underlie excessive rates of cardiovascular disorder among South Asian immigrants; the "thrifty gene" as a possible mechanism explaining the high risk for obesity among Asian and African immigrants; and the mental health resilience of many immigrant and refugee groups. These models of disease occurrence are consistent with an interaction frame of reference.

Reactivation and Tuberculosis

Because many of the major source countries for contemporary immigration are burdened with high rates of TB,[25] it seems highly likely that immigrants have been exposed to this illness before they emigrate. Poor living conditions increase the risk of TB for everyone. Is it possible that immigrants and refugees – who are more likely than members of the receiving society to live in impoverished circumstance[81-83] – suffer increased risk of TB as a consequence? Canadian data showing that it takes an average of 10 years for immigrants to establish themselves economically,[81] and that during that time, one third of immigrant families live below the poverty line[82] lend credence to the hypothesis that resettlement stress and exposure to bad environments explain high rates of TB among new settlers.

However, reactivation, which posits an interaction between predisposition based on previous exposure and the post-arrival dynamics of resettlement, is the most widely accepted and most likely explanation for TB among immigrants. According to this construct, immigrants suffer high rates of TB in resettlement countries not because they were already ill before they arrived, and not solely because they are exposed to pathogen-containing and stressful environments during resettlement, but because socio-environmental circumstances trigger a reactivation of previous infections.[116]

Research demonstrating that the period of greatest risk during which immigrants develop TB is not immediately after arrival, but five to seven years later,[27-32] and that the risk of developing the disease persists for an extended period thereafter[117,118] supports the reactivation hypothesis. Recent research using DNA fingerprinting, which allows investigators to discriminate between primary and reactivated disease also supports the reactivation hypothesis. DNA studies typically enrol patients with active TB, fingerprint their isolates and then classify them as having either shared (clustered) isolates or unique (non-clustered) isolates. People with clustered isolates are assumed to belong to a transmission chain, and those with unique isolates are assumed to have reactivated disease.[119] According to several molecular epidemiological studies, foreign-born people are more likely to have unique, rather than clustered isolates, and there is minimal evidence to suggest foreign-born to native-born transmission.[120,121]

Even if it were the case that most cases of TB among immigrants were due to reactivation rather than to new infection, the possibility that exposure to unhealthy environments makes an independent contribution to the burden of TB among immigrants could not be ruled out.[119] In a study carried out in New York, Geng et al.[122] fingerprinted 546 isolates of *M. Tuberculosis,* about half of which belonged to a cluster (likely transmitted) while the rest were unique (indicative of reactivation). Foreign-born persons were much less likely to be in the clustered group (odds ratio 0.47, 95% CI 0.33-0.67). Nevertheless, this study showed that almost half of all TB patients who had been in the US 10 years or less and who were not HIV positive had clustered isolates, suggesting recent transmission. In a similar study of TB transmission among Somalis in Denmark,[123] 55% of the TB cases were clustered. Although it is possible that some of these clustered cases were acquired in Somalia, it is also possible that many were primary infections acquired in Denmark.

Genetic Predisposition plus Environment

The explanation for TB among immigrants posits an interaction between environment and predisposition, the latter based on previous exposure. Interaction models for other conditions posit genetically based predisposition.

Canadian research[48] suggests that immigrants have better cardiovascular health than the native-born, and that this advantage tends to be lost over time. Immigrants are not, however, all alike. Ethnicity, for example, affects cardiovascular health. A UK study[77] showed that men and women from India had the highest standardized mortality rates due to cardiovascular disease, and that young Indian men were at particularly high risk. Irish, Scottish and Polish immigrants also had high rates, while people from the Caribbean, western Europe, the US and old Commonwealth countries (Canada, Australia, New Zealand) had lower death rates. This study examined mortality rates over two separate periods, 1970-72 and 1979-83. Between the two time periods, mortality due to cardiovascular disease declined by 5% for men and 1% for women. The greatest percentage declines occurred among groups with the lowest rates – immigrants from the US, and the old Commonwealth. Comparatively little improvement was seen among groups with high mortality rates, namely the Irish and Polish. South Asians, the group with the highest rates in 1970-72, actually experienced an increase in risk during the subsequent decade.

Regardless of where they live in the diaspora, South Asians suffer high rates of cardiovascular disease. Based on this observation as well as other studies, researchers have posited that a genetically based insulin resistance, combined with changing dietary habits sets the stage for the development of a high-risk atherogenic profile.[61,80,124,125]

Cancer research also highlights the interplay between predisposition, changes in health behaviours, and the duration and intensity of exposure to etiological agents.[63,126,127] For example, Japanese born in the US are twice as likely as Japanese born in Japan to develop cancer. US-born Japanese not only have higher rates of cancer than their non-immigrant and foreign-born counterparts, but a 60% greater risk of developing the disease than US-born Caucasians.[67] Since rates of colorectal cancer in Japan have historically been very low, the dramatic increase in the disease among Japanese in North America has stirred considerable interest. Kampman et al.[79] have proposed that Japanese harbour a genetic predisposition for colorectal cancer, but that the traditional dietary habits militate against the development of the disease. According to these authors, the adoption of a North American diet, when combined with predisposition, explains elevated risk.

Compared to majority culture Caucasians, most, if not all, minority groups experience a two- to six-fold greater risk of developing non-insulin-dependent diabetes.[89,128] In addition, all minorities living in the US (for whom the data exist) suffer a higher prevalence of diabetes than residents of their respective countries of origin.[89] Although newly arriving immigrants are less likely to be obese than native-born Canadians, the longer they stay, the more likely they are to become fat.[57]

To explain such phenomena, researchers have hypothesized that minority and immigrant groups may share a predisposition for non-insulin dependent diabetes, or that "western" environments place them at elevated risk of exposure to risk-inducing conditions, or a combination of the two. Westernization induces people to adopt a diet higher in total calories and fat but lower in fiber than they are used to, while simultaneously encouraging reduced expenditure of energy.[95,129] Like international migration, rural to urban movement within developing countries is also associated with increased risk for diabetes, an observation that stimulated the development of the thrifty genotype model. According to this model, a thrifty genotype evolved among humans living in situations of scarcity; however, under conditions of plenty, this evolutionary adaptation becomes a predisposing factor for obesity and diabetes.[89]

Predisposition, Stress and Coping: The Case of Immigrant Mental Health

An abundance of inconsistent findings in studies of mental health provides further illustration of the need for more complex explanations than either the sick or healthy immigrant models can provide. For example, although Mexican immigrants in the US suffer a high burden of distress,[78] other research reports no difference in rates of psychological disturbance between immigrants and natives of the receiving society.[130-132] Some community-based inquiries have even suggested that immigrants, and indeed refugees, have fewer emotional problems than the native-born.[114-133,134]

Although they face a fairly common set of stressors, only a small proportion of immigrants and refugees become psychiatric casualties. This observation strongly suggests that it is not immigration *per se*, nor even its challenges that creates mental health risk, but rather the interaction among vulnerabilities, stressors, social resources and personal strengths.[3,114]

Lists of potential mental health stressors usually include pre-migration experience,[113,135-144] acculturation,[145-148] unemployment[84] and structural characteristics of the new society that block opportunity or oppress newcomers.[3,114,115,149]

Pre-migration traumata, such as internment in refugee camps, jeopardize mental health after arrival in a country of permanent resettlement. In the short run, the effect tends to be evanescent; six months or so after arriving in a country of permanent resettlement, it is no longer demonstrable.[11,113,135,150] Furthermore, many traumatized individuals are able to use repression as a coping strategy to buffer the impact of potentially damaging memory.[113]

Although many people can apparently keep the past under wraps for a time, others experience sporadic eruptions of traumatic memory, which take the form of episodes of post-traumatic stress disorder (PTSD), depression and somatisation.[141,151-156] Studies showing a dose-response relationship – that is, the greater the exposure to the stressor, the greater the likelihood of subsequent post-traumatic stress disorder[151,157,158] – support the posited etiological link between adversity and psychopathology. Using a broad definition of mental ill health, Steel[158] and his colleagues showed that, despite having experienced severe trauma about 14 years before they were interviewed in Australia, most refugees from Vietnam were in good mental health. However, people who had been exposed to more than three traumatic events had an almost five-fold greater risk of disorder than the rest of the refugee population. Goldberg and colleagues[159] provide some of the most telling evidence of the effects of trauma: 15 years after the end of the Vietnam War, veterans who had been in combat had a far higher risk of developing PTSD than their non combat-exposed monozygotic twins.

Repression may be an effective short- and medium-term strategy for dealing with past traumas. However, research[114,142-144] suggests that over time, recovery of the past becomes increasingly pressing, and that it is accompanied by increased risk of mental disorder. Carefully planned interventions may help refugees deal with the psychological residue of trauma and with the pain of recapturing the past. However, to ensure that intervention is effective and not harmful, mental-health specialists require more information than is currently available about the psychological means refugees use to deal with trauma, the process and timing of the recovery of repressed memory, and the factors that can mitigate the psychological impact of the past. According to recent research, occupational success and enduring relationships provide effective buffers against the trauma of memory and its recovery.[144,158]

Aside from residual pain, disability, and possible brain damage suffered by its victims, torture betrays core beliefs about, and trust in, human nature. The immensity of the trauma probably helps explain the high rates of depression and PTSD which occur in the aftermath of torture.[153,160]

Although resettlement countries like Canada can do nothing to alter the past that immigrants and refugees bring with them, they can do a great deal to make resettlement as effective and painless as possible. Unfortunately, post-migration experiences – notably acculturation, unemployment, and discrimination – are only too common threats to the well-being of both immigrants and refugees.

In their well-known model of acculturation, Berry and colleagues[161,162] propose four types of reaction to acculturative forces: a) assimilation, defined as abandoning the culture of origin in favour of the new; b) integration, a creative blending of the two; c) rejection, in which the new culture is rejected in favour of the heritage culture, and d) marginalization in which neither the old nor the new are accepted. According to Berry and his colleagues, marginalization is accompanied by the highest degree of mental health risk, integration by the least.

Other research[149,163] suggests that when acculturation changes aspirations, and the means for achieving ambitions are slight, mental disorder is a highly likely result. New settlers are interested in employment and in economic success for themselves and their families. However, it can take as long as 10 years to achieve their economic potential.[81,114] Unemployment not only frustrates ambition but jeopardizes mental health.[84] The relationship between mental health and unemployment is reciprocal: people who are unemployed or who lose their jobs experience a high risk of depression, and people who are depressed are more likely than the non-depressed to be laid off work.[84] One implication of the latter finding is that mental health is part of human capital, affecting the chances of economic productivity as well as being affected by it.

Despite the expectation that immigrants will contribute to the GNP of countries of resettlement, many immigrants find themselves living in poverty. In Canada, for example, more than 30% of immigrant families live below the officially defined poverty line during their first 10 years in Canada.[82] Studies of immigrant poverty reveal an interesting epidemiological paradox. Although poverty is one of the major risk factors for the mental health of children, and although immigrant children are almost three times more likely than their non-immigrant counterparts to live in poverty, immigrant children enjoy better mental health and evidence fewer behavioural disturbances. The strength of immigrant family life provides one of the explanations for the paradox. Poverty among immigrant families appears to be a phenomenon quite different from poverty among non-immigrants. Being poor is, for example, far less likely to be associated with broken homes and family violence in immigrant, as compared with non-immigrant households.[82] Results such as these highlight the need for research to address not only the challenges of resettlement, but the strengths that individuals and families bring to the task.

High levels of immigrant unemployment and of immigrant family poverty suggest shortcomings in immigration policy. Selective admission policies help ensure that immigrants are, on the whole, highly educated, and well-trained: the fact that it takes so long for them to establish themselves suggests that the shortcomings are in the policies regarding resettlement rather than in selection. Lack of recognition of foreign credentials by potential employers[3] is a long-recognized problem that continues to elude solution. Discrimination in the labour market as well as in other social settings is probably another part of the explanation for unemployment and poverty. Research reveals that as many as one in four visible minority immigrants report experiencing some form of discrimination during the early years of resettlement. The research also suggests that perceived discrimination induces symptoms of depression.[114,115] A study of Southeast Asian refugees[115] revealed that passive avoidance was the most effective strategy for dealing with discrimination, perhaps because this was a culturally compatible form of behaviour, perhaps because the comparative powerlessness of refugees in many situations makes confrontation a non-effective or even dangerous response to aggression.

Immigrants are not passive tools of fate, but people who respond to the challenge of resettlement with varying degrees of skill and success. The psychological resources immigrants muster in order to deal with the demands of resettlement is a relatively neglected topic to date and should be an important research priority.

The study of social resources has received comparatively more attention. For example, research has demonstrated the protective effects of a long-term relationship.[112,144,164] Community influence has received even more attention. Early studies in this area derived from critical mass theory, whose premise is that immigrants who settle in areas in which there is an established like-ethnic community have a mental health advantage over immigrants deprived of such community.[16,165,166] Both hospital-[16,17] and community-based studies[112,114] of the risk of mental disorder in immigrant and minority communities support the concept that a like-ethnic community of significant size confers mental health advantage.

Theoreticians have suggested that receiving countries offer different "levels of hospitality" to newcomers.[167] Although the proposition that the more hospitable the reception, the better the chances of maintaining good mental health[168] makes intuitive sense, testing the proposition is difficult because it is hard to know how to measure hospitality. One study compared the mental health and adaptation of government and privately sponsored refugees. Reasoning that refugees sponsored by private groups would receive more individualized attention than others left to the care of government bureaucracies, the study predicted a mental health advantage for the privately sponsored group. Results failed to confirm the prediction. Further investigation revealed that undue pressure by sponsoring groups could have the reverse effect, that is, the dependence of refugees on their sponsors made them vulnerable to exploitation and insensitivity.[113,114,169] However, according to the results of a follow-up study, at the end of 10 years privately sponsored refugees were better integrated than their government-sponsored counterparts.[170]

FUTURE DIRECTIONS

If it could be shown that whatever applies to majority culture Canadians also applies to new settlers, there might be no need to develop an immigrant and refugee database about health. This is not the case, as exemplified by research that demonstrates that, although immigrant families are far more likely than families of native-born Canadians to be poor, immigrant children tend to have better health.[82] Unexpected and paradoxical findings underline the need to take account of heterogeneity in future studies of immigration and resettlement. Immigrants differ by country of origin, entry class (e.g, immigrant versus refugee), prior experience with the western health-care system, levels of acculturation and of cultural retention, and previous health habits, each of which can affect health. Data that are difficult to explain or to reconcile using simple paradigms underline the need for more sophisticated research models that incorporate not only immigrant characteristics and the undeniable stresses of resettlement, but also the effect of protective factors.

The field requires research about immigrants and refugees in comparison to members of the receiving society, investigations comparing migrants with non-migrating members of the society of origin, and studies that address the heterogeneity that is obscured by the term "immigrant." Studies focused on immigration and resettlement shed light on the process of human adaptation, and also reveal health inequities and service gaps. Research that addresses within-group characteristics such as immigration status (immigrant versus refugee), age, gender, educational level, language fluency, length of residence in Canada, and availability of like-ethnic or of other community support are needed in order to reveal specific combinations of factors that give rise to health risk. Variables such as age and gender should not be regarded as just control variables, but as factors affecting resettlement by, for example, helping to determine the likelihood of exposure to certain stresses as well as the availability of psychological and social resources.

Future studies should address methodological difficulties uncovered by past experience. For example, sample sizes must be large enough to permit multivariate analyses that can address confounders. Research in immigrant and refugee communities must be based on methodologically sound and appropriate measurement, an often thorny and difficult topic. For example, cultural relativists caution that concepts like depression, schizophrenia and substance dependence are western and ethnocentric, and that applying such categories to non-westerners violates indigenous assumptions about the nature, antecedents and consequences of behaviour. They also argue that, because of cultural differences, people describe illness differently and possibly even experience different symptoms. For example, since the Cantonese, Mandarin, Vietnamese, Cambodian and Laotian languages have no word for depression connoting an illness, some authorities have concluded that Asians do not experience depression in the same way North Americans or Europeans do.[171-173] It has been proposed that Asian experiences of distress are dominated by bodily symptoms. In its most simplistic terms the proposition states: North Americans psychologize distress; Asians somatize it.[174-177]

Findings that purportedly demonstrate that mental illness wears a unique face in different cultures are usually based on research in clinical settings. Emphasizing somatic symptoms rather than psychic distress may result from the assumption by many cultural groups that psychological problems do not constitute legitimate tender for exchange with a health-care provider. When they feel it is appropriate or likely to be helpful, Asians confide psychic symptoms of depression to a psychiatrist with equal or even greater intensity than their North American counterparts.[178-180] Cultural relativists may have misinterpreted reluctance to divulge as lack of vocabulary. Community-based research reveals similarities across cultures that are more striking than differences.[181-183]

Research also challenges the idea that Asian languages are dominated by expressions for bodily distress to the relative exclusion of terms connoting psychological states. Southeast Asian languages are rich in idioms like "Do you find your life is sad and boring?" or "Do you feel remorseful?" that clearly fall within the spectrum of depressive experience even if they do not connote illness.[184] Furthermore, the way in which symptoms of depression co-aggregate in community samples of Southeast Asians is identical to their patterning among North Americans.[182,183] Somatization symptoms also co-aggregate identically in both groups and, furthermore, they form a dimension completely independent of depression.[182,183] These data suggest that somatization is not a substitute for depression but that depression and somatization are separate and independent ways of expressing and experiencing distress.

To help ensure the appropriateness of measures, attention to community sensitivities and constructive dissemination of information, researchers must engage the immigrant and refugee communities under study as partners in the research enterprise.

Research that challenges what comes to be accepted as common knowledge should be encouraged. For example, the debate about whether people from different cultural groups experience or express distress differently is more than an intellectual curio. It demands serious research attention because it can affect the chances of receiving appropriate care. Aside from needlessly shackling a clinician's ability to diagnose a patient's distress, emphasizing differences rather than universals in human suffering can perpetuate stereotypes. No matter how authoritative its sources, the claim that Asians experience or express distress in one set of terms, North Americans in another, runs the risk of reducing human suffering to an affectation.

Longitudinal studies, such as Australia's longitudinal study of immigrants[45,85,185] and the more recent Longitudinal Study of Immigrants in Canada, although expensive and time-consuming, should be encouraged because they provide an important window on the process of resettlement, and on the shifting salience of risk and protective factors over time.

Preventive and treatment services are currently failing many immigrant communities. Research documents that immigrants are less likely than their native-born counterparts to benefit from either prevention or treatment, partly as a result of linguistic and cultural differences, partly because of lack of information or misinformation – for example, the concept that certain Asian groups are resistant to cancer may lessen any sense of urgency about the importance of screening programs – and partly because the provision and organization of services does not meet immigrants' needs. A growing body of knowledge could and should inform more effective planning for the future.[3]

Socio-political context invariably affects health paradigms and the choice of research topics. It behooves scientists, practitioners and policy-makers to be aware of the way in which the temper of the times influences their thinking. Although the way in which questions and hypotheses are framed, for example, is probably never value-free, the conduct of research must adhere to principles of non-biased observation and honest reporting. Health professionals should also be aware of the potential (mis)use of health metaphors in debates about immigration, whether pro or con.

The socio-politically influenced models of the sick and healthy immigrant are insufficient to account for the complexity of the process of immigrating and resettling, and for the diversity of research findings. To do justice to the phenomenon, researchers and providers must elaborate more complex models, taking into account predisposition, whether genetic and/or developmental, pre-migration and post-migration stressors, psychological and social sources of strength, selection – whether self-selection or selection resulting from administrative process – and local conditions that can affect resettlement.

Most discussion about immigration focusses on human capital, usually translated as education and job skills. Health, like education, is an important component of human capital. Although health receives little attention in Canada's current view of immigrants and refugees, policy decisions have important and potentially far-reaching repercussions on the health of new settlers. For example, most provinces impose a mandatory waiting period before persons can qualify for health care. Researchers[2] have demonstrated that this is not a period of quiescence, but of pent-up demand. When the waiting period is over, there is a surge in immigrant and refugee health-care visits. The consequences of mandatory waiting periods and their effects on decisions regarding preventive health care require careful study.

Just as policy has implications for health, health should be taken into account when formulating policy. For example, in the years 2002 and 2003, Canada seriously considered adopting a program of regionalization, under the terms of which entry could be facilitated for people who promised to settle in areas of low-population density and where there were few other immigrants. None of the debate that swirled around the issue – most of it rightfully centred on human rights issues regarding freedom of movement – took into account studies demonstrating the health advantage of like-ethnic communities, particularly during the early years of resettlement,[16,17,113,114,166] nor research demonstrating an association between dispersion and compromised mental health.[69]

Countries in Europe and Asia have been reassessing their traditional, closed-border policies against immigrants, and have begun looking to the US, Canada and Australia for useful models. Current differences in immigration and settlement patterns in traditional immigration-receiving countries as well as in countries undergoing a change in immigration practice create "experiments in nature," allowing for comparisons that could elucidate the health effects of differing selection and resettlement policies, and of different methods for providing health and preventive services.

For the foreseeable future, migration will continue to challenge nation states as well as immigrants and refugees themselves. Research about health and well-being can help make the process of adaptation as painless as possible for immigrants and as beneficial as possible for the countries in which immigrants resettle.

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RÉSUMÉ

Le Canada accueille un peu plus de 200 000 immigrants chaque année. La politique nationale impose une sélection rigoureuse de ces gens afin de s'assurer qu'ils sont en bonne santé, mais il existe remarquablement peu de politiques pour s'assurer qu'ils le restent. Cette négligence est aberrante quand on considère que maintenir les immigrants en bonne santé c'est faire preuve de justice et d'humanité dans l'intérêt national.

En isolant les vulnérabilités de nature personnelle et les principaux facteurs de stress liés à la réinstallation qui agissent isolément ou en conjonction avec les prédispositions naturelles et se traduisent par un risque pour la santé et, d'autre part, les ressources personnelles et sociales qui réduisent ce risque et favorisent le bien être, la recherche sur la santé serait en mesure d'apporter une contribution à la politique et aux pratiques. Cependant, les paradigmes sur lesquels la recherche sur la santé des immigrants s'est appuyée au cours des cent dernières années – l'immigrant « malade » ou « en bonne santé » respectivement – se sont révélés inadéquats. Une partie du problème vient du fait que la controverse sociopolitique a eu de l'influence sur la nature des questions posées aux immigrants au sujet de leur santé et la façon de les examiner.

Après avoir fait une revue des études qui soulignent les carences des paradigmes de l'immigrant malade ou de l'immigrant en bonne santé, l'auteur de l'article affirme qu'un modèle d'interaction tenant compte tout à la fois des facteurs de prédisposition et des facteurs socio environnementaux offrirait le meilleur cadre explicatif des constatations qui se perpétuent et serait la façon la plus sûre d'orienter la recherche à l'avenir. Enfin, l'auteur de l'article affirme qu'en renforçant les liens entre la recherche, la politique et la prestation des services, on pourrait rendre le processus de réinstallation plus humain, et donner ainsi au Canada la possibilité de profiter du capital humain que les nouveaux arrivants amènent avec eux.

The Embodiment of Inequity

Health Disparities in Aboriginal Canada

Naomi Adelson, PhD

ABSTRACT

Health disparities are, first and foremost, those indicators of a relative disproportionate burden of disease on a particular population. Health inequities point to the underlying causes of the disparities, many if not most of which sit largely outside of the typically constituted domain of "health". The literature reviewed for this synthesis document indicates that time and again health disparities are directly and indirectly associated with social, economic, cultural and political inequities; the end result of which is a disproportionate burden of ill health and social suffering upon the Aboriginal populations of Canada. In analyses of health disparities, it is as important to navigate the interstices between the person and the wider social and historical contexts as it is to pay attention to the individual effects of inequity. Research and policy must address the contemporary realities of Aboriginal health and well-being, including the individual and community-based effects of health disparities and the direct and indirect sources of those disparities.

MeSH terms: Indians, North American; First Nations, Canada; Health Disparities; Social Sciences, Colonialism

In a 2003 press release then-National Chief of the Assembly of First Nations, Matthew Coon Come said that the most recently published statistical profile of Aboriginal Canadians' health status confirmed "the already well-known disparities in our health compared to non-Aboriginal Canadians. Most importantly, it highlights the health determinants that are directly related to our Third World health status; those socio-economic determinants include infrastructure, housing, employment, income, environment, and education. So far, this government is more preoccupied on spending millions of dollars to impose unwanted colonial legislation on First Nations rather than investing in measures that will improve our quality of life."[1] The health disparities outlined in this synthesis article reflect the present-day health effects of decades of inequity as Aboriginal peoples – First Nations, Inuit and Métis – continue to work toward economic, political, social, community and individual health. While there are tremendous successes and powerful indicators of triumph in many sectors, there remain far too many signs of the effects of a protracted history of inequity such that "irrespective of the indicator used, Canadian Aboriginal [peoples] tend to bear a disproportionate burden of illness."[2]

Health *disparities* are, first and foremost, those indicators of a relative disproportionate burden of disease on a particular population. Health *inequities* point to the underlying causes of the disparities, many if not most of which sit largely outside the typically constituted domain of "health". Specifically, the literature reviewed for this synthesis article indicates that time and again health disparities are directly and indirectly associated with or related to social, economic, cultural and political inequities; the end result of which is a disproportionate burden of ill health and social suffering on the Aboriginal populations of Canada. Scholars across all sectors of Aboriginal health studies concur that, despite inadequacies in the health care delivery system and regardless of peoples' relative access to or use of the biomedical system, the problems are entrenched in the history of relations between Aboriginal peoples and the nation-state. These health disparities are related to economic, political and social disparities – not to any inherent Aboriginal trait – and because of

La traduction du résumé se trouve à la fin de l'article.

Correspondence: Dr. Naomi Adelson, Associate Professor, Department of Anthropology, York University, Toronto, ON, Tel: 416-736-2100, ext. 77787, E-mail: nadelson@yorku.ca

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the limited autonomy Aboriginal peoples have in determining and addressing their health needs.[2-4] A history of colonialist and paternalistic wardship, including the creation of the reserve system; forced relocation of communities to new and unfamiliar lands; the forced removal and subsequent placement of children into institutions or far away from their families and communities; inadequate services to those living on reserves; inherently racist attitudes towards Aboriginal peoples; and a continued lack of vision in terms of the effects of these tortured relations – all of these factors underlie so many of the ills faced by Aboriginal peoples today.[5-24]

Societal inequities exact a high personal toll in the form of disease, disability, violence and premature death. Thus, while we may talk about Aboriginal populations in general terms, we must appreciate the individual effects of the collective burden of a history of discriminatory practices, unjust laws and economic or political disadvantage. There are, in other words, far too many Aboriginal people in this country who suffer as a result of a shared history of inequality with non-Aboriginal Canadians. Thus, while some may continue to argue that there is a genetic basis for the disproportionate increase, for example, in chronic diseases such as non-insulin-dependent diabetes mellitus (NIDDM) among Aboriginal Canadians, we must equally examine the role of changing diets, changing or limited work options, poverty, access to resources, societal stressors, and the cultural valuations of foodstuffs as part of the more complex picture of disease in the contemporary context.

Political and economic disadvantage and marginalization are part and parcel of the felt effects of a history of internal colonization, which wear away not only at the individual but at the family, community and nation.[25] Internal colonization, succinctly defined by Emma LaRocque, is "that process of encroachment and subsequent subjugation of Aboriginal peoples since the arrival of the Europeans. From the Aboriginal perspective, it refers to loss of lands, resources, and self-direction and to the severe disturbance of cultural ways and values."[26] Suicide, injuries, drug and alcohol abuse, sexual violence and even some chronic diseases – all occurring in disproportionate numbers across Aboriginal Canada – are not just problems of the individual. In any analysis of health disparities, in other words, it is as crucial to navigate the interstices between the person and the wider social and historical contexts as it is to pay attention to the individual effects of inequity. The Assembly of First Nations' (AFN) mission statement on health similarly reflects this relationship between health and equity: [27]

> We, as First Nations peoples accept our responsibility as keepers of Mother Earth to achieve the best quality of life and health for future generations based on our traditions, values, cultures and languages. We are responsible to protect, maintain, promote, support, and advocate for our inherent, treaty and constitutional rights, holistic health and the well being of our nations. This will be achieved through the development of health system models, research, policy analysis, and communication, and development of national strategies for health promotion, prevention, intervention and aftercare.

What, though, does health mean in the Aboriginal context? Too often programs and resources respond almost exclusively to an individual's departure from health (i.e., disease) and thus neglect the underlying constituents of either health or ill-health. Cultural differences in how we come to understand what health means, economic conditions, living and social conditions, and one's level of formal education are all elements that must be addressed in concert with public health priorities and initiatives if we are to understand and effectively take on the formidable task in reducing health disparities and promoting equity in Aboriginal Canadian populations.[2,4,28-30] The *First Nations and Inuit Regional Health Survey*[31] summarizes and highlights the disparate focus between Aboriginal and biomedical perspectives on health and healing. The biomedical model presumes, for example, a passive and compliant "patient" for whom treatments are prescribed (akin to other societal power imbalances, yet not always immediately perceived in this way). The Aboriginal wellness model, on the other hand, draws from a more comprehensive understanding of the individual and not just the healer/patient relationship and is often neglected in the formalized biomedical environment. Wellness involves the physical, emotional, mental and spiritual aspects of a person and always in connection to his or her family and community.[32] Unfortunately, this model of healing or concept of health priorities does not translate across the boundary of care in a typical biomedically based health-care centre, regardless of its location. If health-care workers are non-Aboriginal, they are at a particular disadvantage in that they are often only able to communicate through the language and culture of biomedicine. Thus, for example, there are many concepts, issues and practices that do not readily translate across linguistic, cultural, social or economic divides between the biomedical caregiver and his or her patient. Issues of time management or diet control, for example, may make little sense to an Aboriginal elder or, for that matter, a young mother with little income or social support. As Samson[33] found in his study in the Labrador Innu communities, non-Aboriginal health care workers talk of "naughty patients" or attribute blame for physical illness directly upon the behaviour of the patient. Doctors and nurses spoke of peoples'

> …inability or unwillingness to teach their children basic safety requirements, their lack of coping skills, aversion to washing, their drinking, poor nutrition, and sexual promiscuity…. [Yet] few health workers stopped to question the many complexities that inevitably surround compliance to medications in places like Davis Inlet. Most Tshenut, even with coaching and translation are unable to follow complicated instructions dictated by the movements of the clock. Others, for example, young mothers in overcrowded households, will find it difficult to comply while there are numerous other crises in the household. Many people are not convinced of the efficacy of biomedicine, preferring to bear their pain alone or to seek an Innu remedy. Furthermore, there is no cultural basis among the Innu for them to adopt the customary deference towards physicians.[33]

Mainstream biomedical health care, as it has evolved in relation to Aboriginal communities, has been shaped by a century of internal colonial politics that have effectively marginalized Aboriginal people from the dominant system of care.[34,35] Thus, despite the current (yet still problematic) thrust towards health transfer and improvements in health services,[30] there are numerous issues that may confound even the best efforts to negotiate the control and delivery of health care to Aboriginal people and communities. We must come to understand that conventional clinical approaches may not fit well with traditional indigenous values or with the realities of contemporary settlement or urban life. Kirmayer and colleagues suggest that there is a "need to rethink the applicability of different models of intervention from the perspective of local community values and aspirations."[36] Indeed, if we are to understand "healing as the rebuilding of nations" and as a process of de-colonization, then we must find ways by which health can be effectively articulated at the levels of the individual, family, community and nation.[5,30]

Included in this synthesis is an overview of the demographic profile and key indicators of the processes and effects of health inequities among the Aboriginal nations of Canada, offering a glimpse into a complex network of factors that impinge upon the health and well-being of Aboriginal Canadians. Demographic and statistical numbers – and synthesis papers that must rely on them – fail to provide a true or comprehensive picture of the Aboriginal peoples of Canada, however, and do little to reflect either the depth or diversity of experiences of First Nations Canada today. The diversity among and between Aboriginal populations can not be readily summarized and are thus diminished in the detached pall of statistical data. The profound cultural, linguistic and social differences between, for example, remote northern-dwelling Inuit, west-coast Haida, the Anishnabe and the Cree; between urban, rural and remote locations; between gender and age; employed or unemployed; poor or not; artist or rap singer; university-educated or full-time hunter; as well as differences in treaty-related rights and resources and nation-based differences in levels of political autonomy, all play a role in the relative (health) equity between Aboriginal populations and individuals. There is no way to adequately summarize these many differences among and between the men, women and children of Aboriginal Canada. The key element that does bring them together as a group, however, is their autochthonous status on this land and the subsequent historical relationship since contact that each and every Aboriginal person continues to have to the nation-state.

While I have not focussed on the growing number of success stories of individuals, communities or nations, these achievements must be acknowledged. From the growth in the number of Aboriginal professionals, artists, musicians and scholars to the latest round of successful negotiations of title and compensation, there are optimistic signs of triumph throughout Aboriginal Canada. Unfortunately, these successes do not yet surpass the struggles faced by those who must continue to contend with the overwhelming disparities in health and social well-being.

Demographic profile

Overview

Aboriginal Canada constitutes all persons of Aboriginal origins, including First Nations, Métis and Inuit. While there are some basic demographic data on all three Aboriginal populations, there are considerably more data available on First Nations peoples. Most of the data presented here have been drawn from two key inter-related sources: Statistic Canada's *Statistical Profile on the Health of First Nations in Canada* and the *Aboriginal Peoples Survey*[37] (APS) as well as the comprehensive findings of the Royal Commission on Aboriginal Peoples (RCAP).* The 1997 Aboriginal Peoples Survey represents a weighted national survey of those 15 years of age or older who identify as Aboriginal (First Nation, Inuit, Métis) living both on- and off-reserve. Those who identified as Aboriginal and/or are registered under the *Indian Act* were randomly sampled from the total Aboriginal population and were selected from reserves, settlements and urban centres. The APS response rate was 75% and the total sample size was 25,122. Despite some presence of Métis in the Canadian census and APS, there remains, across the board, a dearth of demographic and health status literature on the Métis population in Canada.[38]

Census Canada indicates that in 2001 there were 976,310 individuals reporting Aboriginal identity in all of Canada's provinces and territories. These numbers are incomplete, however, and should be viewed as such since they reflect only those individuals who reported to Statistics Canada and who self-identified as being of Aboriginal ancestry and are based solely on the ethnic origin question. As well, the census figures do not distinguish on- and off-reserve populations and do not reflect the total number of Aboriginal persons in Canada. In addition, some individuals may have identified themselves as having Aboriginal ancestry but did not associate with any of the three demographic groups (North American Indian, Métis, Inuit) or may have identified with more than one Aboriginal group. Thus, variances in the statistical data included here reflect the fact that Aboriginal persons who choose to self-identify and/or participate in various demographic exercises is not consistent.

Of that number of almost one million, 608,850 reported being of First Nations ancestry; 292,310 Métis; and 45,070 Inuit. The majority of First Nations persons live in Ontario (188,315), British Columbia (179,025), Alberta (156,220), Manitoba (150,040) and Saskatchewan (130,190). Similarly, the Métis people live primarily in the western provinces of Alberta (66,055), Manitoba (56,795), British Columbia (44,265), Saskatchewan (43,695) and the province of Ontario (48,345). The Inuit live predominantly in the north, with almost half of the entire Inuit population residing in Nunavut (22,560) (Table I). The absolute numbers must be compared to the relative distribution in the total population. For example, whereas Ontario has the highest absolute number of Aboriginal people, they account for only 2% of the total population of this province. In British Columbia, however, Aboriginal people account for 4.4% of the total population. The highest concentrations of Aboriginal people are in the North and the Prairies: 85% of the total population of Nunavut, 51% of Northwest Territories, and 23% of Yukon Territories. Gender distribution among First Nations peoples is reflected in the profile of the registered Indian population. According to

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* The 2002 Aboriginal Peoples Survey results were released shortly after the completion of the penultimate version of this paper. I have included some of the more significant statistics from this more recent APS in the sections on language and education.

TABLE I

Population Reporting Various Forms of Aboriginal Identity, Canada, Provinces and Territories, 2001*

	Aboriginal Number	%	Indian Number	%	Métis Number	%	Inuit Number	%
Canada	976,310	100.0	608,850	100.0	292,310	100.0	45,070	100.0
Newfoundland and Labrador	18,780	1.9	7,040	1.2	5,480	1.9	4,555	10.1
Prince Edward Island	1,345	0.1	1,035	0.2	220	0.1		
Nova Scotia	17,015	1.7	12,920	2.1	3,135	1.1		
New Brunswick	16,990	1.7	11,490	1.9	4,290	1.5		
Quebec	79,400	8.1	51,125	8.4	15,855	5.4	9,532	21.2
Ontario	188,315	19.3	131,560	21.6	48,345	16.5	1,380	3.1
Manitoba	150,040	15.4	90,345	14.8	56,795	19.4		
Saskatchewan	130,190	13.3	83,745	13.8	43,695	14.9		
Alberta	156,220	16.0	84,990	14.0	66,055	22.6		
British Columbia	170,025	17.4	118,295	19.4	44,265	15.1		
Yukon Territory	6,540	0.7	5,600	0.9	535	0.2		
Northwest Territories	18,725	1.9	10,615	1.7	3,580	1.2	3,905	8.7
Nunavut	22,720	2.3	95	0.0	55	0.0	22,560	50.0
Rest of Canada (Inuit only)							3,145	7.0

* From Statistics Canada 2001 Census
Statistics Canada reports that of the total Aboriginal identity population, there were 6,665 "multiple Aboriginal responses" and 23,415 "Aboriginal responses not included elsewhere". This explains the discrepancy between the numbers reporting an Aboriginal Identity and the total of those reporting Indian, Métis and Inuit.

Adapted from the Statistics Canada Table entitled "Aboriginal Identity (8), Age Groups (11B) and Sex (3) for Population, for Canada, Provinces, Territories, Census Metropolitan Areas[1] and Census Agglomerations, 2001 Census – 20% Sample Data", Catalogue 97F0011, January 21, 2003.

the Department of Indian Affairs (DIA) Basic Departmental Data from 2001, of a total of 675,497 registered Indians, 330,883 (49%) are male and 344,614 (51%) are female (Table II). Overall, the data from the 2001 Census indicate that the Aboriginal peoples' total population is on the rise. Just over 1.3 million people reported having at least some Aboriginal ancestry in 2001, representing 4.4% of the total population. In 1996, people with Aboriginal ancestry represented 3.8% of the total population.

TABLE II

Registered Indian Population Distribution by Age and Gender

Age	Male – No.	%	Female – No.	%	Total
0-4	28,965	4.3	27,645	4.1	56,610
5-9	39,085	5.8	37,185	5.5	76,270
10-14	36,595	5.4	34,851	5.1	71,446
15-19	32,217	4.8	30,801	4.6	63,018
20-24	28,647	4.2	28,134	4.2	56,781
25-29	28,243	4.2	28,367	4.2	56,610
30-34	28,628	4.2	28,844	4.3	57,472
35-39	27,133	4.0	29,105	4.3	56,238
40-44	22,153	3.3	25,045	3.7	47,198
45-49	16,367	2.4	19,328	2.9	35,695
50-54	12,458	1.8	15,199	2.2	27,646
55-59	9251	1.4	11,329	1.7	20,580
60-64	6684	1.0	8888	1.3	15,572
65-69	5288	0.8	6855	1.0	12,173
70-74	3622	0.5	4762	0.7	8424
75-79	2367	0.4	3474	0.5	5841
80+	3140	0.5	4783	0.7	7923
Total	330,883	49	344,614	51	675,497

Source: Basic Departmental Data, 2001. Ottawa: Department of Indian and Northern Affairs Canada; p. 21. Reproduced with the Permission of the Minister of Public Works and Government Services Canada, 2005.

Language

While language retention and cultural continuity are not necessarily statistically correlated, we must consider the effect of the decline in Aboriginal languages in concert with the overwhelming media influences and educational priorities available to Aboriginal youth today. The 2001 APS indicates that while there is considerable interest in learning one's Aboriginal language, only 15% of off-reserve Aboriginal people indicated they could speak their language well or relatively well (Table III). By comparison, Inuit children (63%) and

TABLE III

Importance of Keeping, Learning or Relearning an Aboriginal Language by Age Group for the Aboriginal Identity Non-reserve Population 15 Years and Over for Canada, Aboriginal Peoples Survey 2001*†‡

	Total Population§		Very or Somewhat Important		Not Very or Not Important		No Opinion		Not Stated / Refused	
	Number	%	Number	%	Number	%	Number	%	Number	%
Total Aboriginal Identity Non-reserve Population Aged 15+	548,400	100.0	324,360	59.1	203,080	37.0	11,370	2.0	9,580	1.7
15-24	137,360	100.0	78,680	57.2	53,090	38.6	3,150	2.2	2,440	1.7
25-44	251,200	100.0	156,230	62.1	85,790	34.1	5,200	2.0	3,980	1.5
45-64	131,970	100.0	74,820	56.6	52,740	39.9	1,750	1.3	2,660	2.0
65 and over	27,870	100.0	14,640	52.5	11,450	41.0	1,270	4.5	510	1.8

* Excludes the population that did not answer the Language Section of the APS questionnaire and those with invalid or unstated ages.

† Aboriginal Identity population includes those people who reported on the APS at least one of the following: 1) Identification as North American Indian, Métis and/or Inuit; 2) Registered Indian status and/or; 3) Band membership.

‡ Non-reserve population includes Aboriginal people who do not live on Indian reserves, with the exception of the Northwest Territories, in which case the total (on and non-reserve) Aboriginal population is included.

§ The sum of the values of each category may differ from the total due to rounding.

Adapted from Statistics Canada, Aboriginal Peoples Survey, 2001.

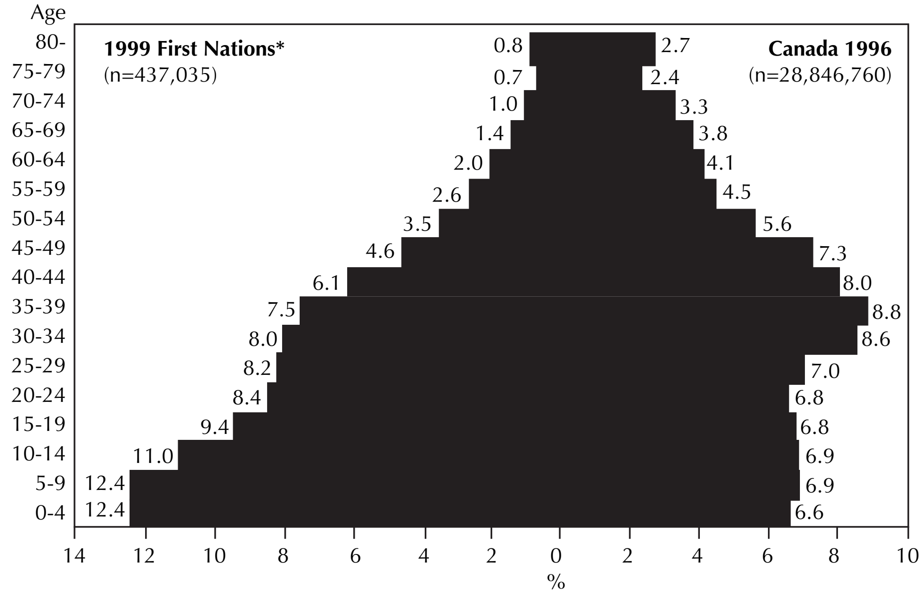

Figure 1. Distribution of the First Nations and Canadian population

* Includes on and off reserve for Alberta and British Columbia

n = size of population

Adapted in part from the Statistics Canada publication, "Age, Sex, Marital Status and Common-law Status (reference products: technical reports: 1996 Census of Population)", Catalogue 92-353, April 1, 1999.

Source: A Statistical Profile of the Health of First Nations in Canada, Figure 2.2, Health Canada (2003). Reproduced with the permission of the Minister of Public Works and Government Services Canada, 2005.

TABLE IV

Registered Indians – Life Expectancy*

	Registered Indians	All Canadians	Gap
Male	68.9	76.3	7.4
Female	76.6	81.8	5.2

* Statistics from Department of Indian Affairs "Basic Departmental Data 2001"

Adapted in part from the Statistics Canada publication, "Report on the Demographic Situation in Canada", 1991, Catalogue 91-209, March 4, 1994.

TABLE V

Estimated Life Expectancy at Birth, Total and Aboriginal Populations, 1991*

Years	Male	Female
Total population	74.6	80.9
Total Aboriginal population	67.9	75.0
Total, North American Indians†	68.0	74.9
Registered North American Indians	66.9	74.0
On-reserve	62.0	69.6
Non-reserve, rural	68.5	75.0
Non-reserve, urban	72.5	79.0
Non-Registered North American Indians	71.4	77.9
Rural	69.0	75.5
Urban	72.5	79.0
Métis	70.4	76.9
Rural	68.5	75.0
Urban	71.5	78.0
Inuit	57.6	68.8

* From Report of the Royal Commission on Aboriginal People, Vol. 3, Table 3.2

† North American Indians includes all who self-identified as North American Indian on the 1991 Aboriginal Peoples Survey, whether or not they are registered under the Indian Act.

Adapted in part from the Statistics Canada publication, "Report on the Demographic Situation in Canada", 1991, Catalogue 91-209, March 4, 1994.

Adapted from "Health Indicators Derived from Vital Statistics for Status Indian and Canadian Populations, 1978-1986", Health Canada (September 1988). Reproduced with the permission of the Minister of Public Works and Government Services Canada, 2005.

those over the age of 15 (80%) indicated they could speak Inuktitut at least relatively well.

Age Distribution and Life Expectancy

The median age for the Aboriginal population in 2001 was 24.7 years (versus a non-Aboriginal population high of 37.7 years). Of a total of 975,497 persons of all ages[39] 267,344 are between 0 and 19 years of age. Significantly, a full third of the total Aboriginal population is under the age of 14 (compared to the corresponding share of 19% in the non-Aboriginal population). There are 309,994 Aboriginal persons between 20 and 49 years of age and 98,159 are between 50 and 80+ years of age (Table II). The overall distribution by age of this population reflects both the new trend toward aging as well as an Aboriginal birth rate that is 1.5 times that of the non-Aboriginal birthrate in Canada.[37] The *Statistical Profile on the Health of First Nations in Canada* similarly reveals a steady and persistent age distribution difference between First Nations and the non-Aboriginal Canadian populations. Thus, while there is a trend towards aging in the Aboriginal population (the number of Aboriginal seniors increased by 40% between 1996 and 2001), there remains a far greater young Aboriginal population due to both the high birth rate and a lower overall life expectancy. By comparison, the non-Aboriginal Canadian population is distributed far more evenly up the age ranges with a single "baby boom" bulge (30-54 years of age) (Figure 1).

Tables IV and V indicate that while life expectancy is increasing overall for Aboriginal populations, it still falls well below the life expectancy for non-Aboriginal Canadians. As of 1990, Inuit men (57.6) and men living on-reserve (62) have the lowest life expectancy of all Aboriginal populations.[37]

Registered Status

People of First Nations ancestry may or may not be registered under the *Indian Act*. The *Indian Act* of 1876, while formally recognizing First Nations ancestry, remains the legislative authority of internal colonization. Bringing the First Nations under federal control, the Act officially abolished the inherent authority of Aboriginal peoples to determine their own lives. The *Indian Act* was amended in 1939

TABLE VI
Adjusted Aboriginal Identity Population by Region and Aboriginal Group, 1991*

Region	Registered No.†	%	Non-Registered No.	%	Métis No.	%	Inuit§ No.	%	Total No.	%
Atlantic‡	15,800	3.6	4,800	4.3	2,500	1.8	4,800	12.7	27,700	3.8
Quebec	43,700	10.0	9,800	8.7	9,100	6.5	7,200	19.0	69,300	9.6
Ontario	91,500	20.9	39,600	35.2	12,800	9.2	900	2.2	143,100	19.9
Manitoba	65,100	14.9	8,500	7.5	34,100	24.5	500	1.3	107,100	14.9
Saskatchewan	59,900	13.7	6,500	5.8	27,500	19.7	200	0.4	93,200	12.9
Alberta	60,400	13.8	18,400	16.3	39,600	28.4	1,400	3.7	118,200	16.4
British Columbia	87,900	20.1	23,800	21.1	9,400	6.7	500	1.4	120,700	16.7
Yukon[||]	4,400	1.0	500	0.4	200	0.1	–	0.25	100	0.7
Northwest Territories	9,300	2.1	800	0.74	200	3.0	22,200	58.7	36,200	5.0
Total	438,000	100.0	112,600	100.0	139,400	100.0	37,800	100.0	720,600	100.0

* From Report of the Royal Commission on Aboriginal People, Vol. 1, Table 2.4
Notes: - population count is less than 100.
† All counts are rounded to the nearest hundred.
‡ The Inuit count for the Atlantic region is actually for Labrador. The APS reported an unadjusted Inuit count of 55 in Nova Scotia and in New Brunswick. These counts were flagged to be used with caution because of sampling variability.
§ To obtain estimated counts for the Inuit population (3,560) in regions other than Labrador, Quebec and the Northwest Territories, the 1991 APS unadjusted counts were used to derive the shares of the adjusted Inuit population in each remaining region.
|| The adjusted count of non-registered North American Indian and Métis populations in the Yukon and Northwest Territories were derived using their respective percentage shares in each territory based on unadjusted 1991 APS data.
Source: "Report of the Royal Commission on Aboriginal Peoples" Royal Commission on Aboriginal Peoples, Volume One: Looking Forward, Looking Back, Chapter 2 titled: From Time Immemorial: A Demographic Profile, Section 2 titled: Current Population, Table 2.4 titled: "Projections of the Aboriginal Identity Population in Canada, 1991-2016" M.J. Norris, D. Kerr and F. Nault found on the following website: http://www.ainc.inac.gc.ca/ch/rcap/sg/sg3_e.htm#11. The Commission c. 1996. Reproduced with the permission of the Minister of Public Works and Government Services, 2005, and Courtesy of the Privy Council Office.
Source: "Projections of the Aboriginal Identity Population in Canada, 1991-2016", prepared by Statistics Canada, Demography Division, for Royal Commission on Aboriginal People (February 1995).

to bring the Inuit under similar federal control. Being registered under the Indian Act confers the rights and privileges of Indian status in Canada yet remains one of the most contentious acts of colonial domination.* There is no commensurate recognition of status or required registration for the Métis people. According to the Royal Commission on Aboriginal Peoples (RCAP),[40] as of a decade ago there were 438,000 registered and 112,600 non-registered Indians across Canada (Table VI).

Geographic Distribution

Reserves are Crown lands that are set aside for the exclusive use of registered Indians. The creation of these reserves reflects a history of domination and early attempts to assimilate the indigenous peoples of Canada. Whereas they remain a reminder of assimilationist practices, they are also the family home to many, regardless of where one may now reside, and they constitute a base from which to negotiate political autonomy. Nonetheless, the number of registered Indians who are moving away from reserve lands (in particular, into urban centres) is on the rise and reflects a significant shift in the geographic distribution of First Nations peoples of Canada. Specifically, of those registered as Indian, the Department of Indian Affairs notes that in 2000 a total of 391,993 lived on-reserve whereas 283,506 lived off-reserve (Table VII) with an overall decline from 33% to 31% in the proportion living on reserves or settlements. Stated differently, as of 2000, 25% of all Aboriginal people lived in 10 of Canada's 27 census metropolitan areas and almost half of the population who identify themselves as Aboriginal lived off-reserve. In Ontario, for example, 78,346 lived on-reserve and 75,600 lived off-reserve (Table VIII). Significantly, there are now more women than men living off-reserve (152,438 women versus 131,068 men). In addition, Aboriginal people are more mobile than other Canadians. This high level of mobility creates particular challenges for planning and implementing programs in Aboriginal-focussed education, social services, housing and health care, especially in urban areas.[41]

TABLE VII
Registered Indian On- and Off-Reserve Population

Year		On Reserve	Off-Reserve	Total
2000	Male	199,815	131,068	330,883
	Female	192,178	152,438	344,616
	Total	391,993	283,506	675,499

Source: Basic Departmental Data, 2001. Ottawa: Department of Indian and Northern Affairs Canada; pp. 9, 13, 15. Reproduced with the Permission of the Minister of Public Works and Government Services Canada, 2005.

Housing and Home

In 1991, the RCAP compared the housing conditions of on-reserve and off-reserve First Nations, Métis and Inuit (Table IX). The findings indicate that far too many Aboriginal people are living in over-crowded and under-serviced homes.[17,18,40-46] The on-reserve registered Indian population averages four persons per dwelling compared to less than three persons per dwelling for the non-Aboriginal population.[47] In reality, however, for most on-reserve registered Indian populations (Prairie provinces, NWT, Québec, and Newfoundland and Labrador), there are more than four persons living together. The 2001 APS indicates that 17% of off-reserve Aboriginal people and 53% of urban Inuit live in crowded conditions (defined as 1 or more people per room), compared to 7% of all Canadians. Off-reserve population and the Métis averaged approximately three persons per dwelling. Comparing Aboriginal and non-Aboriginal Canadian housing indicators

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* Terminology is important as the word "Indian" is considered derogatory and insensitive in the Canadian context. However, the word "Indian" remains in the Indian Act and is the term used in distinguishing status according to the Indian Act.

TABLE VIII

Registered Indian Population by Region (2000) – On and Off-Reserve

	Atlantic	Quebec	Ontario	Manitoba	Saskatchewan	Alberta	BC	Yukon	NWT	Canada
On	17,075	44,274	78,346	70,094	54,093	56,545	56,801	3872	10,893	391,993
Off	9322	19,041	75,600	37,052	52,018	28,828	53,728	3761	4156	283,506
Total	26,397	63,315	153,946	107,146	106,111	85,373	110,529	7633	15,049	675,499

Source: Basic Departmental Data, 2001. Ottawa: Department of Indian and Northern Affairs Canada; pp. 9, 13, 15. Reproduced with the Permission of the Minister of Public Works and Government Services Canada, 2005.

TABLE IX

Housing Conditions of Aboriginal People, 1991*

	North American Indians		Métis	Inuit
	On-reserve†	Non-reserve		
Occupied dwellings	39.870	137,580	65,005	9,655
Average number of persons per dwelling	4.3	3.3	3.3	4.3
Average number of rooms per dwelling	5.5	5.9	5.9	5.4
Tenant-occupied dwellings	5,435 (13.6)	77,445 (56.3)	33,535 (51.6)	7,125 (73.8)
Average gross rent per month ($)	362	517	505	318
Owner-occupied dwellings	10,755 (27.0)	60,025 (43.6)	30.893 (47.5)	2,510 (26.0)
Average owner's major payment per month	207	670	607	538
Band-owned dwellings	23,675 (59.4)	—	570	—
Available water not suitable for drinking	9,575 (24.0)	27,620 (20.1)	10,855 (16.7)	2,430 (25.2)
No electricity	2,585 (6.5)	9,645 (7.0)	3,682 (5.7)	445 (4.6)
No bathroom facilities	4,595 (11.5)	10,530 (7.7)	1,425 (2.2)	85 (0.9)
No flush toilet	7,715 (19.4)	2,880 (2.1)	2,230 (3.4)	496 (5.1)
In need of major repairs	15,445 (38.7)	21,420 (15.6)	10,965 (16.9)	1,770 (18.3)
Needs of residents not adequately met	15,610 (39.2)	22,905 (16.6)	12,090 (18.6)	3,175 (32.9)
Residents on waiting list for housing	5,545 (48.1)	10,065 (22.3)	15,200 (23.4)	2,760 (28.6)

* From Report of the Royal Commission on Aboriginal People, Vol. 3, Table 4.2
Data pertain to dwellings where at least one of the occupants identifies as a member of an Aboriginal group. Numbers in parentheses indicate percentage of total number of dwellings for that group.
† Data from the APS are deficient because of under-reporting but are the only data suitable for comparisons between Aboriginal groups.
— = not applicable.
Adapted from the Statistics Canada publication, "1-disability, 2-housing (The Aboriginal Peoples Survey 1991)", Catalogue 89-535, March 25, 1994.

TABLE X

Comparison of Canadian and Aboriginal Housing Indicators, 1991*

	Canada	Aboriginal†	Aboriginal Position
Occupied dwellings	10,018,265	239,240	2.4% of Canadian households‡
In need of major repairs	9.80%	19.60%	2 times as many in need of major repairs
Built before 1946	17.70%	13.60%	25% less than the Canada-wide proportion
No piped water supply	0.10%	9.40%	More than 90 times as many with no piped water
No bathroom facilities	0.60%	3.20%	More than 5 times as many
No flush toilet	0.50%	5.30%	More than 10 times as many
Average number of persons per dwelling	2.7	3.5	About 30% higher than the Canadian average
Average number of rooms per dwelling	6.1	5.8	Slightly smaller
Tenant-occupied dwellings	37.10%	48.70%	About 1/3 more tenants, not counting band-owned housing
Average gross rent per month	$546.00	$495.00	$51 per month lower on average
Owner-occupied dwellings	62.60%	41.20%	About 34% fewer owners
Owner's major payment per month	$682	$603	$79 per month lower on average

* From Report of the Royal Commission on Aboriginal People, Vol. 3, Table 4.1
† According to the 1991 Aboriginal Peoples Survey (APS).
‡ The actual figure is closer to 2.7 percent of Canadian households, owing to under counting in the APS. Canada data include only non-farm, non-reserve dwellings. The Aboriginal data include all non-farm dwellings, including those on reserves, where at least one of the occupants self-identifies as an Aboriginal person. Note that tenant-occupied dwellings do not include band-owned housing, which is treated as a separate category. Owner's major payment per month refers to the average monthly payments made by the owner to secure shelter.
Adapted from Statistics Canada, "Household Facilities and Equipment, 1995", Catalogue 64-202. (The estimate is based on the household income, facilities and equipment data base at Statistics Canada which contains data from several sources, including the household facilities and equipment survey, Aboriginal Peoples Survey).

(Table X), homes lived in by Aboriginal individuals/families are:

- 2 times more likely to be in need of major repair (19.6% versus 9.8%)
- 90 times more likely to have no piped water supply (9.4% versus 0.1%)
- 5 times more likely to have no bathroom facilities (3.2% versus 0.6%)
- 10 times more likely to have no flush toilet (5.3% versus 0.5%).

Adequate housing, both in terms of adequate basic facilities and the number required to adequately house both an aging and growing population are a high priority at all levels of Aboriginal government.

In addition to the toll that housing shortages and inadequate facilities take on populations, the actual place where people live also affects health status. The same colonialist interests that created the reserve system have also controlled where Aboriginal people may or may not live. The relocation of entire communities, based on the whim or wishes of a government consumed with issues of northern sovereignty or resource management (not with the health or well-being of the First Nations, Inuit or Métis), has directly affected those communities' well-being. From the high Arctic Inuit relocations in

TABLE XI

On-reserve Students Remaining Until Grade 12 for Consecutive Years of Schooling, Canada, 1987/88 – 1996/97

School Year	Percent
1987/88	37.4
1988/89	38.6
1989/90	41.3
1990/91	47.0
1991/92	53.6
1992/93	62.6
1993/94	77.7
1994/95	73.3
1995/96	75.1
1996/97	70.8*

* The percentage for 1996/97 is obtained by dividing the number of students in grade 12 in 1996/97 by the number of students in grade 1 in 1985/86.
Source: Basic Departmental Data, 1997. Ottawa: Indian and Northern Affairs Canada; p. 31. Reproduced with the permission of the Minister of Public Works and Government Services Canada, 2005.

the 1950s, to the forced relocation of the Innu of Labrador (and their subsequent recent second relocation and as yet unsuccessful attempt to quell the initial injurious effects), to the Anishnabe of Grassy Narrows who continue to suffer from methyl mercury poisoning as an indirect effect of relocation, the government mandate imposed upon Aboriginal people continues to resonate as social upheaval, as mental illness, as violence, as crime, as suicide, and as disease.[33,48-51]

Many of those who have moved from reserves, but without adequate education, social support or skills, will likely find themselves outside of the mainstream in an urban centre. Those who move towards the illusory security of the city quickly discover a dearth of services (unlike those available on reserves) and a marginalized and compromised status. Among the many other services required, there is, as Mason[52] has reported, a desperate need for adequate housing, and in particular, housing for women and children.

TABLE XII

Aboriginal and Canadian Populations Age 15+, Showing Percentage by Level of Education Attained, 1981 and 1991*

	1981 Aboriginal People 1	All Canadians 2	Gap 2-1	1991 Aboriginal People 1	All Canadians 2	Gap 2-1
Elementary school	63	80	17	76.1	86.1	10
High school	29.1	52.1	23	42.5	61.8	19.3
Post-secondary certificate	8.9	13.7	4.8	13.3	15.8	2.5
Some university	6.7	16	9.3	8.6	20.8	12.2
University degree	2	8	6	3	11.4	8.4

* From Report of the Royal Commission on Aboriginal People, VoL. 5, Table 2.6
Note: This table shows the number of individuals who have attained the level of education indicated, including individuals who have gone on to higher levels. Thus, in 1991, of the 76.1 percent of Aboriginal people who completed elementary school, many have completed high school and a number have also gone on to study at colleges and universities. The category 'post-secondary certificate' includes those who may not have completed elementary school or high school.
Source: Statistics Canada, "Canada's Aboriginal Population 1981-1991: A Summary Report", research study prepared for RCAP; and data from the Housing, Family and Social Statistics Division, Statistics Canada, January 1995.
Adapted from Statistics Canada, "Canada's Aboriginal Population, 1981-1991: A Summary Report", research study prepared for Royal Commission on Aboriginal People, and data from the Housing, Family and Social Statistics Division, Statistics Canada, January 1995.

TABLE XIII

Highest Level of Education, Aboriginal Identity and Canadian Populations Age 15-65 No Longer Attending School, 1991*

	North American Indian On-reserve %	North American Indian Non-reserve %	Métis %	Inuit %	Total Aboriginal %	Total Pop. %
Less than grade 9	39.6	16.0	19.1	46.6	25.4	11.8
Secondary, no certificate	29.9	33.9	34.2	20.1	32.1	22.8
Secondary certificate	8.3	15.5	14.8	8.7	12.8	21.2
Non-university, no certificate	6.9	8.3	8.5	8.6	8.0	6.2
Non-university certificate	10.6	16.2	15.3	13.2	14.1	17.9
University, no degree	3.4	6.1	4.4	1.8	4.7	7.9
University degree	0.9	3.6	3.3	—	2.6	12.2

* From Report of the Royal Commission on Aboriginal People, Vol. 5, Table 5.7
Note: — = Figures suppressed because of small size; their coefficient of variation is higher than 33.3%.
Adapted from Statistics Canada, 1991 Aboriginal Peoples Survey, and 1991 Census, Custom Tabulations.

TABLE XIV

Education and Employment Income, 1991*

Highest Level of Education Completed	Aboriginal People* (% of population age 15 to 64)	All Canadians† (% of population age 15 to 64)	Average Employment Income Per Aboriginal Person ($000s)
Less than grade 9	25.4	11.8	12.7
Grades 9 to 13	32.2	22.8	15.3
High school diploma	12.9	21.3	19.4
College without certificate	8.0	6.2	15.8
College with certificate	14.2	17.9	20.5
University without degree	4.7	7.9	22.6
University with degree	2.6	12.2	33.6
Total	100.0	100.0	17.8

* From Report of the Royal Commission on Aboriginal People, Vol. 5, Table 2.3
† Population age 15 to 64 no longer attending school full-time.
Adapted from the Statistics Canada publication, "Education Attainment and School Attendance (data products: nation series: 1991 Census of Population)", Catalogue 93-328, May 11, 1993.

Education, Employment and Income

Education

According to the *Statistical Profile*, First Nations children are staying in school longer than in the recent past. Given that educational achievement is positively associated with health, this is good news. In 1997-98, significantly more First Nations' children remained in school until Grade 12 than in the previous decade (74% versus 37%) (Table XI). In addition, the *Profile* optimistically points to an increase (by 54% between 1990 and 2000) in band-operated schools, an increase in federal funding for post-secondary education and a growth in Aboriginal studies programs at the university level. Despite these encouraging accomplishments, however, there is an across-the-board lag in the completion rate of all levels of education when compared to the non-Aboriginal Canadian population. Indeed, as the 2002 APS points out, only 48% of off-reserve

TABLE XV

Participation and Unemployment Rates, Aboriginal and Non-Aboriginal Populations, 1981 and 1991*

	Participation Rate†		Unemployment Rate	
	% 1981	% 1991‡	% 1981	% 1991‡
Non-Aboriginal	65.0	68.1	7.2	9.9
Total Aboriginal	51.8	57.0	15.8	24.6
North American Indians Registered§				
On-reserve	37.4	45.3	19.3	30.1
Non-reserve	55.9	56	15.6	29.4
Non-registered	62.7	67.5	14.3	21.1
Métis	57	63.7	14.5	21.3
Inuit	48.2	57.2	15.2	24.1

* From Report of the Royal Commission on Aboriginal People, Vol. 3, Table 3.11

† Participation rate is the percentage of all persons aged 15 and older who are employed and unemployed, i.e., active in the labour force.

‡ For comparison purposes, the Aboriginal rates for 1981 exclude reserves that were enumerated incompletely in the Aboriginal Peoples Survey.

§ Data for registered North American Indians in 1991 exclude persons who regained Indian status after 1985 as a result of Bill C-31, which amended the Indian Act with regard to eligibility for Indian status. Such persons were added to the 1991 North American Indian non-registered population for purposes of comparing 1991 and 1981 data.

Adapted from Statistics Canada, "Canada's Aboriginal Population, 1981-1991: A Summary Report, research prepared for RCAP; and data from the Housing, Family and Social Statistics Division, Statistics Canada, January 1995.

Aboriginal children are completing Grade 12. Inuit peoples' educational attainment is either lower than or comparable to First Nations people, with proportionately fewer Inuit obtaining a university degree. As a recent study indicates, even with higher levels of post-secondary education, First Nations men and women continue to face barriers to employment (Tables XII-XIV).[53]

Employment and Income

The RCAP reported that as of 1986 just under 45% of First Nations communities, at age 15+, were able to participate in the labour force (comparable communities: 60.3%; Canada: 66.9%). Of that total percentage, 33% of First Nations communities' members were unemployed compared to the national 1986 average of 12%. In a separate study commissioned by RCAP,[40] the total Aboriginal unemployment rate rose from 15.8% in 1981 to 24.6% in 1991 (Table XV).

Comparisons between registered on-reserve, off-reserve and non-Aboriginal Canadian populations indicate that, overall, Aboriginal household incomes are substantively lower than their non-Aboriginal counterparts. Registered on-reserve First Nations household incomes (per occupied private dwelling) are almost half that of the non-Aboriginal (reference) household incomes ($25,040 versus $46,606).[47] At $32,177, registered off-reserve household incomes are dramatically lower than the reference personal incomes. The average individual incomes are, in other words, substantially lower. The average income for the total registered (on- and off-reserve) Aboriginal population in 1991 was $12,800. This is approximately one half of the reference population income of $24,100.

An Assembly of First Nations (AFN) fact sheet of socio-economic exclusion indicators points to an even greater discrepancy between Aboriginal and non-Aboriginal earnings.[54] Their figures identify an unemployment rate of 28.7% among reserve-dwelling First Nations members (compared to a Canadian national average of 9.8%). Whereas 8.2% of non-Aboriginal Canadians earn less than $2,000, 19% of those living on-reserve earn this meagre amount annually.[54] Kendall bluntly states that unemployment is the most immediate cause of poverty.[55] Yet it is the complex interplay of job market discrimination, lack of education, cultural genocide, and loss of land and sovereignty that affects employment status and, ultimately, the degree of poverty faced by those who are caught in a "circle of disadvantage". The income gap between indigenous and non-indigenous Canadians continues to grow, despite efforts at income assistance and community development. Poverty, and the resultant poor living conditions, continue to contribute directly to poorer health status in both children and adults. Studies also continue to show that Aboriginal women face a disproportionate proportion of the burden of poverty and its concomitant social and health effects.[56-58]

The embodiment of inequity – Health status and health disparities

Perceived Health Status

According to the APS, only 13% of the overall Aboriginal population described their health status to be either "fair" or "poor" whereas 26% indicated that they considered their health status to be "excellent". These figures are significant, and even more so in contrast to the overall percentage of people with disability (30%) or who saw either a general practitioner (67%) or health-care professional (73%). Even more striking perhaps is that, by comparison, 23.1% of those living off-reserve rated their health as either fair or poor. In this same population 60% reported at least one chronic condition (e.g., arthritis, high blood pressure, diabetes), 16.2% reported a long-term activity restriction (more than 1.6 times higher than non-Aboriginal population) and 13.2% of those living off-reserve had experienced a major depressive episode in the year prior to the survey (1.8 times higher than the non-Aboriginal population).

Given the discrepancies between the stated health status profile both on- and off-reserve, we need to ask what "health" means for Aboriginal people. Health status and meanings of health are not adequately developed in the APS or other large scale survey instruments. Ethnographic data indicate that "health" means more than just the absence of disease in many cultural contexts and this avenue of health study must be more fully explored to develop a better sense of health equity for Aboriginal Canadians.[25,29,32,59,60] If health is a statement of individual wellness, then the answer may be far less accurate than any statistical outcomes will show. If health is interpersonal, based on a socially driven model of well-being, then this will engender a far different set of answers in an assessment of health.[29,33,61]

When asked what social problems were the most important for Aboriginal peoples, the highest percentage of those who responded to the Aboriginal Peoples Survey indicated that unemployment (67.1%) and alcohol abuse (61.1%) were the greatest (social) health problems in their communities. Drug abuse (47.9%), family violence (39.2%), suicide (25.4%), sexual abuse (24.5%), and rape (15%) followed.[62] These numbers are broken down according to on-/off-reserve First Nations, Métis and Inuit in Table XVI. While at best a broad sweep of the key social health concerns of communities, it is nonetheless a stark indicator of the individual and interpersonal results of social and societal disruption. Thus, while there are cultural differences in how health is understood, there are also social and historical factors that are impinging upon any sense of health and well-being that cannot be remedied with a simple invocation of a return to "culture".

TABLE XVI

Selected Social Problems Reported by Aboriginal Identity Population, 1991*

	Total Aboriginal	North American Indian		Métis	Inuit
		On-reserve	Non-reserve		
	%	%	%	%	%
Unemployment	67.1	78.3	60.2	66.9	74.5
Family violence	39.2	44.1	36.4	39.0	43.5
Suicide	25.4	34.4	20.4	21.6	41.2
Sexual abuse	24.5	29.0	21.8	23.0	35.1
Rape	15.0	16.4	13.3	14.6	25.0
Alcohol abuse	61.1	73.2	56.0	58.8	57.6
Drug abuse	47.9	58.8	43.2	45.2	49.0

* From Report of the Royal Commission on Aboriginal People, Vol. 5, Table 5.4
Note: Percentage of respondents reporting each phenomenon as a problem in their community.
Adapted from the Statistics Canada publication, "Language, tradition, health, lifestyle and social issues", 1991, Catalogue 89-533, June 29, 1993.

Morbidity and Mortality

Infant mortality stands as one of the key indicators of the relative health of populations. Specifically, infant mortality decreases as mothers' health and nutrition improve and as they are better monitored throughout the prenatal period.

In 1999 the infant mortality rate in First Nations was 8 deaths per 1000 live births. This rate is 1.5 higher than the Canadian rate of 5.5. However, this is a significant improvement from the 1979 rate of 27.7 per 1,000 live births and reflects the increase in access to prenatal health-care services and better maternal nutrition overall.[37] Infant mortality should be assessed relative to birth weight as birth weight is normally a strong predictor of infant mortality and child well-being. Birth weight may be influenced by socio-economic conditions, maternal age and weight, previous births by mother, maternal nutrition, smoking or illness during pregnancy, diabetes, and length of the pregnancy. Both low and high birth weights place infants at risk for higher vulnerability to illness later in life and, in particular, to diabetes. In addition, high birth weights place the baby at risk during the delivery process. In 1999, of those First Nations births recorded, 22% were classified as high birth weight (almost twice the non-Aboriginal Canadian rate). Six percent of the recorded births were classified as low birth weight (compared with 5.6% among the non-Aboriginal Canadian population). Yet despite similar percentages, further research has shown that First Nations infants with lower birth weights have a higher mortality rate.[37]

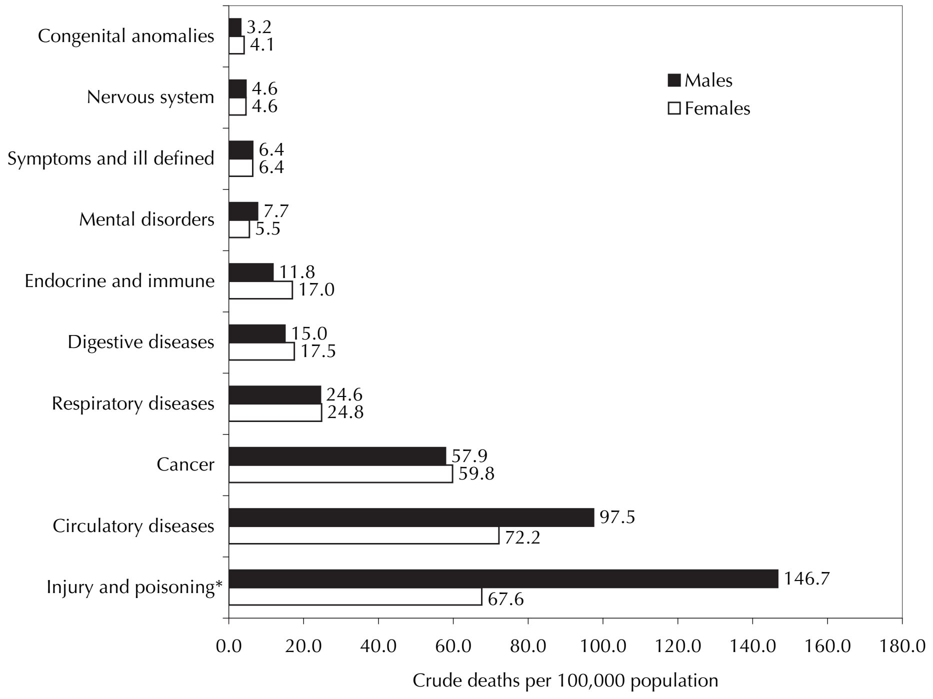

Figure 2. Leading causes of death in First Nations by sex, 1999

* Included in this rate are suicides with a rate of 12.4 per 100,000 for women and 43.3 per 100,000 for men
Ranking based on mortality (deaths per 100,000 population) for First Nations in 1999.
Source: A Statistical Profile of the Health of First Nations in Canada, Fig. 3.4, Health Canada, (2003). Reproduced with the permission of the Minister of Public Works and Government Services Canada, 2005.

Injury, poisoning, circulatory disease, cancer and respiratory disease are the overall leading causes of death in all Aboriginal populations. Suicide and self-inflicted injury is the leading cause of death in those aged 10-19 and 20-44, followed by motor vehicle injuries and then accidental drowning and homicide, respectively. For those aged 45-64, ischemic heart disease, lung cancer, motor vehicle injuries, diabetes, chronic liver disease, and other diseases (including breast cancer) are the leading causes of death.[2] For those aged 65 and over, heart disease, cerebrovascular disease, lung cancer, pneumonia and influenza are the leading causes of death. For those aged one to nine, the leading causes of death are injuries caused by fire and flames, motor vehicle and other injuries (Table XVII and Figure 2).

TABLE XVII

Deaths in First Nations, by Leading Causes and Age Group, 1999

Age group*	Rank	Cause of Death	Frequency	Rate†	%
01 to 09‡	1	Accidents caused by fire and flames (E890-898)§	9	11.2	26
	2	Motor vehicle accidents (E810-825)	8	10.0	24
	3	Other injuries (excludes motor vehicle accidents and fire)	8	10.0	24
	4	Other causes	9	11.2	26
			34		
10 to 19	1	Suicide and self inflicted injury (E950-959)	30	38.6	38
	2	Motor vehicle accidents (E810-825)	24	30.9	30
	3	Accidental drowning and submersion (E910-915)	8	10.3	10
	4	Other causes	18	23.2	23
			80		
20 to 44	1	Suicide and self inflicted injury (E950-959)	84	53.6	23
	2	Motor vehicle traffic accident (E810-819)	56	35.7	15
	3	Homicide (E960-969)	27	17.2	7
	4	Accidental poisoning by drugs (E850-858)	23	14.7	6
	5	Accidental drowning and submersion (E910-915)	20	12.8	5
	6	Other causes	157	100.1	43
			367		
45 to 64	1	Ischemic heart disease (410-414)	67	126.6	17
	2	Lung cancer (162)	23	43.4	6
	3	Motor vehicle traffic accident (E810-819)	20	37.8	5
	4	Diabetes (250)	16	30.2	4
	5	Chronic liver disease and cirrhosis (571)	15	28.3	4
	6	Other causes||	249	470.4	64
			390		
65+	1	Ischemic heart disease (410-414)	117	755.7	20
	2	Other forms of heart disease (420-429)	51	329.4	9
	3	Cerebrovascular disease (430-438)	43	277.7	7
	4	Lung cancer (162)	40	258.3	7
	5	Pneumonia and influenza (480-487)	37	239.0	6
	6	Other causes	287	1853.6	50
			575		

* A total of 37 deaths were excluded because age at time of death was missing.
† Rate per 100,000 population.
‡ There were 65 deaths under the age of one.
§ Codes refer to the ICD-09 Classification System.
|| Breast cancer has been included in the “other” causes category for the 45 to 64 age group. There were 20 cases of breast cancer in this population.
Source: A Statistical Profile of the Health of First Nations in Canada, Appendix 4, Health Canada, (2003). Reproduced with the permission of the Minister of Public Works and Government Services Canada, 2005.

Violence and its Effects

Personal, interpersonal and family violence – including physical abuse, sexual assault and rape – continue to escalate in Aboriginal populations, and with dire effects. The RCAP found that 39% of the overall Aboriginal population reported family violence as a social problem (followed by suicide, sexual abuse and rape, which are all forms of violent interpersonal crimes). Violence, like suicide, does not occur in a vacuum, however, and factors leading to violent and abusive behaviours, including drug and alcohol consumption, must be taken into consideration when assessing the impacts of violence on individuals and communities. In an exploration of the relationship between substance abuse and physical/sexual abuse in an urban Aboriginal population, for example, Jacobs and Gill[19,20] found that those who had experienced physical and/or sexual abuse were more likely to have a current substance abuse problem and that there was a strong intergenerational transmission of violent behaviour and substance abuse. As well, substance abusers were more likely to have a history of legal problems, time spent in jail, and a high level of psychological distress (including depression, anxiety, suicide ideation and attempted suicide).[19,20]

In her submission to the RCAP, LaRocque[26] specifically highlights the effects of family violence on Aboriginal women, teenagers and children. This focus on women is not inappropriate given that up to 75% of the victims of sex crimes in Aboriginal communities are women and girls under the age of 18 (50% of those are under age 14 and almost 25% are under the age of 7), that Aboriginal women are more likely to be living in a social environment in which substance abuse and spousal violence are widespread, and that they are more likely be incarcerated and are at a greater risk of being homicide victims.[63-65] Even with these dismal data, it is still alarming that eight in ten Aboriginal women in Ontario reported having personally experienced violence.[66,67]

Browne and Fiske argue that “the colonial legacy of subordination of Aboriginal people has resulted in a multiple jeopardy for Aboriginal women who face individual and institutional discrimination, and disadvantages on the basis of race, gender and class.”[60,68,69] LaRocque, too, is explicit in locating the underlying cause of violence within colonization and its concomitant damage to the cultural, political, economic and kinship systems of Aboriginal America. She moves one step further, however, in her piercing analysis of the effects of violence on Aboriginal women, stating that racism coupled with sexism leaves Aboriginal women in a highly vulnerable position vis à vis the wider society. This is exacerbated within communities when racism and sexism are internalized by Aboriginal people themselves. Internalization occurs when a colonized group begins to judge itself by the standards of the colonizing society, swallowing externally imposed negative valuations.[70] While many Aboriginal people today are far less inclined to judge themselves by these negative standards, LaRocque argues that internalization still exists and remains part of the problem of family and sexual violence. In addition, in small communities victims of violent and/or sexual assaults face further obstacles, including lack of privacy, humiliation through community gossip and fear of being ostracized and intimidated. Victims may also be confronted with disbelief, anger or denial by other family members. If the victim, most often a woman, chooses to go outside of the community, her claims may not be taken seriously or she may be viewed with indifference or disbelief. Yet LaRocque's solution is not just a turn to strong cultural or political re-assertion. "Political oppression," says LaRocque, "does not preclude the mandate to live with personal and moral responsibility within human communities."[71] She calls for social, cultural and economic revitalization as crucial elements of change, but in concert with a strong, realistic and multi-level approach to youth development as the best and most effective defence against the perpetuation of sexual violence.[71]

Suicide

One wonders if the same approach might quell the disturbingly high rate of suicide in Aboriginal youth and young adults. In 1999, suicide accounted for 38% of all deaths in youth aged 10-19 and for 23% of all deaths in those aged 20-44. The total First Nations suicide rate in 1999 was – at 27.9 deaths per 100,000 – 2.1 times the Canadian populations' suicide rate.[37] Suicide is, bluntly put, the clearest indicator of the severity of social disruption in Aboriginal Canada and the rates are shockingly high by any standard. These suicides are the end result of a toxic mix of poverty, powerlessness, depression and, increasingly, young age[72,73] and each individual suicide simultaneously attests to and hastens further community chaos. The crisis of suicide is set in motion by a series of factors including everything from the immediacy of abuse to the lack of services and local economic, social or cultural resources. Indeed, as Kral[74,75] and Samson[33] both explore in rich ethnographic detail, a long prior history of inequity combined with rapid and growing social and cultural changes, a lack of any political clout, a paucity of economic and social resources, and no apparent end to these inequities are leading to highly traumatic outcomes.

In one study, conducted in 1992, researchers found that of 100 Inuit youth (14-25 years of age) residing in a community on the Hudson Bay coast in Northern Québec, 34 reported a past suicide attempt and 20 had attempted suicide more than once. A full 43 of the 100 reported past thoughts of suicide (26 in the month before the survey) and over 40 had friends who had attempted or completed suicide in the past. The strongest risk factors for suicide attempts were male gender (although the number of young women attempting or completing suicide is on the rise), having a friend who had attempted suicide, experience of physical abuse, a history of solvent abuse, and having a parent with an alcohol or drug problem.[76]

Compounding these stressors may be additional factors such as disorganized band administrations (patterned on the bureaucratic density of Department of Indian Affairs and Northern Development), the limitations on an individual's mobility either from or to a remote community, inadequate family and child services that are replete with jurisdictional disputes between prevention and protection services, and the absence of appropriate counseling.[73] And so, while the rate of suicide or suicide attempts continue to increase – and especially so among younger men and women – there remains a paucity of locally meaningful or effective intervention strategies.[61,77]

Chronic and Infectious Disease Profile

It is widely accepted that the pre-contact period was not so much a halcyon time in terms of a disease-free state but rather a balance of functional health and an "ability to cope with challenges of the environment" including cyclical famines, parasitic infections, accidents and disease.[3] The disease profile shifted, however, when Aboriginal populations – at times already compromised by famine – were in greater contact with Europeans and exposed for the first time to a series of deadly infections. Smallpox, measles, whooping cough, scarlet fever and influenza were among those infectious diseases to take an incalculably high toll on the early contact populations.[3] With the implementation of the reserve system and residential schooling in the early part of the twentieth century, infectious diseases such as tuberculosis plagued Aboriginal populations, especially those already compromised by inadequate reserve housing, poor sanitation and water, and limited food supplies.

While Aboriginal populations still have higher rates of infectious disease, chronic diseases such as diabetes and cancer are now taking a high toll on indigenous peoples. For example, NIDDM (non-insulin-dependent diabetes mellitus) was once unknown to Aboriginal populations. Over the last 25 years, this chronic disease has grown to become a major health concern of Aboriginal peoples around the world. Here in Canada, the prevalence of NIDDM in First Nations, Inuit and Métis peoples is between three to five times the national average, with rates higher in women and highest among those living on-reserve. The data also reveal that First Nations people develop NIDDM at a younger age and by the time they reach their 30s, 5% of First Nations people have developed the disease. The rate increases rapidly with age. The 1997 Regional Health Survey revealed that one third of those over 65 had been diagnosed with NIDDM.[78] Further, Aboriginal people with NIDDM tend to develop complications at a younger age than non-Aboriginal Canadians. Given these statistics, NIDDM has, not surprisingly, become a significant health funding and research priority for the Aboriginal leadership in Canada. The high prevalence of NIDDM has also had unanticipated positive outcomes as well. Stimulated by an attempt to reverse the trend, local research and community health initiatives in one Quebec Mohawk community have turned into some of the most innovative, inclusive, empowering – and emulated – public health projects and research protocols to date (see, for example, the Kahnawake School Diabetes Prevention Project[79]).

Infectious diseases, while not as ubiquitous as in the early part of the last century, continue to impinge on First Nations communities in disproportionate numbers when compared to the rest of Canada. In 1999, for example, the prevalence of tuberculosis was 8 to 10 times higher in First Nations than among non-Aboriginal Canadians. While the rate that year was due in part to large outbreaks in several regions (with just over 40% of the total cases occurring in 5 communities) infectious diseases occur disproportionately in First Nations communities.[37] For example, pertussis rates were three times the Canadian national rate in 1999, hepatitis rates were five times the national rate and chlamydia rates were just over five times the national rate.[37] One other infectious disease is noteworthy, given that it is highly preventable yet occurs at 19.3 times the national rate and was found to occur in one province in particular at 29 times the provincial rate: shigellosis is a bacterial infection that is the direct result of poor water quality, inadequate sewage disposal and, indirectly, poverty. As Rosenberg, Kendall and Blanchard[80] found in Manitoba, household crowding, poor access to clean water, and inadequate sewage disposal were significantly associated with increased incidence of shigellosis on reserves. Unsatisfactory – and unacceptable – living conditions, simply put, make people sick.

HIV/AIDS

In the last decade, the proportion of Canada's total HIV/AIDS cases contracted by Aboriginal people has risen sharply: from 1.0% in 1990 to 7.2% in 2001. The increase has been so dramatic that the Executive Director of the Canadian Aboriginal AIDS Network refers to it as an "epidemic".[81] As in other communities and like many other health issues, HIV/AIDS is a problem of poverty, of under- and unemployment, unstable housing, homelessness, sexual/physical abuse and a concomitant lack of self-worth. HIV/AIDS is also a problem of injection drug use and all its attendant effects. A study sponsored by the Montreal Native Friendship Centre repeats the unsettling refrain that "unless [these] root causes of high risk behaviour are addressed…no amount of HIV/AIDS prevention will be effective."[81] The same study found that when Aboriginal people test positive for HIV infection, they often do not access the available services: "As a consequence of multiple stigmas associated with HIV and AIDS, both within the Aboriginal and non-Aboriginal communities, most Aboriginal people living with HIV/AIDS prefer to remain invisible, silent and anonymous. Many aboriginal people [will] not seek out care, support or urgent treatment upon HIV diagnosis, but rather [do so] at later stages of the disease." The Montreal study indicates that service providers do not know enough about the "lived experience, needs, perspectives, cultures and traditions of First Nations, Inuit and Métis clients" and that there are significant barriers to establishing a trust-based relationship between service providers and HIV/AIDS clients. Here, like with other Aboriginal health-care concerns, there are cultural, linguistic and structural barriers, conflicting expectations and experiences about medical service delivery, financial and non-insured health benefits, or a lack of knowledge about existing services. A national Aboriginal AIDS strategy has been developed to begin to chip away at some of these barriers and is being linked to ongoing provincial urban strategies and community-based initiatives.[81] While strategies like these deserve and require effective and long-term support, the underlying causes of HIV/AIDS (and drug dependency), including under- and unemployment, inadequate housing and abuse, must also be effectively resolved.

The institutionalization of inequity – Services and programs

Health-care services and provision have improved considerably since Aboriginal Canadians came into contact both with non-Aboriginal diseases and biomedicine. The earliest form of biomedical health care arrived in many communities with missionaries, who often saw the opportunity to heal a body as an investment in saving a soul. Nonetheless, the missionaries did provide rudimentary health service prior to any other medical attention to Aboriginal peoples in Canada.[13] While some (meager) form of health-care services was federally instituted at the beginning of the 1900s, it was not until after World War II that health and social services were systematically provided to Aboriginal peoples, and this in part because of concerns regarding questions of the health and safety of non-Native population.[3,82] Guided perhaps more by the need for a visible presence in the North and northern border security than by genuine concern for Aboriginal peoples (as wards of the state), health and social services extended into the farthest reaches of northern Canada through the Cold War period. Hodgson[82] describes the treatment for tuberculosis throughout the 1950s, for example, as interventions that showed only the most rudimentary concern for individual or community well-being. Anyone testing positive for the disease was physically removed from the reserve or residential school to a sanatorium far away from home. Hodgson explains that the government's priorities in caring for Aboriginal peoples with tuberculosis have been perceived as paternalistic, unnecessary, undesirable, and latently hostile, especially when removing people from their home community to southern, and wholly foreign, sanatoria. Treatment, says Hodgson, was imposed upon the people with little attention to the participation or needs of the recipient population who had little or no control over the quality or quantity of their medical care. The long-term effects of the disruption to family life from the long-term removal of family members had a profound impact across the country. To this day, for many Aboriginal peoples, there is a lingering fear of institutions that can be traced directly back to the insensitive treatment of those with tuberculosis.

To be sure, much has changed since initial contact with "western" diseases and biomedical practices and there have been many improvements in health-care services and delivery to Aboriginal peoples throughout Canada. Services alone, however, do not ensure health and what services are available remain largely inadequate and underestimate the link between the local control of health services and practices, meanings of health, and health disparities.

Health-care services are still provided to Aboriginal peoples living on-reserve or in remote communities through the federal government. Those services, a treaty-based federal responsibility, have been a struggle to maintain, regardless of their adequacy or sufficiency. While First Nations have requested an autonomous locally accountable system of health-care provision, the government does not admit that health is an Aboriginal or treaty right. An exception to this rule is if self-government in health care has been negotiated as part of a treaty settlement, as in the case of the James Bay Cree of Québec; through this agreement, the Cree Regional Board of Health and Social Services took over the management of the health and social services needs of the Québec Cree. Outside of that kind of exception, the federal government only acknowledges a "special relationship" between the federal government and First Nations and, since 1989, has been instituting a Health Transfer Policy.

Initiated in 1974 as the "Indian Health Policy", the current Health Transfer Policy emerges out of the federal government's desire to integrate Aboriginal health care into the larger national health-care system. From the period of the late 1960s, when there was a federal push towards devolution of all "special services" first to provinces and then to Aboriginal peoples, to the 1989 government approval of the Health Transfer Policy to First Nations communities, representatives of the First Nations have fought to retain as much autonomy in health care delivery as possible, given the constraints inherent in the negotiation process.

The First Nations and Inuit Health Branch (FNIHB) of Health Canada, with regional offices in every province, supports the delivery of public health and health promotion services on-reserve and in Inuit communities. It also provides drug, dental and ancillary health services to First Nations and Inuit people regardless of residence. Included within the FNIHB are the community programme directorate (which includes the children and youth division, mental health and addictions division, chronic disease prevention division, and other programs related to, for example, obesity and fitness, cancer, and cardiovascular disease), primary health care and public health directorate (which includes the divisions of primary health care, infectious disease control, environmental health, environmental research, and dental and pharmacy programs), non-insured health benefits directorate, the office of nursing services, the office of community medicine, the business planning and management directorate, the strategic policy, planning and analysis directorate, and the chief executive advisor of First Nations and Inuit relations. In addition, the Northern Secretariat was created in Fall 1998 to provide equitable program delivery to the First Nations and Inuit living in the Yukon, the Northwest Territories and Nunavut (see for example: www.hc-sc.gc.ca/fnihb/, www.hc-sc.gc.ca/ns. The National Aboriginal Health Organization has a comprehensive review of Aboriginal health-related initiatives[83]).

The Health Transfer Policy certainly does "achieve an increasing level of health in Indian communities, generated and maintained by the Indian communities themselves" and does acknowledge a "special relationship" between First Nations and the federal government. It does not, however, recognize health as an Aboriginal treaty right and hence summarily removes it from the realm of treaty negotiations.[84] This, fundamentally, is the fatal flaw of the Health Transfer Policy: while it transfers a range of services (including medical and hospital insurance, public health, and non-insured services such as drug and eyeglass prescriptions and dental care), it retains and reproduces the pre-existing dependent relationship. Thus, for example, First Nations proposals for community health plans must be approved by the federal government, there is a "non-enrichment" clause, which freezes funding from the time of transfer (and is calculated according to the number of registered members living on-reserve at the time of transfer); as well, the Transfer Policy does not formally recognize the role of traditional healers in the transfer agreement nor does it fund the training of First Nations health-care professionals.[83,85] Ultimately, says Speck, the position taken by First Nations is that, "in the absence of recognition of title and treaty rights, control over economic resources, political autonomy, improved standards of living and changes in the attitudes of non-Native Canadians towards First Nations, health care services alone are unlikely to result in significant improvements in the health status within First Nations."[30,83,86]

First Nations, Inuit and Métis living in urban centres find themselves excluded from many of the services and benefits that arise from the FNIHB. Aboriginal people moving into or living in urban centres face a range of different health care provision challenges as they ostensibly exit their community's health networks and enter into the provincially-funded public health care system. While those living on-reserve have been, to be sure, "studied to death", the health status of those living off-reserve remains to a large extent ignored.[87] As Goldenberg further summarizes: "Just as most demographic data are difficult to obtain for urban Natives, their health information is often inaccurate, inaccessible, or otherwise buried within the health information of the larger non-Aboriginal population or of the on-reserve Aboriginal population…. The lack of accurate information is compounded by a lack of political will, since the federal government mostly concerns itself with the [statistically and organizationally relevant] health needs and patterns of Indian people on reserve".[88] Thus, while there are various successful, culturally-appropriate urban initiatives across urban Canada (such as Anishnabe Health in Toronto), there remains the problem of inadequate assessments of health-care needs, formidable barriers to timely and appropriate care, and scarce resources to offer appropriate services to the urban – and particularly the poor – Aboriginal women, men and children.[23] For example, Benoit found that Aboriginal women living in the downtown eastside of Vancouver, "expressed a strong desire for a 'Healing Place', where health concerns could be addressed in an integrated manner, where they [could be] respected and given the opportunity to shape and influence decision-making about services that impact their own healing."[89,90]

SUMMARY AND RECOMMENDATIONS FOR FUTURE POLICY AND RESEARCH

The theme repeated time and again in so many of the studies and reports reviewed here is this: those who are the poorest and the most disempowered are the sickest and the least likely to be able to change or remove themselves from their immediate circumstances. Referred to as an "endless circle of disadvantage", too many Aboriginal people in Canada are caught in a seemingly never-ending cycle of poverty, violence, educational failure and ill health.[55] How far must we look and how deep must we dig in order to come to some understanding of these disparities? The context of this inequality emerges with and through a distressing legacy of colonialism and is sustained by ineffective, inappropriate or under-funded programs or services for First Nations peoples in Canada. Thus, it is firmly believed that the ills and illnesses that have been reported here must be seen, at least in part, as the direct and indirect present-day symptoms of a history of loss of lands and autonomy and the results of the political, cultural, economic and social disenfranchisement that ensued.

The path towards a reduction in disparities in First Nations, Métis and Inuit health status is ultimately linked to a larger political will and attendant policy framework that will effectively acknowledge the relationship between inequality and ill-health. A fundamental first step towards the resolution of these disparities begins with an understanding that "[a]ny approach which fails to consider Aboriginal people as active in response to their colonial situation, rather than simply as passive victims, will fail to comprehend not only the past changes in health status and health care, but more importantly the future direction that will be taken in these areas".[4] Steps in that direction are now being taken at the community, regional and national levels and offer a good degree of optimism in among the persistent experience of disease, distress and social suffering for far too many Aboriginal peoples in Canada. The initiatives of, for example, the National Aboriginal Health Organization (NAHO), the National Native Alcohol and Drug Abuse Program, the First Nations Chiefs' Health Committee of British Columbia, the Manitoba First Nations Centre for Aboriginal Health Research, the National Indian and Inuit Community Health Representatives Organization, the Aboriginal Healing Foundation (a direct but time-limited response to the RCAP and acknowledgement of the suffering incurred in residential schools), the Kahnawake School Diabetes Prevention Project,[79] the Native Mental Health Association, as well as the many local community- and nation-based initiatives and the CIHR Institute of Aboriginal Peoples' Health (IAPH), all clearly resonate with promise of a better future for the health of Aboriginal peoples in Canada. Gaps still remain, however, in both the researching and implementation of health initiatives for Aboriginal peoples in Canada. The most significant problem is the lack of control of a comprehensive health-care program. While there are many initiatives being created by and for the First Nations of Canada, there is inadequate control of the resources so that efforts can be stymied or ineffectively funded as a result of the bureaucratic maze of Aboriginal health-care management and policy in Canada.

In addition to this lack of control there remains a paucity of research that is inclusive, engaged and empowering. There is, appropriately, a growing call for "decolonizing methodologies" in Aboriginal research and program initiatives that engage in meaningful dialogue with communities, establish priorities and conduct research that is successfully collaborative.[91] Dion Stout continues to call for research methods that are "just, sustainable and inclusive" as a crucial element in research that is as empowering as it is productive.[65,92] For example, in syntheses such as this one, we assign greater authority to statistics than to case studies and the voices of individuals. Yet statistical data alone reduce individuals to subsets of specific populations and effectively is a methodology that can further colonize peoples into abstract entities. To be sure, there are many good uses for these data as they can expose inequalities in health and health care. Statistical data alone, however, only tell us the degree of health disparity and not enough about the causes and extent of the felt effects. What we now need are research initiatives that will lead toward a clearer understanding of – and emergence from – these disparities. That research must be conducted in concert with the needs and aspirations of First Nations, Inuit and Métis men and women.[30,32,93] Organizations such as NAHO and research institutes such as the IAPH, committed to the overall health, well-being and empowerment of Aboriginal people across Canada through, in part, the advancement and sharing of Aboriginal health knowledge, are making tremendous headway in the shift towards equitable, empowering, culturally appropriate, inclusive and accessible high-quality research.[30,94,95]

We must further be able to envision studies that examine differences within and between age groups, genders, levels of socio-economic status, education, and other significant markers of both identity and inequity. Studies of "health" must be interpreted broadly enough to navigate the terrain between individuals and communities and include studies of housing, water, education, development and resource extraction in addition to the different social and cultural valuations of health and empowerment. We cannot presume an unchanged, single or uniform "Aboriginal" culture, whether people are of First Nation, Inuit or Métis heritage as culture can never be reduced to a variable in a contemporary world of urban Native artists, traditionalists, or poverty-weary young mothers. At the same time, though, we must remain cognizant of the very real cultural and social barriers that may exist between First Nations, Inuit and Métis individuals and health-service providers in communities and urban centres. It is only in this way that we will understand and be able to effectively reduce both the inequities and the disparities of health. Research and policy needs must, fundamentally, reflect the contemporary realities of Aboriginal health and well-being, including the individual and community-based effects of health disparities (including violence, suicide, HIV/AIDS and diabetes) and examine the contribution of direct (e.g., housing, education, employment, and adequate and appropriate health services) and indirect (e.g., colonization, racism) sources of those disparities.

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RÉSUMÉ

Les disparités sur le plan de la santé sont, d'abord et avant tout, les indicateurs d'un fardeau de maladie relatif disproportionné imposé à une population particulière. Les inégalités en matière de santé font ressortir les causes principales des disparités, dont un grand nombre – sinon la plupart – dépassent largement le domaine habituel que constitue la « santé ». Plus particulièrement, la documentation examinée en vue de rédiger le document de synthèse indique que maintes et maintes fois, les disparités sur le plan de la santé résultent directement et indirectement des inégalités sociales, économiques, culturelles et politiques, dont le résultat final est d'imposer un fardeau disproportionné de mauvaise santé et de souffrances sociales aux populations autochtones du Canada. Dans les analyses de ces disparités, il est important d'explorer tout le champ des relations entre les individus et les contextes sociaux et historiques plus larges, tout comme il convient de prêter attention aux effets individuels des iniquités. La recherche et les politiques doivent se pencher sur les réalités contemporaines de la santé et du bien-être des Autochtones, dont les effets individuels et communautaires des disparités sur le plan de la santé et leurs causes directes et indirectes.

Literacy and Health Research in Canada

Where Have We Been and Where Should We Go?

Irving Rootman[1]
Barbara Ronson[2]

ABSTRACT

This article reviews current literature and research on literacy and health and identifies priorities for research on this topic in Canada. Information sources included documents found through an environmental scan, the Alpha Plus collection and a computer search of recent documents. The information was analyzed using a conceptual framework. The review found that low literacy has direct and indirect impacts on health. Families are at risk due to difficulty reading medication prescriptions, baby formula instructions and health and safety education materials. People with lower levels of literacy tend to live and work in less healthy environments. They have more difficulties obtaining employment and income security. Determinants of literacy include: education, early childhood development, aging, living and working conditions, personal capacity/genetics, gender and culture. Action is needed to improve literacy and health through a combination of health communication, education and training, community development, organizational development, and policy development. There is some evidence that such interventions can have a positive effect on health, particularly when combined with one another. Further program and policy development requires greater evidence and evaluation of existing initiatives, more cost/benefit analyses, more culturally specific studies, and greater attention to current social trends and needs.

MeSH terms: Literacy; health; health literacy; research; evaluation; health promotion

Literacy and health research and practice in Canada date back to the late 1980s when the Ontario Public Health Association (OPHA) collaborated with Frontier College, the country's oldest literacy network, on a literacy and health project. Their first report, *Making the World Healthier and Safer for People Who Can't Read*, was published in 1989.[1] Their second report, *Partners in Practice*, documented the increasing collaboration that their work had fostered between literacy workers, health service providers and learners.[2]

In 1994, the Canadian Public Health Association (CPHA) established the National Literacy and Health Program (NLHP) with funding from the Secretary of State's new National Literacy Secretariat. Through the NLHP, CPHA has collaborated with 27 national partners to improve health services for consumers with literacy difficulties. They have carried out several projects, organized conferences and generated the publication and dissemination of countless plain language materials. The NLHP is considered to be a model for raising awareness, exploring issues, developing resource materials and building partnerships in this field. Its work helped Canada to become an international leader in literacy and health. Today, the field is at a critical juncture where further program and policy development requires greater evidence and evaluation of existing initiatives, more cost/benefit analyses, more culturally specific studies and greater attention to current social trends and needs.

Some of the trends we are facing that make this kind of work so timely are that our ethnic and linguistic make-up is changing rapidly; the use of computers and new technologies is proliferating; there are greater literacy requirements for functioning in our knowledge economy; there are unprecedented stresses on our health-care and education systems; we have an aging population at the same time as there is a growing reliance on home and community care in place of institutional care; and Canadians are finding increasing opportunities and responsibility to provide health-care information, support and education internationally as well as locally. Finally, we urgently need multi-sectoral collaboration to solve many kinds of problems. The field of health promotion has a

La traduction du résumé se trouve à la fin de l'article.

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1. Professor and Michael Smith Foundation for Health Research Distinguished Scholar, University of Victoria
2. Consultant and Fellow, Centre for Health Promotion, University of Toronto

Correspondence: Dr. Irving Rootman, Faculty of Human and Social Development, University of Victoria, PO Box 3060, Stn CSC, Victoria, BC V8W 3R4, Tel: 250-472-4102, Fax: 250-472-4836, E-mail: irootman@uvic.ca

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history of experience in partnership building, and literacy and health research can be a guiding light for the kind of work and methods that are needed.

In 2002, a team of researchers from across Canada,[3] in partnership with the Canadian Public Health Association, was funded by the Social Sciences and Humanities Research Council (SSHRC) to develop such a program of research. They began by conducting an environmental scan of Canadian research and practice in literacy and health as well as a needs assessment. In addition, they received funding from three institutes of the Canadian Institutes of Health Research (CIHR) – Aboriginal Health, Gender and Health, and Population Health – to organize a workshop (the "national workshop") to present the findings of the environmental scan and needs assessment and define a national agenda for further research.[4] Figure 1 shows key milestones in the development of the field in Canada.

This article is an attempt to provide an overview of where we have been and a projection of where we should go in literacy and health research in Canada. Specifically, the objectives of this article are to:

1. review existing literature and research on the impact of literacy on health, on the determinants of literacy, and on the effectiveness of interventions to improve health through improving literacy; and
2. identify priorities for research on literacy and health in Canada.

The approach to reviewing the literature used in this article was to employ a conceptual framework developed by the authors and collaborators to identify relevant literature and research and examine it carefully to determine the extent to which it supports the framework. A MEDLINE search was carried out to identify relevant literature using the terms literacy, literacy and health, and health literacy. Computer searches also identified relevant literature through the search engine Alta Vista and through the Alpha Plus collection in Toronto using the terms "literacy" and "health". In addition, sources identified in the NHLRP key informant survey were examined. Existing reviews, particularly those conducted by Perrin[5] and Rudd and her colleagues[6] and those carried out for the US Institute of Medicine report on Health Literacy[7] were used as well.

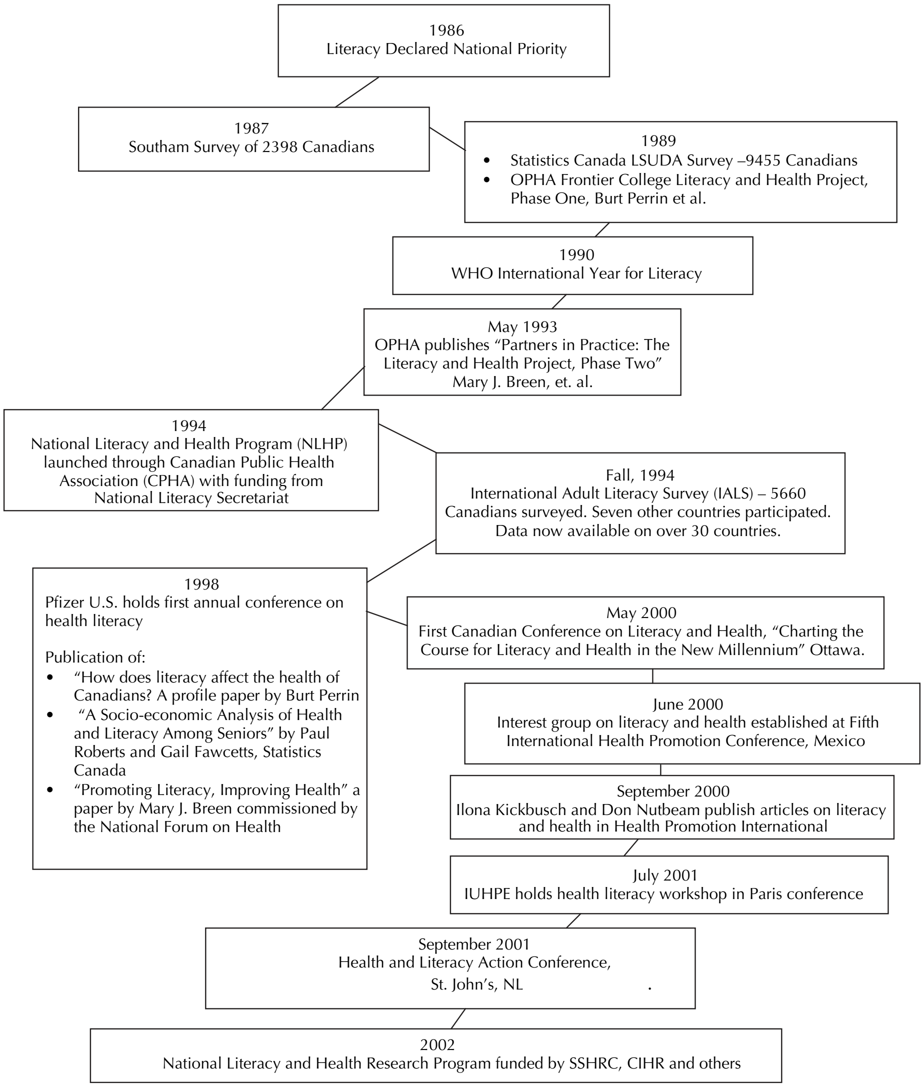


Figure 1. Milestones in literacy and health research in Canada

With regard to identifying priorities for research in Canada, the conclusions of the above-mentioned environmental scan and needs assessment and national workshop were considered, as well as recommendations in the literature and research that were reviewed.

Conceptual framework for literacy and health research

One of the first steps of the National Literacy and Health Research Program was to develop a conceptual framework for literacy and health research based loosely on the work carried out for the OPHA and Frontier College project.[5] An initial framework was discussed in four focus groups across the country and revisions were made based on the feedback received at the focus groups as well as at the national workshop. The resulting framework is shown in Figure 2.

In the middle of the diagram, under the heading "Literacy" we find "general literacy", "health literacy" and "other literacies". General literacy includes reading and listening ability, numeracy, speaking ability, negotiation skills, critical thinking and judgment. Health literacy is thought to include the ability to find, understand and communicate health information and to assess it. Other literacies are thought to include computer literacy, cultural literacy, media literacy and scientific literacy.

To the right of the literacy box are a number of possible direct and indirect effects of literacy on health. Direct effects include medication use and safety practices; indirect effects include use of services, lifestyles, income, work environment and stress levels. In the bottom left-hand box of the framework are a number of possible determinants of literacy including

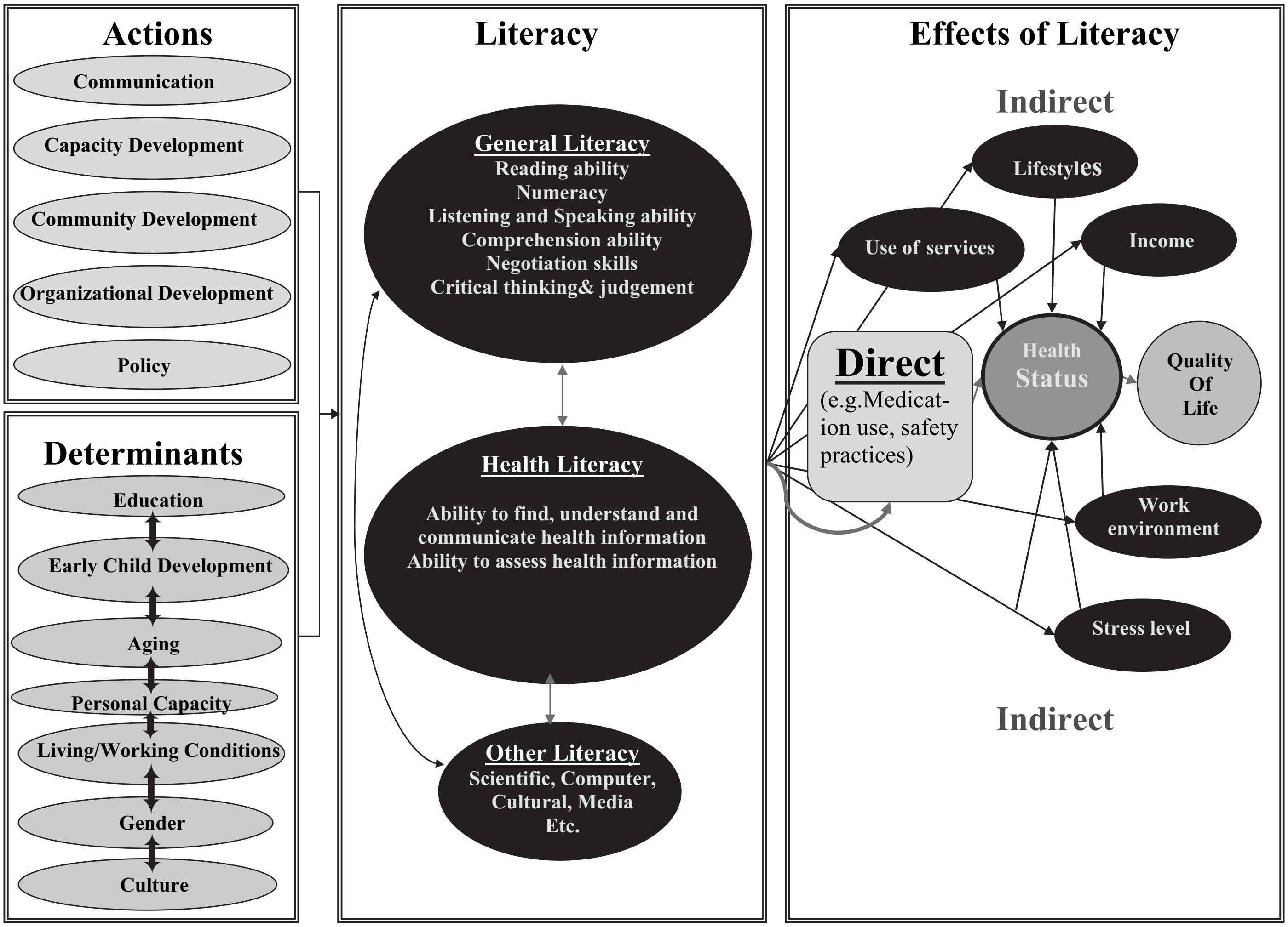


Figure 2. Conceptual framework for literacy and health research

education, early childhood development, aging, personal capacity, living and working conditions, gender and culture. Finally, in the top left-hand box are a number of types of actions (health communication, health education, community development, organizational development and policy development), which might be used to address literacy and health issues. This conceptual framework was used to review the relevant literature.

Specifically, the following sections cover the main components of the framework. That is, the next section focusses on the "literacy" component by covering the definition and measurement of literacy and health literacy and the relationships between the different types of literacy. The section after that focusses on the "effects" component, covering both direct and indirect effects. The one following that on the "determinants" component covers all of the determinants listed. The penultimate section of the article reviews what we know about the four research priorities suggested by the national workshop, namely: effectiveness of interventions; cost-benefit studies; Aboriginal and francophone communities and culturally diverse and challenged groups; and literacy, life-long learning and health. The final section presents conclusions and recommendations for research and practice.

Defining and measuring "general literacy"

Historians estimate literacy rates in other times by the number of people who signed their marriage certificates with an X in church records. Immigration authorities in Canada and the US were known to test literacy by having applicants read a passage from a book, and those who couldn't were often turned back. In the 1950s, UNESCO portrayed literacy as a continuum of skills, suggesting two levels for international comparison: a minimum level marked by the ability to read and write a simple passage; and a functional level demonstrated by literacy sufficiently high for the person to function in society. Over 110 countries have used UNESCO's simple definition that "a person is literate who can with understanding both read and write a short simple statement on his everyday life."[8] Because it is so time-consuming and expensive to test large numbers of citizens, literacy rates have commonly been estimated across countries based on years of schooling. But the skills needed to be literate have increased as more children and youth spend more years in school. UNESCO suggests that "[a] person is functionally literate when he [sic] has acquired the knowledge and skills in reading and writing which enable him [sic] to engage effectively in all those activities in which literacy is normally assumed in his [sic] culture or group."[8] It is now estimated that students in western countries who have less than nine years of schooling have not achieved sufficient skills.

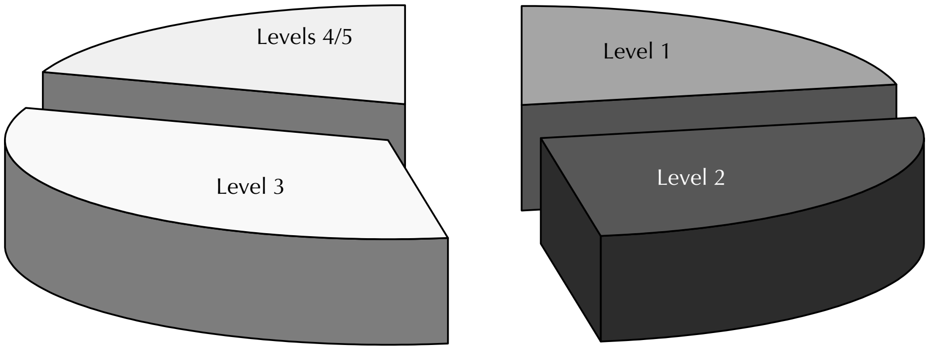
Progress has been made in developing and using measures of “functional literacy” within and across countries. In 1974, the US Office of Education defined 11 skills for functional literacy, such as reading and understanding all sections of a newspaper; reading a driver’s licence test; and reading business letters from debtors and creditors. The Adult Performance Level Study[9] defined four basic areas of skills proficiency: communication, computation, problem solving and interpersonal skills. These were tested across five knowledge areas: occupational, consumer economics, community resources, government and law, and health. A 1987 Southam survey in Canada[10] was based on a functional definition of literacy and items were selected from a US National Assessment for Educational Progress instrument and amended for a Canadian audience. A panel of diverse professionals as well as learners rated each item in order to determine a definition of “literacy”. Eighty percent of the panel had to agree in order for an item to be included as critical for literacy.

In 1992, the literacy level of 26,000 adults across the US was tested by the Educational Testing Service in a National Adult Literacy Survey (NALS).[11] This survey was also based on a functional definition of literacy and participants were assessed on a five-point scale. In 1994, Human Resources Development Canada and others funded the International Adult Literacy Survey (IALS) using a similar instrument that assessed “prose”, “document” and “quantitative” literacy on a five-point scale (see Table I). Originally a seven-country initiative, data are now available from more than 30 countries. The IALS is now the main source of measures of literacy in the general population in Canada and in other countries.[12] The latest figures (1994-95) show that 48% of Canadian adults fall into the lowest two categories. Twenty-two percent of adults have serious literacy challenges, and another 26% do not have the literacy skills necessary to participate fully in the “knowledge economy”.[13] Figure 3 illustrates the literacy levels of Canadian adults over age 16.

TABLE I

Kinds of Literacy Measured in the International Adult Literacy Survey

Prose literacy:	Reading and understanding text in sentences and paragraphs.
Document literacy:	Using and understanding maps, charts, forms and other documents.
Quantitative literacy (or Numeracy):	Using numbers for daily tasks such as balancing a cheque book, calculating a tip, completing an order form, or determining the interest on a loan.



Level 1	A person is not able to read at all or has very serious problems with reading (22%)
Level 2	A person can read simple language (26%)
Level 3	A person can read well enough to get along from day to day (33%)
Levels 4&5	People can read complex reading material (20%)

Figure 3. Literacy level of Canadian adults over age 16

Source: International Adult Literacy Survey, 1994

In the US and Canada, concerns have grown that longer years in school among today’s students have not been associated with rising standards of literacy or skills needed to succeed in the present “knowledge economy”. This has led to widespread literacy testing in schools. In Ontario, approximately 95% of all Grade 3, 6 and 10 students have been tested in the past four years.[14] That amounts to hundreds of thousands of young Ontarians participating each year, far more than the 2,398 of the 1987 Southam survey, the 9,455 of the 1989 Survey of Literacy Skills used in Daily Activities (LSUDA) survey or the 5,660 in the 1994 IALS. Results of these tests on children and youth have recently become available and will undoubtedly add fuel to the interest in literacy studies in general and literacy and health studies in particular. In Ontario, a passing score on the Grade 10 literacy test has become mandatory for high school graduation. Only recently have there been alternatives proposed for the 20% or more unlikely to ever pass the test. The impact of the testing has been massive but as yet there has been little research into its impact on health and learning of our young people.

When regional, international and school comparisons are not important, more flexible definitions of literacy meaningful to individual learners are preferred, at least when it comes to adults. Freire’s highly influential book, *Pedagogy of the Oppressed*,[15] describes literacy as an active phenomenon, deeply linked to personal and cultural identity. His work helped transform understanding of literacy from a received ability to read and write to an individual’s capacity to put those skills to work in shaping the course of his or her own life.[16] Sticht differentiated externally imposed literacy tasks from internally imposed tasks and defined functional literacy as “the possession of those literacy skills needed to perform some reading task imposed by an external agent between the reader and a goal the reader wishes to obtain.”[17] This definition fits within a health promotion framework. The Ottawa Charter for Health Promotion[18] defines health promotion as the process of enabling people to gain control over their health. The related concept of empowerment is considered to be the key mechanism of health promotion. Literacy can be one means of personal empowerment and gaining control over one’s own health if it is internally imposed. Many Aboriginal texts on literacy have adopted the term empowerment as fundamental for literacy and learning.[19-21]

With the advent of functional, needs-based approaches, the definition of literacy may always be a moving target. People have begun speaking in terms of "literacies" not "literacy" and to promote "media literacy", "computer literacy", "health literacy" and the like, instead of a discrete concept of something one either has or does not have.[22] New technologies, bilingualism, multiculturalism and the renaissance of Aboriginal culture in Canada have pushed the meaning of literacy beyond reading, writing and numeracy skills in one official language. Schools that are mainly defined in terms of "reading, writing, and 'rithmetic" may similarly be obsolete. New technologies have given wide access to means of learning other than printed books, pamphlets, lectures and face-to-face conversations — the predominant options a century ago. Cultural pluralism has made us more aware of oral cultures and languages not linked to the alphabet. Leu writes, "if there is one thing that is certain in these uncertain times, it is that the technologies of information and communication will regularly and repeatedly change, regularly redefining what it means to be literate."[23]

Shohet of the Centre for Literacy, Québec concurs: "Electronic media are changing the nature of literacy and forcing a convergence of print, the visual, and the oral."[22] The Centre for Literacy defines literacy as "a complex set of abilities to understand and use the dominant symbol systems of a culture for personal and community development."[24]

Aboriginal literacy has been defined by a coalition of Aboriginal literacy specialists in terms of colours of the rainbow:

- red represents literacy in the language of origin of First Nations individuals and communities
- orange – oral literacy
- yellow – creative means of communicating with speakers of other languages using symbols, artwork and sign language
- green – the languages of the original European newcomers, French and English — now Canada's official languages
- blue – technological literacy; and
- violet – balance, the holistic base to Aboriginal literacy, dealing with spiritual, emotional, mental and physical elements.[25,26]

The Ontario Native Literacy Coalition defines Native literacy as (p.10):[25]

> "…a tool which empowers the spirit of Native people. Native literacy services recognize and affirm the unique culture of Native Peoples and the interconnectedness of all aspects of creation. As part of a life-long path of learning, Native literacy contributes to the development of self-knowledge and critical thinking. It is a continuum of skills that encompasses reading, writing, numeracy, speaking, good study habits, and communicating in other forms of language as needed. Based on the experience, abilities and goals of learners, Native literacy fosters and promotes achievement and a sense of purpose, which are both central to self-determination."

The future of literacy in Canada may be one of multiple literacies with multiple definitions and measures, although at the moment, the official definition of literacy is the one used by the IALS, namely: the "ability to understand and employ printed information in daily activities – at home, at work and in the community – to achieve one's goals and develop one's knowledge and potential."[12]

Defining and measuring "health literacy"

Although the term "health literacy" was first used in health education about 30 years ago,[27] it has only recently been taken seriously as a field of inquiry. In 1998, Pfizer U.S. held its first annual conference on health literacy. The Institute for Healthcare Advancement in the U.S. started annual conferences on health literacy in 2001. An ad hoc Committee of the American Medical Association defined functional health literacy as "the ability to read and comprehend prescription bottles, appointment slips, and other essential health-related materials required to successfully function as a patient."[28] The U.S. Department of Health and Human Services defines it as "the capacity to obtain, interpret and understand basic health information and services and the competence to use such information and services to enhance health."[29] The US government's *Healthy People 2010* describes it as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[30] This was the definition that was adopted by the Institute of Medicine Committee on Health Literacy.[7]

The Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA) are the main tests for health literacy. Both of them are really tests of reading ability in a health context and ignore oral and aural literacy. When the TOFHLA was administered to 2,659 predominantly indigent, minority emergency room patients at two public hospitals in the US, 41.6% were unable to comprehend directions for taking medication on an empty stomach; 26% were unable to understand information regarding when to come for a next appointment; and 59.5% could not understand a standard informed consent document. More than 80% of both English- and Spanish-speaking patients over 60 years of age were found to have inadequate or marginal health literacy. This is significantly more than younger English- and Spanish-speaking patients of whom 31% and 62% had inadequate health literacy respectively.[31] We do not yet know, however, how many of these patients could comprehend directions given orally as opposed to in writing, nor how many were able to find information they needed in other ways. It is conceivable that people can be functionally health literate with minimal reading and writing skills, depending on how health literacy is defined.

A health promotion interest group on health literacy involving participants from different countries has been established and a series of meetings and workshops have taken place to help conceptualize health literacy. One of these was held at the Fifth International Conference on Health Promotion in Mexico (June 2000). This group has generated still more interest in health literacy among health promotion practitioners, as indicated by continued publications on this topic particularly in the *Health Promotion International* journal. A proposed redefinition of health literacy that goes beyond functional aspects is found in a 1998 revision of the WHO glossary of health promotion terms. Health literacy is described there as "the cognitive and *social* skills which determine the *moti-*

vation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health" [emphasis added].[32] In addition, the glossary notes that "[h]ealth literacy means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is crucial to empowerment."[32] Building upon the redefinition of health literacy to encompass concepts of empowerment, Nutbeam[33] defined three levels of health literacy:

1. Basic/functional: "sufficient basic skills in reading and writing to be able to function effectively in everyday situations."
2. Communicative/interactive: "more advanced cognitive and literacy skills which, together with social skills, can be used to actively participate in everyday activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances."
3. Critical literacy: "advanced cognitive skills which, together with social skills, can be applied to critically analyze information, and to use this information to exert greater control over life events and situations."

Nutbeam and others have suggested that health literacy is a key outcome of health education and one that health promotion could legitimately be held accountable for. Some scholars, however, have questioned the utility of redefining health literacy. For example, according to Keith Tones, editor of the journal *Health Education Research*, "the kind of territorial expansion involved in translating limited, but clearly defined concepts into much broader, semantically unrelated constructs is both unnecessary and counter productive."[34] The debate is a healthy one and should continue.[35]

Although we have come a long way in understanding, defining and measuring literacy and health literacy, there is still much to be done. As mentioned, the TOFHLA and REALM measure only a limited range of capacities associated with health literacy and, with the exception of the TOHFLA-Spanish version, are in English only. There are no contextual measures. Similarly, the IALS measures only a limited number of components of literacy (prose, document, quantitative) and misses others (e.g., oral and aural). Thus, measures for literacy and health literacy today are inadequate and new ones need to be developed. This was one of the key conclusions of the recommendations of the recent Institute of Medicine (IOM) Committee on Health Literacy.[7]

Correlations between literacy, health literacy and other literacies

No population survey has measured the relationship between literacy and health literacy. However, correlations between existing measures of literacy and of health literacy suggest an association[36] and the correlates of literacy are similar to those of health literacy[6] suggesting that they are strongly, but not perfectly, related to each other. With regard to other literacies, no studies were found that statistically examined the relationships with either general literacy or health literacy. Thus, we clearly need more research on the relationships between literacy, health literacy and other literacies in understanding literacy and health.

Effects of literacy

Direct Effects

There is evidence in the literature that literacy is directly related to overall health status and mental health status[37-39] as well as co-morbidity burden.[40] In addition, low-literate consumers and their families appear to be at risk of harm due to their difficulty reading medication prescriptions, baby formula instructions and other written material.[41] The direct effects of literacy on health are a matter of concern for all health-care providers. If their communications and instructions are not helpful, and are potentially harmful for up to one-half of their clients, addressing the problem should be a priority. Primary concerns are with medication use, compliance with physician orders[42] and with chronic-condition management.[43] Concerns relate not only to health-service providers' professional effectiveness but also to the costs to the system of drug benefit plans and medical insurance when prescription drugs are misused and patients are unable to follow directions properly. Particularly unsettling is the fact that seniors are among the least literate groups in society and also the most heavily dependent on medications and health services.[39]

Literacy should also be of concern to employers, manufacturers and retailers who handle potentially dangerous products and processes. Direct effects of literacy on health also occur in workplaces and other settings where safety may be dependent on one's ability to read rules, signs and manuals. A Manitoba review of literacy and health, for example, indicated that "difficulty comprehending precautions on farm and recreational machinery such as all-terrain vehicles, water sleds, snowmobiles and farm equipment of all sorts, makes rural life more dangerous."[44] The Canadian Business Task Force estimated that of the $4 billion lost by business due to literacy problems, $1.6 billion is attributable to workplace accidents.[45] Edwards[46] found that The Workplace Hazardous Materials Information System consists of text often written at the college level. In addition, there is evidence that occupational injuries, the degree of awareness of the dangers in the workplace, and installation of home safety features are associated with limited literacy.[42]

Indirect Effects of Literacy

Research suggests that literacy has an impact on lifestyle practices. For example, an Australian study of students in primary schools found that low literacy predicted tobacco use among both boys and girls and alcohol use among boys.[47] Similarly, a study in the United States found that low literacy was associated with choice of contraceptive methods as well as knowledge about birth control.[48] In addition, there is much evidence that education has a powerful influence on a range of personal lifestyle choices.[49]

Literacy is clearly linked to income. People with limited literacy skills are more likely to have lower incomes than those with greater skills.[13,50] People with limited literacy are more likely to be unemployed and to be working for minimum wage in unskilled jobs and are also more likely to be working in older industries.[12] Literacy is related to type of employment. Highest literacy levels in the LSUDA study were found in the teaching, science, engineering, social science and managerial professions (85-92% of respondents tested at the highest of 4 literacy levels). The greatest proportion of respondents testing at the lowest literacy levels were in the product fabricating, service and farming sectors.[51]

People with limited literacy also have less knowledge about medical conditions and treatment[52] and they have trouble understanding health issues generally.[6] They also have more difficulty with verbal communications from practitioners.[43] Overall, they have higher stress levels and feelings of vulnerability.[42]

Considerable research to date discusses the impact of literacy on use of services. People with lower literacy levels tend to be less aware of and make less use of preventive services.[53] They are also less likely to seek care,[54] they have higher rates of hospitalization,[55] and they experience more difficulties using the health-care system.[56,57] Research also suggests a link between low levels of literacy and increased health-care costs. The IOM Health Literacy Committee, drawing on the limited amount of data available, suggested that "there is an association between health literacy, health-care utilization and health care costs" (p. 9).[7] There are no cost estimates available based on Canadian data, however. There is also little research on the relationship between literacy, health literacy and quality of life in the health literature, although much progress has been made in developing measures of quality of life.[58]

Determinants of literacy

Current literature on health promotion and population health focus on a number of determinants of health. The newly established Public Health Agency of Canada lists the following determinants of health: income and social status; social support networks; education and literacy; employment/working conditions; social environments; physical environments; personal health practices and coping skills; healthy child development ; biology and genetic endowment; health services; gender; and culture (see www.phac-aspc.gc.ca/ph-sp/phdd/determinants).

Because health and learning are so inextricably connected, the same factors may also be determinants of literacy. In fact, literacy itself is listed here as a possible determinant of health. However, it is also an outcome of education and may be an outcome of other determinants of health. For the sake of this review, seven determinants have been selected by the authors as particularly relevant: education, early childhood development, aging, personal capacity, living and working conditions, gender, and culture. It should be noted, however, the evidence to date linking these determinants to literacy is mostly correlational. The extent to which they are causal remains to be determined by further research.

Education

There is a strong relationship between educational level and literacy.[12] However, education and literacy are not perfectly correlated, and literacy itself is a strong predictor of health.[39] In fact, recent studies have suggested that literacy skills predict health status even more accurately than education level, income, ethnic background, or any other socio-demographic variable.[59-61] In international studies, this determinant is often estimated by years of schooling, or highest grade level achieved. However, there is potential for serious error bias in literacy estimates based on years of schooling that do not control for a wider set of socio-demographic factors and the quality of years of schooling.[62] There are many examples of discordance between years of schooling and literacy at the individual level. Nevertheless, as noted above, it is clear that education is a major determinant of literacy, which led the Institute of Medicine Committee on Health Literacy to posit the education system as one of three main points of intervention in relation to influencing the level of health literacy in individuals and in the population.[7]

Early Childhood Development

Recent research in brain development has drawn attention to findings that indicate highest capacity for learning in the early years. Studies show a "hard-wiring" of the brain over time that affects capacity for future learning, emotional patterns, lifelong attitudes and problem-solving approaches.[63,64] Early child development programs, moreover, have proven capacity for breaking inter-generational cycles of disadvantage and dramatically improving chances of high school graduation, workplace participation, etc.[65] The critical period for learning a first language is thought to be between birth and three years of age. Learning a second language becomes more difficult after age 10.[66] Thus, it is clear that early childhood development can make a significant contribution to the development of literacy.

Aging

Seniors tend to have higher rates of low literacy[12,39] and literacy levels appear to decline with age. For example, Baker and his colleagues found that health literacy among community-dwelling seniors declined with age after controlling for other factors such as mental state, newspaper reading frequency, health status and visual acuity.[67] In another study, reading ability declined dramatically with age even after adjusting for years of school completed and cognitive impairment.[48] Thus, it appears that literacy is not something which, once attained, stays forever. Many seniors, especially those who do not read habitually, lose their skills and have great difficulties with labels on medications, for example. This has other consequences as well. For example, studies – mostly by Baker and his colleagues – found that low health literacy among older adults was related to lower mental health scores, higher rates of hospitalization, poorer self-reported health, and less use of preventive health services such as vaccinations.[37,38,68]

Personal Capacity

Both early childhood development and aging contribute to personal capacity for learning and literacy. Similarly, perceptual or cognitive difficulties, and disabilities (e.g., sight, hearing or learning) are barriers to literacy.[69] It has been estimated that about one third of participants in literacy programs has a learning disability.[70] Biology and genetics likely also play some role. For example, individuals with the genetically related condition of Downs syndrome have greater difficulty mastering literacy skills. Much progress has been made in differentiating learning styles. Little research has been done to date, however, to apply new methods of genetic research towards a better understanding of learning styles.

Living and Working Conditions

According to the Canadian component of the IALS survey, between 22% and 50% of adults with lower levels of literacy live in low-income households, compared with only 8% of those with high-level literacy skills.[39] Children of parents with reading problems are more likely to have reading problems themselves.[71] In the 2000 Program for International Skills Assessment (PISA), parental attitudes towards academics were found to be a key variable: students with a home environment that stimulated learning did better than all other students in all countries. Students with parents who took them to a variety of cultural events and who discussed current affairs outperformed other students in all countries. As well, students who enjoyed reading, borrowed books from a library and had high career aspirations, did better than other students.[72] Violence and abuse, on the other hand, are key threats to learning capacity. Women in literacy programs have identified men's violence (or its threat) as the greatest barrier to their learning.[73] Violence and abuse undoubtedly affect children's capacity for learning as well, and are key reasons why young people do not complete high school and/or run away from home. According to the National Longitudinal Survey of Children and Youth, students who reported bullying behaviours "sometimes" or "often" scored significantly lower in math and reading scores than those who reported no bullying behaviour.[72] Thus, living and working conditions clearly affect people's ability to learn and consequently, their literacy levels.

Gender

In less developed countries, women tend to have lower levels of literacy than men.[60] One of the strongest predictors of life expectancy among developing countries is adult literacy, particularly the disparity between male and female adult literacy, which explains much of the variation in health achievement among these countries after accounting for gross domestic product per capita (GDPpc). For example, among the 125 developing countries with GDPpcs less than $10,000, the difference between male and female literacy accounts for 40% of the variation in life expectancy after factoring out the effect of GDPpc.[74]

Literacy rates for Canadian adult men and women are comparable, but lower literacy is more prevalent among immigrant women than men.[75] Nearly one third (32%) of foreign-born women have extreme difficulty dealing with printed material or can use printed words only for limited purposes (levels 1 and 2) compared to about one quarter (24%) of foreign-born men and approximately one tenth of Canadian-born women and men.[75] Although most recent surveys of adult literacy show comparable literacy rates for men and women,[10,13] school-aged girls, at least in Ontario, in Grades 3, 6 and 10 consistently score higher than boys.[14] Girls performed significantly better than boys on reading tests in all countries in the 2000 PISA.[76] The average score for 15-year-old Canadian females was 32 points above that of the males. In Ontario, girls scored on average 548 and boys 418. Nationally, 40% of Canadian girls reported reading at least 30 minutes a day for enjoyment compared to about 25% for boys. Still, both genders scored at level three on a scale of one to five "capable of solving reading tasks of moderate complexity such as locating multiple pieces of information, making links between different parts of a text, and relating it to familiar everyday knowledge" (p.27).[72] There is some evidence that such gaps have narrowed in adulthood as women in domestic roles may require fewer skills than men in the workplace, but it remains unclear whether such trends will continue as women play a larger role in the workplace and men take on more domestic responsibilities.

Culture

The Institute of Medicine report on health literacy defines culture as "the shared ideas, meanings, and values that are acquired by individuals as members of a society" (p.9).[7] According to the report: "[d]iffering cultural and educational backgrounds between patients and providers, as well as between those who create health information and those who use it, may contribute to problems in health literacy" (p.9). Thus, one of the conclusions reached by the committee that produced the report was that "[h]ealth literacy must be understood and addressed in the context of language and culture" (p.10). The same is true for general literacy. In Canada, we must take cultural background seriously in addressing issues related to literacy and health. In particular, we need to pay attention to cultural groups whose ideas, meanings and values differ from the dominant culture.

Francophones, Aboriginal peoples and immigrants tend to have lower literacy scores in Canada.[51] For the francophone community, differences tend to disappear among the younger generations. In the US, racial and ethnic minority populations, including Aboriginals and Spanish-speakers, are more likely than others to have lower literacy and health literacy scores.[11,37,77]

There is growing evidence that cultural connectedness or belonging enhances capacity to learn and can also be an incentive for learning. DeWit and his colleagues[78] found a relationship between sense of school membership and achievement. Qualitative evidence for the connection between culture and literacy abounds. For example, Traditional teacher Jim Dumont explains (p.16):[19]

> "Native people want to know what their culture is. Native people want to know what their history is. Native people want to know what their traditions are and what their spirituality is. That's the phenomenon of our times. So if that's the case, then why not use a program such as [literacy] to provide that to them? And use that as the motivating factor in developing literacy amongst our people.... The desire to learn about those things becomes the foundation, the foundation of the literacy program."

Research needed

A number of specific topics have been identified in the literature as requiring further attention. For example, the following have been identified by various individuals and organizations as being of some priority:

- costs of health-care delivery related to direct and indirect impacts of literacy[6,28,42]
- longitudinal studies of potential changes in health status following changes in literacy skills[2]
- effective communication approaches for health providers[28,42] and effectiveness of alternative forms of health communications[6,42]
- evaluation of promising approaches and practices (e.g., community development. and participatory education) addressing literacy and health issues[42]
- study of consent documents and the consenting process[6]
- development and testing of strategies to address the special needs of those with low health literacy[6]

- the role of literacy and other factors in enabling people to feel more confident and empowered to take action regarding their own health[42]
- understanding the causal pathway of how literacy influences health[28]
- developing new measures of literacy and health literacy[7]
- the impact of literacy testing on health and learning of young people.

Fortunately, many of these topics fall under the four priority areas identified by the National Workshop on Literacy and Health Research:[4] a) evaluating the effectiveness of interventions; b) conducting cost-benefit analyses; c) studying literacy and health within the unique circumstances of the Aboriginal and francophone communities, and culturally diverse and challenged groups; and d) studying the relationship between literacy, life-long learning and health. The academic literature reinforces the legitimacy of the four priority research areas named at the national workshop. Each will be examined further below.

Effectiveness of interventions

In order to advance the field of literacy and health, it is important to know what is already working well and build on that. As suggested by the conceptual framework, interventions addressing literacy and health concerns include health communication, education/training (capacity development), community and organizational development, and policy development. Unfortunately, there are few rigorous studies in the published literature to evaluate the effectiveness of any of these types of literacy and health interventions. Moreover, we have no clear consensus definitions of success for interventions and few, if any, standards for health literacy.

Health Communication

Health communication concerns ways of distributing health information to the public to change health behaviour practices. This is the approach that has attracted the most attention from researchers. Even so, very few of the studies would meet the highest standards of rigor. One exception is a randomized controlled trial (RCT) by Davis and his colleagues which compared the use of a simplified polio vaccine brochure with the regular version by parents bringing children to a pediatric care facility and found that those who read the simplified one had significantly higher comprehension than those who read the regular one.[79] However, parents with the lowest reading levels did not show increased comprehension. Another RCT compared the use of a booklet and a videotape with no intervention and found that those who received the booklet or the videotape showed increased knowledge in comparison to the controls.[80] A third RCT examined the effectiveness of an interactive videodisc program on self-care and found that intervention patients reported greater self-care ability.[81] In addition, literacy level did not affect the amount of self-care ability gained, which suggests that this approach was effective with people with lower literacy levels. Finally, a RCT comparing an illustrated brochure with a non-illustrated version found that there was no overall difference in comprehension, but that the illustrated brochure was better understood by patients with lower literacy, suggesting that this was another approach that was effective with persons with low literacy.[82] Thus, although the findings of these studies are somewhat mixed, they do provide some encouragement to those who wish to use improved communication as an approach to addressing issues concerning literacy and health. And indeed, this is probably the most popular approach. However there is a need to encourage the use of more rigorous approaches to evaluating these kinds of interventions, and to compare this approach to other methods and to mixed methods.

It should also be noted that many studies in the United States have found that there tends to be a mismatch between the reading level of health materials and that of those expected to read them and that interventions to make such materials easier to read have had mostly positive effects.[6] Only two published Canadian studies in the literature evaluate the readability of health materials.[83,84] The most recent study found that the reading level of 120 educational pamphlets used in a primary care practice in Montreal was Grade 11.5, which would make the majority of the materials inaccessible to patients with low levels of literacy.[84]

More effective communication approaches for health providers are called for[42] but at this point there are few studies of the effectiveness of alternative forms of health communications beyond the brochure. It has been suggested that we especially need to know how to most effectively transmit complex health information to patients with poor functional health literacy[85] and how to use new information technologies for this purpose.[86]

Education and Training

Education and training is another important approach to addressing literacy and health issues. Again, there is not much rigorous research to draw on. We were, however, able to locate three intervention studies that used randomized trials involving literacy. The first was a comparison of videotapes for diabetic persons with low literacy with monthly group sessions without videotapes.[87] Both approaches appeared to be associated with short-term weight change, but not with knowledge change. A second study examined a comprehensive disease management program and found that the educational intervention appeared to be successful in reducing the effects of low literacy.[88] The third, which tested a combined approach including a personal recommendation, brochure, interactive educational and motivational program, and a video found that the combined approach was associated with mammography use six months later, controlling for literacy and other factors.[89] Thus, it does appear as if there is some evidence to support the use of educational approaches in reducing the effects of low literacy on health, especially if a combination of interventions is used.

Mary Norton, Eileen Antone, Tammy Horne, Pat Campbell and Mary Breen are some of the Canadian literacy specialists who have written about literacy, health and participatory education based on practical experience. Participatory approaches involve learners in issue selection and content development. Examples of participatory development of health information were found in the Canadian needs assessment.[3] One example is a video and discussion guide called *A Better You: The Benefits of a Healthy Lifestyle* produced by the Dartmouth Literacy Network in Nova Scotia. Another example is Heart Health Nova Scotia's work on *Literacy and Health Promotion: Four Case Studies*. A third is the

Canadian Public Health Association's *What the Health!*, a health literacy text that was collaboratively produced by youth at risk. An example of one of many Aboriginal texts is the United Native Friendship Centre's *Personal Growth Manual*. However, these and other efforts are yet to be evaluated.

Researchers have helped increase our understanding of the need to design education/training programs based on learners' interests and motivations. Participants in the LSUDA study who indicated an interest in upgrading programs were asked what topics most appealed to them. Improving writing skills received the widest support, not only overall, but among respondents of all literacy levels. These data suggest that writing in and of itself is a matter of concern to all Canadians.[90] However, literacy programs to date have tended to focus on reading first.

Community Development

There are no studies of the effectiveness of community development in relation to literacy and health using a randomized control trial design. Nor should we expect that there should be such studies; not only is it virtually impossible to use such an approach to evaluating community development, but it is inappropriate to do so.[91] However, there are an increasing number of community development projects involving literacy that use a participatory approach to evaluation. For example, health and literacy expert Marcia Drew Hohn was funded to conduct a two-year participatory action research project in partnership with a student action health team. Qualitative evidence suggested changes in action related to health, perceptions of self and "voice".[92] Her project became a model for Student Action Health Teams across the state in which the project took place.

Health Canada has suggested that there is a need to consider a wider range of promising approaches to literacy and health issues such as community development.[42] Nutbeam's definition of "critical health literacy" encompasses the ability to understand the importance of and act on not just personal health but wider community health concerns. Literacy advocate Sylvia Maracle of the Wolf Clan, Tyendinaga demonstrates such understanding:[19]

> "I think that literacy is a community development process. And I think that as a community development process, it will result in empowerment. In empowering people to make educated decisions about their lives and to do that in the context of being able to assess it in the context of other people's lives."

There has been a growing interest in the role of Freirian theory in health promotion enabling people collectively to move beyond feelings of powerlessness and assuming control in their lives.[93] An example in Ontario of a literacy program initiative that depicts this philosophy is a video on "goal setting" collaboratively produced by learners and staff at a program in Guelph, Ontario.[94] In this video learners describe their motivation for changing their lives, the challenges they encountered and the ways they overcame their challenges.

A number of resources have recently been developed that can enhance literacy practitioners' skills and knowledge of effective community development approaches. Grass Roots Press' Adult Literacy Resources Catalogue for 2003 includes the following: Arnold, Burke, James, Martin & Thomas, *Educating for a Change*; New England Literacy Resource Center's *Civic Participation and Community Action Sourcebook: A Resource for Adult Educators*; Carmen Rodriguez's *Educating for Change: Community-based/Student-centered Literacy Programming with First Nations Adults*; Pat Campbell and Barbara Burnaby's *Participatory Practices in Adult Education*, and *Tools for Community Building: A Planning Workbook for Northern Canadian Community-Based Literacy*. All of these resources appear worthy of evaluation.

Organizational Development

Organizational development strategies are of increasing relevance to health and literacy action since health promoters began to take a "settings approach" in which health and personal capacity are improved in workplaces, families and other environments where people live, work, learn and play.[95] Organizational development strategies should include staff health promotion programs as well as means of promoting the health and well-being of learners and clients. Schools, school boards, public health offices and other organizations are now taking advantage of the change management literature from the private sector. All of these initiatives deserve rigorous evaluation with respect to impact on literacy and health.

In October 1999, Community Literacy of Ontario produced an impressive manual, *Helping your Organization Flourish in the 21st Century*, based on the thoughts and research of organizational change scholars and futurists including David Foot, Nuala Beck, Faith Popcorn, Den Balmer, Peter Drucker and organizations such as Statistics Canada, the Canadian Aging Network, the Angus Reid Group, the Canadian Centres for Philanthropy, the Canadian Advisory Council on the Information Highway, the Association of Colleges of Applied Arts and Technology, and the Conference Board of Canada.[96]

Similarly, in the health field, approaches to promoting health through organizational change have been developing. Skinner[97] has developed a number of tools to aid managers of health-care organizations to help their organizations become more health promoting for their own employees as well as their clients. He used some of these tools while merging three departments into one Department of Public Health Sciences at the University of Toronto. He has also used some of these tools in the development of a TeenNet project. Information is beginning to emerge on the impact of such tools and strategies on emotional well-being, absenteeism and other outcomes. Ronson and Andrews[98] described the profound impact on organizational culture and employee morale of an intensive change management strategy that addressed the strategy, structure, skills and culture at a nurse's union. However, little research is available concerning the impact of such organizational development programs on health, health literacy and literacy.

Policy Development

The potential of law and litigation (e.g., privacy laws, consent) as a means to reduce the difficulties of patients and consumers with low literacy is of increasing interest.[99] There are, however, very few published studies on the effectiveness of this approach in relation to literacy and health though policy development in this area is increasing. For example, health literacy is gaining recognition by health-care accreditation bodies. In Canada, the Achieving Improved Measurement (AIM) accreditation program of the Canadian Council on Health Services Accreditation, sets standards for hospitals and health-care facilities. Several criteria relate to the need for patients and their families to be well informed and involved as active participants and to demonstrate that they understand the information provided. They do not use the term "literacy" but refer to "client's abilities", "clients with special needs" and "clients' level of education". They state that health information must be easy to read and use.[22] Thus, one of the eight themes that emerged from the field at the national workshop was "influencing, developing and evaluating policy related to literacy and health."[4] Relevant policy goes beyond legal aspects to plain language policies for organizations (e.g., the Ontario Literacy Coalition's new policy) and government policy for funding priorities.

In the United States, the Joint Commission on Accreditation of Health Organizations now requires that instructions be given at a level understandable to the patient.[22] There is also interest in improving consent documents and the consenting process.[100] Greater vigilance in health communications has been achieved through case law regarding obtaining informed consent from individuals with lower levels of literacy, and requirements imposed by the Joint Commission for Accreditation of Health Care Organizations and the National Committee for Quality Assurance about the nature and form of information used in patient education.[101] "Health literacy" is now stated as an objective in *Healthy People 2010*, the blueprint document used for both state and national planning. Objective 11.2 under the area of health communication is "to improve the health literacy of persons with inadequate or marginal literacy skills."[29]

Marcia Hohn[101] has recently published an overview of policy issues and initiatives regarding health literacy. Policies that need to be in place to provide a firm foundation for literacy and health work, she says, include those ensuring secure funding, teacher training for integrating health content and handling potentially sensitive situations, support structures for information sharing, and interagency referrals. Hohn draws from a recent survey of state basic education directors in the US to show promising policies and efforts towards interagency collaboration for health literacy in Pennsylvania and California.[22] Other states such as Virginia and Georgia have introduced incentives for integrating health into the programs for English language services, by training Adult Basic Education teachers on how to incorporate health content into existing programs, and by initiating health literacy classes taught jointly by literacy and health education teachers in various sites including hospitals, churches and public health agencies.

Another policy initiative is the government of Massachusetts' decision to allocate a portion of tobacco tax revenue to community-based adult education programs interested in addressing health topics and developing health-related curricula through a participatory process involving adult learners and teachers. At the same time, a model program called Health Education in Adult Literacy (HEAL) focussed on breast and cervical cancer education was supported by a private non-profit agency and the Centers for Disease Control and Prevention.

Dr. Rima Rudd and colleagues from the Harvard School of Public Health investigated the work of the 31 adult learning centers that had received funding from either the tobacco tax monies or from the HEAL project.[100] Thirty-one teachers from twenty-four cities were interviewed. Almost all reported that the topic of the health project was chosen based on learners' needs and interests. Although the tobacco tax did not mandate it, anti-tobacco projects were the most common. Nutrition, HIV/AIDS, substance use, cancer prevention, stress management, accessing the health-care system and parenting skills were other common topics. When teachers were asked to rate the extent to which students' health projects contributed to various skills, it became clear that compared to other topics, health projects were perceived as offering added value for the development of both hard skills, such as reading, writing and math, and soft skills, such as speaking and presentation skills, dialogue and discussion. They also indicated that health projects contribute more to learner participation, motivation and interest.

Combined Approaches

Combined approaches appear to be particularly effective in addressing issues related to literacy and health. In addition, multilevel approaches based on ecological models increasingly are being put forward as being worthy of further exploration. For example, a recent US Institute of Medicine publication on social science and behavioural research to improve the public health recommended that: "[r]ather than focusing on a single or limited number of health determinants, interventions on social and behavioral factors should link multiple levels of influence (i.e., individual, interpersonal, institutional, community and policy levels)."[102]

Conducting cost/benefit analyses

Some progress has been made in assessing the economic cost of low literacy to Canada in other sectors. The Canadian Business Task Force on Literacy (1988) estimated that the annual cost to Canadian businesses from lost productivity due to low literacy was $4 billion.[45] In a Conference Board of Canada survey, DesLauriers[103] found that of Canadian businesses with 50 or more employees, about 70% experienced some problems in their operations as a result of literacy issues in the workplace. Problems were most serious for the acquisition of new or advanced skills, training in general and the introduction of new technology. Negative impacts most frequently mentioned were productivity losses, errors in inputs and processes, reduced product quality, and problems in job reassignment. Less frequently mentioned difficulties included health and safety problems, higher job turnover rates and absenteeism.[104] Both literacy and numeracy play a significant role in explaining labour market outcomes, even after years of schooling are accounted for.[62]

The costs of health-care delivery, however, related to direct and indirect impacts of literacy still need to be ascertained.[6,42] Medical outcomes and economic costs of interventions need to be better understood.[28] As noted above, evidence to date suggests a link between literacy and increased health-care costs,[7] at least in the US. However, research on this topic has been lacking in Canada. In addition, we also need to understand what politicians and decision-makers understand about literacy and health and what can influence them.[4]

Studying literacy and health within Aboriginal and Francophone communities

There is a need to better understand and respect the relationship between literacy and culture in Aboriginal communities and the impact of literacy and literacy programs on health and healing.[4] Investment in Aboriginal literacy development will ensure Canada's Aboriginal peoples have the resources they need to thrive as communities and as full participants and contributors to Canada's future economic and social prosperity. The Aboriginal population reached its lowest point at the turn of the twentieth century, but is now growing twice as fast as the overall Canadian population. Health and education status of this group is very different from that of mainstream groups. Twice as many registered Indians had less than Grade 9 education in 1996 as other Canadians.[105] Their health status is also more severe. Four centuries of colonization – being stripped of their land, religion, culture and autonomy – have taken their toll. Though there has been improvement in recent years, the Aboriginal mortality rates were still almost 1.5 times higher than the national rate in 1996-97.[106] Unique programs for this group deserve careful consideration. According to Dr. Eileen Antone, there is very little understanding of, or funding support for Aboriginal adult education programs that include intergenerational literacy participation and practices, which may be more helpful than non-Aboriginal models of schooling.[107] Thus, the national workshop endorsed research on literacy and health in the Aboriginal community as a priority.[4]

The workshop participants also agreed that priority should be assigned to the study of literacy and health within the francophone community. According to Dr. Margot Kaszap from Laval University, a participant in the workshop and one of the co-investigators in the SSHRC project, literacy and health within the francophone community are significantly different from the anglophone community because of different cultural views of literacy and of health. Thus, to understand these differences requires special efforts. Like the Aboriginal peoples, Canadians of French descent have official status enshrined in Canada's constitution and must therefore have their unique issues identified and considered.

With regard to other cultural groups, the early Southam study shed light mainly on the literacy problem of Canadian-born citizens of European descent.[10] The problem among foreign-born Canadians was not so surprising and received less attention as a result. Further investigation suggests that the burden of need for help with literacy skills may currently lie with immigrants. New immigrants are among the most vulnerable populations in Canada. Some researchers suggest that for many, health actually deteriorates after they arrive (personal communication, Morton Beiser, August 2003). Of the 22% of Canadians at IALS level 1, most are people whose first language is neither English nor French, and people over 55.[108] Those most likely to express a need for literacy programs in the national surveys to date are new immigrants.[51] In the LSUDA study, more than twice as many foreign-born readers at levels 1 and 2 reported dissatisfaction with their skills. Those most likely to express satisfaction with their literacy skills are Canadian-born. Of Canadian-born people, 87% of women and 80% of men with the lowest literacy skills (levels 1 and 2) report satisfaction, while only 59% of foreign-born women and 50% of foreign-born men do so.[75] More Canadian-born women and men with low literacy may have developed coping mechanisms in their daily activities and be reluctant to join programs that label them, reveal their deficiencies, and remind them of past frustrations with schooling.

A better understanding of the unique situation of new Canadians interested in literacy programs is needed. We also need to better understand what are the effective messages and methods of delivery in terms of different ethnic groups and multiliteracies.[4] Foreign-born women and men with low literacy are less likely to be burdened by shame about low skills in English or French, but are more likely to have less time to attend classes. A greater percentage of foreign-born Canadians with low literacy skills participate in the workforce. Of all women in the workforce testing at the two lowest levels on the IALS survey, 52% are foreign-born though they represent only 17% of the female workforce. Foreign-born males represent 18% of the workforce and 34% of the men in the workforce who have low literacy levels 1 and 2.[75] According to literacy advocate Susan Sussman, most literacy programs are not designed to attract learners who fit the level 1 IALS demographic profile (immigrants and seniors). "Level One learners who need the most help and have the most difficulty learning often receive the least amount of instruction from the least qualified instructors."[108](p.9)

One of the key problems appears to be that literacy programs funded through the federal and provincial governments are expected to serve native speakers of French or English only. It is held that the Ministry of Culture and Immigration funds English and French as a second or other language programs for immigrants, and therefore literacy programs funded through other ministries (HRDC, Ministry of Training, Colleges and Universities, Ministry of Education) should only serve native speakers of English and French. Even the resource centers for literacy and English for Speakers of Other Languages classes are housed separately in Ontario despite significant overlap in types of resources needed. AlphaPlus Centre, the largest collection of literacy materials in Ontario, has recently moved its ESOL collection to the Metropolitan Toronto Reference Library. Sussman is not the only literacy worker that finds this situation troubling. Frontline workers are known to hide the fact that their classes mix native speakers of English and ESOL learners for fear of reprisal from their superiors.* Yet literacy workers report that new Canadians and native Canadians benefit from each other's presence in a shared classroom.* Potential benefits of work in health literacy to Canadians of English and French origins as well as immigrants need to be better understood. For example, Canada could gain opportunities to provide health-care information, support and education internationally through better provision of health literacy opportunities for its own immigrants. The need for better interministerial cooperation in this regard is most apparent. Research on this issue could

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* Personal communication, literacy workers at August 2003 literacy conference, OISE/UT.

help determine the extent of the problem and suggest steps towards a solution.

Studying the relationship between literacy, life-long learning and health

One of the key recommendations of the first OPHA report is "the creation of a major shift in the education system to allow for life-long learning. This would establish a drop-in – drop-out philosophy allowing people to acquire the skills they need when they need them."[5](p.34) This theme has gained momentum recently in Canada. Calamai coined the phrase *The Three L's – Literacy and Life-Long Learning* in an address to the Westnet 2000 Conference in Calgary.[109] According to the Canadian Health Network,[110]

> "…thanks in part to the growth of information and communication technologies, participation in adult education in Canada has exploded during the past 40 years. In 1960, only about 4% of Canadians over the age of 17 were thought to be taking any kind of course provided by an educational institution. Twenty years later, that number had increased to 20 percent. By the early 1990s, about 35 percent of Canadian adults were thought to be taking enrichment courses."

The Movement for Canadian Literacy, the hub of Canada's literacy network, has recently advocated for a National Literacy Action Agenda that is grounded in a life-long learning strategy. They suggest that such an agenda be a key part of the federal government's new "innovation agenda" supported by Industry Canada and HRDC (see www.innovationstrategy.gc.ca). The Ontario Ministry of Education defines literacy education as (p.9):[25]

> "…part of a process or cycle of life-long learning, based on life experience, shared knowledge, and decision-making by learners supported by their instructors. Literacy education contributes to the development of self knowledge and critical thinking skills. In turn, this development empowers individuals and communities."

The recent national workshop on literacy and health research thus supported this direction, in concluding that "studying the impact of literacy and life-long learning on health" was one of the top four priorities.[10]

An agenda for life-long learning may better address new understandings about multiple literacies and encourage learners previously held back by stigma. A Canadian Federation of Labour Education Coordinator provides the following description of previous counter-productive initiatives:[111]

> "Human nature is such that a statistical focus on skill deficiencies make it more challenging…. Many people have the impression that a shockingly large percentage of the workforce sign their name with an X and can't add two plus two. Even worse is the impression that critical thinking skills, among those who have difficulty reading or writing, are marred. These, and similar myths, act as barriers to those who wish to improve their basic skills. Literacy should be framed within an empowering paradigm that highlights opportunities and choices for people. Unfortunately, much of the print generated has been devoid of empowerment. The blatant fostering of disease-laden image (e.g., "stamping out the epidemic of illiteracy") is one such counterproductive example. It is not helpful when literacy is promoted – wittingly or unwittingly – as the predominant solution to Canada's economic woes. A balanced viewpoint recognizes that the skills of workers are one of many factors that affect economic growth. Equally pertinent components include business investment in new equipment, work processes (that is, the way work is structured and jobs are designed), fiscal policy, and the amount of money allocated to training."

An agenda for life-long learning could begin to treat adults and teenagers on more similar terms and make high schools or "community education centres" welcoming and appealing to the young and old who are "ready to learn" (Saskatchewan is calling for renaming schools as "community learning centres" in their document *Schools Plus* and for creating a paradigm shift in the way schools are organized). It would also go some way towards reducing the stigma of dropping out, and to reducing the number of students who are not engaged in their school work, if alternatives such as extended co-op placements can be found for them. Such innovations in life-long learning provide valuable opportunities for studying the role of literacy in health.

CONCLUSION

Much progress has been made by health-service providers in Canada in addressing literacy and health by raising awareness of the issue among health workers and disseminating plain language guides and health education materials. Progress has also been made in supporting non-medical aspects of the issue, encouraging literacy practitioners to help address it, and developing collaborations between health and literacy workers. Access to health information with reduced reliance on print and increasing use of new technologies has improved. But, due to several important social trends, the issue is likely to become more and more important and further research will be needed.

This literature review leads to the conclusion that additional research is needed with respect to virtually all of the areas covered by the conceptual framework. We need to know more about the relationships between general literacy, health literacy and other kinds of literacies, about the relationships between various kinds of literacies and health and quality of life outcomes, about the determinants of literacy and health literacy, as well as the effectiveness of various kinds of actions to improve health though improving literacy. We also need more cost-benefit analyses, more studies that consider the unique circumstances of the Aboriginal and francophone communities and culturally diverse and challenged groups, and more study of the relationship between literacy, life-long learning and health.

It is clear that research in literacy and health can help us spend our scarce health care dollars more efficiently. There are pockets of very promising work being done across the country, but there are huge gaps in between, with very little knowledge of what is being done elsewhere and what works best. Research of this nature can help span the divides between traditional jurisdictions of work for improving the lives of Canadians and have an impact on effective use of government spending in education as well as health care. To this end, based on this review of the evidence and discussion at the Think-Tank in

September 2003, we would make the following recommendations:

1. That CIHR, SSHRC and the Canadian Health Services Research Foundation develop a joint strategic initiative on literacy and health based on the priorities and information needs identified in this article. Such an initiative should fund both research and capacity development.
2. That federal and provincial governments develop and implement policies and programs related to literacy and health and ensure that they are evaluated appropriately.
3. That non-governmental agencies such as the CPHA and the members of the NLHP form partnerships with researchers to ensure that their initiatives in literacy and health are evaluated appropriately.
4. That community agencies and health and literacy practitioners form partnerships with researchers to evaluate literacy and health initiatives and conduct participatory research on literacy and health.
5. That researchers and research organizations, such as the Canadian Consortium for Health Promotion Research, collaborate with research funding agencies, governments, non-governmental agencies and community agencies to develop an infrastructure for the evaluation of literacy and health initiatives using a participatory approach.

Clearly, movement in these directions can benefit all Canadians. We should not miss the opportunity to advance the field of literacy and health in Canada.

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RÉSUMÉ

L'auteur de l'article fait une revue de la documentation actuelle et de la recherche sur le lien entre l'alphabétisme et la santé et dégage des priorités pour la recherche dans ce domaine au Canada. Parmi les sources d'information, mentionnons des documents repérés grâce à une analyse de l'environnement, la collection Alpha Plus et une recherche informatisée des documents récents. Cette information a ensuite été analysée au moyen d'un cadre conceptuel. Selon la revue, un alphabétisme limité a un impact direct et indirect sur la santé. Les familles sont à risque à cause de la difficulté qu'elles ont à lire les ordonnances médicales, les instructions des aliments pour bébé et le matériel d'éducation sur la santé et la sécurité. Les gens dont le niveau d'alphabétisme est peu élevé ont tendance à vivre et à travailler dans un environnement moins sain; ils ont plus de difficulté à trouver de l'emploi et à assurer la sécurité de leur revenu. Les déterminants de l'alphabétisme sont les suivants : éducation, développement de la petite enfance, vieillissement, conditions de vie et de travail, capacité/génétique individuelles, sexe et culture. Il convient de prendre des mesures afin d'améliorer le niveau d'alphabétisme et de santé par une combinaison d'éléments tels la communication, l'éducation et la formation, le développement communautaire, le développement organisationnel et l'élaboration de politiques. Certaines indications donnent à penser que les interventions de ce type ont un impact positif sur la santé, en particulier si elles sont combinées. L'élaboration de politiques et de programmes requiert une analyse approfondie des initiatives actuelles et davantage d'analyses coûts avantages et d'études qui mettent l'accent sur les différentes communautés culturelles. Un soin accru doit également être accordé aux tendances et aux besoins sociaux actuels.

Engendering Health Disparities

Denise L. Spitzer, PhD

ABSTRACT

How is gender implicated in our exploration of health disparities in Canada? Set against the backdrop of federal government policy, this review paper examines the ways in which gender intersects with other health determinants to produce disparate health outcomes. An overview of salient issues including the impact of gender roles, environmental exposures, gender violence, workplace hazards, economic disparities, the costs of poverty, social marginalization and racism, aging, health conditions, interactions with health services, and health behaviours are considered. This review suggests health is detrimentally affected by gender roles and statuses as they intersect with economic disparities, cultural, sexual, physical and historical marginalization as well as the strains of domestic and paid labour. These conditions result in an unfair health burden borne in particular by women whose access to health determinants is – in various degrees – limited. While progress has certainly been made on some fronts, the persistence of health disparities among diverse populations of women and men suggests a postponement of the vision of a just society with health for all that was articulated in the Federal Plan on Gender Equality. Commitment, creativity and collaboration from stakeholders ranging from various levels of government, communities, academics, non-governmental agencies and health professionals will be required to reduce and eliminate health disparities between and among all members of our society.

MeSH terms: Gender; gender bias; inequalities; research; health behaviours; health services

La traduction du résumé se trouve à la fin de l'article.

Department of Anthropology, University of Alberta.
Correspondence and reprint requests: Dr. Denise Spitzer, Department of Anthropology, University of Alberta, 13-15 Tory Bldg., Edmonton, AB, T6G 2H4, Tel: 780-492-0139, Fax: 780-492-5273, E-mail: denise.spitzer@ualberta.ca.

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Health disparity can be defined as a "marked difference or inequality between two or more population groups defined on the basis of race or ethnicity, gender, educational level or other criteria" (p. 274).[1] Engendered by the inequitable access to health determinants such as income, social support, good quality housing and clean environments, and the stresses imposed by structural forces, multiple roles and discrimination, health disparities reflect a gradient in socioeconomic status and power.[2,3] When health disparities are examined in terms of gender, Matthews, Manor and Power observe that the relationship between health outcomes and social hierarchy appears to be more linear in predicting men's health while the association to women's health appears to be more complex.[4] The relationship between gender inequities and health is seldom static and intersects with factors such as ethnicity, sexuality, age and disability in dynamic and complex ways.[5]

While gender refers to the cultural constructions and layering applied to sex categories, the existence and persistence of gendered social hierarchy in our society means that women are most often associated with health disparities. This recognition is reflected in policies, programs and research that often focus on women. Importantly, some men are vulnerable to marginalization and impoverishment and must therefore be considered in the context of reducing health disparities; however, we must also attend carefully to the possibility that the term "gender" can inadvertently mask discrepancies *between* women and men.

Policy context

Are gendered disparities in health a problem in Canada? Canada has been viewed as a world leader in forwarding gender equality and encouraging other nations of the world to adopt similar goals, yet the response by the United Nations Committee on the Elimination of Discrimination of Women to a recent government report on the status of gender equality was not wholly laudatory.[6] Some committee members opined that a country with Canada's wealth and reputation should have made greater progress in terms of its commitment to reducing inequality between women and men. Their comments focussed on a number of key issues including: the high percentage of women who live in poverty and report poor health status, the persistence of violence against Canadian women and the apparent decline in funding for shelters, the vulnerability of Aboriginal women to domestic violence and incarceration, the diminished status of immigrant and refugee women and the promulgation of neo-liberal policies as well as changes to federal-provincial transfer payments that have reduced spending on social and health services. The committee, however, praised Canadian efforts to improve parental leave and child tax benefits, to introduce measures to reduce the trafficking in women, and to further develop gender-based analysis and indicators to monitor governmental progress on gender equality.

A variety of international commitments inform the Canadian government's approach to improving women's access to determinants of health. The United Nations' *Declaration on the Elimination of All Forms of Discrimination Against Women*[7] proclaimed that discrimination against women – defined broadly as denying or limiting women's equal rights with men – is unjust. The *Declaration* forwarded an agenda in support of public education and the abolition of practices that reinforced the notion of male superiority. Importantly, it also stated that women had the right to equal pay for work of equal value and to appropriate retirement, sickness and old age security benefits. In 1981, the *Convention on the Elimination of All Forms of Discrimination Against Women* (CEDAW)[8] moved these issues further by drawing attention to topics of poverty and racism in a variety of forms. The CEDAW identified discrimination against women as any means by which women are prohibited from obtaining, exercising and enjoying rights equal to those of men. Signatories to the Convention are obliged to abolish laws, regulations, customs and practices that likewise discriminate against women. Additionally, the CEDAW urges respect for maternity and details the right of women to health and safety in the workplace. Notably, Article 11, no. 2(c) urges governments to "encourage the provision of the necessary supporting social services to enable parents to combine family obligations with work responsibilities and participation in public life, particularly through the establishment and development of a network of child-care facilities." The CEDAW further states that women have a right to participate in sports and cultural life and draws attention to the particular needs of rural women with respect to access to health care including family planning, employment, good quality housing and sanitation.

Canada is signatory to the *Declaration on the Elimination of Violence Against Women*[9] that identifies unequal relationships between women and men as the source of violence against women. Defined "as any act of gender-based violence that results in or is likely to result in physical, sexual or psychological harm or suffering to women including threats of such acts, coercion or arbitrary deprivation of liberty," governments are asked to consistently work to prevent, investigate and punish acts of violence against women. Additionally, the *Declaration* notes that particular groups of women, including indigenous women, immigrants and refugees, women with disabilities and the elderly, are particularly vulnerable to violence. Signatories are urged to develop appropriate and sufficient support services for women surviving violence. In 2000, Canada joined other countries in supporting the *United Nations' Millennium Declaration*[10] thereby committing itself to the support of human dignity and equality and to eliminating the scourges of poverty and racism that interfere with the ability of individuals and communities to live their lives with self-respect and in good health.

Canada has responded to its international commitments by supporting the implementation of various initiatives under the auspices of the *Federal Plan for Gender Equality*.[11,12] The *Federal Plan* was designed to engage all levels of government as well as non-governmental agencies in the development of policies and programs that would enhance gender equality in Canada. The document acknowledges the disparate and multiple realities of women and the need for government policies to engage in gender-based analysis as a matter of routine to ascertain the potential impact of policy on women and men in all of their diversity. The authors emphasize that gender-based analysis demands attention to social context, therefore, policy-makers must account for the fact that women perform a disproportionate amount of care work and domestic labour, and are pooled in low-wage positions. In Canada, the *Federal Plan for Gender Equality* identifies various sites of action including promoting affordable housing, reducing violence against women, enhancing women's economic participation, developing child care programs with other levels of government and addressing health inequities by learning more about sex differences in disease presentation and treatment and identifying the health needs of marginalized women.[12]

The Women's Health Bureau provides much of the leadership in efforts to examine government policy and health disparities using a gender lens. Established within Health Canada in 1993, the Women's Health Bureau's mandate is to ensure that the Canadian health care system responds to the needs of women.[12] The *Women's Health Strategy*[13] was designed to improve our state of knowledge about women's health and to support the development of health services and preventive health measures that will meet the needs of women. The Women's Health Bureau also oversees the administration of the Centres of Excellence for Women's Health who conduct research and work with the Canadian Women's Health Network to disseminate information and advocate for gender equity and improvements in women's health. In addition, the Women's Health Bureau produces a variety of tools to enable policy-makers and programme planners to engage in gender-based analysis of their own work. In a recent publication, *Exploring Concepts of Gender and Health*,[14] the need for mainstreaming gender-based analysis is demonstrated through a discussion of concepts and examples. Finally, in response to feedback from researchers, organizations and the public, the federal government established the Institute of Gender and Health in 2000 as one of the Canadian Institutes of Health Research.[15]

Overall, the Canadian government has demonstrated a commitment to gender equality and improving the health of women through its varied international and national agreements and programmes; however, the need for a symposium on health disparities in 2003 suggests that these issues persist. This synthesis article will provide an overview of gender and health in Canada and describe the potential mechanisms through which women and men may be vulnerable to poor health outcomes. It will conclude by offering recommendations for future action and research.

Engendering health disparities

A Canadian child born in 1997 can expect to live to just under 76 years if male or over 81 years if female;[16] however, in a trend referred to as the gender paradox, the girl child is more likely to experience those years as unhealthy ones. For instance, 11% of Canadian women versus 4% of men suffer from chronic conditions;[16] in particular, women are diagnosed more often than men with conditions such as multiple sclerosis, lupus, migraines, hypothyroidism and chronic pain.[17,18] The disparities in life expectancies between women and men in Canada can be attributed primarily to higher rates of accidents and injuries leading to excess mortality among men.[19] General statistics, however, belie the considerable diversity in circumstances of birth and life that confer both advantage and disadvantage to the health and well-being of individuals throughout their life course. The question must be asked: what makes people sick?

Certainly increased longevity results in greater risk of disability and chronic illness associated with aging;[20] however, the consequences of aging do not explain the existence and persistence of health disparities throughout the life cycle. While genetic heritage and negative health behaviours can contribute to susceptibility to certain ailments, a population health approach that considers the full range of health determinants suggests that social factors are more salient overall than health behaviours in determining health status.[21]

Gender itself is a determinant of health and is interlinked with biological and social determinants. If prominence is granted to social factors, then health must be considered within the context of gender roles, access to social and economic capital, the geopolitical environment, cultural values and the impact of racism, sexism and ageism.[22] Gender disparities in health are further configured by ethnicity and the potentially corresponding discrimination. As the rubrics "women" and "men" mask heterogeneous populations marked by disparate class statuses, ethnicities and sexualities, so too are the pathways through which women and men are constituted in various degrees as vulnerable to health risks. Certain common touchstones, however, manifest themselves on the journey. A review of the literature suggests that health inequities emerge from the dynamic intersections of the demands of multiple gender roles, environmental exposures, the threat and consequences of gender violence, workplace hazards, economic disparities, the costs of poverty, social marginalization and racism, aging, health conditions and interactions with health services and health behaviours. Psychosocial resources, whether positive, such as social networks and systems of support, or negative, such as stress and its physiological expressions, also mediate embodied expressions of inequality although the mechanisms through which these factors influence health status are poorly understood.[22,23] A consideration of these intersecting issues that contribute to the development and persistence of gendered disparities and health follows.

Gender Roles and Status

Gender is generally regarded as the culturally ascribed attributes and roles assigned to the biological categories of, at minimum, the dichotomous pairing of male and female. This definition, however, denies both the complexity of gender as an interactive and socially influenced performance and that sex categories themselves can be regarded as historically situated constructions whose boundaries are perhaps more blurry than is often recognized. Gender disparities in health, then, must be viewed in the context of the contingencies of these categories.

Male gender roles may, for example, produce deleterious health effects that contribute to excess male mortality. For instance, notions of masculinity that valorize risk-taking behaviour, aggression and stoicism are associated with increased injury and death.[24-27] Once they have survived childhood, where boys are more susceptible to disease than girls, adolescent males are generally healthier than their female counterparts – with the exception of injuries.[28,29] Adolescent injuries in turn are linked with behaviours such as binge drinking, smoking and having multiple sexual partners, which are associated with masculinity by young Canadian males.[30] Notably, not all men ascribe to this definition of masculinity as this construction differs along economic, educational, sexual and ethnic lines.[25]

Gender roles and relations produce different responses and exposures to stressors that in turn result in varied health outcomes.[31,32] Additionally, gender roles and statuses change throughout one's lifetime and may influence access to health resources. In some societies, women's status increases with the birth of male children and as women reach maturity, while in others status peaks in married adulthood and declines as women age.[33] Female gender roles generally require women to be responsible for a disproportionate amount of domestic labour, cultural transmission and socialization of children and kin work that includes attending to familial social relations. In many parts of the world, women are engaged in subsistence production and may be further engaged in the labour market. The multiplicity of roles enacted by women make them vulnerable to role conflict between family and work demands that can further lead to a variety of negative health outcomes.[34]

Gender differences in health are linked to disparate access to resources determined by cultural attitudes towards gender, class, social policy and labour market patterns[22,35] and are replicated in the household. Intra-household allocations of resources are usually invisible and not always equitable; therefore, even though household income and occupational status of the head of household – usually regarded as a male income earner – are used to determine socio-economic status, not all members may share in this rank position.[22] Income-earning individuals, usually male, may receive preferential access to health services where financial constraints are a factor and may be provided with more nutritious food than female members of the household. Cultural notions that women are meant to be smaller and that women's labour requires less energy expenditure provide the rationale for unequal distribution of food resources that in some instances can result in under-nutrition.[36]

Cross-culturally, women are presumed to be the most appropriate caregivers for children, the infirm and the elderly. While these responsibilities are presumed to be "natural", they can also be overwhelming; for instance, an average American woman will have spent 18 years caring for an elderly spouse and 17 years caring for children.[37] The care work activities of women must also be situated within a broader context. Globalization has impelled the waves of health care restructuring that have resulted in a movement towards de-institutionalization and abbreviated hospital stays. The resultant off-loading of responsibilities onto families that have neither extended networks nor an equitable division of labour results in "compulsory altruism" on the part of women.[38-40] Moreover, the types of tasks required by caregivers have changed; caregivers are now expected to handle complicated medicines, insert catheters and change dressings among other tasks.[38,41] Certain groups of family caregivers are most affected by these changes in policy and programs. Low-income women who are least likely to have supplementary insurance are now required to pay for medications that would have been distributed free of charge in hospital.[39,40] Rural communities are also hard hit as services once available are shifted to larger communities, requiring caregivers to travel long distances to obtain services or contend without additional assistance.[39]

Caregiving activities of immigrant women must also be contextualized by the migration experience, value systems and the roles prescribed for women and as well as the centrality of caring to women's lives.[42] Truncated familial support networks, limitations placed by provincial governments on access to auxiliary health services, culturally inappropriate services, and lack of information about what kinds of resources are available to help caregivers, all contribute to an intensification of caregiving responsibilities for many immigrant women. The centrality of care work to gender and ethnic identities means that women are generally unable and unwilling to relinquish these responsibilities, regardless of emotional, physical or financial cost.[43,44] Even affluent caregivers appear reluctant to relinquish these responsibilities although they may be amenable to purchase the services of others to assist with other domestic tasks.[44,45]

While caregiving may be a rewarding activity, even if obligatory, it may also have considerable health costs for the caregiver.[46] Indeed, North American studies suggest that demanding social ties are strong predictors of depression in women.[47] Backaches, insomnia, arthritis, depression and hearing problems are among the conditions associated with caregiving and are especially trying for women who caregive more frequently, in more complex situations, and for double the hours of male caregivers.[41,48-50] Moreover, women are more likely to forgo their own health to meet the needs of the care recipient first.[51] The role can be so burdensome that even its anticipation can contribute to health problems for those who have prior experience with the role.[52]

Environmental Exposures

Environmental influences – both biological and social – are greatly significant to early childhood development especially in the first five years of life when normal brain development occurs. Factors such as poverty, housing and caring relationships contribute to lifelong capacities (emotional, cognitive and behavioural development) and vulnerabilities; as a result, holistic early childhood interventions are vital to decreasing health disparities.[53-55] These issues are of vital importance in Canada where child poverty rates remain at approximately 20%.[56,57]

Toxic exposures are socially distributed[58] and assert influence from fetal development through older adulthood. Maternal nutrition, smoking, alcohol consumption and stress can have an impact on birthweight and contribute to problems with bone mineral density in adulthood.[59-61] Maternal stress, engendered by any number of conditions including material deprivation, may have a significant impact on the fetus and contribute to longer-term consequences. Children whose mothers sustained stress during their pregnancy are at higher risk for diagnosis with ADHD and psychiatric conditions. In addition, they may experience delayed early motor development and behavioural problems. Animal studies suggest that post-natal maternal attention can moderate the effects of stress.[62]

Women and girls are more likely to spend time at home where they may be exposed to a variety of environmental hazards. Household cleansers can contain toxic properties and home cooking may expose women to noxious substances accumulating from cooking fumes due to poor ventilation. Poor housing, related to socioeconomic status, can further contribute to respiratory problems as can exposure to second-hand tobacco smoke.[63-66] Additionally, low-income households are disproportionately located in the vicinity of industrial sites, whose pollutants residents are expected to eliminate from their homes through their own efforts.[67] Exposure to smoke can also facilitate the accumulation of trace metals, such as cadmium. Cadmium concentrations tend to be higher in women due to higher rates of absorption at low levels of iron. In addition, while males tend to have higher levels of lead in their bodies compared to women, the effects can be more deleterious to women due to the pace of its release from the bone marrow where it is stored.[68,69]

Outside the home, women are exposed to environmental hazards in female-dominated workplaces including electronics plants, fireworks and brick factories, agricultural and floral industries and laundry operations.[64] Moreover, women may also have differential access to public space depending upon ethnicity, sexual orientation and disability that may pose various threats to health and safety. For instance, a study of rickets among British South Asian women found that women lacked exposure to sunlight as they feared traversing public walkways after a series of racist attacks were reported in their neighbourhood.[70]

Gender-based Violence

Males are the most frequent perpetrators of violence against women, children and other men.[71-73] Violence can take the form of physical, sexual or psychological harm and while males are more likely to be subjected to physical violence, women and members of sexual minorities are more often subject to a range of violent acts, including sexual assault, and are more likely to be targeted because of their gender status at the hands of men.[72-74] While gender-based violence may take a variety of guises throughout the life cycle, it is often presented in gender-neutral terms such as child and elder abuse.[75] Only in preschool years are there no gender differences found among victims of sexual abuse by male family members.[76] It is important to note that violence against women is tolerated and legitimized in many societies such that if similar acts were perpetrated against neighbours, strangers or employers, they would be regarded as punishable crimes.[75]

In the US, four million women are battered by their partners each year while one in five women will be abused by a partner or ex-partner at some point in their life. Domestic violence is a major cause of injury and accounts for 40% of female homicides in the US, resulting in an estimated four deaths daily.[77,78] US authorities also estimate that 38% of pregnant adolescents and 25% of pregnant women of all ages, are physically or sexually abused during pregnancy, generally by their partners.[75] In 1992, the American Medical Association estimated that 35% of emergency room visits were from women suffering from injuries relating to battery or rape.[79] In Canada, gender-based violence is estimated to cost health and justice services $1.6 billion annually.[80] Furthermore, 4.5 women and 1.1 men per million married couples per year are murdered by their spouses while 26.4 women and 11.5 men per million common-law couples and 38.7 women and 2.2 men for every million separated couples meet the same fate.[81,82]

Women in abusive relationships are often isolated socially and financially, making it increasingly difficult to remove themselves from a violent situation. Additionally, they may be conflicted by the desire to keep their family together.[83]

Unfortunately, separating from a violent partner does not ensure that the threat will cease. Forty percent of women and thirty-two percent of men who experienced spousal violence within the previous five years revealed that the violence commenced after separating from their partner.[81] Notably the type of violent activities reported by women and men differed. Fifty-seven percent of these women were beaten, sexually assaulted, threatened with a weapon or choked while fifty-eight percent of men were kicked, bitten or hit.[82]

Exposure to gender-based violence is not limited to any one socio-economic class or ethnicity; however, geographic variation in violence against women has been noted. Prince Edward Island currently leads the country in rates of male partner violence. In Quebec, the odds of encountering male partner violence decreases by 18% for each unit increase of education; while the impact is 6% for the rest of Canada. Partners with similar levels of education are most vulnerable to abuse in the rest of Canada, while in Quebec dissimilar education is associated with violence.[84]

As noted in the Canadian report to the CEDAW committee indigenous women in Canada are particularly vulnerable to violence.[11] Aboriginal women are three times as likely to report violence by a current or former spouse than Euro-Canadian women. Over 12% of Aboriginal compared to 3.5% of non-Aboriginal women reported experiences of violence in the past five years;[85] moreover, they generally report experiencing more life-threatening forms of violence than non-Aboriginal women.[82] Higher levels of education increase Aboriginal women's odds of violence by 22%. Living common law increases the likelihood of violence 13% among non-Aboriginal women and 217% for Aboriginal women.[85]

While under-reporting of gender-based violence is problematic overall, the issue is particularly troublesome in some sectors of society. Immigrant and refugee women who regard themselves as having precarious immigration status may fear deportation for themselves or their partners if they report violent episodes to the authorities.[86,87] Fear of reinforcing negative stereotypes about men from ethnic minority communities may also reduce rates of complaints from women in those communities.[78] Members of sexual minorities who may feel too stigmatized to report crimes are also particularly vulnerable to violence. Over 50% of transgendered persons have experienced some form of violence in their lifetime.[88] Lesbian survivors of violence may be hesitant to access support services as it may require them to disclose information about their own or their partner's sexuality in what they may perceive as a hostile or judgemental environment.[89] Violence is increasingly common in the lives of homeless women who may also hesitate to report abuse.[90] Lastly, women who have survived state-sanctioned violence as either subjects of or witnesses to torture may not readily disclose their experiences to health or social service personnel in Canada, even though these experiences are present in their lives today.[91,92]

As our knowledge of the experiences of the survivors of torture attest, the sequelae of violence are dramatic for both victims/survivors and witnesses of such acts. Depression, post-traumatic stress disorder, spinal injuries, low-self esteem, sexual dysfunction, substance abuse problems, HIV/AIDS, and other sexually transmitted diseases have been associated with a legacy of violence for survivors.[93-96] Children of batterers have lower self-esteem and suffer from anxiety and inattention; they also hold more stereotyped views of gender and tend to regard physical force as an appropriate outlet or tool of persuasion.[97] The consequences of child sexual abuse, experienced by an estimated 16% of men and 27% of women in the US, includes an increase in risky sexual behaviours, depression, suicide, sexual difficulties, alcoholism and drug abuse.[98-100] Self-medication is one way of coping with undesirable emotions that can emerge from abuse.[96] Generally, adolescent girls are believed to internalize their experiences while boys externalize their pain resulting in anti-social behaviour.[101,102] Abuse sustained in childhood may have long-term effects that are unrecognized in later years. One study examining the impact of childhood abuse found that 80% of survivors developed at least one psychiatric disorder by the age of 21.[103] Depression in older women is often undiagnosed and while it may be co-morbid with other conditions, it may also be the legacy of childhood abuse and exposure to violence or the result of more current elder abuse.[104]

Detecting the health impact of violence, however, can be problematic. Women may present non-specific somatic complaints that compel health care personnel to label them as difficult patients.[95] Health professionals are also at times hesitant to involve themselves in domestic violence. For instance, some professionals are reluctant to engage in issues pertaining to gender violence in minority communities and may instead relegate these incidences to religious and cultural differences.[105] A recent survey of British health professionals revealed that only 54% of respondents knew that hitting one's partner was a crime and 44% felt uncomfortable asking patients about violence.[106]

While gender-based violence is not universal, it is widespread and more common where males have witnessed abuse or been abused as children, where masculinity is linked to notions of male honour and toughness and where violence is tolerated.[75,94] Male identity crises wherein male abusers perceive threats to their masculinity precipitated by loss of economic power and status are seen as potential instigators of male violence.[94] Alcohol and other substances have been regarded as incendiary factors; however, it is not clear whether substance abuse problems are the result or the cause of these behaviours.[75,106] Generally, higher education is regarded as protective for women, but this is not always the case as the statistics for Canadian Aboriginal women attest. However, as isolation and lack of social support allows violence to be perpetuated, more opportunities for women to become financially and emotionally independent will be vital to halting these crimes.[75,94]

The Hazards of Work

Occupational injuries, job insecurity and unemployment may be distributed differentially across class, ethnic and gender categories.[107] Specifically, conditions of employment (including control in the workplace, exposure to sexual harassment, and job insecurity), exposure to occupational hazards, and the intersections of paid and unpaid labour, are all implicated in producing gendered health disparities.

Epidemiological studies of the British civil service, the Whitehall Studies, have drawn attention to the relationship between health status and social gradients and the salience of lack of control in the workplace as a workplace hazard.[108] Control in the workplace is socially distributed and women are generally afforded less of it. Even women in female-segregated occupations tend to have lower levels of control than men in the same positions.[109] Jobs with low control and high demand are associated with poor self-rated health.[110] Women working in low control environments have a 40% increased risk of developing depression compared to women who have high decision latitude in the workplace; these effects are intensified if women experience low control at home as well.[111] Low-control work environments can have an impact on cardiovascular disease. High diastolic blood pressure has been found among laundry and dry cleaning operators, food service workers, private childcare workers and telephone operators, while risk of coronary heart disease is heightened among clerical and sales staff.[112] Stymied self-efficacy and eroded self-esteem exacerbated by the gap between high work demands and little perceived gain can induce autonomic and neuroendocrine stress responses that may underpin the health problems associated with low control work environments.[113]

Brooker and Eakin[108] suggest that power – organizational, social and material – is a more salient concept to consider in relation to health and stress. They maintain that lack of power is a stressor and that coping resources are differentially distributed. Discrimination, restricted mobility and restricted access to power networks are particularly pervasive issues for women.

Sexual harassment, the impact of the double shift and environmental hazards in work disproportionately affect women.[114] Women in the workforce, particularly those who are employed part-time or as home-workers, are more likely to report negative work characteristics than male counterparts.[115] In addition, job insecurity appears to have the greatest effect on high strain jobs[110] and more women report high job strain that is associated with poor self-rated health status.[116] Men, however, are not immune from the effects of job insecurity; the Whitehall II study demonstrates that men anticipating privatization in their workplace were more likely to report poor health status than those who anticipated a secure position in the public service.[117] Changes in the labour market suggest that dissatisfactory work conditions, and their attendant health effects, may become more commonplace among certain sectors of society. Nearly one-third of the Canadian workforce is self-employed, employed part-time or engaged in multiple part-time jobs wages.[118] Conditions of these forms of employment, most commonly associated with young workers, women and recent immigrants, are characterized by a paucity of employee benefits, high levels of job insecurity and low wages. Lax occupational health standards, lack of control in the workplace and irregular work schedules, coupled with uncertainty about current and future employment, tasks, earnings and workload contribute to poor self-rated health status and increased stress among this sector of the workforce.[118]

In addition to employment conditions that may have more impact on women workers and certain male employees – predominantly immigrants and youth – occupational exposures also contribute to health problems. While men encounter considerable hazards in industrial and agricultural labour, most occupational health regulations are predicated on male labour and male bodies.[119] Women's health at work is jeopardized by inappropriate workplace configurations and tools designed for men, job segregation, resulting in increased task fragmentation and monotony, the stress of discrimination and sexual harassment and the paucity of employee benefits as women are disproportionately relegated to low-wage, low-control and part-time labour.[112,120] Importantly, the rate of workplace accidents is higher among temporary employees, the majority of whom are female.[121] While employers may disregard the effects of workplace hazards on women's health, in some instances these concerns can affect the opportunities women have to obtain employment. Women have often been constrained from entering certain positions due to the potential endangerment of a fetus by workplace materials; men, whose reproductive health may be similarly jeopardized by these conditions, generally do not face the same prohibitions.[122,123]

Women can, however, face considerable health costs for their labour. Women tend to lift materials for longer periods and are subject to a faster pace of repetitive labour than men, resulting in disparate but nonetheless significant pattern of injuries.[124] Ergonomic exposures, repetitive work and high psychological demands contribute to job strain that results in poor self-rated health.[117] Depression is commonly associated with computer processing and women employed in the poultry and garment industries experience musculoskeletal problems and stress-related disorders attributable to their working conditions.[114] Long hours standing and cold exposure can contribute to peri-menstrual symptoms in poultry slaughterhouse workers and hairdressers.[112] Additionally, standing for long periods can also lead to the development of varicose veins.[125] Three times more women than men report sick building syndrome related to working in an open plan office or reception area, exposure to tobacco smoke, and handling paper; low control and more negative perception of psychosocial and physical environments contributed to symptoms.[126] Exposure to pesticides is also problematic for those who work and live in agricultural areas, although the issue may be underestimated among women in part due to measurement standards.[127,128] Professional women such as accountants also report higher levels of anxiety than their male colleagues.[129] Much of women's work is characterized by monotony and repetition that can contribute to mental and physical health problems.[112,130]

Other female-dominated occupations appear to be injurious to women's health. For instance women employed in home care agencies report a host of complaints including stress, respiratory illnesses, arthritis, back problems, hypertension, migraines and work-related injuries.[131] In hospitals, the stress wrought by the instabilities of health care restructuring, particularly coupled with heavy domestic responsibilities, has contributed to health problems among nursing staff.[132] Another study found that practical nurses were particularly vulnerable to assault by patients.[133] In the US and Hong Kong, foreign domestic workers contend with stress stemming from immigration issues, long hours of labour and isolation in addition to exposure to toxic cleaners and physical strain.[134,135] Call centre employees, predominantly women, suffer from a variety of complaints including headaches, neck and eye strain and insomnia attributable to the stress of work surveillance, job insecurity and shift work.[136]

The health effects of working conditions are compounded by domestic responsibilities that further enhance gender disparities in health. The interaction between work and home environment on socio-economic inequalities and health differ for women and men. For example, family structure had a more significant impact on inequality for women but not men.[4] While women find employment generally beneficial in terms of improving social position, social support and control in the family, the pressures of the second shift can be disadvantageous.[111] In one study, female clerical workers with major domestic responsibilities and a punitive psychosocial environment showed highest risk of stress. Repressed hostility, low job mobility, a non-supportive employer, children and a blue-collar husband, were all associated with higher incidences of coronary heart disease.[109] In the Framingham Heart Study, incidence of coronary heart disease was twice as high among employed women with three or more children than those without. Other studies suggest that while men's stress levels may decline at night, women's do not due to familial and household responsibilities. Distress appears to intensify when domestic labour is unequally shared. The interactions, therefore, between work, household and child care responsibilities can have deleterious effects on women's mental and physical health.[137,138] The double shift of domestic and labour market responsibilities also means that women have little time to engage in physical activity, relaxation or self-care.[131] In fact, although marriage can be a source of social and economic support for women, it may also contribute to enhanced levels of stress due to increased responsibilities and lack of control at work as well as at home.[139] Conversely, job strain can be moderated by the effect of satisfying spousal partnerships and mothering roles.[140] Others have observed that social support and appropriate levels of self-esteem operate to reduce work-related stress more effectively for women than for men.[141]

Economic Disparities and the Costs of Poverty

Economic inequities, evidenced by income, employment and the demands of domestic labour, appear to underpin gendered health disparities most broadly. Economic status has significant impact on health and well-being and as gender figures prominently in income generation, health effects are decidedly gendered. Moreover, gender roles intersecting with household configuration, social mobility, immigration status, and disability further influence economic status contributing to poor health status.

Income disparities between women and men in Canada have been well documented. Statistics Canada[16] reported that as of 1997 average annual income for women was 67% of that of men. Individual women may earn as much or more than individual men; however, the composite wage gap is due to a disproportionate number of women who are either low-waged or unwaged.[16,142] The Survey of Labour and Income Dynamics (SLID), a longitudinal study that collected data from 1993-94 revealed that 1.4 million women over 16 (13.4% of all women) were persistently poor. Nearly 25% of women were poor for one year. Among seniors, 29% of women versus 12.9% of men were poor for at least one year. Women's chances of persistent poverty change over the life course: they are greater in youth and reduce in middle age and increase as labour market participation declines and family composition changes.[143] Certain groups of women are particularly vulnerable to poverty. By 1996, female-led single parent households were twice as likely to be poor as those led by single males.[144] Statistics may mask a more complex picture, as men and women of colour are further disadvantaged not only with regards to the population as a whole, but in comparison to Euro-Canadian women.[142]

Income disparities between women and men in Canadian society mean that women's access to education, housing, child care and nutrition are potentially compromised.[114] On a population level, increasingly unequal distribution of income is associated with increased mortality – especially for working-age populations.[145] Economic disparities between women and men are also reflective of their relative differences in power in a variety of spheres. Moreover, the disparities may be detrimental to men's health as well. In their examination of the relation between women's status and health in the US, Kawachi, Kennedy and Gupta found that in regions with a smaller wage gap between women and men and higher political participation, mortality rates were lowest for women and men as were deaths from specific causes such as stroke, ischaemic heart disease, cervical cancer, homicide, and infant mortality.[146]

Socio-economic class and gender differences account for disparities in self-rated health status, chronic disease and disability among older populations.[147,148] Gender differences in health vary according to stage in the life cycle and evidence suggests that socio-economic facts acting over the lifetime can have cumulative effects.[149] Caution, however, must be applied when considering factors such as socio-economic status. As mentioned earlier, determining the social class of women is complicated by the assignation of class status based on the occupation of the male head of household and the presumption that household resources are equitably shared.[22,150] Moreover, calculating women's social class based on the traditional elements of education, income and occupational prestige is also problematic as women's education does not always translate into well-paying jobs nor is women's work necessarily commensurate with occupational prestige.[151]

Women's self-rated health status also appears to be more sensitive to the effects of low-wage employment, declining more than men's health and improving less than men's health status when work and economic circumstances are on the upswing.[117] Men and women appear to experience differential health effects of poverty. In Britain, standard mortality rates for people of colour are higher than those for the general population and the disparities are even more apparent when female mortality is considered.[152] Furthermore, while material disadvantage contributes to higher rates of mortality overall, there appear to be gender distinctions in the pathways leading to this outcome. European and US studies suggest that men respond differently to poverty than women by embracing poor coping strategies such as alcohol consumption and smoking, contributing to substance-related conditions that lead to their demise, while women succumb more often to diseases such as diabetes and heart disease exacerbated or precipitated by psychosocial stressors and poor diet related to their impoverishment.[153,154]

Domestic roles also contribute to economic disparities between women and men. Women who are absent from the labour market during childbearing and childrearing are often penalized financially over the course of their lifetime as income levels and accrual of pension benefits are affected.[155] Furthermore, familial and economic roles that contribute to gender inequality result in differential mortality rates both in childhood and adulthood.[156] In addition to discrimination, women's poverty is linked to low-wage, part-time employment, the demands of caregiving, and the impact of divorce or separation.[57,157] The unequal distribution of household resources can further impoverish women.[158]

Change in household configuration – whether due to an increase in family size or loss of household income earners through death or desertion – is a major factor driving women into poverty.[143] Once in poverty, women's economic mobility is limited. The so-called feminization of poverty must be contextualized by contemporary global economic trends that have resulted in the loss of full-time industrial jobs and the expansion of part-time, non-unionized positions, designed to meet the flexible demands of the market, that have increasingly become the domain of women's labour.[159] Engagement in part-time labour is also regarded as desirable for women who must balance caregiving responsibilities, especially in the absence of universal daycare programs or adequate home care services.[160]

The dynamics of social mobility may further render health impacts. Adult members of the working class who had non-working class childhoods are more likely to have higher levels of low-density lipoproteins and glucose levels, placing them at higher risk for heart disease and diabetes, and are inclined to report fair or poor health than those who were not downwardly mobile.[161] Women who lead single-parent households and immigrant and refugee women and men are most vulnerable to the effects of downward mobility, which are associated with changes in household configuration and migration.

Most foreign-born workers experience a decline in socio-economic status after migrating to Canada.[162] Lack of Canadian experience and employers' unwillingness to accept foreign credentials and education on par with Canadian ones produce formidable barriers to fair labour market participation by migrants – even for those who were selected to enter Canada based on employment criteria.[163,164] Women in particular tend to relinquish their efforts to obtain positions commensurate with their skills or education and will take on low-wage employment in order to contribute to household income.[163] In addition, while most migrants recover their former socio-economic status in the following generation, this trend does not hold true for visible minority migrants, suggesting that racism plays a significant role in economic mobility in Canadian society.[162]

Similarly, persons with disabilities face considerable barriers in obtaining remunerative work and are also disproportionately poor, with women facing higher rates of poverty than men.[57,165] Fifty-two percent of working-age persons with disabilities are unemployed.[163] Over 33% of women with disabilities live below the poverty line compared with 28.2% of men.[57] A survey conducted by the Canadian organization, DaWN (Disabled Women's Network) found that 60% of women with disabilities have relied on social assistance at some point. Moreover, women with disabilities often incur greater costs for aids and services than male counterparts.[166] When married women become disabled, divorce is almost inevitable: 99% of them will face the end of their relationship compared to 50% of men.[167]

The social and health implications of poverty include ongoing stress that increases health problems and low participation in sports and education that is especially troubling for children.[168] Living in poverty is associated with higher rates of chronic disease, distress and low self-esteem. Children raised in poverty are more likely to have learning disabilities, language delay and to exhibit anti-social behaviour.[57] Almost half of low-income single mothers show signs of clinical depression. Maternal depression can likewise result in poor parenting of offspring.[169] Intersecting issues of racism and poverty may enhance the risk of contracting HIV/AIDS. For instance, despair may contribute to drug use that could lead to infection or incarceration in prisons where disease rates are high. A study in Los Angeles found that African American women who relied on a male partner for financial assistance for housing were less likely to insist on condom use. Threats of violence are also an issue.[170]

Marginalization and Health

Marginalization refers primarily to the lack of equitable access to social, political and economic benefits and exclusion from full participation in these realms due to one's membership in an identifiable group. Marginalization, economic disadvantage and gender are closely related, and social exclusion engendered through low income, culture, gender, ability or geography can have deleterious health effects.[40,171] In Canada, members of visible minority communities, immigrants and refugees, Aboriginal peoples, the homeless, sexual minorities and persons with disabilities are among the marginalized.

The term "visible minority" – regarded as a creation of the Canadian government – tends to collapse a heterogeneous group of persons into a singular category, thereby masking class and ethnic disparities.[172] While the term is problematic, there is some evidence that both foreign- and Canadian-born persons of colour are responded to by Euro-Canadian society in a similar fashion. In turn, these responses have real repercussions in terms of opportunities and experiences that are further reflected in the colour gradient of our socio-economic hierarchy. Regarded as evidence of structural inequalities, racism can in fact be viewed as a chronic stressor that can illuminate disparate health conditions reported by members of marginalized communities.[173,174] Discrimination is enacted through a variety of means ranging from structural inequities promulgated by state and non-state institutions to the personal racist behaviours of individuals who as employers, landlords, classmates, colleagues, neighbours or strangers may have disparate impacts on the lives of their targets. The impact of discrimination is often rendered in the form of social and economic marginalization evidenced by limited labour market participation and highly charged familial roles that may have health consequences for women in particular.[175] Living in an environment that is characterized by economic and social deprivation, exposure to environmental hazards, socially inflicted trauma or the marketing of drugs, alcohol, junk food and inadequate health care are also ways in which discrimination is experienced by members of ethnic minority groups. These circumstances may constitute conditions for chronic stress that can, directly or indirectly, have a deleterious impact on health and may, therefore, provide the potential link between social context and individual health outcomes.[176] Overall, social inequities are embodied in such a way that social arrangements of power – that are structured by gender, class and ethnicity – influence ecological context and individual life course status.[176]

The impact of racism on health is also influenced by gender. Reports of racist encounters have been linked with hypertension, depression, distress, self-reports of poor health status, increased rates of smoking, increased sick time and low birthweight.[174] Respondents who experienced verbal abuse were 50% more likely to describe their health as poor or fair; those who were personally attacked or had their property vandalized were 100% more likely to do so. Among the informant sample, women were more apt to internalize their response contributing to health effects and 60% were more likely to report poor health than men.[174] Conversely, those who were able to confront the situation were found to have lower blood pressure than those who attempted to ignore it.[174]

Discrepant expectations, racism and downward mobility may contribute to chronic stress that may become more evident to new Canadians as they settle in this country. Resettlement is associated with a variety of stress-related health effects including diabetes, hypertension and negative health behaviours in concert with experiences of trauma.[149,177,178] In addition, precarious immigration status produced while awaiting refugee claims, under conditions of trafficking or through participating in programs such as the Live-In Caregiver Program, is more common to women; therefore, women are more vulnerable to the health effects of stress related to immigration concerns.[179,180] Among non-European immigrants those who are more likely to report poor health did so after a decade of life in Canada. Single migrants and those who felt unloved were also more likely to report fair or poor health.[21] Moreover, women may be more vulnerable to mental health problems due to previous trauma, the impact of discrimination, social isolation, and economic and social marginalization.[181] A British study revealed that the type of trauma Somali refugee women experienced in their homeland in conjunction with their current social, economic and familial context led to different health outcomes such that women who were identified as housewives were more likely to express suicidal ideation.[182] In a study of migrants who came to Canada under the auspices of the Live-In Caregiver Program, women who had fulfilled their contracts and were living in Canada as permanent residents were more likely to rate their health as poor than those who had arrived in Canada within the previous two years and were still employed under the program.[180]

The legacies of colonization and conditions of neo-colonialism have contributed to severe health and social conditions that contribute to high rates of violence and substance abuse in Aboriginal communities.[183,184] Even though they are more likely to use alcohol than women, Aboriginal men also forgo alcohol at higher rates, report better health status and engage in more positive health behaviours such as physical activity than women.[184,185] Aboriginal women face high suicide rates, cardiovascular disease, diabetes and gastrointestinal problems. Diabetes, for instance, occurs two to three times more often among Aboriginal women as among other Canadians and is diagnosed at twice the rate of Aboriginal men. Furthermore, Aboriginal women residing in urban areas may be relegated to living in substandard housing and may be isolated from their customary sources of social support.[114,183]

The lack of affordable housing has contributed to the proliferation of homelessness in Canada. The estimated number of homeless individuals in Canada ranges from 35 to 40 thousand to several hundred thousand.[55,186] Depression and high levels of stress are common to the experiences of homeless mothers who often lack access to services such as child care.[90,187] Many homeless women have also sustained abuse and suffer from higher rates of mental illness than men.[90] Homeless men, however, appear to engage in binge drinking more often than women.[188]

In the US, 1.3 million youth have run away from home or are homeless. In this constitutency, girls are more likely to rate their health as fair compared to boys.[189] Homeless youth are often at risk for contracting sexually transmitted diseases including HIV/AIDS. While they may be cognizant of the risk, safe sex behaviours require a sense of self-efficacy, future orientation, support and power to be able to control sexual encounters.[190] Lesbian, gay, bisexual and transgendered youth comprise anywhere from 6% to 35% of the homeless population. Many are more vulnerable to health problems due to a history of abuse and addiction. Violence poses a significant threat and some may be compelled to trade risky sexual behaviours for food and shelter. Fourteen percent of respondents in one study left home due to a conflict over sexual orientation: this group was more likely to be physically and sexually abused since becoming homeless.[191]

Members of sexual minorities do not need to be homeless to experience marginalization. Gay, lesbian, bisexual and transgendered students experience more harassment in school; a Massachusetts study found that they were four times more likely to have attempted suicide and five times more likely to admit they missed school because of feeling unsafe. Authorities tend to view harassment as normal adolescent behaviour and underestimate its impact on mental health.[192]

Women tend to have higher rates of disability than men.[193] School-aged boys, however, are diagnosed with learning disabilities more often than girls – possibly because they garner greater attention.[194] Moreover, men with disabilities are often granted more household assistance and training than their female counterparts.[195] Disability rates are higher for those who are poorly educated, live alone, live in poverty, and/or are suffering from depression and anxiety. In the US, these characteristics tend to describe a disproportionate number of women and African Americans.[196] In some communities, women with disabilities are discouraged from finding a partner even though marriage and childbearing are highly valued.[197]

Aging

Aging is one of the major demographic features of Canadian society, although some cultural communities do not share in this trend. Both economic status, which is closely linked with gender, and gender roles, which influence use of health services, influence the health trajectory of individuals as they age.

As of 1996, women accounted for 70% of Canadians over 80 years of age and 58% of those over 65.[198] The National Advisory Council on Aging[199] reports that a greater proportion of older women are diagnosed with dementia. Moreover, senior women are less likely to be able to perform daily tasks and more likely to experience restricted mobility than men.[147] Nearly half of all women over 75 years of age reside by themselves and may therefore require more formal support to attend to daily activities.[200,201] Men, too are likely to experience increased morbidity with age. As men are more likely to eschew preventive health measures and avoid medical encounters, they are more likely to present with more advanced health conditions when they seek medical treatment.[202] Lunenfeld asserts that five out of six men in their 60s contends with a chronic degenerative disease.[202]

Aging also intersects with poverty for many women. Over 20% of senior women have not engaged in the paid labour market, resulting in little or no pension benefits, even though they may have been engaged in household labour and caregiving activities for much of their lives.[199,203] Importantly, the relationship between poor health status and socioeconomic status often emerges with age such that health problems associated with maturation are reported at an earlier age by those who are less affluent. Nearly 25% of senior women, compared to 12% of men, live below the poverty line. Single and widowed mature women have even higher rates of poverty: just under 50%.[204] This contrasts with the situation south of the border where 80% of widows are plunged into poverty after the death of their partners.[203] Women of colour are more vulnerable to poverty and many women who have witnessed the disadvantages of gender, ethnicity and age are more anxious about growing old than Euro-Canadian women.[205-207] Gay, lesbian, bisexual and transgendered seniors may confront additional problems as they mature; single lesbian seniors may report poorer health than those who are living with a partner.[208]

Health Conditions and Interaction with Health Services

Health services utilization is influenced by gender as it interacts with socio-economic and immigration status and gender roles. Moreover, diagnosis and treatment options are potentially shaped by the patient's gender, as are decisions to access health services and social support, these all contribute to disparate health outcomes.

Health care reform has been implemented without consideration of its potentially gendered impact,[209] yet restructuring has had a tremendous impact, particularly on women as caregivers, patients and health care staff. Immigrant and visible minority women comprise a disproportionate number of health care workers who have been employed in positions such as: food and laundry services that have been contracted out to non-union employees;[210] and the most recently hired nursing staff who were laid off during the height of restructuring.[211] In hospitals, nurses are required to economize their interactions with patients in ways that can potentially further disadvantage minority women, as has been observed in labour and delivery units.[212] Furthermore, early discharge policies that involve releasing women from hospital 24 to 36 hours following delivery have resulted in increased re-admission rates for disadvantaged newborns.[213] Time stress and restructuring of health services mean that nurses and other health professionals are unable to invest in building ongoing trusting relationships with migrant women.[179,212,214]

Health services utilization has been problematic at times for some culturally, physically and sexually marginalized women. Once diagnosed, women with disabilities are often regarded as problem patients and may be patronized if they desire to become pregnant.[215] Lesbian and bisexual women may avoid health care providers due to previous experience with homophobia or fear of disclosure, especially in rural regions. In a Canadian survey, 38% of the respondents admitted to avoiding seeking help due to sexual orientation. Lesbian and bisexual women may also avoid health screening and diagnostic and preventive services.[216]

Access to health services is also problematic for many migrant women and women of colour who generally occupy the lowest echelons of the Canadian workforce. Low-wage jobs are less likely to provide supplementary employee benefits and may also lack the flexibility that would allow employees to take time off for health appointments. Lack of interpreter services may make the hospital an unwelcoming environment for non-English or French speakers. In addition, the focus on individualism and self-care in our health care system makes it difficult for economically and culturally marginalized women who may not be able to afford, or are unwilling to expend, household resources on individual self-care.[155,212,217,218] Reductions in settlement services and community health programs, new co-pay arrangements for prescription medications and longer waiting periods to be eligible for provincial health care insurance plans have been burdensome for many new Canadians.[219] In certain regions of the country, newcomers have a difficult time finding physicians who can take on new patients. Language barriers, lack of information about services and the impression that physicians are not listening to them may also affect the use of medical services.[220] Isolation from Euro-Canadian society due to differing values can affect health not only due to inappropriate health services, but also stigmatization.[118] Stereotyping, lack of respect and inappropriate care have been cited as barriers for Aboriginal women seeking health services[183,212,221] as well as for migrant women.[164,210,220] In the U.K., women of colour are offered more hysterectomies and more Depo-Provera than other British women, sending the message that this group of women should be encouraged to control their reproduction.[222]

Overall, gender has not figured prominently in health-care policy and planning. In their review of provincial regional health plans, Horne, Donner and Thurston[223] found that policy-makers and planners lacked appropriate sex-disaggregated data on the health of women and men, relegated women's health to reproductive issues and breast or cervical cancer, refrained from consulting women's organizations and feared backlash if they moved forward with any women's health initiative. Despite this apparent lack of attention to gender, women tend to use the health care system with greater frequency than men. Ninety-five percent of women compared to ninety percent of men consulted a health professional between 1996 and 1997. Moreover, women were more likely to be hospitalized than men primarily due to pregnancy and childbirth and conditions related to aging.[16] Notably, low-income individuals avail themselves less often of preventive health programs.[224]

Males tend to access health services for specific problems rather than preventive services. Help-seeking behaviour is viewed by some men as incompatible with masculinity.[25,225,226] The pattern of eschewing health services appears in late adolescence. Young adolescent boys use health service at the same rate as girls; however, as they become older, they begin to avoid health professionals.[227] This avoidance behaviour, coupled with value placed on stoicism, may result in delays in diagnosis and treatment that may account for higher mortality rates for conditions such as cancer.[228]

If reproductive health services are excluded from consideration, health-care expenditures for women and men appear fairly similar;[20] however, women may not receive an equitable share of certain treatments and technologies. For instance, women are less likely to undergo kidney transplants, cardiac catheterization and revascularization when presenting with coronary heart disease than men. Men are more apt to be candidates for hip-replacement surgeries, renal and heart transplants and to be offered AZT for treatment of HIV/AIDS.[229]

Some conditions, such as multiple sclerosis and fibromyalgia, can be difficult to diagnose. This can contribute to health professionals' perceptions that women are neurotic clients.[215] Women with disabilities are more likely to have their conditions attributed to psychiatric causes than men and physicians are more inclined to provide a diagnosis of depression to female patients.[20,230,231] Depression has also been cited as a reason why women report more symptoms and functional decline than men.[232-234] Differential patterns of symptoms and disparate responses to pain may be grounded in physiology as the result of hormonal influences on opiate receptors.[235] Moreover, women may be more perceptive about somatic stimuli due to an internal focus, the sensations produced by the menstrual cycle, and gender socialization that shape response to such bodily sensations.[236] While women complain of pain more often than men, men receive stronger and more frequent prescriptions of analgesics.[235]

The proliferation of mental health diagnoses for women has been contentious. Some authors assert that notions of normalcy are configured by hetero-normative standards that reinforce narrow gender stereotypes and unjustly pathologize women.[237-239] For instance, Stein and Nair[240] note that routine aspects of female physiology such as the luteal phase of the menstrual cycle, pregnancy, and lactation are being placed under medical surveillance, constructing an image of the female body as one that requires medical intervention.

Both under-diagnosis and over-medicalization are problematic; however, these issues cannot allow us to lose sight of the fact that some women truly suffer from mental health problems, most notably depression; women in North America report significantly higher rates of depression than men,[169,241] although suicide rates are higher among men.[242] Weidner[243] suggests that men are less able to cope with the effects of depression due to more limited social integration and social support than can be generally mobilized by women. Furthermore, men who subscribe to more traditional gender roles are more likely to experience anxiety, depression, distress and problems with intimacy.[244]

Depression is disproportionately found among low-income populations such that nearly half of single mothers in the US can be defined as clinically depressed.[169] Stress pertaining to finances, personal safety and household inequality can predict depression.[137,245] In Canada, single mothers who are unemployed report twice the rates of distress compared to all other groups.[246] Patel[247] observes that depression has become a world-wide issue for women as globalization contributes to gender inequities, declining living standards and reduced government spending on health and social services as well as the disruption of social support networks engendered by movements of urban and out-migration for economic survival. Poor mental health among women can also be the result of physical and sexual abuse and state violence.[248,249] Females are generally socialized to internalize distress and indeed adolescent girls report more depression, eating disorders and suicide attempts than their male counterparts.[191,250,251] The internalization of distress is also problematic for lesbian and bisexual women who report higher levels of depression than heterosexual women.[252,253]

The attribution of complaints to psychological origins and misunderstandings about sex differences in presentation of symptoms may result in misdiagnosis of conditions, most notably heart disease. Studies have found that some physicians have failed to appropriately diagnose the condition, postponing access to appropriate care and have prescribed contraindicated activities in the interim.[254,255] This delay can be even more problematic as women suffer twice the number of silent heart attacks as men and thus may have already sustained damage prior to presenting in a physician's office.[255] US statistics demonstrate that women under 50 years of age perish from heart attacks at twice the rate as men and are five times more likely to die in hospital.[256] Once diagnosed, women are less likely to be offered invasive treatments; those who have been are more inclined to suffer from surgical complications.[257-260] Some pharmaceutical therapies are also less effective or even contraindicated for women; for instance, according to one randomized controlled trial, digoxin increases mortality for women.[261] Women's propensity to succumb to heart disease is related to social location. Heart disease is greater amongst those who suffer from depression and anxiety, people who work in low-control environments and those who care for large families – all factors that indicate women.[138,262,263]

Social environment plays a role in the development of osteoporosis throughout the lifecycle. Stress, maternal and childhood nutrition, constrained use of public space (which limits physical activity and exposure to sunlight), and eating disorders such as anorexia nervosa all contribute to loss of bone mineral density.[59,264-266]

While marginalized women throughout the world are increasingly vulnerable to HIV/AIDS due to low sexual autonomy,[267] lack of power is also linked to the pattern of HIV/AIDS in Canada. Socially, culturally and geographically marginalized individuals such as rural residents, Aboriginal Canadians and intravenous drug users are less likely to seek medical attention for the condition; as women appear to decline faster than men, this delay may be particularly detrimental. HIV-positive women face particular challenges in prioritizing their needs as women are often inclined to meet their family's needs before their own.[268,269]

Health Behaviours

Gender differences in drug and alcohol use have been noted; men are more likely to use them to socialize, cope with distress and reaffirm their masculinity while women may use them to relieve stress.[244,270-272] Moreover, women with addiction issues are judged more harshly by others than men and tend to be of lower socio-economic status.[273] There is, however, a paucity of data on women's use of substances in Canada.[274] The impact of alcohol abuse appears to be more deleterious for women as they sustain brain and liver injury more quickly and die at rates 50-100% higher than males.[275-277] Female alcoholics are also more likely to experience physical and emotional abuse than males.[278] A history of family violence, childhood abuse and negative life events are associated with substance use by young women.[279] Birth mothers of fetal alcohol syndrome (FAS) children have often contended with mental health problems, violence and abuse, and controlling relationships. FAS is an outcome often associated with First Nations women who are already familiar with the impact of systemic racism, therefore, imposing further surveillance and labels can only contribute to further marginalization.[274]

While alcohol consumption is more prevalent among Canadians in higher status occupations, smoking rates are higher in low-income populations.[55,280] Smoking is also more prevalent among adolescent women who may use tobacco as a means of weight loss, as a coping mechanism or as a projection of their identity.[281-283] According to 2001 statistics, 25% of men and 21% of women smoke. Among low-income Canadians, 40% of men and 36% of women are smokers. Rates are highest among Francophone and Aboriginal women.[282,284] In British Columbia, 17% of adolescent females and 13% of adolescent males smoke. Girls who feel more adversarial about school are likely to be smokers while boys who share these sentiments are generally non-smokers. Smoking, therefore, may be a way for disenfranchised young women to assert themselves.[285] Smoking may also be regarded both as a coping mechanism used by women managing the stress of poverty and motherhood and as a method of claiming some time and space for themselves.[286] Female smokers tend to have poorer nutrition than non-smokers and can suffer miscarriage, infertility, increased menstrual symptoms, reduced bone density as well as increased risk of lung cancer, COPD, heart disease, stroke and myocardial infarction.[287-291] When coupled with oral contraceptives, risk of coronary heart disease increases status dramatically as well.[287] Smoking during pregnancy can produce conditions such as gestational diabetes and can increase risk of miscarriage and low birthweight infants.[61,288] While these issues must be addressed, much of the literature on pregnant women and mothers tend to blame them for harming the health of their children.[292]

Health-promoting practices differ across geographical, cultural, educational and economic divides.[293] Men engage in leisure activities more often and for longer periods of time than women.[294,295] Rates of physical activity decline with income, although the trend is more obvious for women than men.[296] While physical activity is a decidedly healthy option, women may find it increasingly difficult to pursue these activities. The demands of the double shift mean that women have more fragmented time, resulting in less potential time to engage in exercise. Moreover, women are often too fatigued to engage in physical activities. In addition, activities may be too costly and difficult to partake in if child care is not readily available. Some activities may be regarded as culturally inappropriate and facilities may feel unwelcoming to members of minority groups if participants are relatively homogeneous.[297-302]

FUTURE DIRECTIONS

This review suggests health is detrimentally affected by gender roles and statuses as they intersect with economic disparities, cultural, sexual, physical and historical marginalization as well as the strains of domestic and paid labour. These conditions result in an unfair health burden borne by women in particular whose access to health determinants is, to various degrees, limited. The federal government, however, has documented its commitment to gender equality in the *Federal Plan on Gender Equality*[12] and its support of international conventions on the elimination of discrimination and violence against women. Many of the issues identified in those agreements, such as racism and violence against women and members of other marginalized communities, are deeply entrenched in Canadian society and will require concerted and committed efforts to dislodge them from the social landscape; however, without ongoing work, the wounds they produce will continue to fester. Progress on other issues such as affordable housing, child-care programs, equal pay for work of equal value, assistance for rural women, and a commitment to gender-based analysis throughout all levels of government, however, appear to have slowed or stalled over the past number of years. Indeed, government representatives responding to the criticisms of CEDAW committee members to its 2002 report[11] concede that the country has struggled with its priorities in the period since 1995 as it moved on efforts to address deficit and debt issues.[6]

While progress has certainly been made on some fronts, the persistence of health disparities among diverse populations of women and men suggests a postponement of the vision of a just society with health for all that was articulated in the *Federal Plan on Gender Equality*. The evidence presented in this paper demonstrates that there is a considerable amount of work to do to bring this vision to fruition; however, a blueprint for action detailed in a host of documents produced by the federal government and its agencies provide a solid basis from which we can take action.

If Canada is to meet its international commitments and adhere to policy as outlined by Health Canada, then it must move forward with strategies that will address major issues regarding women's poverty, discrimination against women, migrants and people of colour, violence, and inappropriate and inadequate health services. Furthermore, more attention must be paid to the health consequences of male gender roles among men who are members of both dominant and marginalized communities.

Interdisciplinary initiatives that facilitate holistic and situated approaches to gender and health research will not only be useful to this field, but can enrich the disciplines involved in the projects. Innovative programs have been developed in Canada and beyond that have worked to reduce health disparities by building on the strengths of local communities, using peer mentorships and community health development. For instance, the work of a cultural brokers cooperative where bi-cultural women have been trained in health promotion and community health development has not only helped employ immigrant and refugee women, but has benefited client families and contributed to the development of greater gender and culture sensitivity in the mainstream health institutions with whom they work.[303] In other instances, the use of photo-novellas, storytelling and focus groups have been used to convey the voices of women and minority community members to policy-makers and program planners; these processes can also engender further collective action.[304-307] For example, Kieffer et al.[306] describe how ongoing community-university alliances that foster participatory research have not only helped to illuminate explanatory models of disease for health professionals, but have contributed to community action to enhance availability of nutritious foods and demands for safer streets in disadvantaged neighbourhoods. Resources such as the Commonwealth Secretariat's 2001 publication, *Models of Good Practice Relevant to Women and Health: Women's Health Initiatives* contains numerous examples of innovative participatory programs that attend to issues of gender and health.[308] Overall, these models may all contribute to a re-shaping of community-based as well as institutional health services. More participatory research is required that can build on the strengths of women, men and their communities to help develop empowering, appropriate and long-term solutions.[309] Enhancing health by strengthening resistance resources such as social support and social capital are also offering potential avenues of insight and intervention.[310,311]

On a more general level, mainstreaming gender analysis is essential to health-care planning and setting the agenda for health research. Developing what Miers terms gender-sensitive care, wherein health services are designed to account for the gendered lives of groups and individuals[312] – both clients and staff – is also vital. Health Canada's 2003 publication *Exploring Concepts of Gender and Health* is an important resource available to policy-makers and program planners that can help them work through the gendered implications of programs and policies.[313]

Finally, the root of an individual's experience of health disparities lies predominantly in economic inequalities and unequal gender roles; therefore, efforts to close the gap in health must address these issues. Raising the rates for provincial minimum wages and social assistance levels might bring about improvements in health that exceed those of a singular intervention. Studying the impact of these issues and experimenting with other schemes such as a guaranteed annual income might provide some valuable information about the importance of economic security to health. In addition, the health of foreign-born Canadians might be improved if the means of adjudicating foreign credentials and enhancing opportunities for educational or occupational upgrading were given greater priority. A national child-care program might have considerable impact on alleviating the caregiving burden on women and would enable women to participate more actively in the public arena. National investment in an affordable housing program including cooperative housing could reduce homelessness, build safer neighbourhoods and enhance social capital.

CONCLUSION

The considerable affluence of Canadian society may mask the disparities that exist between women and men and within these categories. Individuals occupy various locations on our social landscape that can change throughout the life cycle; each position offers a range of potential opportunities and experiences, oppressions and insights. The pathways by which persons can be constituted as vulnerable – or conversely, placed on the road to good health – depends in part on where one is located in this social tableau. Health disparities may begin prior to birth as maternal health will have an impact on the life chances of children. Notions about what is appropriate behaviour for boy or girl children will have an impact on physical activity, the development of social skills and sense of self. At the level of the household, exposures to hazards, violence or other adverse conditions, allocation of health resources, nutrition, education, and gender socialization will further influence health and well-being. Neighbourhood and community can offer opportunities to form trusting relationships with others, provide a sense of identity and security or conversely, be a source of anxiety, the setting for discrimination and/or the site of environmental hazards and poor housing stock. Ethnicity, sexual orientation, mental health, physical ability, age, and socio-economic status also shape identities, opportunities and attitudes that dominant Euro-Canadian society has towards individuals and groups of individuals. Access to health and social service facilities and housing, the status, conditions and strains of paid employment, the configuration of domestic life and its interaction with labour market involvement can all enhance social capital or contribute to stress. Importantly individual pathways are largely shaped and constrained by cultural values and gender roles and ideologies as well as structural phenomena including the "isms" of racism, sexism, ableism, agism and homophobia, globalization and neo-liberalism that underpin the policies and practices that have wrought a restructuring of workplace and home life with little concern over their impact on women and men. Examining these pathways through a gender lens suggests that – in general – women are decidedly more vulnerable to worsening health status due to their association with lower socio-economic status, domestic and familial responsibilities and gender ideologies. Notably, some men, particularly those who are members of marginalized groups, are similarly affected. The result is that, to differing degrees, all Canadians need more equitable access to determinants of health – or to phrase it more precisely, power – in order to reduce health disparities. Commitment, creativity and collaboration from stakeholders ranging from various levels of government, communities, academics, non-governmental agencies and health professionals will be required to reduce and eliminate health disparities between and among all members of our society.

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RÉSUMÉ

Quelle est l'importance du genre dans l'analyse des disparités sur le plan de la santé au Canada? Dans le contexte de la politique du gouvernement fédéral, l'auteur de ce document de synthèse analyse la façon dont le genre interagit avec les autres déterminants de la santé pour créer des disparités. Il examine les problèmes prépondérants dont l'impact des rôles assignés à chacun des sexes, l'exposition à l'environnement, la violence liée au sexe, les risques sanitaires en milieu de travail, les disparités économiques, les coûts associés à la pauvreté, la marginalisation et le racisme dans la société, le vieillissement, l'état de santé, l'interaction avec les services de santé et les comportements en matière de santé. Ce document montre que l'interaction entre, d'une part, les rôles et le statut selon le sexe et, d'autre part, les disparités économiques, la marginalisation culturelle, sexuelle, physique et historique et les tensions du travail impose un fardeau inéquitable sur le plan de la santé et fait en sorte que l'accès aux déterminants de la santé – en particulier celui des femmes – est limité à divers degrés. Cette situation se traduit par un fardeau injuste sur le plan de la santé, porté en particulier par les femmes dont l'accès aux déterminants de la santé est, à divers degrés, limité. Des progrès ont sans nul doute été réalisés sur certains fronts, mais la persistance des disparités en matière de santé entre divers groupes de femmes et d'hommes indique que la vision d'une société juste et de la santé pour tous énoncée dans le Plan fédéral pour l'égalité entre les sexes ne peut s'incarner aujourd'hui. Les intervenants, qu'il s'agisse des divers paliers de gouvernement, des communautés, des universitaires, des organismes non gouvernementaux et des professionnels de la santé, devront faire preuve de détermination, de créativité et de collaboration pour réduire et éliminer les disparités en matière de santé entre tous les membres de notre société.