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The population health perspective as a framework for studying child maltreatment outcomes

Lil Tonmyr, Harriet L MacMillan, Ellen Jamieson and Katharine Kelly

Abstract

The population health perspective (PHP) is commonly used in addressing a wide range of health issues. In this article, the determinants of health that are an integral part of the PHP are used as a framework in considering the range of outcomes associated with exposure to child maltreatment. The article examines the strengths and limitations of the perspective and outlines directions for further research.

Key words: child maltreatment; outcomes; population health perspective

Introduction

Since the 1990s, child maltreatment has increasingly been viewed as a major public health problem in Canada. This has occurred, in part, because mounting evidence highlights the relationship between child maltreatment and impairment in both emotional and physical health. This paper examines the usefulness of the population health perspective (PHP) as a framework for studying child maltreatment outcomes by critiquing the approach and by applying the PHP-adopted list of determinants of health to these outcomes.^a It also outlines future directions for research in examining health outcomes related to child maltreatment from a PHP.

Population health perspective

The overarching goal of the PHP is “to maintain and improve the health of the entire **population** and to reduce the inequalities in health between **population groups** [emphasis added].”¹ Defining populations

is problematic; there are some examples given in the PHP, such as children and Aboriginal people. But what is a “population”. Is it a neighbourhood? A nation? Further, what constitutes “population groups” and why are boundaries created in some instances and not in others?² The unit of analysis is important if we are considering the impact of factors on the “health” of a population. For instance, increased economic prosperity at a national level is not necessarily reflected at regional or local levels,³ resulting in uneven health outcomes in these population groups which, when aggregated, may appear to have no impact on health.

The PHP marks a shift away from a narrow definition of health as the absence of illness, to a broader definition as “enablement to function within daily life and creation of conditions for people to develop capacities for the realization of their life pursuit”.¹ This notion of health recognizes that many factors, including social, economic, and environmental ones, contribute to health. As stated in *Women’s Health Sharing*:

We refer to health in its broadest sense, to include a state of physical, mental, spiritual and social well-being. Thus, political, social and environmental conditions are all health issues. It is not enough to quit smoking, run five miles a day, eat only organic food, if our environment remains polluted, our living and working conditions oppressive. Discussion of individual involvement and responsibility can be an empty exercise for a person who is struggling just to feed her children.⁴

Changes in our view of health affect our definition of “health problems” and affects how research is conducted. The PHP “places the person within a broader context”.⁵ However, concern has been raised that a concentration on larger circumstances can obscure important elements of individual experiences.⁶ The balance between macro and micro factors is important. Individuals can alter some determinants of health; others must be changed by groups or organizations.¹ Income inequality, for example, is a characteristic of a population rather than of an individual.⁵ Personal income level is partly attributable to personal skills, but also to tax policies and redistributive programs, factors beyond the control of the individual. Thus, the PHP addresses issues on conceptually distinct levels encompassing the individual, family, community and society. These different levels take into account the antecedents, developmental processes and experiences of the individual. Health issues, then, have to be addressed at several levels simultaneously.

^a The term “outcomes” from a purist standpoint should be used only when exposure to child maltreatment precedes the outcome of interest; however, in this discussion, the term refers to dependent variables which have shown an association with exposure to abuse.

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The PHP has something to offer both “neo-conservatives” and “welfare state advocates” in that it simultaneously addresses economy and equity. This has contributed to widespread support.⁷ Economic growth (a conservative argument) is seen as an essential component to improved health status at the population level, as is equitable distribution of wealth (a social welfare argument). Populations with more equitable income distribution are healthier than other populations.⁸

Another important feature of the PHP is its multidisciplinary nature. This has broad

appeal at one level, but it also poses certain challenges: terminology differences, difficulty evaluating the quality of “evidence” from other disciplines, “turf wars” or “health imperialism.”

Determinants of health

The Canadian Institute of Advanced Research (CIAR)^b influenced the development of the PHP by publishing policy reports that provided information on determinants of health. They identified a broad range of determinants. Initially, sex and gender were not differentiated,⁹ and ethnicity and reli-

gion were used solely as control variables in analyses.¹⁰ More recently, the importance of social environment, gender and culture has been recognized (Table 1).

The determinants overlap and may interact. Influences on health are interdependent, reciprocal, subject to the contingency of time, non-linear but cumulative or latent in pathways. Their interaction is not fully understood. Studies of the determinants of health have identified correlates; causality has rarely been established.²¹ Individual determinants may function as risk or protective factors; gender, for example,

TABLE 1
Determinants of health^c

Determinant	Relevance
1. Income and social status	the most important determinant of health nationally. ⁸ However, it is the distribution, rather than the actual amount of wealth that is associated with healthier people amongst the population. ¹¹
2. Social support networks	the effects of social support may be as important as identified risk factors such as smoking, physical activity, obesity and high blood pressure. ⁸ It is not the quantity of relations that matter but the quality. ¹²
3. Education	provides skills useful for daily tasks, employment (income and job security) and community participation ¹³
4. Employment and working conditions	health status is improved with increased control of work circumstances and lower levels of stress. ⁸ Unemployment is highly correlated with poorer health as well. ⁸
5. Physical environment	factors in the natural environment, such as air, water and soil quality are key influences on health. Human-built factors such as housing, workplace, community and road design are also important. ⁸ Many of the writings from a PHP do not account for environmental implications. ^{2,14}
6. Biology and genetic endowment	the functioning of body systems and genetic endowment contribute to health status as well as the process of development. ⁸
7. Personal health practices and coping skills	psychological characteristics such as personal competence, locus of control and mastery over one's life contribute to mental and physical health; ¹⁵ however, the focus on personal health practices has been characterized as blaming the victims instead of societal factors. ¹⁶
8. Healthy child development	a wide range of chronic conditions seem to have their origins in fetal and infant life. ¹⁷ Prenatal and early childhood experiences are also important in the development of coping skills and competence. ⁸
9. Health and social services	contribute to healthier people. ¹⁸ However, increased expenditures on health care seem to be less successful in improving the health of Canadians. ¹⁹
10. Gender	biological differences in sex and socially constructed gender influence health ¹⁸ and health service use. ¹⁸
11. Culture	may influence the way people interact with health care systems, participation in prevention activities, health-related lifestyle choices and understanding of health and illness. ¹⁹ Racism, language barriers, prejudice and misunderstandings may reduce access to health care. ¹⁹
12. Social environment	low availability of emotional support and low social participation have a negative impact on health and well-being. ¹⁸ Hayes ²⁰ questions if there was any value added in including “social environment” as a health domain, since it already exists within at least seven of the determinants.

^b CIAR contributes to research in many different disciplines. The Institute has a program in population health that supports research on the determinants of health.

^c Health Canada built on previous knowledge when this list was developed as shown in the references both to CIAR and other sources. The list is useful in investigating a range of health issues. The present article provides references to outcomes of child maltreatment. For instance, Wolfe has addressed the determinants and child maltreatment surveillance.¹³

increases the risk of some health outcomes and decreases the risk of others. “Determinants seem to function as a resource with different degrees of necessity”.²¹

The PHP has been criticized for a number of reasons. The health promotion movement criticizes it for ignoring the importance of participatory communities in developing policies.^{7,22} However, this position risks “blaming the community” for not mobilizing and providing sufficient support²³ without the provision of needed infrastructure. There is also a risk of “blaming the individual” instead of societal factors.¹⁶ Furthermore, the PHP emphasis on early childhood development has been criticized for ignoring the reinvesting and reinforcement period (6–18 years). This period is important because research indicates that developmental lags may be overcome if assistance is provided.¹⁵

Child maltreatment

This section addresses child maltreatment and PHP. There are four main types of child maltreatment: physical, sexual, and emotional abuse, and neglect. Child physical abuse includes acts such as hitting, shaking, choking, biting, kicking, burning, slapping, poisoning or any other dangerous use of force.²⁴ Child sexual abuse occurs when someone involves the child in any activity for the purpose of his or her own sexual pleasure. This might involve intercourse, touching, or exposure to developmentally inappropriate sexual behaviour, including exposure to pornographic material.²⁴ Child emotional abuse may involve degrading, rejecting, terrorizing, isolating and corrupting acts; it includes witnessing domestic violence.²⁴ Child neglect occurs when a caregiver fails to provide one or more of the following: adequate food, clothing, shelter, cleanliness, supervision, medical care, protection from harm and exploitation, and denial of emotional responsiveness.²⁴

No national figures for the prevalence of child maltreatment are available. The best information comes from the Ontario Mental Health Supplement (1990), a province-wide community survey. A history of child physical and/or sexual abuse is common: child physical abuse was reported more often by males

(31.2%) than females (21.1%) whereas child sexual abuse was more common among females (12.8%) than males (4.3%).²⁵

Researchers studying the long-term correlates of childhood maltreatment have shown an association with a variety of physical, emotional, social and cognitive impairments in later life^{26–28} – impairments which may result in increased health care costs and, most importantly, human suffering. This has led to an emphasis on early intervention and treatment both to assist survivors and to reduce demands on the health care system.²⁹ Child maltreatment is a serious population health problem, given that it affects almost one in three Canadian children, and its consequences early and later in life are often widespread and negative.

Due to its multidisciplinary nature and because it is possible for it to incorporate ideas from other perspectives, the PHP is useful in studying child maltreatment. The major contribution of PHP may be the holistic approach – the equitable consideration of both societal and personal factors. The determinants of health provide an opportunity to study child maltreatment across the whole spectrum from prevention through rehabilitation. For example, there is some evidence to suggest that persons who have knowledge of child development are less abusive.³⁰ Obtaining this knowledge is an individual responsibility, but it is also the obligation of society to provide the opportunity for learning.³¹

Determinants of health and outcomes of maltreatment

Health Canada’s interpretation of the determinants of health (Table 1) provides a framework for the following section. Outcomes of child maltreatment are considered at the individual level, and where data exists, at the community and societal level.

Few studies have discussed the *income* level of adults abused as children. Findings from a followup study of adults physically abused in childhood showed that many of the respondents had never been employed, “despite being in the so-called prime of their life”.³² The National Lesbian Health Care Survey (1985) (n = 1,925) found that the average income in adulthood of child

sexual abuse survivors was lower than non-abused women.³³ Furthermore, abuse victims may have additional costs associated with a need to feel safe.³⁴ Higher income allows a wider range of possibilities for rehabilitation; for example, it could provide the means for counselling or legal follow up. The moderating effects of income on consequences of maltreatment have not been investigated.³⁵ Since income is an important determinant of health, it merits further investigation. Decreased earning capacity for a substantial portion of a population has far-reaching effects on that population.

A strong *social support network* may be a protective factor for coping with abusive experiences. However, the social support system can also be an obstacle. Individuals within a social support network may focus on protecting the abuser instead of the abused. At the community and society levels, support of survivors after disclosure is needed, in the form of information and access to resources.

The experience of child maltreatment may create difficulties in developing social support networks. Abused children may have to establish new relationships in foster care or in institutions. This can be beneficial if a positive relationship with the new caregiver is developed. Some children, however, move from foster home to foster home,³⁶ this can present difficulties in creating and maintaining social networks. Further, abusive experiences as well as acculturation problems (especially for Aboriginal children and youth) have been reported.³⁷ As adults, intimate relationships are harder to form and maintain for the sexually abused³⁸ due to fear of rejection,³⁹ and divorce rates are higher.³⁸

Does *education* affect the outcomes of child maltreatment? Several studies have found that abuse is associated with negative outcomes in college-based studies as well as in population-based studies^{40–45} Are college students better able to cope with exposure to sexual abuse than persons in the general population?⁴⁶ Or are survivors with more adverse outcomes not attending college?⁴⁷ If it is true that survivors are less likely than the non-abused to attend col-

lege, then society loses in innovation and productivity

In one study, severely abused men were found to be more likely to be *unemployed* than those who had not experienced abuse.⁴⁸ However, there may be confounding factors, such as interpersonal problems or social isolation that may antedate the abuse or the outcome. As in the case with income, higher levels of unemployment decrease earning capacity and affect the health of the nation.

Exposure to child sexual abuse is associated with fear and anxiety in adulthood.⁴⁹ Any number of factors in the *physical environment*, for instance, place and circumstances of residence, may increase the anxiety level of survivors. These relationships need to be explored; research is needed to determine if the feeling of safety or fear in the physical environment varies after exposure to child maltreatment.

Intelligence, which is at least partly a *genetic endowment*, may affect the response to child maltreatment. Research suggests that intelligent children who have suffered exposure to maltreatment may have more effective coping skills. These children do better in school, which may create a sense of competence; this in turn influences self concept.⁵⁰ A positive school experience creates self worth and a sense of control, both important components of recovery.⁵¹

Some survivors turn to unhealthy *coping* mechanisms, such as alcohol, as a way of avoiding traumatic memories related to child abuse.⁵²⁻⁵³ Research indicates that resilient survivors have less tendency to blame themselves; they tend to minimize the impact, cognitively re-frame the experiences and refuse to dwell on them.⁵⁴ There is a danger in using the term “resilience” too loosely, however: it could lead to blaming the victim, implying that if people were just resilient enough they would survive adversity. It could be used as a reason for refusing assistance to people in need.⁵⁵

The *developmental* level of the child at the time of the abuse mediates the response to maltreatment. For instance, toddlers and preschoolers may exhibit behaviour problems, and have less ability to communicate

verbally. In middle childhood, exposure to maltreatment is associated with academic problems in addition to emotional and behavioural impairment, such as depressive symptoms and sleeping disturbance.^{26,49} However, studies into child abuse rarely distinguish between the time of exposure to the abuse and the response, nor do they control for pre-existing health status. The developmental stage of the child when s/he experiences abuse may also affect response to abuse as an adult.²⁶

Professionals in the *health and social services* sectors are uniquely positioned to identify and respond to abuse. It is important that such services be well equipped to provide assistance and referrals for support. When abuse goes unrecognized as it frequently does, the necessary services do not reach those exposed to maltreatment.⁵⁶ Detecting and reporting the abuse initiates the medical, social services and legal intervention that may prevent further harm to the child and begin rehabilitation. At the same time, it is important to underscore that detection alone does not necessarily lead to better outcomes, and may do more harm than good if it is not linked to services.

Gender mediates the response to child maltreatment. Evidence about the negative effects of child abuse on women is mounting. Fewer studies have been conducted on men. The risk of psychiatric disorder in adulthood after exposure to child maltreatment is greater for women than men.⁵² Differences between genders may be attributable to age at time of abuse and relationship to perpetrator.⁵⁷ Protective factors may be different for boys and girls who have been maltreated.⁵⁸ Gender and child maltreatment merits further investigation.

Limited research has been conducted on outcomes of child maltreatment across different *cultures*. However, in the abuse literature there has been some discussion regarding culture and healing; for instance “blaming the victim” attitudes may introduce barriers to healing.⁵⁹

In instances where the *social environment* conveys a sense of familiarity and comfort, it provides a safe place where individuals can address fears, desires, beliefs and feelings.⁶ An environment where abused per-

sons can feel safe is important. If foster homes and shelters do not exist, or do not meet the needs of the abused, the street may be the only solution to escaping an abusive home. Evidence suggests that many runaway and homeless children have been abused.⁶⁰

The PHP does not include the legal system as a determinant of health. Legislation is needed to deter child maltreatment and to assist victims after disclosure. The aim of the law is to protect and provide support to victims, and to punish and rehabilitate perpetrators. Child maltreatment involves both civil and criminal law. The focus of criminal law is punishment, while civil law focuses on protection (“best interest of the child”).⁶¹ Civil law also deals with claims for harm and suffering. In the civil law context, treatment of victim and perpetrator is considered humane.⁶¹ However, it may not be so straightforward. Is punishment of the abuser helpful to the victim? Is the victim further hurt if the perpetrator and provider go to jail, assuming that they are one and the same? Is there a stigma that outweighs the potential benefits of reporting? Does an abused person do better if s/he receives financial compensation? These are all questions that need to be considered in examining the outcomes of child maltreatment.

Dorne presents the following arguments from a criminal law perspective.⁶¹ The victim may not directly benefit from punishment of the perpetrator but society as a whole does. First, there is a symbolic value; second, the punishment may prove to be a deterrent to others; third, society is safer when the perpetrator is in prison; and last, retribution is achieved.⁶¹

Court proceedings are traumatic for victims of abuse, whose testimony under cross-examination may not be believed.⁶¹ However, there are some procedures now available to protect the child victim such as closed courtrooms, interviews by as few people as possible, and *in camera* testimony.

Availability of legal services is a population issue; services are expensive, and not within everyone’s reach, although some are provided free of charge to those on so-

cial assistance. A criminal justice system that provides public defenders would be consistent with the philosophy of PHP.

Further conceptual developments

The PHP is an evolving approach and some earlier criticisms have led to modifications. One of these changes is a shift to the increased use of qualitative approaches. Quantitative data with an implicit notion of “objectivity” used to be preferred.⁶² “Quantitative data allows us to estimate the magnitude and type of health issues in the population, and to identify health outcomes. Qualitative data add a richness and a depth to quantitative data that is necessary to understand why health problems occur in the population and what strategies are needed to address them”.¹ This is important in child maltreatment research since data and in-depth information must be gathered about underlying circumstances and children’s experiences. It is important to study what determines health but also to establish strategies by which the determinants can be influenced.³ A combination of approaches may be most useful.

The research on determinants of health has been criticized for concentrating on positivist methodologies. There is a risk that this methodology comes to represent “objective” knowledge rather than *one way of obtaining* knowledge. Theory (ideology) needs to be made explicit. Robertson states “...[the] argument is not to get the ideology out of science but to get the ideology out of hiding”.⁶³ There is a further risk that experiencing, for example, racism and poor housing is devalued by “objective” risk factors like heart disease and smoking.²

The CIAR model of population health has been criticized for simplifying complex phenomena by flowcharting them. A model substitute is created, instead of actually describing, theorizing and explaining.⁹ The notion of social structure is foreign to CIAR.³ How do the pieces in the model fit together?²⁰ In the writings of CIAR, wealth creation is championed even though the data suggest that it is inequality of distribution rather than lack of prosperity that is the problem.⁶² The PHP proponents have not educated the public adequately on the

impact of the health determinants outside the health care system. That is one of the reasons for lack of “political motivation or public appetite for developing an integrated policy framework dedicated to promoting just and equitable social relations”.⁶⁴

Other determinants

The list of determinants is still evolving. *Spirituality* could be identified as a component of the PHP. Health may have a spiritual dimension partly linked to social support. Religious advisors have been shown to have a supportive role.⁵⁵ Religious affiliation and church attendance have been identified as factors contributing to positive health outcomes.⁵⁵ The link between healthy outcomes and spirituality may also arise from optimism, hope and belief in the meaning of life.⁵⁵

Should *age* be considered a determinant of health? Age influences the risk and protective factors for different health problems. Physical health and functional ability decline with age; there is more stress and depression in the extremes of life – young and old.⁶⁵ Further, age is socially constructed when a person is judged based on assumptions related to age instead of abilities. Both young people and seniors may have this experience.⁶⁶

Technology has consequences for our health, in relation to accessibility and knowledge. Knowledge production in medical technology has increased the survival rate but has also created complex health needs.⁶⁷ In rural and socially disadvantaged areas, there may be problems in having access to medical technology.⁶⁷ *Politics* is another area often absent from lists of determinants of health.²³ For example, changes in population health status were related to mode of production in the transformation of the Soviet Union. In the *Ottawa Charter*, peace is discussed as influencing health.⁶⁸ These “new determinants” need to be investigated in relation to child maltreatment.

Conclusion

The PHP addresses a range of determinants of health at multiple levels that are relevant to maltreatment outcomes. The literature indicates that because child mal-

treatment is a significant health problem in terms of its human and economic costs, it is important to PHP. Clearly, those who have experienced maltreatment are at increased risk for a wide range of health problems.

However, as demonstrated in this paper, the child maltreatment field faces gaps in knowledge. There is a need for further investigation of child maltreatment from a PHP. Although the PHP generates testable predictions, the interactions among the determinants should be studied. Longitudinal and prospective research is especially needed. Focussed studies that examine smaller segments of the problem are essential as well, if survivors of maltreatment are to be assisted.

The social and economic determinants of health have demonstrated relevance to the health status of populations. Thus, PHP is useful in examining outcomes of child maltreatment at both the individual and societal level. Investment in the non-medical determinants, such as anti-poverty measures which may alleviate some parental stress, and support for healthy child development, which fosters healthy children, are important in reducing exposure to child maltreatment and promoting the health of the population.

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Perceptions of disease severity and barriers to self-care predict glycemic control in aboriginal persons with type 2 diabetes mellitus

Mark Daniel and Lynne C Messer

Abstract

The Health Belief Model (HBM) was evaluated for secondary prevention of type 2 diabetes mellitus in an Aboriginal population in British Columbia. Glycemic markers (glycated hemoglobin [HbA_{1c}]), insulin and post-load glucose), diabetes health beliefs (susceptibility, severity, benefits and barriers), knowledge and behaviour were measured for 16 men and 18 women with diabetes (age [SD] = 57.7 [11.6]). Eighteen months later, HbA_{1c} and behaviour were measured for all participants, and health beliefs obtained for 17 of them. Perceived severity and perceived barriers were related to glycemic status at baseline and follow up, and predicted reduction in HbA_{1c} (β [SE] \geq |0.40| [0.18], $p < 0.05$). The results support a therapeutic emphasis on belief in the severity of diabetes complications, and the complementary belief that barriers to therapeutic behaviour can be overcome in efforts to support Aboriginal persons with diabetes to manage their disease. The empirical utility of the HBM in glycemic control was partially upheld.

Key words: Aboriginal, North American; diabetes mellitus, type 2; glycemic control; health beliefs

Introduction

Diabetes mellitus, mostly type 2 diabetes mellitus, is a serious public health problem in the Canadian Aboriginal population.¹ Among First Nations and Inuit peoples, diabetes prevalence is 8% for men and 13% for women, corresponding to age-adjusted rates 3.6 and 5.3 times greater for Aboriginal men and women, respectively, than for their counterparts in the general Canadian population.²

Community-level strategies against diabetes attempt to screen for and prevent development of the disease amongst susceptible persons and the community in general.³ Prevention initiatives also try to help persons with diabetes to control hyperglycemia and limit the risk of macrovascular and microvascular complications. Behavioural therapy

is informed by an understanding of relations between effective treatment and health beliefs associated with having diabetes.⁴ For persons with type 1 diabetes, treatment compliance is positively associated with perceived benefit, emotional stability and supportive structure, and negatively related to perceived barriers and negative social environment.⁵

Effective control of type 2 diabetes requires behavioural compliance with diabetic regimens, which is difficult to predict and challenging to influence. The Health Belief Model (HBM)⁶ was initially developed to understand why people did not participate in disease detection programs^{7,8} but has since been used to explicate factors underlying patient compliance with treatment regimens for diseases, including diabetes.⁹ In its application to diabetes, the theoretical

utility of the HBM lies in its potential to inform more effective interventions for treatment adherence and improved glycemic control.¹⁰ Founded on the value-expectancy theories of social psychology, the HBM posits that individuals will be more likely to take healthful behavioural action if they desire to stay healthy and believe such action will effectively protect their health.^{9,11} The HBM posits further that positive behavioural action depends on convictions about the severity of the disease threat and the belief that barriers to the execution of therapeutic behaviour can be surmounted.¹²

The utility of the HBM in accounting for health behaviour has been examined in studies ranging from acceptance of preventive health recommendations^{7,8} to adherence to treatments for acute and chronic illness.^{13,14} While positive health beliefs are linked to patient compliance for chronic diseases, including diabetes, barrier perceptions are most strongly, and severity perceptions are most weakly, related to positive health behaviour.¹⁴⁻¹⁹ A meta-analysis of the HBM's consistency of validation found the evidence to be lacking, however, in its overall utility for predicting behaviour change.²⁰ Conceding that some behavioural research upheld a simplistic cognitive emphasis on changing attitudes or beliefs in isolation from the contexts in which they occur,²¹ it can also be challenging to assess behaviours with sufficient sensitivity to link them to specific health beliefs,²² especially in ethnically distinct and disadvantaged populations.

Author References

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Studies applying the HBM to diabetes have relied largely on self-reported data in focusing on relationships between health beliefs and behavioural compliance with prescribed treatment regimens. Early research on diabetes tended to target beliefs in relation to behaviour alone, but a growing pool of studies has targeted relationships between health beliefs and behaviour as well as glycemic control in the same individuals.^{10,23} Such studies are important in assessing the utility of the HBM in relating health beliefs to indicators of glycemic control, yet the evidence would suggest the model explains behavioural compliance better than glycemic control.^{10,23,24} Few studies, however, have examined the capacity of the HBM in longitudinal prediction of glycemic control while allowing for the potential influence of behaviour on such relations.²⁵ We undertook such an analysis in a sample of Aboriginal Canadians from a population at high risk for diabetes and its complications, and this is the report of the results. Research on health beliefs and glycemic control in Aboriginal people has not yet been published. The hypotheses tested were that in a cohort of individuals with diabetes: (a) health beliefs would be related to glycemic outcomes at baseline screening and a followup survey 18 months later; and (b) health beliefs would predict improved glycemic control at follow up.

Methods

Population and setting

Data analyzed in this report are from a diabetes screening program implemented among on-reserve “registered” Indians in British Columbia’s rural Okanagan region. Persons indigenous to this area are of the Interior Salishan linguistic group and the Plateau area culture. Registered Indians in this area are of limited educational attainment and low socio-economic status relative to the general population.²⁶ Of adults age 15–49, 50% have completed secondary school, and of adults age 50–64, 40% have completed grades 1–8. Of the total adult population 44% are employed, 16% are unemployed, and 40% are not involved in the labour force.

Participant selection and measurement protocol

Participants were volunteers for a community-based diabetes diagnostic and risk factor screening initiative. Pregnant women and minors under 18 years of age were excluded from screening. The study received ethical approval from the University of British Columbia Behavioural Sciences Screening Committee, and all participants provided their informed consent. Of the eligible adult population, the study participation rate was 57% ($n = 202$). The main reason for non-participation was lack of interest. Male gender and age less than 30 years were the primary correlates of non-participation. Tests were done in meeting halls between 7:30 a.m. and 12:00 noon. World Health Organisation criteria²⁷ were applied to classify individuals as normoglycemic ($n = 155$), having impaired glucose tolerance (IGT) ($n = 10$), or having diabetes ($n = 37$).²⁸

This paper reports on relations among persons with diabetes only, as established at the study baseline. Of 37 individuals identified as having diabetes, 34 agreed to provide data on health beliefs. Seventeen of these persons were verified as having existing diabetes (self-reported, median duration of 3.2 years), with the rest being newly diagnosed cases of diabetes. All persons with diabetes were referred for education and management to local medical practitioners and to a diabetes day program at a regional hospital an hour’s drive away. Eighteen months after the baseline survey, HbA_{1c} was obtained for all 34 individuals and health beliefs obtained for 17 of them. Persons for whom follow-up data were available all complied in keeping referrals to medical practitioners and biannual visits to the diabetes day program.

Blood samples and analytic methodology

For screening purposes, participants gave a venous sample after fasting overnight. Concentrations were determined from these samples for glycated hemoglobin A_{1c} (HbA_{1c}) and insulin. Post-load glucose levels were determined from blood drawn two hours after consumption of a 75-g glucose load.

HbA_{1c}, insulin and two-hour glucose concentrations were determined at baseline, but HbA_{1c} alone was re-measured 18 months later.

Whole blood specimens collected in ethylenediamine-tetra-acetate (EDTA) anticoagulant were used to determine HbA_{1c}. Analyses for insulin and two-hour glucose were performed on serum specimens. Specimens were transported at 4° C for analysis at a regional laboratory on the day of collection. Insulin concentration was measured using microparticle enzyme immunoassay kits. Percent HbA_{1c} was determined using ion capture assay kits. Two-hour blood glucose concentration was assessed using enzymatically linked assay kits. Intra- and inter-assay coefficients of variation were, respectively: insulin, 3.8% and 4.2%; HbA_{1c}, 4.4% and 4.6%; and two-hr glucose, 1.2% and 1.8%.

Anthropometric measurements

Participants wore light clothing, with footwear removed. Weight and height were assessed using a beam balance and stadiometer. Body mass index (BMI) (weight [kg] / height [m²]) was calculated.

Diabetes knowledge and behaviours

Knowledge and behaviours were measured at both baseline and follow up. *Knowledge of diabetes* was assessed as the number of correct responses to 13 questions on diabetes risk factors, symptoms and complications. The two-week test-retest stability for responses was high ($r = 0.89$). *Physical activity* was assessed using the Pima Indian physical activity scale²⁹ to obtain metabolic equivalent [MET] hours of occupational and leisure-time physical activity for the month preceding measurement. For Pima Indians, correlations for test-retest stability (over two weeks) are 0.62–0.96. *Dietary behaviour* was determined using self-completed records for food and drink consumed over three consecutive days (including one weekend day). The reliability of three-day food records is well established.³⁰ Follow up interviews resolved imprecise entries. Nutrient intakes were computed using a nutrient

database/software system for Canadian nutrition surveys.³¹ Energy intake (in kilocalories) and the relative quantity of protein, lipid, and carbohydrate consumed (g/100 kcal) were determined.

Diabetes health beliefs

Beliefs about diabetes were assessed at six weeks after baseline testing and at follow up using the 16-item Health Belief Model Diabetes Scale³²⁻³⁵ (Appendix). This instrument surveys four domains of perceived beliefs relevant to having diabetes: (a) susceptibility to diabetes complications; (b) severity of diabetes complications; (c) benefits of diabetes control; and (d) barriers to executing therapeutic behaviours. Responses were scored on a five-point Likert scale. The construct validity of the scale has been established, and concurrent and predictive validity estimates uphold its criterion validity.^{33,34} The instrument was pre-tested with 10 persons with IGT, for whom test-retest stability, *r*, for subscales after three weeks ranged from 0.67–0.73. Cronbach's α for subscales, based on the 34 persons with diabetes, ranged from 0.69–0.82. The questionnaire required 15 minutes to complete.

Statistical analysis

The hypotheses that diabetes beliefs about susceptibility, severity, benefits and barriers are related to HbA_{1c}, insulin and two-hour glucose concentrations were tested using linear regression models with adjustments for age and gender. Separate models were analyzed for each of the four diabetes beliefs. The linearity of dependence relationships was established by evaluating plots of residuals. Standardized beta coefficients are reported. *P*-values less than 0.05 are considered to be statistically significant. STATA (6.0) software was used for analyses.

Diabetes knowledge, behaviour and BMI, at baseline and follow up, were included separately and together in preliminary analyses, to assess their effect together with diabetes beliefs on glycemic outcomes. Behaviours were not related to beliefs, and in no case was any *association* between beliefs and glycemic status influenced by behaviour, nor was any behaviour related

to any glycemic measure in models including beliefs. For example, in assessing relations between perceived severity at baseline and 18-month change in HbA_{1c}, the inclusion in models of behaviours measured at follow up, with or without BMI, yielded results in keeping with models omitting behavioural variables altogether. In all such preliminary analyses the relationship between perceived severity and change in HbA_{1c} stayed significant, with the strength of the association (β [SE]) ranging from 0.39 (0.18) (when specified with knowledge) to 0.50 (0.22) (when specified with carbohydrate intake). In such models, β (SE) for BMI ranged from -0.25 (0.21) to -0.18 (0.18) (*i.e.*, BMI was negatively related, but not significantly so, to healthful change in HbA_{1c}). Furthermore, in no case was any behaviour related to change in HbA_{1c}. For behaviours, β (SE) ranged from 0.03

(0.21) for knowledge to 0.31 (0.24) for protein intake. Given a consistent lack of any *measurable* effect of behaviour, to conserve statistical power, final models did not include knowledge, BMI or any behaviour, and focused solely on beliefs and glycemic outcomes.

Results

Descriptive characteristics at baseline for the persons surveyed are given in Table 1. There were no significant differences between men and women for age, BMI, HbA_{1c}, insulin, or years of schooling. Diabetes beliefs did not differ between the genders (Table 2). Correlations between diabetes beliefs are given in Table 3. Knowledge of diabetes and behaviours did not differ by gender at baseline or follow up, and there were no significant changes in behaviours, nor

TABLE 1
Characteristics at baseline of Aboriginal persons with type 2 diabetes

	Men (n = 16)		Women (n = 18)		Pooled (n = 34)	
	Mean (standard deviation)					
Age (years)	59.6	(17.4)	56.2	(15.5)	57.7	(11.6)
Body mass index (kg/m ²)	29.1	(8.5)	32.4	(7.6)	30.9	(5.7)
Glycated hemoglobin (%)	7.5	(3.0)	7.3	(2.0)	7.4	(1.7)
Insulin (pmol/L)	144.1	(33.2)	117.1	(44.4)	134.6	(26.6)
Years schooling (%): 1–5	6.3	(6.1)	5.6	(5.4)	5.9	(4.0)
6–9	43.7	(12.4)	44.4	(11.7)	44.1	(8.4)
9–12	50.0	(12.5)	50.0	(11.8)	50.0	(8.6)

TABLE 2
Baseline diabetes health beliefs for Aboriginal persons with type 2 diabetes

	Men (n = 16)		Women (n = 18)		Pooled (n = 34)	
	Mean (standard deviation)					
Beliefs-susceptibility (20-pt) (high score = high susceptibility)	7.5	(2.4)	9.1	(2.1)	8.4	(1.6)
Beliefs-severity (20-pt) (high score = high severity)	10.3	(2.9)	10.5	(2.6)	10.4	(1.9)
Beliefs-benefits (20-pt) (high score = high benefits)	9.4	(2.1)	8.7	(1.9)	9.0	(1.4)
Beliefs-barriers (20-pt) (high score = high barriers)	6.7	(3.9)	7.0	(3.5)	6.9	(2.6)

TABLE 3
Correlations between diabetes health belief constructs for Aboriginal persons with type 2 diabetes ($n = 34$)

	Susceptibility	Severity	Benefits	Barriers
Susceptibility	1.00	–	–	–
Severity	0.16	1.00	–	–
Benefits	0.50	0.43	1.00	–
Barriers	-0.31	-0.28	-0.12	1.00

TABLE 4
Knowledge and behaviours for Aboriginal persons with type 2 diabetes at baseline and 18-month follow up ($n = 34$)

	Baseline		Follow up		P-value (t-test)
	Mean (standard deviation)				
Knowledge-diabetes (13-pt) ^a	8.4	(3.6)	9.2	(2.9)	0.07
Physical activity (MET-h/wk) ^b	11.0	(6.9)	8.5	(7.4)	0.27
Carbohydrate (g/100 kcal) ^c	12.0	(14.4)	12.5	(14.6)	0.86
Protein (g/100 kcal) ^c	5.1	(5.6)	4.5	(3.8)	0.47
Lipid (g/100 kcal) ^c	3.6	(5.1)	3.6	(4.7)	0.91
Energy (over 3 days) (kcal)	4506	(1363)	4529	(1648)	0.93
Alcohol (drinks per week)	1.1	(2.9)	1.3	(3.1)	0.52

^a High score = high knowledge

^b Leisure time and occupational physical activity, as metabolic equivalent (MET) hours per week

^c Grams constituent intake per 100 kcal total energy intake, over three consecutive days

TABLE 5
Diabetes health beliefs at baseline and 18 months follow-up in relation to glycemic outcomes and change in glucose control (HbA_{1c}) in Aboriginal persons with type 2 diabetes^a

Outcome ^b	n	Susceptibility	Severity	Benefits	Barriers
Baseline					
Insulin _{t1}	34	-0.03 (0.18)	-0.36 (0.17)*	0.08 (0.19)	0.33 (0.16)*
2-h Glucose _{t1}	34	0.42 (0.27)	0.44 (0.26)	-0.62 (0.23)*	0.04 (0.32)
HbA _{1c} _{t1}	34	-0.10 (0.18)	0.09 (0.18)	-0.04 (0.19)	0.01 (0.19)
ΔHbA _{1c} _{t1-t2}	34	-0.08 (0.20)	0.40 (0.18)*	0.29 (0.19)	-0.21 (0.19)
Follow up					
HbA _{1c} _{t2}	17	0.20 (0.28)	-0.52 (0.23)*	-0.30 (0.26)	0.88 (0.19)**
ΔHbA _{1c} _{t1-t2}	17	-0.43 (0.24)	0.48 (0.22)*	0.03 (0.26)	-0.63 (0.24)*

^a Standardized beta coefficients (and standard errors), controlled for age and gender.

^b Glycemic outcomes: *t1* indicates measured at baseline, *t2* indicates measured at 18 months follow-up, and Δ indicates change score between baseline and follow-up (*t1* – *t2*).

* $p < 0.05$, ** $p < 0.001$.

HbA_{1c} or BMI, between baseline and follow up (Table 4). Knowledge and behaviours were not related to beliefs or glycemic measures.

After 18 months of following up the 34 individuals classified at baseline as having diabetes, 16 were managing the disease by diet alone, 16 were managing by diet and medication with oral hypoglycemic agents, and two were managing by diet and insulin therapy. Management strategy and existing versus newly diagnosed diabetes were not associated with HbA_{1c} at baseline or follow up. Diabetes beliefs at follow up for 17 persons who provided such data, were not related to treatment strategy or existing versus newly diagnosed diabetes. The distribution of gender and age did not differ between persons participating in both surveys and those participating at baseline only.

Baseline health beliefs and baseline glycemic measures

Diabetes health beliefs were not associated with HbA_{1c} concentration at baseline (Table 5). Insulin concentration was inversely associated with perceived severity ($p = 0.042$) and positively associated with perceived barriers ($p = 0.05$). Hence low insulin concentration was related to high perceived severity of complications and low perception of barriers to therapeutic behaviours. High perceived benefit to complying with a diabetic regimen was related to low two-hour glucose level ($p = 0.012$). Perceived susceptibility to complications was unrelated to any glycemic measure.

Baseline health beliefs and change in HbA_{1c}

Perceived severity of consequences of uncontrolled diabetes at baseline was positively related (Table 5) to positive change in HbA_{1c} concentration ($p = 0.036$) over the 18 months of follow up, and thus predicted reduction of HbA_{1c}. Perceived susceptibility, perceived benefits and perceived barriers at baseline were not significantly associated with change in HbA_{1c}.

Health beliefs at follow up and HbA_{1c} at follow up

HbA_{1c} concentration was inversely associated at follow up with perceived severity of complications ($p=0.037$), and positively related to perceived barriers ($p=0.0004$) to therapeutic behaviours (Table 5). Greater perceived severity and low perceived barriers were thus associated with healthful HbA_{1c}. Perceived susceptibility and perceived benefits were not related to HbA_{1c} concentration at follow up.

Follow up health beliefs and change in HbA_{1c}

Perceived severity of diabetes complications at follow up was positively associated with positive, or healthful, change in HbA_{1c} concentration between baseline and follow up (Table 5). Similarly, low perceived barriers to upholding therapeutic behaviours was associated with healthful reduction in HbA_{1c} between baseline and follow up. Perceived susceptibility and perceived benefits at follow up were not related to change in HbA_{1c} concentration.

Discussion

In this sample of Aboriginal people with type 2 diabetes, neither diabetes health beliefs nor HbA_{1c} concentration changed at the group level between baseline and a follow up survey conducted 18 months later. All participants were referred to and followed through in consulting local medical practitioners for treatment of diabetes, in addition to participating in a diabetes education program at a regional hospital. This report aimed not to evaluate treatment strategies or patient compliance with them, but to assess diabetes health beliefs at both points in time and to determine their relations to glycemic outcomes. Despite no relation at baseline between diabetes beliefs and HbA_{1c}, baseline perceptions of the severity of diabetes predicted reduced HbA_{1c} at the follow up survey. At follow up, high perceived severity of diabetes and low perceived barriers to therapeutic behaviours were related to healthful HbA_{1c} concentration as well as reductions in HbA_{1c}. Such results indicate that individual beliefs about barriers related to control and sever-

ity of complications are important factors influencing the ability of Aboriginal people with diabetes to achieve control of blood glucose.

Of further importance is the evident utility of extending the HBM from its original purpose to predict health-related behaviour from health beliefs, to directly predicting physiological outcomes. Restricting use of the HBM to planning and assessing behaviour change strategies in diabetes could short change health professionals and clients alike, as the model is of modest utility in this task.^{10,23-25} It is noteworthy that controlling for behaviour at baseline and follow up in estimating relationships between diabetes beliefs and glycemic measures *at each time*, and controlling for behaviour at follow up in estimating relations between beliefs and *change* in glycemic control, was associated with either no change or minor attenuation only of model coefficients. This does not necessarily mean, however, that behaviour did not influence the positive results observed. Despite the lack of relationship found between any behaviour and belief or glycemic outcome, it is possible that behaviours, unlike HbA_{1c} and perceived beliefs, were not measured with sensitivity sufficient to implicate their mediation of the link between diabetes health beliefs and glycemic outcomes.

The consistent relation found between perceived severity and glycemic control in this study is an important finding, and is supported by earlier research indicating that perceived severity is the component of the HBM most strongly related to behavioural compliance.³⁶ Nevertheless, while a link between high perceived severity and healthful HbA_{1c} has been reported before,¹⁹ most studies indicate that high perceived severity is related to poor glycemic control.^{10,37} Some of the discrepancy in these findings could reflect those studies linking poor glycemic control to high perceived severity being of a cross-sectional rather than longitudinal design, as well as their focus on persons with long established diabetes (five years or more). The duration of diabetes cases may influence such findings. In the present study, newly diagnosed cases were surveyed on diabetes beliefs six weeks after diagnosis, and the median du-

ration of diabetes among established cases was 3.2 years at the time of the survey.

A relation between perceived severity and HbA_{1c} could be framed in terms of the “perceived threat” (of diabetes complications) reflecting the consequence of initial perceptions about severity, followed by perceptions of susceptibility.⁶ Thus, a heightened state of perceived severity could be required before perceived susceptibility might predict glycemic control. That susceptibility was not related to glycemic outcomes in this study suggests many persons surveyed were in the process of adjusting to diabetes. One might expect susceptibility to increase, and severity to decrease, given further experience with diabetes. Longitudinal research is necessary to clarify whether the inverse relation between perceived severity and HbA_{1c} reverses over time, and whether susceptibility mediates such a change. At this time, the role of perceived susceptibility in diabetes management is inconsistent.³⁶

The second component of the HBM explaining positive glycemic control in this analysis, consistent with other reports,^{6,10,19,37} was perceived barriers at follow up. Baseline perceived barriers were positively related to insulin concentration. Underlying the HBM is an assumption that the value one places on health influences his or her health-seeking behaviour.^{10,38} This premise presupposes freedom to pursue health-oriented behaviour. Aboriginal peoples face obstacles to improving health, including educational, economic and power disparities.² Conceding various challenges of daily living for Aboriginal populations, both subjective (perceived) and objective (structural) barriers to health-related activity must be addressed by clinical and community level initiatives to predispose, enable and reinforce health-related behaviour and reduce risk of developing diabetes and its complications.³

A combination of the perceived benefits and perceived barriers components of the HBM is believed to provide “direction” for motivated health actions.⁹ Thus, understanding the nature of the barriers faced by Aboriginal people may shed light on why the perceived benefits component of the scale did not predict glycemic outcomes. It

could be difficult, perhaps, for Aboriginal people to be impressed by the potential benefits of glycemic control, given the more immediate hardships they face on a daily basis. That two-hour glucose concentration was associated with perceived benefits at baseline is supported by other research documenting an association between perceived benefits and behavioural compliance in self-management of diabetes.³⁷ The physiological response to a diagnostic glucose load given by two-hour glucose concentration is in large part a function of risk behaviours linked to the development of diabetes, embedded as they are in lifestyle.³

The hypotheses evaluated by this study were only partly upheld. The four HBM component beliefs were not consistently related to glycemic outcomes. Perceived severity and perceived barriers were the best predictors of glycemic status. Perceived benefits was related to insulin concentration but not glucose control *per se* (i.e., HbA_{1c} concentration), and perceived susceptibility was not related to any glycemic outcome. This modest empirical confirmation of the model is consistent with the balance of the literature on the capacity of the HBM in diabetes control and management.³⁶ While this in itself may be a reasonable conclusion, there are additional aspects of this application of the HBM that merit appraisal, including its applicability to the Aboriginal population surveyed. It may be that the predictive value of the HBM is limited for populations facing extensive socio-structural barriers to health action, where non-attitudinal factors inhibit those beliefs, or the effects of such beliefs, that in more advantaged populations might relate better to health outcomes. One might also question how much the Health Belief Model Diabetes Scale, in terms of perceptions of susceptibility to diabetes complications and benefits of effective control, captured salient beliefs held by the Aboriginal population surveyed.³⁹

Limitations

The primary limitation of this study is its small sample size and the consequence of this on statistical power. It seems unlikely, though, that low statistical power was

a factor influencing the limited effect of perceived benefit and a lack of effect of perceived susceptibility on glycemic outcomes. Standard errors for the standardized beta coefficients for these two components of the Health Beliefs Model Diabetes scale are stable relative to those for other components of the model, and beta coefficients are close to zero. Low statistical power also precluded performing multivariate analyses including all four diabetes belief constructs in the same model at the same time (each construct was tested alone).

The small sample size also limits the generalizability of the study results to populations. As noted, however, empirical research on health beliefs and glycemic control in Aboriginal people with diabetes has not been published, and a longitudinal analysis, however small, is arguably a worthwhile contribution to the literature on diabetes in this disadvantaged and under-researched population.

A third matter is the cultural appropriateness of the Health Belief Model Diabetes Scale. The scale appears to have some utility for the population reported on here, as evidenced by the reliability of the instrument sub-scales. Wider use of the scale in other Aboriginal populations would benefit from further psychometric evaluation to see how accurately it captures the constructs it purports to tap. Scales assessing diabetes health beliefs may be population specific in their applicability.^{38,40}

Practice Implications

Recommended strategies for secondary prevention of type 2 diabetes include individualized, patient-centred strategies drawing on physicians, diabetes educators and other health personnel.⁴¹ High-risk populations may also benefit from community-based initiatives to support individual interventions to control diabetes.^{3,42} Advocated aggressive diabetes treatment strategies (e.g., low saturated fat diet, regular activity and medication use) are complex, however, and Aboriginal people with diabetes can experience difficulty in interactions with non-Aboriginal health professionals with different values.⁴³

The results of this study support a therapeutic emphasis on belief in the severity of diabetes complications and a companion belief that barriers to therapeutic behaviour can be surmounted in efforts to support people with diabetes to manage their disease. The utility of beliefs in the benefits of diabetes control, and susceptibility to complications, was not upheld. But it may be reasonable not to entirely preclude attention to such perceptions. The manner by which an emphasis on perceptions is effected is likely to be key. This is because the value placed on respect for autonomy in Aboriginal culture contra-indicates attempts to influence the autonomy of others, and Aboriginal people may regard western, didactic education as interference, interruption of lifestyle, or invasion of privacy.⁴⁴

Aboriginal understandings about diabetes do not simply reflect health education rhetoric or the teachings of biomedical practitioners, which are largely ahistorical, framed at the individual level, and fail to explain the rapid emergence in the 20th century of diabetes among Aboriginal populations with little earlier experience with the disease.^{45,46} Cultural convictions about the nature of the illness experience dictate Aboriginal responses more than beliefs about the disease *diabetes*.⁴⁷ Negotiating a shared understanding of diabetes process and control between Aboriginal people and western health practitioners has proved important in diabetes education, treatment and community intervention.⁴⁸

Conclusion

Diabetes beliefs are amenable to change through health education,²⁵ and this analysis in Aboriginal people has illustrated empirical relations between glycemic outcomes and perceptions about having diabetes. Little research has reported on cognitive factors influencing diabetes control in Aboriginal persons.⁴⁹ The majority of studies on beliefs, behaviour and diabetes have been cross-sectional. The primary recommendation arising from this longitudinal study is for culturally sensitive education of Aboriginal people emphasizing the severity of diabetes complications and beliefs about overcoming perceived barriers to diabetes

control. Further research on diabetes beliefs, behaviour and glycemic control is required to better control the growing epidemic of diabetes in Aboriginal populations.

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APPENDIX

Health Belief Model Diabetes Scale

All questions are scored on a five-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). Higher scores (agreement) correspond to positive beliefs, other than as noted.

Susceptibility:

- 1) Diabetes can be a serious disease if you don't control it.
- 2) My diabetes would be worse if I did nothing about it.
- 3) I believe that my diet, exercise or medications will prevent diabetes complications.
- 4) My diabetes is well controlled.

Severity:

- 1) My diabetes is no problem to me as long as I feel all right.^a
- 2) My diabetes will have a bad effect on my future health.
- 3) My diabetes will cause me to be sick a lot.
- 4) I believe I will always need my diabetes diet, exercise or medications.

Benefits:

- 1) I believe I can control my diabetes.
- 2) I believe that my diet, exercise or medications will control my diabetes.
- 3) If I change my eating and exercise habits it will probably help me.
- 4) My diabetes diet, exercise or medications will help me feel better.

Barriers:

- 1) I would have to change too many habits to follow my diet, exercise or medication regime.^b
- 2) It is difficult following the diet prescribed for me.^b
- 3) I cannot understand what I've been told about my diet.^b
- 4) Exercising and/or taking my medication interferes with my normal daily activities.^b

^a Reverse scored so that disagreement indicates positive belief;

^b Lower scores indicate positive belief, but not reverse scored, hence higher scores correspond to higher perceived barriers

Do hospital E-codes consistently capture suicidal behaviour?

Anne E Rhodes, Paul S Links, David L Streiner, Ian Dawe, Dan Cass and Samantha Janes

Abstract

Hospital separation data are used to study suicidal behaviour; however, there is little information about the appropriateness of these data for research and planning activities. The study purpose is to examine how consistently hospital separation E-code data reflect suicidal behaviours. Expert clinicians reviewed medical records of individuals who had a separation for self-poisoning to determine whether the self-poisoning was deliberate. Agreement among clinicians was evaluated and latent class analysis performed to derive a summary estimate of the prevalence of deliberate self-poisoning. This estimate was then compared to the prevalence of deliberate self-poisoning based on the external cause of injury (E-codes). Clinicians estimated the prevalence to be 63% higher than the E-code-based prevalence. Much larger discrepancies were apparent among older age groups, those whose care was primarily medical in nature and those with a longer length of hospital stay. In acute care settings, self-poisonings among the elderly may not receive adequate attention and/or documentation. Estimating the prevalence of admissions for suicidal behaviour using hospital separation data is of questionable validity, particularly among older age groups.

Key words: hospitalization; poisoning reproducibility of results; suicide, attempted

Introduction

Suicidal behaviours are a serious public health problem contributing to morbidity, lost productivity, health care costs and premature mortality.¹⁻⁴ The impact on significant others can be devastating. In the year after an attempted suicide, 10–15% of individuals will make a repeat attempt and 1% will die. Within 10 years, about 3–10% will die by suicide. Continuous, population-based monitoring of suicidal behaviours, however, is rare.⁵ Nevertheless, hospital separation data are collected systematically in many countries and contain information about whether an injury is self-inflicted, characteristics of the method, and whether

the person died during the hospital stay. A number of countries have used these data for descriptive and analytic studies of suicidal behaviours: *the United States*,⁶⁻⁸ *Canada*,^{1,9,10} *New Zealand*,¹¹ *Australia*^{12,13} and *the United Kingdom*.¹⁴⁻¹⁹ At issue is the paucity of information on the appropriateness of these data for population-based research and planning activities. The purpose of this study is to examine how consistently hospital separation data reflect suicidal behaviour within a universally insured Canadian setting.

Some jurisdictions report that suicidal behaviours are one of the most common causes of acute care admissions,¹⁶ particu-

larly among adolescents.²⁰ Mean annual prevalence estimates for these admissions range from 61 per 100,000 in the United States⁶ to approximately 200 per 100,000 in the United Kingdom.¹⁶⁻¹⁸ Over 90% of these admissions are self-poisonings as opposed to injuries.^{12,16}

Although wide variations in admitting practices occur in relation to suicidal behaviour,^{16,21,22} hospital admission predicts future suicidal behaviour. Repetition often occurs within the first few months.²³ Within a year, approximately 10% will be readmitted after another attempt.^{16,19} Deaths from all causes are elevated in this group. Mortality rates are about 2–4 times higher than in the general population.^{8,9,19,20,23} The time spent in hospital and the post-discharge period, therefore, offer an opportunity to intervene and prevent further morbidity and mortality.

Hospital separations connected to deliberate self-harm are identified by the presence of an external cause of injury or poisoning code, an “E-code”, according to the International Classification of Disease system (ICD). E-codes designate whether the injury or poisoning was “accidental”, “deliberate” or “cause undetermined”. Because of the sensitive, stigmatizing nature of suicidal behaviours and lack of knowledge about how to best treat these individuals, recording and practice patterns may vary.^{24,25} E-codes are identified as “supplemental” within ICD-9 and their application is not mandatory in all settings.²⁶ In the United States, only about half of the states rou-

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tinely collect E-coded hospital discharge data.⁶ Financial disincentives may be a reason if E-codes are not reimbursable.^{27,28} If payment for treatment is tied to psychiatric or medical diagnoses where established guidelines exist, there would be little incentive to implement E-coding. In managed care settings, patients and providers may be reluctant to report/record these behaviours due to a possible loss of insurance benefits.⁶ Payment for admissions for suicidal behaviour have been disallowed retrospectively by managed care organizations.²⁹

In one study, conducted in Oxford, England, only 20% of 500 known cases of deliberate self-poisoning among 10–20-year-olds were captured as deliberate in the corresponding hospital separation records.³⁰ In contrast, in a study of adult subscribers to a health maintenance organization in California, chart reviews confirmed that 86% of hospitalizations assigned “deliberate” E-codes were suicide attempts.⁸ The potential for misclassification by relying on “deliberate” E-codes has been acknowledged and definitions of suicidal behaviour expanded by including “accidental” self-poisonings related to medications (E-codes: 850–859) and/or “undetermined” (E-codes 980–989).^{15,16,18}

Widespread acceptance and application of these data for the purposes of monitoring the burden of suicidal behaviours and the effectiveness of interventions in reducing these behaviours within populations would seem to be premature and potentially harmful. For instance, if there is sizable under-reporting of these behaviours and/or systematic biases about who is affected, relying on these methods could lead to an inappropriate allocation of resources. On the other hand, the level of error in the data may be reasonable for some populations and could be an underutilized valuable resource. As more evidence comes in about beneficial treatments, and standards of practice are solidified, hospitals and/or communities might be able to use hospital separation data for quality assurance purposes. Those involved in the production and utilization of these data for research and planning purposes have a shared responsibility to the public to insure the data are managed and interpreted appropriately.

Materials and methods

Study setting and sample

The setting for this study was an urban, teaching hospital that specializes in the care of trauma patients in a large Canadian city. In Canada, when a person is discharged from hospital, trained hospital personnel review the medical record for the index admission and assign discharge diagnoses according to standardized coding practices. There are 16 potential diagnostic fields. Whenever a principal or “N-code” diagnosis of self-poisoning or injury is present, an E-code must be applied.³¹ As hospital-based care in Canada is fully covered under provincial health insurance plans, financial disincentives in applying E-codes are less likely. In the study hospital, emergency and psychiatric staff are regularly exposed to persons who are admitted to hospital after a suicide attempt. Accordingly, this setting was chosen to represent a best-case scenario. Our reasoning was that if the data were inconsistently applied in this setting, then the problem is probably as likely or more prevalent elsewhere in Canada.

This study received ethical approval from the Research Ethics Board of the participating hospital. In the fiscal year 1998/1999, there were 274 initial hospital separations for individuals that included a diagnosis of self-poisoning (ICD-9-CM 969–989) in at least one of the diagnostic fields. Most (89%) were poisonings by drugs, medicinal and biological substances. One hundred and four (38%) had self-inflicted injury codes assigned (E950–E959), and 21 (7.7%) had undetermined codes (E980–E989). For the purposes of this study, we selected a random sample of 181 separations from the original 274 (66.1%).

Study measures and procedures

In order to examine how consistently hospital separation data reflect deliberate self-poisonings, a definitive method is desired for comparison purposes. Regrettably, there is little consensus in the literature about how to define suicidal behaviours, and definitions vary across research studies.^{32–34} Even when definitions are provided, often little or no information is given about who made the decisions and the reliability of

the decisions made.³⁵ In the absence of a definitive method, we derived a best estimate of deliberate self-poisoning based on expert clinical judgement and latent class analyses (LCA). Latent class analysis answers the questions, “What would the diagnostic accuracy of the raters and the probability of deliberate self-poisoning need to be to produce the patterns of agreement and disagreement observed?”³⁶

To estimate the presence or absence of a latent class three or more ratings are necessary.³⁷ Accordingly, we conducted an inter-rater reliability study among three well trained physicians in emergency psychiatry and emergency medicine to estimate the latent class of deliberate self-poisoning. For each of the index admissions, the chart was copied and blinded in terms of identifying information and hospital separation codes by a research assistant. The blinded copies were then distributed to the physicians. The physicians examined each of the medical records for the stay in question, including records from the emergency department, and independently rated whether they believed the self-poisoning was deliberate or not. They then returned the materials to the research assistant for data entry.

We also abstracted data often used in research and planning, readily available and reasonably accurate: age, sex and the length of hospital stay (LOS). To differentiate between those whose care was primarily medical in nature as opposed to psychiatric, we identified whether the most responsible physician was a psychiatrist and whether the most responsible diagnosis corresponded to an ICD-9 mental disorder (codes: 290–319).^{38–41}

Statistical analyses

Sample characteristics

To examine whether the proportion of the select subject characteristics in our sample of 181 differed from the original 274, we conducted Chi Square tests. This analysis was repeated to determine whether subjects assigned a self-inflicted injury E-codes ($n = 66$) differed from those who were not ($n = 115$).

Ratings between physicians

The level of agreement between each physician pair was assessed according to the percent agreement, Kappa statistic and corresponding 95% confidence intervals. Kappa statistics were interpreted in relation to the guidelines of Landis & Koch.⁴² Using a maximum likelihood method⁴³ we estimated the following parameters and corresponding standard errors: the prevalence of the latent class of deliberate self-poisoning, and the false positive and the false negative rates of each physician overall.

Consistency in the prevalence estimates of deliberate self-poisoning

The proportions of deliberate self-poisoning (self-inflicted E-code vs. LCA) were compared overall and according to select sample characteristics. 95% confidence intervals around these estimates were calculated and overlap assessed.⁴⁴

Results

Sample characteristics

The sample of 181 did not differ from the group of 274 in terms of the subject characteristics (Table 1) or the proportion who died during their hospital stay (9%). The sample subjects tended to be middle-aged (mean age 49.4 years; SD ± 19.6). The diagnoses most responsible for the length of hospital stay (in the first diagnostic field) were typically medical in nature. Physicians most responsible for the care given during these hospital stays were usually not psychiatrists (82%). The mean length of stay (LOS) varied widely (mean LOS 16.6 days; SD ± 46.4). Approximately 25% of subjects had stays of two days or less; 50% with five days or less, and 75% 10 days or less. Two had a LOS that neared the one-year mark or exceeded it.

When the sample was divided in terms of whether the E-code assigned identified the self-poisoning as deliberate or not, a different picture emerged (Table 2). Those identified as having deliberately poisoned themselves were more likely to be younger, have a shorter LOS, have a mental disorder as the most responsible diagnosis and to have a psychiatrist as the most responsible physician.

TABLE 1
Sample characteristics

Characteristics	N = 181 n (%)	N = 274 n (%)
Age		
16–24	13 (7.2)	16 (5.8)
25–34	38 (21.0)	56 (20.4)
35–44	35 (19.3)	53 (19.3)
45–54	30 (16.6)	48 (17.5)
55–64	20 (11.1)	32 (11.7)
65+	45 (24.9)	69 (25.2)
Sex		
Male	102 (56.4)	159 (42.0)
Female	79 (43.7)	115 (58.0)
Most responsible diagnosis – mental disorder		
	31 (17.1)	46 (16.8)
Type of self-poisoning according to E-code		
Deliberate	66 (36.5)	104 (38.0)
Accidental	101 (55.8)	149 (54.4)
Undetermined	14 (7.7)	21 (7.7)
Most responsible physician – psychiatrist		
		39 (14.2)
Length of stay		
0–2 days	44 (24.3)	70 (25.6)
3–5 days	45 (24.9)	66 (24.1)
6–10 days	46 (25.4)	66 (24.1)
11+ days	46 (25.4)	72 (26.3)

Ratings between physicians

Agreement beyond chance between each of the physician pairs was excellent and did not vary between physician pairs. In contrast to the other raters, Rater 3 identified fewer poisonings as deliberate in nature, i.e., this rater was less sensitive. The overall sensitivity and specificity of each of the raters was high ranging from 86.3% to 98.9%.

Consistency in the prevalence estimates of deliberate self-poisoning

The E-codes indicated that 36.5% of the self-poisonings were deliberate in nature (95% CI: 30%; 43%). In contrast, the LCA indicated that 59.5% were deliberate (95% CI: 50%; 70%). In comparison to the E-code estimate, the LCA estimate was 63% higher.

Higher estimates of deliberate self-poisoning according to the LCA were particularly evi-

dent in certain subgroups. LCA estimates were about two to seven times higher than the comparable E-code ones in those aged 55 years or more, those whose most responsible diagnoses were medical in nature and those who had a longer LOS (Table 4). LCA estimates of deliberate self-poisoning were about 90% lower among those whose care was largely psychiatric in nature.

Discussion

In an urban, teaching hospital in Canada, clinicians estimated the prevalence of deliberate self-poisoning to be 63% higher than the prevalence as determined by E-codes among separations for self-poisoning. Much larger discrepancies were apparent among older age groups, those whose care was primarily medical in nature and those with a longer LOS.

Before discussing the results in detail, some interpretive cautions are necessary. We

TABLE 2
Deliberate self-poisoning vs. other self-poisoning in the hospital separation data

Characteristics	Accidental or undetermined	Deliberate	Total
	n (%)	n (%)	
Age	$\chi^2 = 27.09, 5 \text{ df}, p < 0.0001$		
16–24	6 (46.2)	7 (53.9)	13
25–34	21 (55.3)	17 (44.7)	38
35–44	15 (42.9)	20 (57.1)	35
45–54	16 (53.3)	14 (46.7)	30
55–64	17 (85.0)	3 (15.0)	20
65+	40 (88.9)	5 (11.1)	45
Sex	$\chi^2 = 0.14, 1 \text{ df}, p = 0.71$		
Male	66 (64.7)	36 (35.3)	102
Female	49 (62.0)	30 (38.0)	79
Most responsible diagnosis			
Mental disorder	$\chi^2 = 31.52, 1 \text{ df}, p < 0.0001$		
Yes	6 (19.4)	25 (80.7)	31
No	109 (72.7)	41 (27.3)	150
Most responsible physician	$\chi^2 = 39.89, 1 \text{ df}, p < 0.0001$		
Psychiatrist	3 (2.6)	25 (37.9)	28
Other	112 (97.4)	41 (62.1)	153
Length of stay	$\chi^2 = 9.28, 3 \text{ df}, p = 0.03$		
0-2 days	24 (54.6)	20 (45.5)	44
3-5 days	24 (53.3)	21 (46.7)	45
6-10 days	30 (65.2)	16 (34.8)	46
11+ days	37 (80.4)	9 (19.6)	46

TABLE 3
Agreement between physician pairs

Rater	% agreement	Kappa	95% confidence interval
1 vs. 2	88.3	76.6	0.67; 0.86
2 vs. 3	88.8	77.8	0.69; 0.87
3 vs. 1	93.9	87.4	0.80; 0.95

Rater	False positive rate	Standard error	False negative rate	Standard error
1	6.1	3.4	1.1	1.1
2	1.2	1.5	4.3	2.2
3	1.4	1.5	13.7	3.9

selected a sample based on whether a diagnosis of self-poisoning occurred anywhere in the 16 possible diagnostic fields. Based on previous abstraction studies, coding for self-poisoning at the three-digit level was likely quite accurate.⁴⁵ Compared with other settings, our sample may have over-

represented persons with more lethal behaviours even though the sample was limited to self-poisonings effectively excluding trauma admissions. Our sample contained only a small number of subjects under age 25 and overall, men and women did not differ according to E-code or clini-

cian-based estimates of deliberate self-poisoning. Most study samples have contained more women than men,^{1,9,19,23} and in some, younger women (15–24 years of age) predominated.^{1,6,8,13,17} However, eventual suicide was more likely in men and those in older age groups.^{9,19}

Clinical relevance

From a clinical standpoint, the findings are perhaps most relevant to hospital settings where older persons are medically treated for self-poisoning. A higher degree of suspicion about the presence of suicidal behaviours in admissions for self-poisoning and improved documentation may be necessary. Better screening and integration of medical and psychiatric care during and after the hospital stay may prevent future suicide attempts or completions. Alternatively, the quality of the care provided may be excellent but insufficient documentation of suicidal behaviours⁴⁶ contributes to missing E-code data or ambiguity noted in the elderly.²⁸

In this study, the prevalence of deliberate self-poisoning among younger persons was about 50%, whether E-codes or LCA methods were employed. This estimate did not change appreciably when the most responsible diagnosis of self-poisoning N-code (regardless of the nature of the E-codes) was applied. These findings suggest that in younger age groups, the prevalence of hospitalizations for deliberate self-poisoning may be estimated with more consistency than in older age groups in specific settings. This is further reinforced by the study of 10–20-year-olds in Oxford where nearly all hospitalizations for self-poisonings were verified as being deliberate. Nevertheless, only 20% of these hospital separations were deemed “deliberate” according to the E-codes³¹ in contrast to the near 50% in our study. Iribarren et al. confirmed 86% of the hospitalizations within a health maintenance organization, however it is not known whether “out of plan” use by various age/sex groups bear upon this estimate.

Public health relevance

From a public health standpoint, estimating prevalence rates of persons who are

TABLE 4
The consistency in the prevalence estimates of deliberate self-poisoning

Characteristics	% E-code (95% CI)	% LCA (95% CI)	% Relative difference (E-code-LCA/E-code)
Age			
16–24	53.9 (23; 85)	46.2 (6; 86)	–14.3
25–34	44.7 (27; 62)	45.3 (20; 70)	1.3
35–44	57.1 (39; 75)	34.3 (14; 55)	–39.9
45–54	46.7 (28; 66)	46.7 (25; 69)	0
55–64	15.0 (0; 33)	85.0 (43; 127)	466.7
65+	11.1 (1; 21)	91.2 (76; 106)	721.6
Sex			
Male	35.3 (26; 45)	59.0 (46; 72)	67.1
Female	37.8 (26; 49)	60.0 (46; 74)	58.7
Most responsible diagnosis			
Mental Disorder	80.7 (65; 96)	12.9 (8; 33)	–84.0
Other	27.3 (21; 34)	67.5 (61; 74)	147.3
Most responsible physician			
Psychiatrist	37.9 (19; 57)	3.6 (0; 12)	–90.5
Other	62.1 (53; 71)	69.7 (63; 76)	12.2
Length of stay			
0–2 days	45.5 (29; 62)	48.3 (26; 71)	6.2
3–5 days	46.7 (31; 63)	53.3 (36; 71)	14.1
6–10 days	34.8 (20; 50)	60.9 (43; 79)	75.0
11+ days	19.6 (8; 31)	73.7 (52; 95)	276.0

admitted to hospital for deliberate self-poisoning based on “deliberate” E-codes is of questionable validity, particularly among older age groups. Depending upon the underlying population structure and admitting/referral practices in a region, deliberate self-poisonings could be affected dramatically by relying only on these data. Time trend studies may be affected by changes in the underlying population over time but also by changes in coding practices. For example, E-coding may have improved over time in younger populations due to the heightened media exposure concerning suicide in youths. Reports that parasuicide admissions for men^{14,47} particularly younger men¹⁸ have increased over time based on “deliberate” E-code data are suspect and could deflect attention away from the elderly.

Clearly, the elderly need to be monitored given their greater access to medications in general,⁴⁸ greater fatality of behaviours⁴⁹ and the potential for an increasing burden

arising from an aging population.⁵⁰ Elderly persons may be more likely to use prescribed drugs in suicide^{17,49} and physicians may find themselves in the “unenviable position of having unwittingly prescribed the drugs used”.¹⁷ Prevention of further morbidity and mortality may be achieved through clinical and population based approaches concerning access to medications.^{48,51–53}

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The impact of missing birth weight in deceased versus surviving fetuses and infants in the comparison of birth weight-specific feto-infant mortality

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Abstract

Birth weight-specific is preferred to crude feto-infant mortality in epidemiologic studies comparing rates across jurisdictions, because it can help limit the bias arising from regional differences in the completeness of reporting of vital events and in classification of live versus stillbirth among extremely small and immature infants. The potential impact of missing birth weight information in deceased versus surviving fetuses and infants in the comparison of birth weight-specific feto-infant mortality has been seldom examined, however. The authors investigated this issue, using data collected from two nationwide surveys of all pregnancy outcomes occurring 15–17 May 1989 and 12–16 February 1996, respectively, in Taiwan and the 1989 and 1996 linked birth and infant death records in Canada (excluding Ontario and Newfoundland). The proportions with missing birth weight information in Taiwan in 1989 were 25.0%, 15.4%, 0%, and 0.6%, respectively, for stillbirths, neonatal deaths, post-neonatal deaths, and survivors, and in 1996 were 100%, 5.0%, 0%, and 0.2%. The proportions with missing birth weight information in Canada in 1989 were 5.8%, 2.6%, 1.2%, and 0.6% for fetal deaths, neonatal deaths, post-neonatal deaths, and survivors, respectively, and in 1996 were 5.0%, 2.4%, 1.1%, and 0.6%. Infant and (especially) fetal death rates were substantially higher in Taiwan than in Canada among births with missing birth weight. The authors concluded that differences in missing birth weight information between deaths and survivors can bias comparisons of birth weight-specific feto-infant mortality.

Key words: bias; birthweight; infant mortality; stillbirth

Introduction

Infant mortality has been considered the single most comprehensive index for comparing health status in a society.^{1–3} Many different sources of data, including routine vital statistics and records collected from perinatal health surveillance systems or health surveys, have been used for such comparisons.^{4–10} An essential issue in the

comparison of infant mortality across different countries and regions is ensuring that the observed differences reflect true differences in infant mortality among the countries/regions to be compared, rather than artifacts.

The most frequently reported artifact is due to regional differences in registration and reporting practices. For example, coun-

tries and regions differ in the completeness of their reporting of vital events and in their classification of live births versus fetal deaths among extremely small and immature infants,^{10–14} and such comparisons may therefore be biased. Analysis of birth weight- and age-at-death-specific infant mortality rates may help in this regard. If most of the observed difference in fetal and early neonatal mortality occurs in infants near the borderline of viability, registration practice is the probable explanation. Otherwise, other factors, such as maternal health and the quality of and access to maternal and infant health care services, should be considered.

Theoretically, differences in any process of data collection, editing, and reporting among countries/regions may bias the comparison of infant mortality. For example, if birth weight information is missing more frequently among deaths than among survivors and if this differentially missing birth weight information varies among the countries or regions to be compared, birth weight-specific infant mortality comparison will be biased. The potential bias introduced by differential missing birth weight information between deaths and survivors has seldom been assessed.

We recently initiated a project comparing birth weight- and age-at-death-specific feto-infant mortality between Taiwan and Canada. In the preliminary analysis, we found a

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substantially higher proportion of missing birth weight information among fetal deaths than in live births in Taiwan. This disproportionately higher missing birth weight information in Taiwan prevented us from further comparison of birth weight- and age-at-death-specific fetoinfant mortality between Taiwan and Canada. Because a similar problem is likely to occur in other countries and regions, we highlight these observed differences and examine their impact on birth weight-specific fetoinfant mortality.

Materials and methods

The 1989 and 1996 Statistics Canada Linked Birth and Death files were used for the Canadian analysis, and the data collected in two national surveys in Taiwan in 1989 and 1996 were used for the Taiwanese analysis.

Birth and death information in Canadian data is collated from birth and death registrations.¹⁵ Information on birth weight in the birth registration is obtained from the responsible physician or the mother. These data have been extensively evaluated for quality, and the successful linkage rate is more than 97%.¹⁶ Ontario data were excluded because of documented problems in data quality.¹⁷ Births to mothers residing in Newfoundland were also excluded, because data from this province were not available prior to 1991.

Because Taiwan's official vital statistics are known to severely under-report perinatal deaths,^{4,5} we analyzed data collected from two nationwide surveys of all pregnancy outcomes occurring at ≥ 20 weeks' gestation in 15–17 May 1989 and 12–16 February 1996, respectively. Both surveys were designed and coordinated by a research team led by the local principal investigator (Prof. Li-Mei Chen). A two-stage data collection was designed. At the first stage of data collection, a birth event recording form specifically developed for the surveys was issued by each county and city health bureau to the medical facilities (including hospitals, clinics, health stations, and midwife's offices in the corresponding administrative area) before the start of the full-scale data collection to record all pregnancy outcomes occurring at ≥ 20 weeks gestation during the study period. After receiving the completed

recording forms from the corresponding medical facilities, pre-assigned administrative staff in each county and city health bureau carefully reviewed the completeness of the recording forms and then transferred the completed forms to the corresponding public health nurses for preparation of the second stage of data collection. In the second stage, public health nurses from each health station conducted face-to-face interviews in the women's homes to collect additional information. All completed forms were carefully checked by the associated administrative staff in each health bureau. Finally, all completed forms were compiled and sent back to the research centre for data entering and editing.

To ensure accuracy and consistency of data collection, the research coordinating centre provided an intensive one-day training course for all of the participating administrative staff and public health nurses before the full-scale data collection. The training course included an explanation of the purpose of the study, the techniques of household interview, and detailed instructions for each questionnaire item. All study procedures were compiled into a field operations manual to further standardize data collection. Information on birth weight was obtained from the delivering hospitals, and mortality was ascertained during the second stage data collection (home visit by public health nurses). The response rate was high ($> 95\%$) and ascertainment of pregnancy events was complete in both surveys.^{4,5} No systematic differences were detected between those who responded and those lost to follow-up.^{4,5} Because there is no seasonal variation in fetoinfant mortality and morbidity in Taiwan,⁵ the data from these two nationwide surveys can be considered as representative of all births for the corresponding years in Taiwan.

Fetal death reporting in Taiwan is restricted to ≥ 20 weeks of gestation, while in Canada the restriction is ≥ 500 g or ≥ 20 weeks of gestation, depending on the province. The definition of live birth in both Taiwan and Canada follows the World Health Organization: the complete expulsion or extraction from the mother of a production of conception, irrespective of duration of pregnancy, which after such separation breathes or shows any other evidence of life. Infant

death is defined as death among live births in the first year (0 to 364 days) of life. Neonatal death is defined as death among live-born infants in the first 28 days (0 to 27 days) of life. Post-neonatal death is defined as death among survivors at 28 days of age in the post-neonatal period (28 to 364 days). To avoid the impact of temporal trends in fetal and infant mortality and their determinants in the two countries, we analyzed the two years' data separately.

We first compared the distribution of maternal age, parity, plurality, and birth weight between Taiwan and Canada. To assess the magnitude of missing birth weight by survival status, we compared the proportion of missing birth weight among fetal deaths, neonatal deaths, post-neonatal deaths, and survivors in the two countries.

We hypothesized that the missing birth weight information in deceased cases may have different effects on the Taiwan-Canada comparison within different categories of birth weight- and age-specific fetal and infant mortality. Specifically, we expected a major impact of missing birth weight in the comparison of fetal and neonatal mortality at the lower birth weights, with a much smaller impact on comparisons of post-neonatal mortality and at higher birth weights. We therefore compared fetal and infant mortality in the overall study sample and in three sub-samples:

- births with missing birth weight information;
- births with recorded weight < 500 g; and
- births with recorded weight ≥ 500 g.

We then compared fetal, neonatal, and post-neonatal mortality among births with birth weight of 500 to 1499 g, 1500 to 2499 g, and ≥ 2500 g in Taiwan and Canada. Relative risks and 95% confidence intervals were used for comparison of mortality rates, with Canada as the reference. All analyses were performed using SAS-PC 6 version statistical software.

Results

The proportions of women of young and older ages and high parity were higher in Canada than in Taiwan (Table 1). While the rate of multiple birth was lower in Taiwan

in Cohort I, the rate was higher in Cohort II (Table 1). The low birth weight rate was slightly lower in Taiwan, whereas the proportion of births with missing birth weight information was slightly higher (Table 1). The proportion of women of older age increased in Cohort II in both countries (Table 1). The proportion of women of high parity increased in Canada but decreased in Taiwan (Table 1).

The proportions with missing birth weight information were substantially higher among deaths than among survivors in both Canada and Taiwan, but there were substantial variations in missing birth weight according to age at death and country. In Canada, missing birth weight occurred most frequently among fetal deaths and least frequently among survivors, with an apparent gradient in both years (Table 2). In Taiwan, the pattern was more complicated, with the highest frequency of missing birth weight among fetal deaths, the second highest among neonatal deaths, and the third among survivors, with no missing birth weight among post-neonatal deaths in either year (Table 2). Overall, missing birth weight among deaths was more frequent in Taiwan than in Canada. However, because the sample sizes in some cells in the Taiwan cohorts were very small, the results were unstable.

Fetal and infant mortality rates were somewhat higher in Taiwan than in Canada (Table 3). When the comparison was restricted to the three sub-samples, different patterns emerged, however; infant and (especially) fetal death rates were substantially higher in Taiwan than in Canada among births with missing birth weight but smaller among infants with birth weight < 500 g and those with birth weight ≥500 g (Table 3).

Among births with a birth weight of 500 to 1499 g in Taiwan, the fetal death rate was lower than in Canada, while the neonatal and post-neonatal death rates were higher. Among infants with a birth weight of 1500 to 2499 g, no fetal deaths were observed in Taiwan, but both neonatal and post-neonatal death rates were higher in Taiwan. Among births weighing ≥2500 g, the fetal death rate was lower in Taiwan, whereas the neonatal and post-neonatal

TABLE 1
Distribution (per 1000 total births) of important maternal and infant characteristics between Taiwan and Canada*

Variable	Cohort I (1989)		Cohort II (1996)	
	Taiwan (n = 1,662)	Canada (n = 240,699)	Taiwan (n = 3,623)	Canada (n = 221,621)
Maternal age (years)				
<20	42.1	64.5	36.2	64.9
20–34	913.4	860.8	886.0	812.5
≥35	44.5	74.8	77.8	122.6
Parity				
0	379.1	431.6	449.8	425.9
1–2	553.5	493.3	510.8	492.9
≥3	67.4	75.2	39.4	81.2
Multiple birth	13.2	20.3	27.0	23.0
Birth weight (grams)				
<500	1.2	1.2	2.2	1.8
500–1499	6.6	10.3	9.1	10.0
1500–2499	27.1	49.0	54.9	47.5
≥2500	956.7	933.5	934.6	934.3
Missing	8.4	6.0	7.2	6.5

* Data sources: The 1989 and 1996 Statistics Canada Linked Birth and Death files the 1989 and 1996 national surveys in Taiwan

TABLE 2
Comparison of missing birth weight information (number and percent) among fetal deaths, infant deaths, and survivors between Taiwan and Canada*

	Cohort I (1989)		Cohort II (1996)	
	Taiwan (n = 1,662)	Canada (n = 240,699)	Taiwan (n = 3,623)	Canada (n = 221,621)
Missing birth weight in fetal deaths	4 (25.0%)	84 (5.8%)	18 (100.0%)	59 (5.0%)
Missing birth weight in neonatal deaths	2 (15.4%)	28 (2.6%)	1 (5.0%)	20 (2.4%)
Missing birth weight in post-neonatal deaths	0 (0.0%)	7 (1.2%)	0 (0.0%)	4 (1.1%)
Missing birth weight in survivors	10 (0.6%)	1328 (0.6%)	8 (0.2%)	1353 (0.6%)

* Data sources: The 1989 and 1996 Statistics Canada Linked Birth and Death files the 1989 and 1996 national surveys in Taiwan

death rates were higher, although substantial variations in rates were observed in the two cohorts, owing to limited sample sizes (Table 4).

TABLE 3
Comparison of fetal and infant mortality* between Taiwan and Canada**

Variable	Cohort I (1989)			Cohort II (1996)		
	Taiwan	Canada	Relative risk (95% CI)	Taiwan	Canada	Relative risk (95% CI)
Overall sample						
Fetal death	9.6	6.0	1.61 (0.99, 2.63)	5.0	5.4	0.92 (0.58, 1.47)
Infant death	10.2	7.0	1.47 (0.92, 2.37)	8.0	5.3	1.50 (1.04, 2.17)
Missing birth weight data						
Fetal death	285.7	58.1	4.92 (2.10, 11.56)	692.3	49.5	16.85 (11.78, 24.10)
Infant death	142.9	24.2	5.56 (1.48, 20.91)	38.5	16.7	2.21 (0.31, 15.70)
Birth weight <500 g						
Fetal death	1000.0	683.7	1.46 (1.35, 1.58)	0.0	531.3	NE
Infant death	0.0	295.9	NE	625.0	433.6	1.44 (0.83, 2.49)
Birth weight ≥500 g						
Fetal death	6.1	4.8	1.26 (0.68, 2.34)	0.0	4.2	NE
Infant death	9.1	6.5	1.40 (0.84, 2.32)	6.4	4.5	1.44 (0.95, 2.17)

* Per 1000 total births for fetal death rate and per 1000 live births for infant death rate; NE: Not estimable;

**Data sources: The 1989 and 1996 Statistics Canada Linked Birth and Death files the 1989 and 1996 national surveys in Taiwan

TABLE 4
Comparison of birth weight- and age-specific feto-infant mortality* between Taiwan and Canada

Variable	Cohort I (1989)			Cohort II (1996)		
	Taiwan	Canada	Relative risk** (95% CI)	Taiwan	Canada	Relative risk** (95% CI)
500 to 1499 g						
Fetal death	545.5	213.8	2.55 (1.48, 4.40)	0.0	173.4	NE
Neonatal death	600.0	255.4	1.47 (0.60, 3.60)	272.7	170.0	1.60 (0.91, 2.83)
Post-neonatal death	0.0	45.8	NE	83.3	16.3	5.10 (1.29, 20.13)
1500 to 2499 g						
Fetal death	0.0	23.3	NE	0.0	21.3	NE
Neonatal death	88.9	13.3	6.15 (2.37, 15.93)	0.0	11.8	NE
Post-neonatal death	0.0	7.7	NE	10.1	5.0	2.03 (0.50, 8.27)
≥2500 g						
Fetal death	2.5	1.6	1.62 (0.60, 4.32)	0.0	1.5	NE
Neonatal death	2.5	1.4	1.86 (0.69, 4.98)	1.5	1.0	1.51 (0.62, 3.65)
Post-neonatal death	2.5	1.9	1.34 (0.50, 3.59)	1.5	1.3	1.18 (0.49, 2.86)

* Per 1000 total births for fetal death rate, per 1000 live births for neonatal death rate, and per 1000 survivors at 28 days of age for post-neonatal death rate; NE: Not estimable

** Taiwan versus Canada; Canada as reference;

***Data sources: The 1989 and 1996 Statistics Canada Linked Birth and Death files the 1989 and 1996 national surveys in Taiwan

Discussion

Our original purpose in comparing birth weight- and age-at-death-specific fetoinfant mortality between Taiwan and Canada was to assess the reasons why the overall infant mortality rate was 30% higher in Taiwan than in Canada.^{4,5,10} We hypothesized that the higher infant mortality in Taiwan was caused by gaps in perinatal care. Previous studies have shown that because of their more favourable birth weight distribution (with fewer low birth weight infants) and lower maternal exposure to risk factors for perinatal death,^{6–9} perinatal mortality rates are actually slightly lower in ethnic Chinese than in ethnic whites in societies with comparable perinatal care. We sought to test this hypothesis by analysing birth weight- and age-at-death-specific fetoinfant mortality.

Although we have limited available information on risk factors, the lower proportions of mothers of young and older age, high parity, and low birth weight infants in Taiwan (Table 1) support our hypothesis. However, our attempt to compare birth weight- and age-at-death-specific fetoinfant mortality between the two countries was impaired, at least in part, by the problem of missing birth weight.

Major differences were observed in missing birth weight information between deceased and surviving infants, with substantially more frequent missing birth weight information among the deaths than in the survivors both in Canada and Taiwan. In Canada, there was an apparent gradient in the proportion of missing birth weight information according to survival status, with the highest proportion among fetal deaths and the lowest among survivors through infancy. The nine-fold increase in missing birth weight among fetal deaths versus survivors in Canada in both years of study, even after rigorous scrutiny of data quality, raises serious concern in comparing birth weight- and age-specific fetoinfant mortality.

The situation was even more complicated in Taiwan. While the proportion of missing birth weight information among fetal deaths was 5- to 20-fold higher in Taiwan than in Canada, this proportion was actually lower than in Canada among survivors and (especially) post-neonatal deaths. Because births

with missing birth weight cannot be included in the calculation of birth weight-specific mortality, disproportionally missing birth weight information between deaths and survivors can substantially bias all comparisons.

As expected, fetal and infant death rates were much higher in Taiwan among births with missing birth weight information. On the other hand, fetal and infant mortality rates in Taiwan among birth weight < 500 g or ≥ 500 g may be artificially reduced, because some of the otherwise eligible deaths were excluded in the calculation of these rates. Among births weighing 1500–2499 g or ≥ 2500 g, both neonatal and post-neonatal death rates were higher in Taiwan, suggesting true differences rather than artifacts. However, substantial variations in these rates made any attempt to draw inferences from the comparison of birth weight- and age-specific mortality difficult. Although limited sample size in Taiwan data and differences in data collection between the two countries undoubtedly affected the comparison of birth weight- and age-at-death-specific fetoinfant mortality, there is no doubt that the substantial variation in missing birth weight information according to survival status also undermines any such attempt.

We do not know why a higher proportion of birth weight information was missing in deaths than in survivors. Parents' attitudes may play a role here. Information on birth weight in Canada is provided by the responsible physician or parents who register the birth. When parents register their infant, they may be more careful about details such as birth weight and gestational age if their infant is healthy, while less attention may have been paid to these details if their infant dies or is seriously ill. The situation in Taiwan may be different. Because of apparent problems in official vital statistics, we have used information obtained from the two surveys. The two cohorts represented the most complete and accurate fetal and infant mortality statistics on the island. In the 1989 Taiwan survey, Chen et al found that the survey-derived infant mortality rate was 9.72 per 1000 live births, whereas the official statistic for the same calendar year was 5.71 per 1000 live births.⁵ Cultural factors may have played a role here. Most of the under-registration of

infant deaths in Taiwan occurs during the first 27 days of life, because parents appear reluctant to register an infant who dies soon after birth.⁵ It is known that in Taiwan, no record of birth weight was kept for some births born in local hospitals or homebirths, especially for stillbirths or infants who died early in life. Although the research team for the Taiwan surveys made every effort to identify the deaths, it was impossible for them to obtain birth weight information if it was not recorded in the first place. We do not know why information on birth weight was missing for all 18 cases of fetal death in the 1996 cohort in Taiwan. It should be noted that this is a highly unstable estimate because of the small number.

Previous studies of the impact of registration practices on international comparisons of fetal and infant mortality rates have focussed on incomplete reporting of death events and variation in classification of live births and fetal deaths.^{5,10–14} This study adds to this literature by highlighting an additional source of bias when comparing birth weight- and age-at-death-specific fetoinfant mortality: differences in missing birth weight information between deaths and survivors.

Acknowledgments

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Cross-Canada Forum

Cancer Care Ontario's New Drug Funding Program: Controlled introduction of expensive anticancer drugs

William K Evans, Marilyn Nefsky, Joseph Pater, George Browman and Donald H Cowan

Abstract

In the mid 1990s, the high cost and increasing number of new anticancer and supportive care drugs began to result in an inequality of access to promising new treatment approaches in the Province of Ontario. Starting with a single drug, paclitaxel, in 1995, Cancer Care Ontario's New Drug Funding Program has evolved into a provincial program that enables cancer patients in Canada's most populous province to equitably access new and expensive, intravenously administered drugs. This article describes the development of the program, including the evolution of the administrative mechanisms necessary to manage the program and the decisions of the policy advisory committee that shape provincial funding policies. In fiscal year 2000/2001, the Program made 14 drugs available for 24 indications for a total provincial expenditure of approximately \$37.7 million. These intravenous drugs can now be accessed through nine Regional Cancer Centres, the province's only cancer hospital (Princess Margaret Hospital) and 80 community hospitals and will directly benefit more than 8,700 patients.

Key Words: equitable access; funding policy; New Drug Funding Program

Background

Cancer Care Ontario (CCO), a provincial agency funded by the Ontario Ministry of Health and Long Term Care (MOHLTC), is mandated to integrate and coordinate the cancer control services in the province of Ontario, Canada. CCO is the principal advisor to the MOHLTC on all cancer issues. It manages the province's nine Regional Cancer Centres, the Ontario Breast and Cervical Screening Programs, as well as the Ontario Cancer Registry. The Regional Cancer Centres are ambulatory treatment facilities associated with major hospitals in the larger cities of the province. They provide multidisciplinary consultation and care by medical, radiation and surgical oncologists. The Regional Cancer Centres also provide supportive care and operate outreach programs that link the tertiary

treatment facilities to surrounding community hospitals and care providers. Through community clinics, CCO is able to deliver at least some chemotherapy in smaller communities close to home.

In Canada, the method of funding medications for cancer patients varies somewhat between provinces. However, all drugs administered to patients in hospitals, or intravenous drugs given in the outpatient departments of hospitals or ambulatory cancer centres, are provided to patients as an insured service in Canada's publicly funded universal access health care system. Chemotherapy drugs are either paid for through the global budgets of the hospital providing the care or through dedicated cancer centres. The institutional global budgets are set by the provincial governments through their Ministries or Departments of

Health. In Ontario, under the terms of the *Canada Health Act*¹, it is not possible to bill patients or their third party insurance provider for the cost of intravenous drugs administered in a hospital or cancer centre.

In some provinces, chemotherapy is administered through community hospitals by medical oncologists not affiliated with provincial cancer agencies. In Ontario, approximately 50% of the chemotherapy administered in the province is given through this informal cancer system. Until recently, when a new chemotherapy drug was approved for release in Canada by the federal government, its availability in a particular facility was dependent on whether the hospital or cancer centre could accommodate the additional cost of the drug in its operating budget. With the fiscal restraint exercised in Ontario's health care system over the past 10 years, it has been increasingly difficult for institutions to accommodate expensive new drugs in their budgets, leading to inequality of access to new drugs by patients.

Initial steps in establishing a provincial systemic therapy funding program

Between 1993 and 1994, the Ontario Ministry of Health undertook a series of consultations with patients, the public and care providers to determine how the cancer care system in Ontario could be improved. At that time, patients reported that care was of high quality, but fragmented. Strong arguments were made for an organization that could integrate the care and services

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of all cancer care providers. A Provincial Cancer Network was established, which in turn set up a number of working groups, including a Systemic Therapy Working Group. This group recommended that a managed systemic therapy program be established in Ontario and that all cancer-specific and relevant supportive care drugs be managed and funded through a single agency, rather than through the multiplicity of players that existed at the time.² It was felt that such a program would help to ensure equitable access to anticancer drugs by all patients in the province.

At approximately the same time, there was concern that breast and ovarian cancer patients were having difficulty accessing paclitaxel (Taxol[™]), one of the first of the new and expensive anticancer agents. Many Ontario physicians, who wanted to prescribe paclitaxel for their patients, were unable to do so because their hospital budget could not absorb the unplanned and large expense. In an effort to address this inequity, Cancer Care Ontario made the decision to fund paclitaxel from its reserve funds for those breast and ovarian cancer patients treated in CCO Regional Cancer Centres until such time as the MOHLTC agreed to fund it.

CCO's Practice Guideline Initiative

Cancer Care Ontario's Practice Guidelines Initiative was established about the same time that CCO was confronting the issue of paclitaxel funding for breast and ovarian cancer. This initiative, which is now based at McMaster University and funded through the MOHLTC, coordinates the development of clinical practice guidelines in Ontario using systematic literature reviews to identify the current best evidence to guide practice.^{3,4} Twelve multidisciplinary Disease Site Groups, comprising health care providers, community representatives and researchers, use a consistent literature search strategy, specific data analysis methodology and a standardized format to report a detailed summary of the best available evidence on a clinical topic. The program is intended to provide practitioners with evidence-based recommendations on current best practice for specific clinical situations in the treatment

of cancer patients. Reports are published in peer-reviewed journals and are available on the CCO Practice Guideline Web site at <www.cancercare.on.ca/ccopgi> .

In 1995, the CCO Practice Guideline Initiative developed guidelines for the use of paclitaxel for patients with metastatic breast cancer and Stage III and IV ovarian cancer. These guidelines defined the criteria by which patients would be eligible to receive paclitaxel.

The Paclitaxel Funding Program

Cancer Care Ontario proposed to the provincial government that paclitaxel be funded according to the guidelines and that CCO take on the role of reimbursing institutions for their usage of the drug and for the monitoring of its use and effectiveness. The government accepted this proposal in April 1995. Only those hospitals with appropriate facilities and medical personnel to supervise chemotherapy administration were permitted to participate in the paclitaxel funding program. The guidelines for the use of paclitaxel were provided to the participating hospitals, as well as eligibility and follow-up forms to be completed for each patient. This information allowed CCO to track the number of patients treated, the indication for treatment, the number of cycles administered to patients and the drug expenditure by treatment facility.

Institutional billing forms for monthly submissions for reimbursement were also developed. Hospitals were reimbursed by CCO quarterly for the drug if it was administered to eligible patients according to guidelines. Funding was not provided for the chemotherapy administration costs, such as the cost of personnel to prepare and deliver the drugs.

The development of the new Drug Funding Program

Subsequent to the establishment of the paclitaxel funding program, Ontario's Ministry of Health asked CCO to develop a proposal for a managed systemic therapy program. A program design committee recommended that the Program be phased in over several years and that the first phase

be the funding for the new and expensive intravenous drugs. The committee addressed issues such as facility and professional standards, information systems, financial management and contract purchasing. It also recommended that a policy advisory committee be formed to guide the development of the Managed Systemic Therapy Program. Based on the initial success of managing the provincial paclitaxel funding program, the MOHLTC approved the establishment of the provincial New Drug Funding Program (NDFP) in May 1997.

The Policy Advisory Committee and the approval process for new drugs

The Policy Advisory Committee (PAC) for the New Drug Funding Program includes cancer centre oncologists, community oncologists, a nurse, a pharmacist, an epidemiologist, community representatives, a representative of the Ontario Hospital Association, an ethicist, representatives of the Practice Guideline Initiative, and a representative of the MOHLTC. It reviews the evidence in practice guidelines received from the Disease Site Groups of the Practice Guideline Initiative and recommends to CCO whether the new drug should be funded through the NDFP and under which circumstances.

The PAC judges the evidence presented to it through the Guideline initiative according to a hierarchy of evidence in which multiple randomized trials or meta-analyses are most valued, followed by single randomized trials of reasonable size, small randomized trials and data from Phase II trials.⁵

Over the several years of its deliberations, the PAC has established a hierarchy of benefits that places the greatest value on cure, followed in order of importance by prolongation of survival, relief or prevention of symptoms or complications of disease, improved quality of life, reduction in symptomatic toxicity compared with standard therapy, prolongation of disease-free survival and tumour shrinkage.⁵ When there is evidence that a new drug alone or in combination with other agents increases the survival of a particular group of cancer patients, a decision to recommend funding

is invariably made without difficulty. The values of the members of the PAC play an important role when the evidence is limited to improvement in response rates, reduction in the toxicity of treatment or enhanced quality of life. In these cases, there is much discussion as to the value to society of making expensive treatments available for these indications. Decisions are made by consensus and are generally unanimous, although occasionally there are dissenting views.

The need for a guideline to support the provincial funding policy on a new drug is usually recognized by the members of one of the 12 Disease Site Groups (DSGs) of the Practice Guideline Initiative. The DSG then develops the guideline using the practice guideline development cycle previously described by Browman et al.³ On occasion, the impetus for a provincial policy may come from CCO's Systemic Therapy Program leader, the Director of Treatment Services, the MOHLTC, patient advocacy groups or industry. In these cases, the Systemic Therapy Program leader makes a request to the Director of the Program in Evidence-based Care to direct the development of a guideline through the appropriate provincial Disease Site Group.

Recommendations to fund new intravenous anticancer drugs are taken forward by CCO to the MOHLTC, with an economic impact analysis based on an estimate of the total population of patients who might be expected to benefit. These estimates are crude, given the lack of tumour stage specific information, detailed information on practice patterns and knowledge of the rate of uptake of new treatment approaches. The MOHLTC has invariably supported the recommendations coming from the PAC and has provided the funds necessary to meet the patient care needs.

Current scope of the New Drug Funding Program

The scope of the New Drug Funding Program has continued to broaden, and in fiscal year 2000/2001 included 14 drugs for 24 indications. These 14 drugs represent all of the new intravenous drugs that have come on the market with evidence in support of their use since the inception of the

TABLE 1
New OCC Drug Funding Program

Drug	Indication	CCO Practice Guideline*
1. Clodronate	metastatic breast ca	Breast #1-11
2. Docetaxel	metastatic breast ca	Breast #1-9
	2nd line non-small cell lung ca	Lung #7-7-2
3. Epirubicin	Metastatic breast ca	Breast #1-6
4. Gemcitabine	pancreatic ca	Gastrointestinal #2-10
	non-small cell lung ca	Lung #7-8
5. Interferon	Melanoma	Melanoma #8-1
6. Irinotecan	1st line metastatic colorectal ca	Gastrointestinal #2-16
	2nd line metastatic colorectal ca	Gastrointestinal #2-16
7. Liposomal anthracycline	HIV positive Kaposi's sarcoma	Sarcoma #12-8
8. Paclitaxel	Metastatic breast ca	Breast #1-3
	1st line ovarian ca	Gynecology #4-1
	2nd/3rd line ovarian ca	Gynecology #4-1
9. Pamidronate	Plasma cell myeloma	Hematology #6-4
	Metastatic breast ca	Breast #1-11
10. Raltitrexed	Metastatic colorectal ca	Gastrointestinal #2-17
11. Rituximab	non-Hodgkin's lymphoma	Hematology #6-8
12. Topotecan	advanced ovarian ca	Gynecology #4-2
13. Trastuzumab	metastatic breast ca	Breast #1-15
14. Vinorelbine	metastatic breast ca	Breast #1-4
	non-small cell lung ca	Lung #7-5

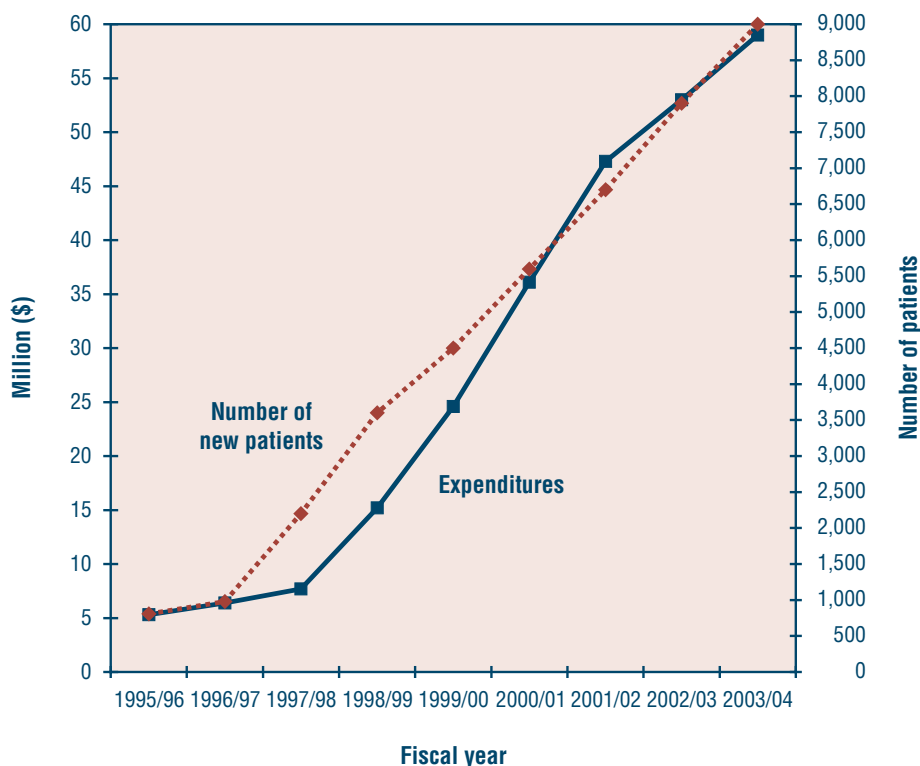
* Complete Cancer Care Ontario Practice Guideline can be found at <<http://www.cancercare.on.ca/ccopgi>>

NDFP. New drugs and new indications for previously approved drugs are constantly under review. The chemotherapy agents and their indications for funding are listed in Table 1. In addition, the Table shows the CCO guideline number where full details of the guideline recommendations can be found on the website at <<http://www.cancercare.on.ca/ccopgi>>. The rapid growth in the number of drugs funded and the number of patients treated is shown graphically in Figure 1. It is estimated that the 2001/2002 drug budget will be approximately \$50 million and benefit over 9,000 patients. This represents an average growth in expenditures of approximately \$10.7 million per annum.

The average chemotherapy drug cost per treated case reimbursed through the NDFP was \$5,528 in 1999/2000.

To date, the NDFP is only responsible for making recommendations on the new intravenous anticancer and supportive care drugs. Oral and subcutaneously administered drugs are reviewed and approved through a separate process by the Ontario Drug Benefit Program (ODB). Agents approved by ODB are placed on the provincial drug formulary and are provided free to patients 65 years and over and to those on social assistance.

FIGURE 1
New Drug Funding Program
annual expenditures and number of new patients
with projection to fiscal year 2003/2004



The total chemotherapy drug cost for the province of Ontario is difficult to estimate because accurate information is difficult to obtain from the non-CCO centres delivering intravenous chemotherapy. The amount expended on oral drugs through the Ontario Drug Benefit Plan can be obtained more readily but the direct expenditures by patients not covered by the plan can only be estimated. When evaluated in 1993, oral agents made up 58% of the total chemotherapy drug expenditures and CCO centres represented 24.5% of expenditures on intravenous drugs.⁶ Assuming that these ratios applied in 2000/2001, the total provincial chemotherapy drug budget would have been approximately \$200 million, of which 18.9% would have been attributable to the New Drug Funding Program.

The number of health care facilities participating in the NDFP grew from 49 in 1995 to 92 in 2000. The amount of funding reimbursed to some hospitals for the new expensive drugs has grown to approximately 50% of their entire oncology drug budget.

CCO reimburses facilities only for those patients who meet the agreed-upon eligibility criteria. Costs for patients who do not meet the criteria must be absorbed by the hospital or cancer centre's budget. The costs of administering these drugs must also be addressed through an institution's operating budget. Within CCO regional cancer centres, complexity-adjusted workload – staffing ratios for nurses and pharmacy staff – guide the development of the institutional operating plans. In non-CCO institutions, the absence of accepted planning standards for systemic therapy staff is a source of difficulty, but the development of such standards is being addressed through a collaborative initiative with the MOHLTC.

As the number of drugs and indications funded by the Program has grown, the number of patients and the information being transmitted to CCO on paper forms has increased enormously. To ease the burden of collecting and processing this vast amount of data, a software program was specifically developed for the Program. ChemoTrac™,

developed by DKK Health Systems Inc. (www.dkk.net) in consultation with CCO and pharmacists from community hospitals, allows users to identify the disease, the drugs and the treatment regimen, including all of the treatment dates. The primary purpose of the program is to provide information to CCO so that CCO can reimburse the hospitals for the use of the approved systemic therapy drugs. The program is currently used by 43 hospitals. As soon as a suitable encryption process is developed, the data will be transmitted by e-mail. Drug utilization is monitored by CCO to ensure that patients being funded meet the criteria and that CCO is not paying for more than the recommended dose or number of treatment cycles. The program provides a unique opportunity for the review of data that has been collected on a province-wide basis. Data from ChemoTrac™ is imported into a CCO database, which also interfaces with CCO's Oncology Patient Information System (OPIS). Using these databases, outcome studies for specific new drugs (taxanes in breast cancer; rituximab in lymphoma) have been undertaken and provide a population-based experience with these agents in contrast to the results of treatment in highly selected patient populations in clinical trials.

The large and growing amount of data available in the New Drug Funding Program's database and the potential to import the data from ChemoTrac™ into either the Ontario Cancer Registry or Canadian Institute for Health Information databases will make it possible to undertake health services research to address questions about equality of access, compliance with guidelines, and the outcomes achievable in the general population with these new agents. An ongoing audit is determining the consistency of practice in relation to the PAC approved indications for drug use.

Benefits to patients, hospitals and the MOHLTC

The New Drug Funding Program has been of benefit to patients, hospitals and to the MOHLTC. The Program has been successful in expediting the introduction of new and expensive drugs in a standard manner on a provincial basis. Access to expensive

drugs is not limited by a patient's ability to pay, place of residence or the capacity of the health care facility's drug budget to absorb the cost of a new drug. Eligible patients can gain access to new drugs from a great many locations in the province, as funding follows the patient rather than being sequestered in the budgets of individual institutions. Health care institutions need not be concerned about finding funds within constrained budgets to cover the cost of new drugs. CCO is the advocate for funding for each new drug on a provincial basis, so hospitals do not have to negotiate a budget increase each time a new drug becomes available. The MOHLTC benefits because CCO, as the sole purchaser of a number of the new anticancer drugs in the Province, has been able to negotiate lower prices than individual health care institutions, thereby reducing the cost to the health care system. CCO recommends to the Ministry which new drugs should be funded based on the best available evidence. The process of rigorous guideline development and policy review provides the MOHLTC with reassurance that new anticancer drugs are only introduced after a careful review of the evidence and that the recommended therapeutic indications will be of value to Ontarians. The Program

has been able to provide equal access to effective new intravenous agents for eligible patients throughout the province.

A weakness of the current program is that its scope does not include all anti-neoplastic and relevant supportive care drugs, unlike the situation in British Columbia, where the British Columbia Cancer Agency has responsibility for the approval of all agents. The great strength of Ontario's program is that it is built on a very strong evidence base through the work of disease site groups within CCO's Program in Evidence-based Care. The Policy Advisory Committee completes the final step in translating research evidence to clinical practice by establishing policy based on the value of the clinical benefits described in the CCO guidelines. This valuation is undertaken in the context of other new agents being considered for use in cancer, not within the larger context of all cancer control activities. The importance to patients and families of receiving state-of-the-art treatment results in treatment being given a high priority in any discussion of cancer control resource allocation. Within the chemotherapy treatment domain, CCO's New Drug Funding Program assures that policy decisions on the use of new and expensive drugs are evi-

dence based, prioritized on the basis of a hierarchy of benefits and values and implemented in a manner assuring equitable access.

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Book Review

Pharmacovigilance from A to Z: Adverse Drug Event Surveillance

Barton Cobert and Pierre Biron

Malden, Mass., USA, Blackwell Science Inc., 2001
256 pp; ISBN 0 63 204586 8; \$92.30 (CDN)

Cobert and Biron's *Pharmacovigilance* is a welcome addition to the dictionaries that help us to cope with an ever-expanding world of 'Babylonian priest languages': our ways of communicating within our specialties, often strange and impenetrable to the outside world. The authors offer us a reader-friendly dictionary, particularly interesting to anyone involved in clinical pharmacology and drug research.

Dictionaries, like any specialty book, may be written either by an extended number of contributors, as are Last's *Dictionary of Epidemiology*, Armitage and Colton's *Dictionary of Biostatistics* or Gail and Benichou's *Encyclopedia of Epidemiologic Methods*, or by one or two writers, like this volume or Paul Vogt's *Dictionary of Statistics and Methodology: A Nontechnical Guide for the Social Sciences*. The former approach produces high-quality information, which is sometimes more detached from some unifying concept. The latter allows the authors to put more of their souls into their writing and produce, in a more harmonized state of mind, a better line of thought throughout the whole message. As always, the product depends more heavily on the experience of its authors.

Pharmacovigilance appears to me to be a very informative text. Its major asset is its originality in covering the growing field of drug surveillance, which is known to the authors from within and in many subtle details. However, any reader of book reviews is interested not only in kudos but also in drawbacks and in at least some major aspects where there is space for improvement.

This dictionary covers pharmacovigilance as a part of the domain of pharmacoepidemiology, which itself is a part of fundamental and clinical epidemiology. The authors should stress the definitions or

concepts that are more specific to this subdomain and that are different from those used in the outside world of clinical epidemiology and biostatistics in particular.

Some entries are not specific enough. For example, epidemiologic studies (p. 74) are seen solely as observational. While discussing phases of clinical trials and assessment of drugs, the authors might be more clear about what is covered by pharmacovigilance itself. Pharmacovigilance also covers what may be called "phase V" assessment of drugs. In phase V, as in Phase IV, there are no pre-selected patients, but instead of desired treatment effect, phase V focuses on any rare consequences resulting from the administration of a drug.

Elsewhere, I was puzzled by what "statistical causality" means. Levels of causality, as proposed by the authors, are solely conceptual and not operational. For example, what distinguishes a "probable" causal relationship from a "possible" one in clear and usable terms? Categories of causality are defined in the book by their field of use, such as medicine or law, rather than by their substance. Do the authors perceive different concepts as identical to different domains of use? The same applies to other entries, where it is not clear whether the definition and field of use are within some more general concept or if they are different.

Some other entries describe situations of their use rather than definitions of terms themselves. For example, "case reports" or "case series" are not defined at all! If some terms are not defined well enough, the authors should guide the reader to their definitions elsewhere, for example, the abovementioned *Dictionary of Epidemiology*, endorsed by the International Epidemiological Association. Hence, the reader

Overall Rating:

Original contribution

Strengths:

Easy to read and informative, particularly for readers from outside the field of pharmacoepidemiology

Weaknesses:

Lack of bridging with mainstream dictionaries in connected domains

Audience:

All health professionals interested in the evaluation of drugs

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should not expect that *Pharmacovigilance* will provide an essential dictionary of epidemiological and other terms without pairing this reading with other *ad hoc* references.

Some more than ubiquitous terms, such as "epidemiology" or "evidence-based medicine" are not mentioned and defined. The "Introduction" section of this book might be improved by the addition of a reference to other dictionaries and basic reading, which might help the reader to expand and complete his or her understanding of pharmacovigilance terms as they are gathered in this volume. I would like to find definitions of "efficacy", "effectiveness" or "efficiency of treatment", as well as a cost/benefit assessment including non-monetary considerations. Adverse effects represent one of the costs of treatment.

What about evidence-based principles to be kept in mind in pharmacovigilance and how might we define “evidence-based pharmacovigilance” itself? A word about “evidence-based pharmacology” would also merit a place in this book.

Even if we dislike or disagree with some term or domain, it is not a sufficient reason to exclude it from a dictionary.

All this reviewer’s ramble should not blur the relevance and the originality of *Pharma-*

covigilance. This dictionary will stand as a useful and very original tool for years to come. It will also help health professionals who are farther away from clinical pharmacology to better understand the domain it covers. ■

Book Review

A Veritable Scoff: Sources on Foodways and Nutrition in Newfoundland and Labrador

Maura Hanrahan and Marg Ewtushik

St. John's, Nfld, Flanker Press Ltd., 2001

100 pp: ISBN 1 894463-21-8; \$14.95 (CDN)

"A *Veritable Scoff* presents summaries of 170 writings on Newfoundland and Labrador foodways and nutrition for the past several centuries. Is the popularity of boiled dinner – salt beef or pork with root crops – on the wane? Why do the Innu of Davis Inlet call Social Services "the food boss"? How prevalent was beriberi in pre-Confederation Newfoundland? What are dietitians and food scientists in the province concerned about now? The only book of its kind in Canada, this bibliography answers these questions and asks others that are equally compelling." [Text from the book jacket.]

Overall Rating:

This book was both enjoyable and interesting to read, which for a bibliography is very good. I confess to my bias towards the subject as a nutritionist from this province.

It provides a fascinating historical review capturing the highlights of foodways and nutrition from 1600–2000. It is applicable to today's decisions regarding health and nutrition policy and provides a transferable guide to other jurisdictions where such a review is being considered.

Strengths:

The studies have been well-analyzed and the summaries are succinct and relevant. They provide a picture of the real nutrition issues facing people over time and they are grouped together well.

Weaknesses:

Lack of bridging with mainstream dictionaries in connected domains

Audience:

The range of topics covered would be of interest to many professions and interested individuals as the perspectives are quite broad. It links studies from a variety of disciplines and jurisdictions including anthropology, biochemistry, education, agriculture and government. It would be a very useful reference for libraries and governments.

Eleanor Swanson

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Calendar of Events

January 24–25, 2002 Toronto, Ontario	“Better Breathing 2003” The Ontario Thoracic Society’s annual scientific conference on respiratory health	The Ontario Thoracic Society 573 King Street East, Suite 201 Toronto, Ontario M5A 4L3 Tel.: (416) 864-9911 x 254 Fax: (416) 864-9916 E-mail: ots@on.lung.ca < www.on.lung.ca >
February 19–21, 2003 St. Louis, Missouri, USA	“Gateway to Lifelong Health: The Community Connection” 17 th National Conference on Chronic Disease Prevention and Control	Department of Health and Human Services Centers for Disease Control and Prevention Mail Stop K-11 Atlanta, GA 30341-3717 USA < www.cdc.gov/nccdphp/conference >
April 9–11, 2003 Melbourne, Australia	“Tobacco Control: A Blue Chip Investment” 2 nd Australian Tobacco Control Conference <i>Call for Abstracts by: January 30, 2003</i>	The Meeting Planners 91– 97 Islington Street Collingwood, Victoria, Australia, 3066 Tel.: + 61 3 9417 0888 Fax: + 61 3 9417 0899 E-mail: tobaccocontrol03@meetingplanners.com.au < http://tobaccocontrol03.conference.net.au >
April 23–27, 2003 Banff, Alberta	CAPO 2003 6 th World Congress of Psycho-oncology	c/o Psycho-social resources Tom Baker Cancer Centre Alberta Cancer Board 1331– 29 Street NW Calgary, Alberta T2N 4N2 Tel.: (403) 670-1767 Fax: (403) 283-6032 E-mail: banffcongress@cancerboard.ab.ca < www.capo.ca >
May 12–16, 2003 Vancouver, British Columbia	“Child Health 2003” 3 rd World Congress & Exposition	Venue West Conference Services Ltd. Tel.: (604) 681-5226 Fax: (604) 681-2503 E-mail: congress@venuewest.com
September 21–25, 2003 Orlando, Florida, USA	5 th International Symposium on the Role of Soy in Preventing and Treating Chronic Disease	American Oil Chemists’ Society PO Box 3489 Champaign IL 61826-3489 USA Tel.: (217) 359-2344 Fax: (217) 351-8091 E-mail: meetings@aocs.org Information: Mindy M. Cain at: mindyc@aocs.org < www.aocs.org/meetings.soy03 >
June 13–16, 2004 Milan, Italy	“Technology, Bridging the Digital Divide – Strategies for Global Heart Health” 5 th International Heart Health Conference	E-mail: sihh@g8cardio.org < www.g8cardio.org >

CDIC: Information for Authors

Chronic Diseases in Canada (CDIC) is a peer-reviewed, quarterly scientific journal focusing on the prevention and control of non-communicable diseases and injuries in Canada. This may include research from such fields as epidemiology, public/community health, biostatistics, behavioural sciences and health services. CDIC endeavours to foster communication on chronic diseases and injuries among public health practitioners, epidemiologists and researchers, health policy planners and health educators. Submissions are selected based on scientific quality, public health relevance, clarity, conciseness and technical accuracy. Although CDIC is a Health Canada publication, contributions are welcomed from both the public and private sectors. Authors retain responsibility for the contents of their papers, and opinions expressed are not necessarily those of the CDIC Editorial Committee or of Health Canada.

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Submit manuscripts to the Editor-in-Chief, Chronic Diseases in Canada, Population and Public Health Branch, Health Canada, 130 Colonnade Road, CDIC Address Locator: 6501G, Ottawa, Ontario K1A 0K9, e-mail: cdic-mcc@hc-sc.gc.ca.

Since CDIC adheres in general (section on illustrations not applicable) to the “**Uniform Requirements for Manuscripts Submitted to Biomedical Journals**” as approved by the International Committee of Medical Journal Editors, authors should refer to this document for complete details before submitting a manuscript to CDIC (see < www.cma.ca/publications/mwc/uniform.htm > or *Can Med Assoc J* 1997; 156(2):270–7).

Checklist for Submitting Manuscripts

Cover letter: Signed by all authors, stating that all have seen and approved the final manuscript and have met the authorship criteria of the Uniform Requirements and including a full statement regarding any prior or duplicate publication or submission for publication.

First title page: Concise title; full names of all authors and institutional affiliations; name, postal and e-mail addresses, telephone and fax numbers for corresponding author; separate word counts for abstract and text.

Second title page: Title only; start page numbering here as page 1.

Abstract: Unstructured (one paragraph, no headings), maximum 175 words (100

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Text: Double-spaced, 1 inch (25 mm) margins, 12 point font size.

Acknowledgements: Include disclosure of financial and material support in acknowledgements; if anyone is credited in acknowledgements with substantive scientific contributions, authors should state in cover letter that they have obtained written permission.

References: In “Vancouver style” (consult Uniform Requirements and a recent CDIC issue for examples); numbered in superscript (or within parentheses) in the order cited in text, tables and figures; listing up to 6 authors (first 3 and “et al.” if more); without any automatic reference numbering feature used in word processing; any unpublished observations/data or personal communications used (discouraged) to be cited in the text in parentheses (authors responsible for obtaining written permission); authors are responsible for verifying accuracy of references.

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