

## **Nurses Begin a National Plan for the Integration of Supportive Care in Health Research, Practice, and Policy**

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La demande à l'égard des services en matière de santé et de service social n'est pas liée au type de maladie ou à sa gravité, mais plutôt aux caractéristiques socio-économiques, cognitives et affectives de la personne atteinte, ainsi qu'aux circonstances relatives au milieu. On a organisé un atelier sur les soins de soutien avec les objectifs suivants : favoriser un milieu de recherche vigoureux, apporter des nouvelles connaissances, établir un programme de recherche intégré, attirer l'attention sur l'évolution du système de santé et prévoir les défis à venir. D'abord organisé pour répondre au mandat de recherche établi pour les Instituts canadiens de recherche en santé, l'atelier a débouché sur une vision élargie, englobant les volets défense des droits, système d'information, surveillance et élaboration des politiques exigées par les structures institutionnelles, communautaires, bénévoles, du secteur privé, de la famille et de la prestation des services. L'élaboration d'une stratégie nationale en matière de soins de soutien permettra aux Canadiens et aux Canadiennes aux prises avec la maladie et l'incapacité à relever les défis de la vie quotidienne; elle favorisera en outre la participation des chercheurs et chercheuses, des cliniciens et des cliniciennes, des groupes de défense des droits et des personnes aux prises avec des problèmes de santé.

The demand for and use of health, social, and other human services is related not to the type or severity of disease but rather to a person's socio-economic, cognitive, and emotional characteristics and environmental circumstances. A workshop on supportive care was held to promote a robust research environment, the creation of new knowledge, the setting of an integrated health research agenda, a focusing of attention on the evolving health-care system, and anticipation of emerging health challenges. While the workshop

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was intended to address a research mandate for the Canadian Institutes of Health Research, a larger vision emerged, to include advocacy, information system, surveillance, and policy development required by institutional, community, voluntary, private sector, family caregiver, and provider systems. The development of a national supportive care strategy will enable Canadians with disease and disability to live with all of their challenges, and could engage researchers, clinicians, advocacy groups, and people experiencing major health challenges.

## **Introduction**

The purpose of this article is to describe the process of developing a national supportive care strategy across a spectrum of chronic conditions and circumstances. It is postulated that supportive care is an important issue cutting across many disease entities and is worthy of funding from the Canadian Institutes of Health Research as it is relevant to the CIHR's research mandate. To reach an acceptable level of knowledge and expertise in supportive care, we must initiate research into society's treatment of the chronically ill throughout the entire continuum of care, from prevention through diagnosis, treatment, support, and palliation. Education- and practice-related research must also recognize that chronic illness is but one of the reasons why high users of services carry a significant cost to society. Using cancer as a context for discussion, however, the National Cancer Institute of Canada (NCIC) has made a number of recommendations in support of intersectoral collaboration through research (June 1998). The use of a framework to produce research across disciplines is essential to the sharing of knowledge. The NCIC recommends the Canadian Framework for Cancer Control (Till, 1996), thereby affirming the importance of coordination between research and education at all levels and the need for leadership and mobilization of both academic and community resources. Adequate funding mechanisms and support for research into dissemination initiatives will lead to improved quality of life for communities at risk for chronic illnesses such as cancer.

## **Background**

In April 2000 the CIHR was established with a mandate to "provide new opportunities for health researchers through the introduction of new programs which will emphasize collaboration, capacity building, partnerships and translation of research information into improved health and health care" (Health Canada, 2000). The federal government provided the established national funding agencies with specific funds in support of these objectives: to help the research community plan col-

laborative projects such as a workshop/networking program to promote multi- and interdisciplinary research linkages.

Supportive care research traditionally has been under-funded and has lacked a coherent, organized approach to its conduct and dissemination. Typically, it has been carried out by busy clinicians and academics who have not been released from their workloads in order to concentrate on a program of research and have not been funded to synthesize and disseminate results and thus effect policy and service delivery. It is fragmented, disconnected, and episodic. Dissemination and utilization are further complicated by the existence of multiple delivery systems, since supportive care is often provided by those with little research training. Also, there is a dearth of supportive care research on culturally sensitive needs. Much of the work done to date has been disease-specific and separate from the economic evaluation of interventions. It is now being shown that supportive care interventions across the spectrum of diseases, ages, genders, cultures, and circumstances are sufficiently effective and efficient to justify supportive care as a field of inquiry pertinent to a cross-section of research endeavours (Browne, Watt, Roberts, Gafni, & Byrne, 1997b; Roberts et al., 1995). The demand for and use of health, social, and other human services is related less to disease type or severity than to a person's socio-economic, cognitive, and emotional characteristics in the context of their environmental circumstances. The accumulation of stressors in the absence of the supports that drive health-seeking behaviour results in the utilization of insured services, however inappropriate (Browne et al., 1999).

Supportive care research is central to the mission of the CIHR and the institutes it comprises. Nursing's vision for supportive care aligns closely with the objectives of the CIHR.

It was proposed that a workshop be organized to promote a robust research environment, the creation of new knowledge, the setting of an integrated health research agenda, the focusing of attention on the evolving health-care system, and the anticipation of health challenges as they emerge. However, a wider vision of supportive care would extend beyond the research and training perspective of the CIHR to include advocacy for a supportive care information system, surveillance, and policy development, as required by institutional, community, voluntary, private sector, family caregiver, and provider systems.

The first two authors were charged with the preparation of a summary report of the workshop proceedings. Over a period of 2 months, iterations of the report were circulated among the workshop

participants for refinement. To foster collaborative strategic planning in support of the CIHR, various recommendations emerging from the workshop were identified as within the mandate of existing health-related organizations. Small task forces were assigned to forge links with these organizations in order to develop collaboration and partnerships with the CIHR for the purpose of promoting supportive care research. The recommendations were incorporated into the final draft of the proceedings.

## **Present State of the Knowledge**

### ***Importance of Partnerships***

Complex societal issues such as those related to chronic illness and disability require a variety of knowledge and skill sets. Knowledge that is acquired, synthesized, and disseminated through partnerships with agencies, academic bodies, government, and the public is more likely than other types of knowledge to be effective in changing the behaviour of both providers and members of the public. Partnership facilitates the development and delivery of cost-effective services and support that are tailored to people's needs and that thus enhance people's ability to live with their circumstances, including illness. Improved patient outcomes and decreased expenditures on care are dependent upon the dissemination and utilization of innovative approaches to early detection, assessment, diagnosis, treatment, rehabilitation, palliation, and bereavement support, as well as to other determinants of overall health, such as personal circumstances.

Community (service)/university(research) alliances are being encouraged, with a view to promoting the convergence of scientific curiosity and social responsibility: "Academic independence can be balanced with involvement, rigor with relevance, freedom with social responsibility, security with risks attached to opportunity, impartiality with advocacy and empirical knowledge with experiential wisdom" (Browne, Watt, Roberts, Gafni, & Byrne, 1997a, p. 129). The role of consumers, such as their characteristics and circumstances that might predict their use of and response to screening, treatment, and palliative services, has received less attention in these strategic alliances. However, pilot projects have been carried out (Johnston, Murnaghan, Buehler, & Nugent, 1998).

A number of disease-related organizations, such as the Canadian Mental Health Association and the NCIC, have identified the need for

partnerships in the dissemination of research and the use of evidence-based information. A shift is now occurring in the end-user requirements of the system. Patients and families are no longer victims of a disease; rather, they are survivors who wish to be informed consumers of health and social services (Johnston & Short, 1999). They need to know what questions to ask, what information they require, and the extent of their problems, and their health professionals need to have the most current information in order to provide them with the best possible care.

### *Determinants of Health-Service Utilization*

The major determinants of health are those factors that together form one's capacity to respond to one's circumstances, such as through the utilization of health services. They are understood to be closely related to socio-economic situation, employment, degree of social support, and coping and cognitive ability (including the meaning given to illness). The capacity to respond to one's circumstances plays a greater role in health and service utilization than type or stage of disease, prognosis, or treatment (Arpin, Fitch, Browne, & Corey, 1990), and therefore in degree of reliance on the intersectoral service system (Browne et al., 1994).

As a disease with high mortality and morbidity rates, cancer represents a great economic burden. *Canadian Cancer Statistics* (Canadian Cancer Society/National Cancer Institute of Canada [CCS/NCIC], 2001) reports that each year, as the population ages and increases in size, the number of new cancer diagnoses increases; it predicts 134,000 new cases of cancer and 65,300 cancer deaths for Canada in 2001. Health Canada's Cancer Bureau estimates that if current trends continue the number of new cancers will increase by another 70% by the year 2010 (CCS/NCIC, 1999). In 1993 the economic burden of cancer in Canada, in both direct and indirect costs, exceeded \$13 billion (Moore, Mao, Zhang, & Clarke, 1997). It is only reasonable to expect that this figure will climb as the incidence of cancer rises. These facts, combined with the mounting pressure on the health-care system to contain and reduce costs, point to the need for evidence-based interventions that will produce the best outcomes in terms of both health and expenditures. Consequently, economic analysis has been established as an important tool in the planning, management, and evaluation of health care.



## **Workshop Process**

The invitational workshop in supportive care research was held in May 2000. Using cancer as the model, the workshop set out to create a template for supportive care research by focusing on two outcomes: a national research agenda that is groundbreaking in its approach to multidisciplinary and intersectoral supportive care research, and expert support and guidance for the mobilization of regional research teams to implement the national research agenda.

Workshop participants were noted researchers and advocates for the enhancement of quality of life and recognition of the supportive care needs of patients and families. They were a multidisciplinary, intersectoral group: health professionals, researchers, graduate students, and representatives of the private, public, and voluntary sectors. This seemingly broad inclusion of individuals supports CIHR's objectives. The workshop represented 2 days of vigorous small-group debate and in-depth plenary discussions using a consensus-building process. The group adapted the Canadian Cancer Control Strategy's (1999) definition of supportive care/rehabilitation, as follows:

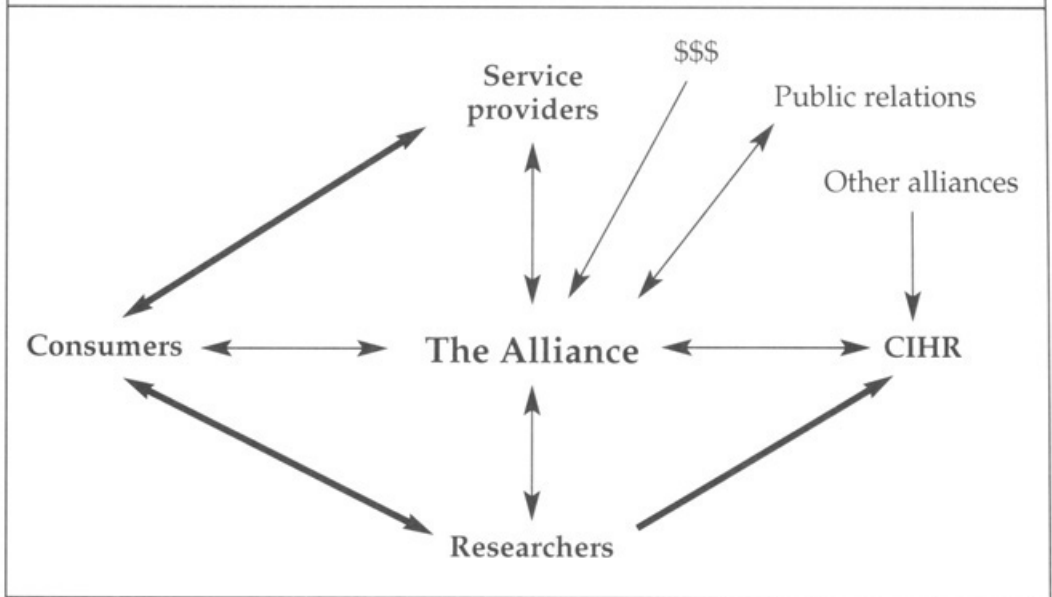
The provision of the necessary services as defined by those living with or affected by an illness to meet their physical, social, emotional, informational, psychological, spiritual and practical needs throughout the spectrum of the illness experience. These services must be available during the diagnostic, treatment and follow-up phases and encompass issues of survivorship, palliative care and bereavement. The breadth and complexity of supportive care/rehabilitation demands that a range of disciplines and organizations work together to provide the necessary services. (p. 7)

The group agreed to broaden the supportive care template by examining the issue across disciplines, sectors, and diseases. To this end, it assumed the task of supportive care advocacy from the perspective of chronicity (see Figure 1). A forward-thinking and achievable vision was developed: "All Canadians with disease and disability receive timely supportive care in the right amounts and duration to enable healthy living with all their challenges." The participants agreed that "the timing is right" for supportive care research to receive the attention it needs in our restructured health-care system. A readiness for action was considered critical.

## **Integrating Supportive Care Research Within the CIHR**

In the 21st century, innovation and creativity will be required to effectively manage the burden of chronic disease on the health-care system.

**Figure 1** *Supportive Care Research Alliance*



Inherent in the present restructuring of health-care delivery is a conceptual shift in considering end-user involvement. It is through intersectoral and multidisciplinary collaboration that research in supportive care will be most effective and efficient. This ideal was derived from the CIHR's guiding principles.

A comprehensive approach, from the basic sciences to supportive care interventions, will be taken in answering the following questions, with a view to advancing research in supportive care that is inclusive of family and other care providers throughout the trajectory of chronic illness:

***Increasing supportive care capacity.*** How can we develop criteria for identifying weaknesses and strengths in supportive care capacity in Canada? How can research be enhanced and strengthened regionally/locally and in underdeveloped areas of health research?

***Promoting the development of interdisciplinary and intersectoral research.*** What are the best means of developing domestic and international partnerships? What are the best program mechanisms? What interdisciplinary practices should be encouraged? How can we improve or develop partnerships with provincial governments, municipalities, and community groups?

***Dissemination and synthesis of research.*** How can researchers improve the translation, dissemination, and synthesis of research results for the benefit of health care and economic development? How

should research results be made available to the front-line workers and volunteers who provide much of supportive care and to the media?

*Role of an institute and its participants.* What should be expected of a member of an institute? Will expectations concerning supportive care differ for a researcher, a government official, a health professional, a member of an advisory group, and a member of a health charity? How should the frequently multiple roles and responsibilities of researchers be managed and rewarded?

*Development of world-class researchers and projects.* How can research leaders develop a pyramid of world-class researchers and projects? How can the institutes create and maintain the environment and conditions necessary for the development of world-class supportive care research in Canada?

### The Vision

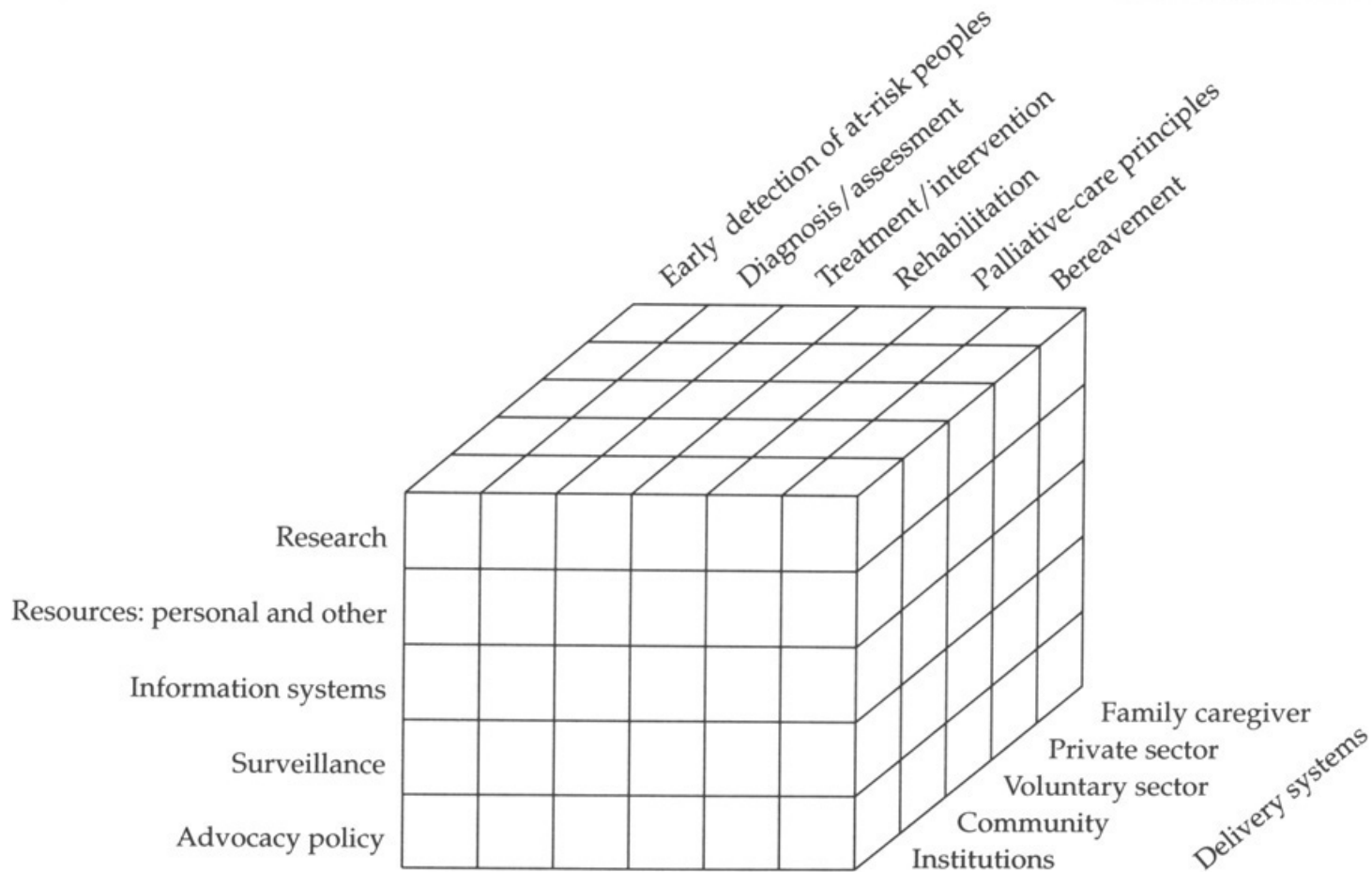
"All Canadians with disease and disability receive timely supportive care in the right amounts and of the right duration to enable healthy living with all their challenges."

The realization of this vision requires an awareness of the "profound and universal impact" of disease on the quality of life of individuals, families, and communities and an "invincible alliance" of organizations, constituents, and collaborators (Carlow, 2000, p. 32). The CIHR cannot realize the vision alone, but it can realize it by acting in concert with those many others who share it. The outcome will be a capacity to continuously link research with policy and with delivery of services. Through the CIHR institutes, Canada will be well positioned to provide global leadership in supportive care research and health-related quality-of-life outcomes.

Realization of the vision requires an alliance of advocacy and provider organizations involved in supportive care research, education, and delivery. This alliance would address the goals of a broad framework of supportive care inclusive of age, gender, and cultural sensitivity (see Figure 2), within which research and personnel training awards would be focused on the early detection and diagnosis of persons at risk and on assessment of the interplay of their challenges. Supportive care treatment, intervention, and rehabilitation strategies would be aimed at the level of individual, family, community, and population and would encompass palliative-care principles and bereavement. The framework would extend to all systems in which supportive care might be provided (institutions, voluntary sector, private sector, family).



**Figure 2** *Broad Strategy for Supportive Care*



Supportive care would be integrated across the CIHR themes of biomedical, clinical, and health services and the culture/society population perspectives inherent in each disease-specific institute. This vision is consistent with the visions suggested in the bioethics and health law submission to CIHR.

### **Research and Program Evaluation Needs**

The evaluation of new and established programs, though politically important, is usually not valued as research. There is a need for reflection on whether program evaluation is truly desirable in a social system of health. Workshop participants expressed the opinion that supportive care should be viewed as an essential component of research and that CIHR could take a leadership role by fostering an environment in which each component of the model is considered. As institutes make research decisions, the viewpoint inherent in the model for supportive care should prevail and evaluation should be funded as a critical aspect of research (see Figure 2). The approach to evaluation would ideally be interdisciplinary, multi-jurisdictional, multi-disease, inclusive of multiple illness trajectories, inclusive of multiple methodologies, cross-cultural, and inclusive of the under-served and the hard to reach.

Research and evaluation will include hypothesis-generating, epidemiology, multiple perspectives, and measurement using qualitative and quantitative methodologies. Supportive care will be inclusive of symptom management, health promotion, implications of genetics research, testing of alternative supportive care strategies, and the financing of supportive care structures as applicable to cross-cultural, under-served, and hard-to-reach populations, be they located in institutional or community settings.

### **Recommendations**

#### ***Supportive Care Research as a Distinct Field of Scholarship***

There was overwhelming support for the inclusion of supportive care research *as a component of all institutes* established under the CIHR. The delegates proposed a cross-cutting model that recognizes the distinct contribution of supportive care research to the mission and goals of each institute. While the establishment of a separate institute for supportive care was discussed, decision-making was influenced by a concern that this field of research would become further marginalized and that researchers presently working in this field would become further isolated. The advantages of a separate institute could be incor-

porated into a cross-cutting model through the collaboration of an alliance.

### *Development of a Supportive Care Research Alliance*

The role of the alliance would be to consistently advocate for supportive care research, as depicted in Figure 2. The alliance would set the priorities for the areas of supportive care research that should be strategically targeted across institutes. It would have the means to consider the broader mandate and ensure a cohesive strategy versus isolation and fragmentation.

The alliance would also work towards the dynamic partnering of various work groups. For example, the NCIC, the Canadian Cancer Society, Health Canada, and the Canadian Association of Provincial Cancer Agencies are working towards a coordinated approach to cancer control (Luciani & Berman, 2000; Foster & Boscaino, 2000). Within this structure, an Integration Group examines topic and themes including research, supportive care, and palliative care. Once a strategic framework is agreed upon, the establishment and implementation of a research agenda is logically linked to the appropriate CIHR institutes through the alliance. Less well-developed areas may require additional leadership and support.

### *Permeation of Supportive Care Throughout the CIHR*

To promote research and evaluation in all areas of supportive care and rehabilitation, a comprehensive approach would be taken, spanning the basic cellular to behavioural interventions that enhance quality of life, promote health, prevent illness, and reduce mortality and the impact of disease and treatment at both individual and population levels. This continuum of research is inclusive of genetics research, biomedical aspects of complementary therapy, clinical research, epidemiology, synthesis/dissemination for health service and policy decisions, and social determinants of health relative to supportive care.

### *Supportive Care Position on CIHR Governing Council*

The CIHR Governing Council should emphasize the concept of supportive care/rehabilitation and gear the CIHR's objectives, resource allocation, and budget to the realization of the vision. The Governing Council should provide for the exchange of supportive care knowledge and expertise across the institutes. In keeping with these goals, a promi-

nent researcher in supportive care should sit on the Governing Council. At the institute level as well, the structures developed to govern the work of each institute or advisory body should include an established researcher in supportive care.

### *Supportive Care Peer-Review Panel*

While supportive care research is not new, it is only now emerging as a scientifically relevant field of research in Canada, and the CIHR presents a unique opportunity for it to grow and develop. The peer-review process is critical to the recognition and acceptance of this body of science. In the absence of a national critical mass of researchers in supportive care, the academic and scientific integrity of the research is of the highest priority. A cross-institute panel could be established to review any application related to supportive care. In view of the cross-cutting themes of the model, a representative of the supportive care research community would be invited to sit on such a panel. Lay representatives knowledgeable in the area of interest would contribute to the review, particularly concerning the relevance and application of the proposed research, but would not be involved in the scientific ranking of the applications.

### *Capacity Building*

Canada does not have an abundance of behavioural scientists working in any one field ready to provide strong leadership within the CIHR institutes. Cancer may be the area best prepared to offer a national perspective through the theme-based sociobehavioural research networks. However, those presently working in the field are scattered across the country, in both academic and clinical settings, and are bound by the disease-oriented model of the dominant disease-based research funding systems. These barriers have contributed to the absence of an established critical mass of researchers with a common interest in sociobehavioural research from the perspective of chronicity and health challenges. A major gap identified by the Cancer Control Strategy Working Group (2000) is that between the best practice approach of clinical practice standards and behavioural research. The result is a huge deficit between possible supportive care interventions to enhance the effective and efficient use of the guidelines and the exploration of a full range of associated biopsychosocial outcomes.

Canada lags behind other developed countries in its commitment of funding and structure for research that is inclusive of supportive

care. If current trends continue, we will fall further behind. Canada has a history of missed opportunities in sociobehavioural, palliative, and end-of-life research. Based on the principles of the CIHR, “the timing is right” to rectify past mistakes and move forward in our understanding of the determinants of health and health-risk behaviours (2000).

The following initiatives warrant immediate attention: provision of graduate, doctoral, and post-doctoral fellowships in supportive care; provision of infrastructure grants; funding for a network of (non-disease-specific) supportive care researchers; provision of investigator-driven grants; provision of targeted research programs (those in cross-cutting areas warrant special attention as they may not fall within the priorities of any one institute).

### *Synthesis and Dissemination Research and Evaluation*

Funding should be made available for the synthesis of information on publicly, privately, and voluntarily funded models of supportive care and best practices in supportive care for people with acute or chronic physical/mental health problems or in challenging circumstances (poverty, immigrant status, etc.). In addition, funding should be made available to test ways of disseminating this synthesized information to decision-makers and thus fostering its use in policy and practice. Priority areas are: conferences and colloquia, synthesis of policy papers, and evaluation of different approaches to the dissemination of information and its application in policy and in practice.

### **Implications for Nursing**

In the absence of a national strategy for supportive care research, policy, and practice, people with chronic illness use a disproportionate quantity of crisis and expensive health-care resources that are not related to the type or severity of their disease or their treatment status (Browne et al., 1999). Consistent with the proposed vision, a national supportive care strategy would enable Canadians with disease and disability to live with all their challenges. A national nursing association would be well positioned to take a leadership role in formulating a national multidisciplinary, multi-sectoral strategy that engages researchers, clinicians, advocacy groups, and people facing major health challenges. The outcome would be to collectively advocate for a national secretariat that will move beyond the development of a strategic plan, to facilitate communications and implementation by decision-makers in the delivery of services at the provincial level. Future work-



shops should include strong representation from the service agencies and government decision-makers in addition to researchers.

This workshop provided an opportunity to begin addressing supportive care research. The participants acknowledged the need to move from a disease-specific model to embrace a chronic illness perspective. This represents a significant transformation in the conceptualization of supportive care. The CIHR has been challenged to be vigilant of the need for supportive care research across all institutes and to stress the relevance of research-policy-practice linkages. This is an opportunity for nursing to play a leadership role in the creation of a national strategy in an area of care that clearly represents the work of nurses in this country.

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### **Authors' Note**

The workshop discussed in this paper was funded by a grant from the Social Sciences and Humanities Research Council of Canada.

The authors wish to acknowledge the time and expertise provided by the delegates to the workshop and to thank Marilyn Landry for assisting with manuscript preparation.

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