SSHRC/CHSRF Health Institute Design Position Paper:

Canadian Institute for Research on Nursing and Caregiving

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- The related practices of nursing and caregiving are of great importance to the health and wellbeing of many Canadians. Nursing and caregiving research has not achieved suitable recognition on the Canadian scene because there has been no visible place for it in the national health research infrastructure. The goals of the Canadian Institutes of Health Research can not be realized without a vibrant and productive research community engaged in the study of problems central to the domains of nursing and caregiving.

- Caregiving is practiced by disciplines such as nursing (the largest health care discipline), family medicine, physical, occupational and hearing/speech therapy, social work, midwifery and clinical psychology -- disciplines which share responsibility for humane and supportive care during health and illness. Their common scientific interest, which might be called “the science of caring”, requires an orientation toward both the social-behavioral and the life sciences. Both major scientific perspectives must be brought to bear in understanding the human experience of health and illness, and in developing and testing effective and efficient approaches to enhancing human health.

- The current CIHR sector model should be revised to include a new sector of ‘basic human research’. This change would result in three basic fields (biomedical, basic human research and society, culture and health) in balanced and dynamic interaction with each other and with the two applied fields of research (applied clinical research and health systems research), thus avoiding the appearance that basic biomedical research is the only form of basic science in the CIHR.
The creation of a Canadian Institute for Research on Nursing and Caregiving exemplifies the spirit of innovation and transformation of the CIHR -- by making visible its commitment to the improvement of nursing and caregiving practice.

Executive Summary - SSHRC/CHSRF Health Institute Design Project

The Canadian Institute for Research in Nursing and Caregiving

Health care in Canada is provided by 377,000 health professionals, thousands of skilled and unskilled health care workers, and countless family members. It is often assumed that caregiving is a natural human behaviour, intrinsic to the provision of health care and therefore does not require study in and of itself. However, there is growing evidence that caring practices, when informed by a strong scientific base, can promote health, potentiate the effects of treatment and contribute substantially to quality of life. The process of caregiving has profound impact on the health of Canadians.

In 1996, approximately 66% of employed health professionals or 247,000 were nurses (Canadian Nurses Association, 1998). Nursing care has always been and continues to be the major “product” of hospitals, extended and long term care facilities, since individuals are admitted to such institutions primarily because they require continuous nursing care. Nurses care for individuals of all ages across the full range of health and illness experiences, and work with many others to direct and provide care in institutional, community and home settings.

The practices of nursing and caregiving are closely related. Nursing is the diagnosis and treatment of human responses to illness and threats to health in individuals, families, groups and communities. It is concerned with the prevention of illness, the restoration and promotion of health and the achievement of peaceful death. Caregiving is a set of activities focused on helping others to do what they would do for themselves if they had the ability and knowledge. Caregiving may be provided by a wide range of individuals, and does not always occur simultaneously with medical treatment. Caregiving is a collaborative practice typically involving disciplines that share a central interest in the quality of life and health such as nursing, family medicine, midwifery, social work, occupational, physical and speech therapy, clinical psychology and others that share an intrinsic interest in the quality of life and health, as well as non-professional health care workers, volunteers and family members.

Statement of need and potential contribution: The practices of nursing and caregiving require a scientific base of knowledge that is biopsychosociocultural in nature, and can be thought of literally, as "the science of caring". The science of caring provides a basis for practice for a broad spectrum of caregivers through the examination of and attention to the needs of humans in the context of their own life experiences of health and illness.

Despite the predominant place of nursing and caregiving in health care, designated funding for research into nursing and caregiving issues has been absent in any substantive way at federal and provincial levels. The lack of an appropriate and visible structure for support of research in nursing and caregiving has resulted in fragmentation and lack of recognition of the field. For instance, scientists have been...
successful in obtaining funding by tailoring proposals for SSHRC, NHRDP, CHSRF, voluntary national and provincial health research foundations, and there have been some recent successes with MRC. However, this wide array of funders has disbursed research in nursing and caregiving such that there is no “critical mass” of caregiving research investigators visible at the national level. Further, funding patterns have contributed to a predominance of psychosocial-behavioural and health systems research in Canadian nursing. Research in these areas is clearly important, but it represents only a part of the ‘natural reach’ of nursing science. The relative inaccessibility of training and program funding in physiologic and biobehavioural aspects of nursing research has seriously limited the field’s capacity for discovery and innovation.

Given appropriately structured funding mechanisms, Canadian researchers in the fields of nursing and caregiving would have the opportunity to explore important new directions for research. Such directions might include developing pre- and post-doctoral research training programs drawing from both the life and human sciences, and establishing funding priorities in areas such as individual and family adaptation to chronic illness, symptom reduction and management, the impact on comfort measures on physiological parameters in critically ill children, and the interface of caregiving and physiological instrumentation.

The problem of access to appropriate funding mechanisms can also be seen in a particular lack of recognition of the field at the national level. In the last five years, several outstanding Canadian nurse scientists have been unsuccessful in MRC funding reviews, yet received substantial awards for virtually identical proposals from multidisciplinary review panels of the National Institutes of Health/National Institute for Nursing Research (NINR). It is clear that in these cases, the quality of the research was not at issue. Nor can a lack of recognition of the field easily be attributed to insularity on the part of nurse scientists. The majority of awards to nurse scientists from MRC, SSHRC, NHRDP, and CHSRF have involved interdisciplinary teams. A number of interdisciplinary research centres are already directed or co-directed by nurse scientists, such as La Chaire de recherche à la personne âgée et à la famille du Centre de recherche de l’Institute universitaire de gériatrie de Montréal, the Quality of Nursing Worklife Research Unit (University of Toronto/McMaster), the System-Linked Research Unit (McMaster), the International Institute for Qualitative Methodology (University of Alberta) and the Institute for Health Promotion Research (University of British Columbia).

Thus, we argue that the critically important field of nursing and caregiving research has not achieved suitable recognition on the Canadian scene -- not because there are too few well-qualified investigators engaged in strong programs of research, or because these investigators fail to grasp the importance of interdisciplinarity -- but because there has been no visible place for it in the national health research infrastructure.

Research in nursing and caregiving can be better understood and therefore more effectively integrated into the wider arena of health research when an appropriate funding structure is in place. Evidence of this can be seen in the results of the Low Birth Weight Research Initiative, sponsored by the NIH-NINR in the early 1990’s. Leading scientists in nursing and other fields concerned with the prevention and treatment of low birth weight were assembled and a consensus paper on research priorities was developed and circulated. Over the three years of the initiative, project awards were made by NINR through this initiative. Funded projects ranged from basic investigations focusing on unintended negative consequences of preterm labor treatments on
individuals and families, and clinical trials to test the effects of prolonged activity restriction on high-risk pregnant women, and new breast milk feeding techniques for very low birth weight infants.

Because this NINR initiative was visible across the NIH structure, studies directed by nurse investigators attracted the attention of investigators in perinatology, developmental physiology and health systems research. Findings from NINR-funded studies influenced the subsequent work of at least two biomedical investigators funded elsewhere in NIH, not because they read published findings, but because the research teams connected while work was in progress. As a result, new scientific knowledge has been incorporated into clinical practice guidelines ranging from home-based care and treatment of preterm labor to feeding techniques for very low birth weight babies.

In summary, the potential range and scope of nursing research and research in caregiving in Canada can be more fully realized and better utilized if suitable structures existed at the national level. Such structures would literally transform this important field of health research -- by facilitating a focused national research agenda, and by creating suitable research training and capacity-building mechanisms.

Consensus development and position: The project team gathered information and opinion on ways to incorporate appropriate support for research in nursing and caregiving within the emerging CIHR structure. The project team held discussions with representatives of major nursing organizations, and consulted with individuals in other health disciplines (rehabilitation sciences, social work, child and youth services), social sciences, humanities and health research teams working on CIHR-related projects at several research-intensive universities, and with NIH/NINR staff. Based on these discussions, an electronic survey was then distributed to Canadian nurse scientists, clinicians and administrators. Responses were received from 47 of 160 distributed over a seven-day period in August. The project team met for two days to review survey input and discuss the state of nursing and caregiving science, and considered the following options: nursing and caregiving as a cross-cutting theme; the creation of an institute for nursing research, and the creation of an institute including nursing research and the broader area of research in supportive care and caregiving.

The following actions are recommended: first, the current ‘sectors/pillars of health research’ model now under discussion be revised as follows: to include a new sector of ‘basic human science’ which complements biomedical science and which acknowledges the importance of basic research at the level of the individual, as well as the level of society and culture. While biomedical research employing animals and human tissue provides necessary information at the cellular level, basic studies with humans provide invaluable information at the level of the person. There is no question that the sector currently identified as ‘society, culture and health’ is a critically important area of basic research and must be preserved in the sector model. Nevertheless, important questions to be answered in regard to the improvement of human health must be posed at the interface of the biological, the psychosocial and the sociocultural realms; the current description of the ‘culture, society and health’ sector renders that critical interface invisible. This proposed change to the sector model would have the advantage of showing more clearly two basic fields (biomedical and basic human science) in balanced and dynamic interaction with each other and with the two applied fields of research (applied clinical research and health systems research).

Second, an Institute for Research in Nursing and Caregiving (IRNC) should be created within the CIHR structure. The IRNC would have several critical functions:
o the creation of a national research agenda in nursing and caregiving, and the representation of nursing and caregiving science perspectives in priority-setting activities of other CIHR structures, as appropriate;

o the establishment of targeted pre-and post-doctoral training initiatives in service to this research agenda in collaboration with other research organizations and CIHR structures;

o the establishment of effective information and communication networks within the broad field of nursing and caregiving research and across the CIHR community to promote better integration of health research.

Investigators from a wide array of disciplines will find the IRNC a logical ‘home’ for their scientific work, just as nurse scientists will most certainly participate in other CIHR institutes. It is clear that robust collaborations will evolve between the IRNC, other CIHR institutes and groups, and organizations in Canada and globally, as has been the experience of the NIH/NINR. Finally, we maintain that the visibility which will result from the creation of this institute may well attract new sources of research support, by virtue of the growing public awareness of caregiving issues in the health care arena. Such an institute, with its implicit orientation toward both the human and the life sciences, would establish new links between dominant and emerging scientific traditions in health research. Its creation will signal a recognition of the centrality of care and caregiving in the improvement of human health. It will make visible and enhance the research capacity of a field that 2/3 of the working health professionals in the Canadian health care system call their own. Finally, it will link within the CIHR structure those researchers from a number of disciplines who are concerned with the “science of caring”.

Introduction

The primary objectives of the Canadian Institutes of Health Research (CIHR) are to promote the creation of new knowledge and its translation into improved health for Canadians, more effective health services, and a strengthened Canadian health care system. The CIHR is envisioned as a catalyst for innovation, promoting interdisciplinary and integrative health research ranging from basic research to applied clinical and systems-level research, and fostering collaboration across voluntary, community and private sectors. The establishment of the CIHR presents an opportunity to capitalize on existing strengths in Canadian health research, as well as to create conditions in which critical emergent areas of research may be fostered.

In this spirit of innovation and opportunity, we propose that a Canadian Institute for Research in Nursing and Caregiving (CIRNC) be created within the CIHR. This paper will outline the scope and significance of research in nursing and caregiving, identify the relationship of this realm of research to other fields in the proposed CIHR structure, and describe the benefits to Canadian health care which will be realized by the creation of this institute.

Nursing and Caregiving - Scope and Significance

Health care in Canada is provided by 377,000 health professionals, nearly 66% of whom are nurses.¹ Care is also provided by thousands of skilled and unskilled health care workers, volunteers and family members, sometimes with minimal or no support from health professionals. Knowledge and skills in the processes of caregiving cannot be assumed. The related practices of nursing and caregiving are of growing importance to the health and wellbeing of many Canadians. Unfortunately, even a cursory examination of past research funding patterns in Canadian health research will reveal
that, by any reasonable standard, the Canadian investment in creating and transferring new knowledge to improve the quality of nursing and caregiving services to date has been inadequate.

**The Science of Caring**

The centrality of care and caregiving in the protection and restoration of health is unquestionable. Given this, the overarching goal of the Canadian Institutes of Health Research -- to develop knowledge which can improve the health of Canadians -- will not be fully realized without steps to promote a vibrant and productive research community prepared to engage in the study of problems central to the domains of nursing and caregiving.

**Nursing:** Nursing is the diagnosis and treatment of human responses to illness and threats to health in individuals, families, groups and communities. It is concerned with the prevention of illness, the restoration and promotion of health and the achievement of peaceful death. Caring practices have assumed a central place in the contemporary philosophy of nursing, with caring defined as a complex human-to-human activity mediated by professional, personal, scientific, esthetic and ethical concerns. 

The comprehensive scope of nursing practice requires a knowledge base that is biopsychosocial in nature. Both nursing practice and nursing research focus on the human experience of health, illness and disability in the context of daily life. Nursing as a profession has strong links to a number of other disciplines and integrates its own knowledge base with knowledge from a wide range of fields.

Nursing is, quite literally, at the core of health care. Nursing care has always been and continues to be the major “product” of hospitals, extended and long term care facilities, with individuals admitted to such institutions primarily because they require continuous nursing care. Moreover, nurses work in virtually every sector of the health
care system caring for individuals of all ages across the full range of health and illness experiences, and collaborating with other professionals and laypersons to direct and provide care in institutional, community and home settings.

**Caregiving:** Caregiving is the meaningful and intimate process of meeting basic human needs during period of dependence, illness and disability. Caregiving is at the core of the practice of a number of disciplines, including nursing, family medicine, social work, occupational, physical and hearing and speech therapy, midwifery and clinical psychology. Each discipline plays a unique role in the health care system and thus defines caregiving in its own way. Even within disciplines, caregiving is defined a number of ways, but one of the oldest and most well-accepted definitions in nursing is as a set of activities focused on helping others to do what they would do for themselves if they had the ability and knowledge.³

Caregiving practices, when informed by a strong knowledge base, can promote health, potentiate the effects of treatment and contribute substantially to quality of life. Caregiving practices include:

- relieving discomfort and distress,
- assisting individuals to understand the nature of their illness and assume a role in their own care consistent with their desire and ability,
- facilitating family wellbeing during periods of dependence, illness or disability,
- supporting the processes of recovery, rehabilitation and adaptation, or of peaceful death.

Caregiving often but not always occurs in concert with medical treatment, and thus is also practiced by a wide range of individuals who are not health care professionals. Among lay people, family members are the most common caregivers. It
has been estimated that 80% of the eldercare in Canada is delivered by members of their families.\(^4\)

Caregiving is practiced by disciplines with rather distinct histories and patterns of practice, but which nevertheless share as a major focus the provision of humane and supportive care during health and illness. These disciplines also share somewhat similar approaches to the development of knowledge for the improvement of practice. This common approach could literally be thought of as “the science of caring”. The science of caring requires an orientation toward both the social-behavioral and the life sciences, because both major scientific perspectives must be brought to bear in understanding the human experience of health and illness, and in developing and testing effective and efficient approaches to enhancing human health.

Nursing research provides a useful example in this regard. Nurse researchers usually have a predominant orientation toward the social-behavioral or the biological-physical sciences, but invariably account for both perspectives in framing their research questions. Thus, an individual investigator’s program of research may begin with questions about a particular phenomenon of concern to nursing, such as more effective care of children with cancer pain. However, questions would be framed, based on an understanding of the nature of cancer and cancer pain (biophysical and physiological), the therapies currently in use, as well as developmental (psychosocial and behavioral) theories pertaining to childhood, and family and social dynamics which influence the care of children. Thus, it is apparent that, even before a specific research question has been delineated, the researcher is already drawing on knowledge from nursing as well as a number of other domains.

This integration of the life sciences and social-behavioral sciences is typical of research in caregiving disciplines. Because of the inherent complexity of “whole person”
research, such programs are often innovative in their approach. Designs and methods employed in caregiving research typically range from those appropriate for understanding biophysical and physiological phenomena through to those approaches typically used to understand human behavior in the context of larger social and cultural dynamics.

It is the very nature of research in this field -- highly integrative, focusing on the complex and multifaceted phenomena of human health and illness and encompassing physical, psychosocial, cultural and even spiritual dimensions -- that makes it somewhat unique within the wider realm of health research. It also is one of its significant strengths, since by its very nature, caregiving research has the capacity to establish new links between dominant scientific traditions.

**The Place of ‘Whole Person” Research in CIHR Vision**

It is this particular perspective on “whole person” science that researchers in nursing and caregiving bring, which highlights one aspect of the proposed CIHR structure which we suggest requires further thought.

**Basic Biomedical Science vs Basic Human Research:** Missing from the proposed sector model of the CIHR (basic biomedical, applied clinical, society, culture and health, and health services/systems research) is a place for basic human research. Although such work might conceivably be placed within the basic biomedical sector, the fit is less than ideal. Basic biomedical research typically involves the use of animal or in-vitro models while basic human research involves humans as subjects. While basic studies with animals and human tissue provide valuable information at the cellular level, basic studies of humans and their responses to health and illness provide essential information at the “whole person” level. The research designs and methods, as well as
the criteria for judging rigor, differ in these two sectors of research in critical ways, and rarely does expertise in one of these sectors translate well to the other.

**Basic Human Research Sector:** We recommend that the sector model be revised to include a new sector of ‘basic human research’ which complements biomedical research and which acknowledges the importance of basic research at the level of the individual in addition to the level of society and culture. There is no question that the sector currently identified as ‘society, culture and health’ is also a critically important area of basic research and must be preserved in the sector model. Nevertheless, important questions to be answered in regard to the improvement of human health must be posed at the interface of the biological, the psychosocial and the sociocultural realms. The current descriptions of the ‘basic biomedical research’ and the ‘culture, society and health’ sectors render this interface quite invisible. Critical issues such as human responses to pain, individual choices about health behavior, and daily coping in the context of chronic illness would be subsumed in this new ‘basic human research’ sector.

This proposed change to the sector model would have several advantages. First, it would show three basic fields (biomedical, basic human research and society, culture and health) in balanced and dynamic interaction with each other and with the two applied fields of research (applied clinical research and health systems research), thus avoiding the appearance of basic biomedical research as being the ‘gold standard’ of basic work in the CIHR.

Second, this modification of the sector model would enable researchers in the field of nursing and caregiving to align themselves across the spectrum of basic research through services and systems level research without necessarily having to use the ‘basic biomedical’ sector as the starting point of the continuum. For example, while
nurse scientists can and do use physiological and biophysical data to answer basic questions of significance in their field, it is unlikely that such work would appropriately be categorized as being “basic biomedical” in nature. Finally, the addition of a ‘basic human research ’ sector will allow basic human research done by a number of other disciplines unlikely to rely on basic biomedical knowledge (such as social work, clinical psychology), as well as those which may use biophysical or physiological data in their basic human research (such as nursing, occupational and physical therapy, speech and language pathology) to be appropriately accounted for in the model. It should be noted that this recommendation is consistent with one contained in the paper “Creation of an Institute for Public Health Research”, presented at the SSHRC/CHRSF Health Institutes Design Interactions Workshop held in October 1999.  

**Underinvestment in Research at the Core of Canadian Health Care**

Many Canadians are increasingly concerned about the quality and cost of nursing and caregiving services, and the depth of their concern should not be underestimated. In 1996, two million informal caregivers (usually a spouse or daughter) were providing an average of 4-5 hours of care per week to seniors with long-term health problems in Canada. The repercussions of that caregiving responsibility can be seen in financial strains from reduced income from lost time from paid employment and out-of-pocket costs, as well as physical, emotional and social consequences of caregiving. Given the aging population and the recent reductions in funding for health care and social programs, there is increasing pressure on informal caregivers to participate in meeting the health care needs of their loved ones. The challenge of providing adequate nursing and caregiving services in the foreseeable future is daunting in and of itself. However, this challenge looms even larger because of the historic
underinvestment in health research to improve services which lie at the core of health care.

This tendency of decision-makers to overlook research in nursing and caregiving is apparent, not only in federal and provincial research funding allocations, but also in institutionally-based research support within the health care system itself. Although nursing and caregiving services are the major “product lines” in the Canadian health care system, research and development funding directed toward these fields from within the system itself has been virtually non-existent. Most provincial hospital acts mandate support for medical research activities and infrastructures at teaching hospitals, and many provincial health agencies maintain intramural programs of biomedical health research. There are virtually no similarly targeted allocations for research in nursing and caregiving, and health care agencies, including a number of academic health science centres, do not employ any individual with research preparation and resources to conduct research in these critical areas. Indeed, at a national meeting on the future of Canadian academic health sciences several years ago, the domains of nursing and caregiving were not even mentioned by conference speakers as critical areas of activity and deserving of research investment, until nurse scientists and nurse administrators in the audience raised the issue themselves. 8

However, recent signs suggest that this legacy of underinvestment may be changing. Some academic health science centres have begun to recognize the critical need for knowledge generation in these areas, through the creation of organized research units in patient services and the appointment of senior scientists with preparation in nursing and caregiving research on staff. However, such investments do not even begin to approach the commonly accepted standard of investing 2% of available resources in research and development pertinent to major institutional
objectives, which would of necessity include nursing and caregiving services. Further, these allocations are but the smallest fraction of what is routinely allocated by those same institutions for basic biomedical and applied clinical (medical) research.

The recent allocation of Federal support to create what has been called the “Nurse Fund”, with its goal to stimulate nursing research specifically in the areas of nursing administration and policy development through a targeted investment in senior nurse scientists across the country, is a welcome first step. Nevertheless, this investment of $25 million over a 10 year period represents only a small allocation, given the magnitude of nursing’s contribution in the health care system. Further, it must be remembered that this fund is specifically intended to focus on nursing policy, administration, human resources and service delivery. This fund will have no direct effect on nursing research in general, or on nursing research addressing caregiving issues.

Finally, while caregiving is receiving increasing attention from government and voluntary agencies, at times the importance of research still goes unrecognized. The recent announcement by the Ontario government that it was allocating $68 million to what it called “Canada’s first comprehensive plan to tackle the epidemic of Alzheimer’s disease” was notable in this regard. This funding was being specifically targeted for caregivers who are looking after their loved ones, and would not be spent on “medical research”. Unfortunately, no mention was made of supporting critically important research into caregiving itself, such as developing and testing ways to improve support to family caregivers, or examining the most efficient and effective ways to use non-professional caregivers. Quite literally, in this announcement, research (defined as medical research) was ruled out, while the necessity for other critical research to
improve our understanding of the processes of caregiving appears to have gone unnoticed.

Invisibility of Research in Nursing and Caregiving in the Canadian Health Research Arena: A Function of Structure?

There are probably many reasons why research in nursing and caregiving is often overlooked or absent from the Canadian health research scene. Some argue that this is because, until only very recently, research funding in nursing and caregiving has been extremely limited both at Federal and provincial levels. Others point to the relatively recent development of research training in nursing and other caregiving disciplines in Canada, and question whether this scientific community is sufficiently mature to justify substantial increases in funding at the national level. Still others argue that high-quality research is already being funded and the scientific community is developing reasonably, but the absence of an appropriate and visible structure for support of research in nursing and caregiving has significantly limited growth.

The conditions in Canadian nursing research probably mirror those in other disciplines that have a compelling interest in care and caregiving. Research training in nursing came into its own only relatively recently in Canada, although many nurses sought doctoral preparation in other related fields, or in nursing programs in the United States. By 1990, a critical mass of active investigators with provincial and federal funding allowed the development of doctoral programs in nursing to begin; programs were subsequently established at the University of Alberta, the University of British Columbia, the University of Toronto, McGill University, the University of Montreal and more recently, at McMaster University.

Since that time, increasing numbers of nurses have received research training in Canada each year. In 1998, there were 551 nurses with doctorates in Canada (184
with doctorates in nursing, and 367 with doctorates in other fields. As would be expected, nurses with doctorates are concentrated in education (n=284) with a smaller but growing number in research positions outside academic nursing units (n=39). In addition, there are 7885 nurses with masters preparation, many of whom are suitable to enter doctoral programs in nursing or related fields.⁹

One has only to examine the range of funding sources tapped by nurse scientists to conclude that the scientific community in nursing is vibrant, committed and rather resourceful in competing for available research support on the national scene. Examples of highly successful programs of research in nursing currently or recently funded at the national level can be seen across the country, focusing on critical problems in nursing and caregiving, such as:

- Development and testing instruments to measure pain in premature infants and testing of non-pharmacological interventions that work to reduce pain;
- Development of ways to teach non-professional caregivers how to assess demented long-term care residents to determine what abilities they have retained and then to help residents use these abilities, thus reducing aggression and distress in daily care;
- Development of highly effective strategies to promote smoking cessation among postpartum mothers, adolescents and surgical patients;
- Exploration and documentation of comforting actions and behaviors by nurses from the perspective of hospitalized patients;
- Examination of the utility and applicability of conventional health care ethics in the context of multiculturalism;
- Examination of women’s responses to caregiving of spouses following myocardial infarction;
testing of home- and hospital-based strategies to facilitate coping with HIV;
examination of the long-term impact of children's experiences with invasive
procedures in pediatric intensive care and general units;
development of criteria for segregating vs integrating cognitively impaired and
non-impaired elderly in institutional settings;
development and testing of a nursing intervention to reduce stress and
increase effective coping in families with a handicapped child;
examination of factors associated with well-being of caregivers of
institutionalized demented elders in regard to family-level intervention;
examination of alternative approaches to psychiatric deinstitutionalization
through partnerships between hospitals, community health care agencies and advocacy
groups.

The capacity of the Canadian nursing research community for interdisciplinary
work is apparent. Many nurse scientists have graduate training in other fields, and
maintain those linkages in their post-doctoral work. For example, nurse scientists
currently conduct programs of research in symptom management among cancer
patients that involves pharmacokinetics and psychoneuroimmunology. Some explore
fetal and newborn sensory and cognitive development using techniques long regarded
as the domain of “basic science”. Others develop and test models of exercise in
cardiac rehabilitation, evaluate educational strategies aimed at improving symptom self-
management among asthmatics, and examine models of community integration for
individuals discharged from psychiatric hospitals. There are established interdisciplinary
centres headed by nurse scientists across Canada, such as La Chaire de recherche à la
personne âgée et à la famille du Centre de recherche de l'Institute universitaire de
gériatrie de Montréal, the Quality of Nursing Worklife Research Unit (University of
Toronto/McMaster University, 1989-1997) and the subsequent Nursing Effectiveness, Utilization and Outcomes Research Unit (1998), the System-Linked Research Unit (McMaster), and the International Institute for Qualitative Methodology (University of Alberta).

Regrettably, these successes have been achieved in spite of the fact that there has been no targeted national investment in nursing science and in the development of nurse scientists, and that the most accessible sources of funding have been less than stable in recent years. For example, nurse scientists have a strong record of funding support through training and career awards as well as operating grants through the National Health and Research Development Program (NHRDP). However, change to NHRDP's mandate over recent years, as well as a significantly reduced base budget, has limited the scope of its research activities. In particular, research focused on evaluating clinical nursing interventions, as well as caregiving interventions by other health professionals or family members, is no longer eligible for funding consideration by NHRDP. Without stable sources of funding, the development of strong research teams and the conduct of multi-site nation-wide research on nursing and caregiving has been difficult. In addition, the number of NHRDP personnel awards has decreased dramatically and some are no longer offered (e.g., scientist award). This has meant that worthy applicants have not been funded, many from disciplines with historically limited access to MRC support.

Along with these changes, other sources of targeted funding in Canada have terminated (e.g., Alberta Foundation for Nursing Research, Canadian Nurses Foundation), and provincial funding for health research varies substantially between provinces and from year to year. For example, this year in British Columbia, uncertainties related to budget allocations from the provincial government for health
research forced the BC Health Research Foundation to cancel its operating grant competition and decrease the number of personnel awards. This was a critical source of preliminary funding for all health researchers in the province, but its loss was particularly damaging to emerging fields such as nursing research where other sources of funding have been quite limited.

Further, past funding practices (and even elements of the current Federal funding strategies for nursing) have contributed to a predominance of psychosocial-behavioral research in Canadian nursing and a concomitant underdevelopment in physiologic and biobehavioral areas, areas of equal scientific importance to the profession. The discipline of nursing is intrinsically holistic and there is justifiable resistance to being dichotomized as either ‘psychosocial’ or ‘biomedical’. However, the majority of career development awards and operating grants received by nurse investigators in the last 10 years have been from agencies that emphasized the social and behavioral sciences or health systems research. Such research clearly plays an important role in the development of knowledge relevant to nursing care, but it represents only a part of the ‘natural reach’ of nursing science.

The relative inaccessibility of training and program funding in physiologic and biobehavioural aspects of nursing research has seriously limited the field’s capacity for discovery and innovation. This can be seen most clearly when one compares the state of scientific development in areas of nursing research involving biophysical measurement in the United States and in Canada, resulting in very large part from the creation of the National Institute for Nursing Research (NINR) within the National Institutes of Health (NIH).

**The National Institutes of Health-National Institute of Nursing Research example:** Despite its modest funding level, the National Institute for Nursing Research
(NINR) has had a significant impact on the health research agenda in the U.S. over the last decade, and early reservations about the appropriateness of a discipline-specific institute in NIH have long since been forgotten. The NINR was established in 1986 with $16M (US) as a base budget, by far the smallest of the NIH institutes. Their funding levels have steadily increased, and the proposed 1999 allocation is $80M (still the smallest within the NIH structure) in support of 2.5 million practicing American nurses.

The NINR now funds 100% of postdoctoral fellowships in nursing and approximately 12% of predoctoral students in graduate nursing programs in the United States. It currently funds research projects across the spectrum of nursing science, and has strategic initiatives in areas such as:

- chronic illness and long-term care,
- health promotion and risk behaviors,
- cardiopulmonary health and critical care,
- neurofunction and sensory conditions,
- immune responses and oncology, and
- reproductive and infant health.  

The visibility of nursing research within the NIH also allows questions of central importance to the discipline to be addressed by an appropriate funding agency, rather than expecting agencies with only a tangential interest in these questions to respond. Perhaps the best example of this dynamic can be seen in the recent experience of several senior nurse scientists in Canada, who were unsuccessful in MRC funding reviews, yet subsequently received substantial awards from the National Institutes of Health/National Institute for Nursing Research for virtually identical proposals. The problems these investigators were addressing in their proposals were topics such as:

- the human experiences of comfort and suffering in hospital settings, and
o the effects of specialized nursing interventions during labor and birth on maternal and neonatal outcomes

There is no question as to the quality of the work proposed and eventually conducted by these investigators; the problem quite simply was the absence of an appropriate funding structure for nursing research in the Canadian health research arena. Thus, we argue that the critically important field of nursing and caregiving research has not achieved recognition on the Canadian scene -- not because there are too few well-qualified investigators engaged in strong programs of research, or because these investigators fail to grasp the importance of interdisciplinarity -- but because there has been no visible place for it in the national health research infrastructure.

Research in nursing and caregiving can be better understood and therefore more effectively integrated into the wider arena of health research when an appropriate funding structure is in place. Evidence of this can be seen in the results of the Low Birth Weight Research Initiative, sponsored by the NIH-NINR in the early 1990’s. Leading scientists in nursing and other fields concerned with the prevention and treatment of low birth weight were assembled and a consensus paper on research priorities was developed and circulated. Over the three years of the initiative, project awards were made by NINR, ranging from basic investigations focusing on unintended negative consequences of preterm labor treatments on individuals and families, and clinical trials to test the effects of prolonged activity restriction on high-risk pregnant women, to the development and testing of new breast milk feeding techniques for very low birth weight infants.

Because this NINR initiative was visible across the NIH structure, studies directed by nurse investigators attracted the attention of investigators in perinatology, developmental physiology and health systems research. Findings from NINR-funded
studies influenced the subsequent work of at least two biomedical investigators funded elsewhere in NIH, not because they read published findings, but because the research teams connected while work was in progress. As a result, new scientific knowledge has been incorporated into clinical practice guidelines ranging from home-based care and treatment of preterm labor to feeding techniques for very low birth weight babies.

Why a Canadian Institute for Research in Nursing and Caregiving Now?

We acknowledge that this proposal may seem to run counter to prevailing views about the nature and scope of institutes and the integration of research across sectors within CIHR. In fact, we agree with much of the public discourse to date. The four sectors currently identified as central in the CIHR (basic biomedical research, applied clinical research, society, culture and population health, and health-related services and systems) reflect a strong commitment to fostering high-quality science across the spectrum of health research. While we have made specific suggestions earlier in this paper as to how the sector model might be even more “inclusive”, the underlying logic of the model is quite sound.

Nor do we disagree that the institute structure should be forward-thinking and flexible, capable of fostering integration of health research across sectors and innovation “at the margins” of established and emerging fields. The CIHR will not be well served by the creation of a large number of institutes, or rigid structures reflecting outdated thinking. Nevertheless, the institute structure lies at the very heart of the CIHR concept, and the potential of the CIHR will be realized only to the extent that this structure captures both the commitment of Canadian health researchers and the changing demographics, health care needs, and even perhaps, the imagination of the Canadian public.
Indeed, the average Canadian taxpayer readily understands that scientists in the Canadian health system may be divided roughly into two groups: those interested primarily in research directed at preventing and/or curing disease, and those interested primarily in research directed at caring for those experiencing illness and incapacity. Both groups are seen to play a vital role in contributing to the health of Canadians. Both groups and, in all likelihood, subdivisions of each group, will argue for the need for research institutes to develop the science underpinning their respective fields.

In this proposal, we argue for the creation of a Canadian Institute for Research on Nursing and Caregiving, because it makes visible the commitment of the CIHR to the improvement of care and caregiving. These endeavours have an enormous impact on families and the health of Canadians, by virtue of their central place in the health care system, and their centrality in the human experience of health and illness. An institute with such a mandate -- one which acknowledges the largest discipline in modern health care (nursing) and emphasizes a broadly defined domain of activity (caregiving) which spans a number of disciplines as well a legions of “non-professional” caregivers -- may well be unique among the institutes to be created. We argue that this uniqueness is entirely in the spirit of innovation and transformation of the CIHR.

The creation of the CIRNC will bring researchers who have not previously been included in the conventional health research community into the broader concept of the CIHR. We suggest that targeted funding structures and mechanisms are necessary to stimulate a full range of research activity and to ensure appropriate knowledge development for nursing care in the future. Given appropriately structured funding mechanisms, caregiving disciplines in Canada would have the opportunity to explore important new directions for research. Such directions might include developing pre- and post-doctoral research training programs drawing from both the life and human sciences, and establishing funding priorities in areas such as individual and family
adaptation to chronic illness, symptom reduction and management, the interrelationship of caregiving practices with physiological and biobehavioral parameters.

**Vision and Principles of the CIRNC**

Given the nature of caregiving, CIRNC will be intrinsically multidisciplinary, and is likely to attract investigators from disciplines such as family medicine, social work, occupational, physical and hearing and speech therapy, and midwifery. Since nursing is such a large component of the caregiving contribution in health care, we argue that this should be reflected in the institute’s name. We do not see this as exclusionary in any way; rather, our conception of institutes within CIHR is an inclusive and dynamic one in which institutes serve as the research home of individual scientists as well as the home for those disciplines that choose to affiliate with them. The provision of efficient and effective nursing and caregiving services requires collaboration with disciplines such as family medicine, midwifery, social work, occupational, physical and speech therapy, and clinical psychology. These disciplines likewise have similar needs for high-quality research to inform practice, and for research training support.

Through the creation of the CIRNC, disciplines choosing to affiliate would then have the opportunity and responsibility to define the programs of research important to their fields as well as interdisciplinary research programs where fields converge. Such an institute will allow scientists not only to design training and career support programs that are uniquely needed by respective disciplines and are complementary to the programs run centrally by CIHR, but also to explore the potential for cross-disciplinary research training to meet emerging research needs. CIRNC would collaborate with other institutes and other CIHR structures to ensure that critical high-quality research
pertinent to the field of nursing and caregiving is supported across the CIHR structure.

Investigators from a wide array of disciplines will find the IRNC a logical ‘home’ for their scientific work, just as nurse scientists will most certainly participate in other CIHR institutes. We fully expect that robust collaborations will evolve between the IRNC, other CIHR institutes and groups, and organizations in Canada and globally, as has been the experience of the NIH/NINR. The visibility of Canadian nursing and caregiving science which will result from the creation of this institute may well attract new sources of research support, by virtue of the growing public awareness of nursing and caregiving in the health care arena.

**Structures and Partnerships:** The relationship of the CIRNC to other CIHR structures would be similar to those of other institutes, i.e., CIRNC representation on the Governing Council, the appointment of a Director and an Advisory Council for CIRNC with representatives from the affiliated disciplines and their respective organizations, consumer groups and voluntary health agencies concerned with nursing and caregiving, and representatives appointed by such organizations as the Canadian Nurses Association (CNA), the Canadian Association of University Schools of Nursing, the National Federation of Nurses’ Unions and the Aboriginal Nurses Association of Canada. We envision CIRNC establishing dynamic partnerships with other institutes and CIHR structures to ensure that the national research agenda in nursing and caregiving is communicated broadly, and that opportunities for collaborative, transdisciplinary research are maximized. Formal partnerships in regard to funding initiatives would be established with organizations already providing funding support in nursing and caregiving, such as with the Canadian Health Services Research Foundation, the Canadian Nurses Foundation and major voluntary health agencies.

**Functions:** We envision the CIRNC as having several critical functions:
the creation of a national research agenda in nursing and caregiving, and the representation of nursing and caregiving science perspectives in priority-setting activities of other CIHR structures, as appropriate;

- the establishment of training and capacity-building initiatives in service to this research agenda in collaboration with other research organizations and CIHR structures;

- the establishment of effective information and communication networks within the broad field of nursing and caregiving research and across the CIHR community to promote better integration of health research.

**National Research Agenda in Nursing and Caregiving:** CIRNC, through its Governing Council and Director, would be responsible for setting into motion a process for generating a Canadian research agenda in nursing and caregiving. This would be done in several ways: an advisory board structure that includes broad representation from caregiving disciplines, voluntary health organizations and consumers; a national forum for presentation of research priorities from stakeholder groups, and strategic planning for future targeted initiatives by CIRNC. This agenda would take into account the most pressing issues confronting Canadians, eg., intact families and single parents caring for handicapped children and the assistance they require; the effectiveness of various types of respite programs for caregivers of cognitively impaired older people, and the most pressing issues facing the disciplines that provide the care to Canadians, eg., the nature of the skill mix and expertise required of caregivers to institutionalized individuals.

**Training and Capacity Building Initiatives:** The development and continued maintenance of capacity to conduct research is vital to the Canadian health research enterprise. The most important element of capacity is the human one, i.e., the number
and expertise of the scientists who actually conduct the research. Most health research training is discipline-specific and takes place in relatively autonomous academic departments/faculties. This serves the needs of many disciplines (including nursing) to develop capacity to conduct research specific to that discipline. Recently, there has been an increasing emphasis on interdisciplinary research and programs of research that require the participation of researchers with a variety of backgrounds who can work together because they are knowledgeable about and respectful of each others’ research expertise and traditions. The latter requires opportunities for cross-training to acquire such skills and attitudes. This may be done as part of a Ph.D., through post-doctoral training or through other mechanisms (e.g., visiting scientist awards).

Two of the major responsibilities of the Canadian Institutes of Health Research will be to provide the resources to prepare the next generations of health researchers and to create opportunities for the best researchers in all disciplines to devote the majority of their time to carrying out research. We believe this is especially critical in the areas of nursing and caregiving, given the enormous pressures on Canadian nursing at present, and the challenges of providing appropriate caregiving services over the next several decades. Most active nurse scientists in Canada will retire over the next 10-15 years and those beginning their research careers in nursing today have less access to career development support than was true five years ago. The deepening nursing shortage will have disastrous effects on the supply of nurse scientists for the future unless steps to promote nursing research as a visible and attractive career path are taken now.

We propose that CIHR undertake these responsibilities through a combination of centralized competitions for pre and postdoctoral fellowships and career scientist awards, and through competitions managed at the level of the institutes for both training
and career awards that meet the special needs of disciplines affiliated with an institute.

In such an integrated approach to training and capacity-building, CIHR would run a set of training and career programs under the guidance of a T&C advisory committee that would serve all disciplines. Peer review committees would be interdisciplinary. It is expected that these central programs would include predoctoral and postdoctoral training programs and career support for junior and senior researchers.

CIRNC would also have a T&C program that would include only competitions to meet the unique needs of its affiliated disciplines. It is likely that not all disciplines would have competitions every year. In this model CIRNC and all other institutes would negotiate for its T&C budget to support its competitions and could compete for additional funds for extraordinary needs. This model would have the advantage of efficiencies and responsiveness to excellence across disciplines at the central CIHR level and opportunities to meet the unique capacity building needs of each discipline that will evolve and change over time at the level of the Institutes.

Types of T&C programs needed: As noted above, CIHR will need to provide a range of training award programs and career support programs that will meet the capacity building needs of all of the disciplines involved in the health research enterprise. Currently, there are very good T&C programs available through MRC; however, too few students and scientists are funded each year, especially in emerging fields not seen as central to the Council’s mandate. Within the CIHR structure, much greater concentration of resources will be needed for these programs.

Programs that we see being organized and administered centrally would include:

- Predoctoral training awards to be available for all students seeking master’s and doctoral health research training and including scientists with or without training as health professionals;
Postdoctoral awards, long established for basic scientists, and increasingly important for all health disciplines. Criteria must take into account the needs of women scientists and the increasing need for scientists to be trained for interdisciplinary work.

Entry-level, mid-career and senior scientist awards that allow concentrated salary support to allow recipients to concentrate on research. Research in the caregiving disciplines is mainly (but not exclusively) based in academic centres where demands of teaching compete with research. It is critical that scientists have access to research career support so that they can gain protected time for research.

**Unique Institute-based T&C programs:** The National Institutes for Health provide an array of training and career awards that may be established at the individual institute level. Many of the programs in the NIH-NINR would serve the caregiving disciplines very well and should be explored for the feasibility of adapting them to the Canadian scene.

Among the more important NINR competitions are ones that allow individual schools/faculties to apply for funding to establish a research infrastructure and seed funding for entry level scientists. In Canada, MRC has historically allocated funds to deans of medicine, pharmacy and dentistry for years so they could provide start-up funds for their new scientists. However, most other health science disciplines, including nursing, have not had this type of support, clearly an important component of building a robust research program.

In 1988, MRC and NHRDP jointly established a program to support both entry level and senior scientists in faculties of nursing. Although this program was small in scope (18 scientists in total were funded in eight faculties/schools of nursing), it has had an impact far beyond its limited scale. This initiative made it possible for nursing programs to recruit scientists, and to allow others to move out of administrative
positions into a scientist role with protected time. All of the researchers funded through this initiative went on to receive research scholar awards after their MRC/NHRDP awards ended. They built strong, interdisciplinary, internationally-recognized research programs that have served as a locus for doctoral student training. Programs funded through this initiative were able to build teams of researchers to focus on particular areas of research because of the resources provided through the program; and several schools were able to protect the time of newly prepared faculty that allowed them to accelerate their research productivity. This type of program, designed to meet a unique capacity-building need is an example of what may be required by a number of health disciplines within the CIHR structure, and which is likely to be a high-priority in institutes such as CIRNC.

**Effective Information and Communication Networks:** The CIRNC would be responsible for establishing and providing ongoing infrastructure support for important inventory and network functions regarding research conducted under its mandate. These functions will involve collaboration with the Canadian Nurses Association, the Canadian Association for Nursing Research, and the Canadian Association of University Schools of Nursing. Priorities would include a comprehensive data base of federally and provincially funded research pertinent to nursing and caregiving, and of investigators working in these fields.

**Conclusion**

In summary, the potential range and scope of nursing research and research in caregiving in Canada can be more fully realized and better utilized if suitable structures existed at the national level. We believe the most efficient and effective structure to support research in nursing and caregiving into the next century would be a CIHR
institute designated for this purpose. Such an institute will literally transform this important field of health research -- by facilitating a focused national research agenda, and by creating suitable research training and capacity-building mechanisms.

The Canadian Institute for Research in Nursing and Caregiving, by virtue of the disciplines that will affiliate with it, will provide a unique orientation toward both the human and the life sciences, and would establish new links between dominant and emerging scientific traditions in health research. Its creation will signal to all Canadians that decisionmakers recognize the importance of improving the quality of care and caregiving to human health and are prepared to foster knowledge development in service to that goal.

The creation of such an institute will make visible and enhance the research capacity of a field which 2/3 of the working health professionals in the Canadian health care system call their own. This proposal is broadly supported within the communities of researchers, clinicians, and academic leaders within nursing, as well as leaders in the wider field of health care and the voluntary health agency community (Appendix 2). The deepening worldwide shortage in nursing will definitely bring into clear focus the importance of supporting the profession and the discipline so that it is able to continue to play its essential role in the protection and promotion of human health. However, if support only focuses on the immediate human resource challenges, and fails to acknowledge the equally critical knowledge needs of the profession, nursing’s contribution will be attenuated and the price will be paid by all those requiring care in illness and disability.

Finally, the Canadian Institute for Research in Nursing and Caregiving within the CIHR structure will attract those researchers from a number of disciplines who are concerned with the “science of caring”. This emerging field is one with considerable
promise for the future, and one that can encompass many investigators from a range of disciplines, but all focusing on one goal: the development of new knowledge to improve the quality of care and caregiving for generations to come.
References


future and funding of academic health science centres. Health Human Resources Planning, Toronto, ON. (December 1995).


Appendices

Appendix 1  Project Team

Appendix 2  Letters of Support for Proposed

Canadian Institute for Research in Nursing and Caregiving

as of 1 October 1999:

Canadian Nurses Association Board of Directors
Association of Registered Nurses of Newfoundland
Ontario Nurses’ Association
Registered Nurses Association of Ontario
Registered Nurses Association of British Columbia
Western Region of the Canadian Association of University
Schools of Nursing (CAUSN)
Canadian Association of Neuroscience Nurses
Sigma Theta Tau Internation - XI Eta Chapter (University
of British Columbia)
Community Health Nurses Association of Canada

University

Canadian Breast Cancer Network
Family Caregivers’ Network Society
International Institute for Qualitative Methodology,

of Alberta
I.W.K Grace Health Centre, Halifax, Nova Scotia
London Health Sciences Centre Research, Inc.
The Scarborough Hospital Nursing Department
Cross Cancer Institute Nursing Department
Sunnybrook and Women’s College Health Sciences

Centre

Nursing Department, Ontario

University of New Brunswick Faculty of Nursing
University of Western Ontario School of Nursing
University of Calgary Faculty of Nursing
University of Victoria School of Nursing

Letters forthcoming, but not received as of 1 October 1999:

National Federation of Nurses’ Unions
Provincial Nurses Associations of Alberta, Saskatchewan,
Manitoba, New Brunswick, Quebec, Nova Scotia
University of Alberta Faculty of Nursing
McGill University School of Nursing
Université de Montréal Faculté des science infirmières
Quebec and Atlantic Regions, Canadian Association of University Schools of Nursing
Caregivers Consortium of Canada
Appendix 1 -- Project Team

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