

Revue canadienne de recherche en sciences infirmieres

Summer/Été 1997 Volume 29 No. 2

#### Canadian Journal of Nursing Research Revue canadienne de recherche en sciences infirmières

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#### SUMMER EDITORIAL

# Globalization of Information: New Challenges and New Opportunities

For the first time in nearly 30 years, Canada has hosted the International Council of Nurses 21st Quadrennial Congress. More than five thousand nurses, representing 119 countries, met in Vancouver in June 1997. During the opening ceremonies nurses carried their national flags and many wore their national attire. The official languages were English, French, and Spanish, yet the participants transcended language barriers and found new ways to communicate. Nurses from developed and developing countries, from urban and rural areas, exchanged e-mail and Web addresses and telephone and fax numbers.

New telecommunications technologies have led to the process of "globalizing" many things — making them universal. Perhaps the most important thing to be globalized is information. The globalization of information presents new challenges as well as new opportunities for the nursing profession.

The most obvious benefit, for nurses, of the Information Age is our ready access, for the first time, to the latest research findings and nursing theories. However, each nurse will have to decide which piece of information is relevant for him or her. Most nursing research studies and theories deal with human responses to illness and health. Many of the responses are culturally determined and context-specific, yet the findings and theories tend to be applied regardless of their relevance for a particular culture. We need to differentiate between general, universal principles of human response to illness and health — and the basic tenets of nursing theory — and those responses that are context-specific and culturally determined. This will require more cross-cultural studies that build generic nursing theory. The Internet can greatly facilitate our task in conducting such investigations.

Another challenge posed by the ready access to information relates to its transfer. We tend to think of transfer of information in unidirectional terms — North to South, developed to developing world. For the past 30 years the preponderance of nursing publications has come from the United States, followed by Canada and some European countries.

#### Summer Editorial

Yet we have much to learn from our many nursing colleagues in the South and in developing countries. The Internet conveys information in many forms. We need to encourage the participation of professionals in developing countries by recognizing, valuing, and requesting information from all experts. For example, nursing, as the oldest health-care profession, has accumulated wisdom in the area of comfort. Many of the so-called new "alternative medical treatments" have been part of nursing's tradition and form part of current nursing practice in several regions of the world. As nurses in North America reclaim this aspect of our profession, we have much to learn from our colleagues in other countries about the wide array of comfort strategies available. The possibility for developing consortiums to test different nursing strategies is there.

Another consideration relates to quality control. At the moment, any person with Internet access can make any piece of information available. The obvious problem is how to discern quality from garbage. Who is going to monitor the quality of information that is available? The international nursing community must immediately consider establishing structures to monitor and control quality of information.

Finally, we need to consider how information is organized. Researchers have tended to work alone or in small groups and to view their data as belonging to themselves or their funding organization. Our colleagues in the biological and medical sciences have long recognized that answers to research questions must be based on larger sample sizes from diverse sources; they have begun organizing and developing databases that pool information from various researchers around the world. The Internet has made this possible. This trend will undoubtedly spread to nursing science. We must consider organizing nursing information into useable, accessible databases.

The challenges and opportunities afforded by the globalization of information require that nurse researchers "think globally as they act locally" (Naisbitt, 1995). The new telecommunications technologies are creating new rules for conducting science. Many nurses have begun to equip themselves for the Information Age by using these new technologies. However, they must not stop there. Nursing science has made great strides in the past 30 years. We must now advance nursing science by using telecommunications technologies in new and innovative ways. We must seize the new opportunities; otherwise we will be left far behind.

Laurie N. Gottlieb Editor

#### Reference

Naisbitt, J. (1995). Global Paradox. New York: Avon.

#### A Note from the Editor

We intended to focus this issue on Developing Families. We called for papers accordingly, and although we received some very interesting submissions the range and quality of manuscripts were insufficient for a theme issue. The idea of focusing an issue of the journal on the theme of Developing Families is dear to my heart. The topic is critically important in light of published research on the significance of the developing family for the health of its members, particularly children under the age of three. We have scheduled another issue to focus on Developing Families, to be guest edited by the eminent nurse-researcher Dr. Kathryn Barnard from the University of Washington. The issue is scheduled for publication December 15, 1998, Volume 30, 3.



#### ÉDITORIAL D'ÉTÉ

# La mondialisation de l'information : De nouveaux défis et de nouvelles possibilités

Pour la première fois depuis près de 30 ans, le Canada a accueilli le 21° Congrès international du Conseil des infirmières <sup>1</sup>. En juin 1997, plus de cinq milles d'entre elles, venues de 119 pays, ont participé à une rencontre à Vancouver. Elles ont arboré leur drapeau national à la cérémonie d'ouverture et plusieurs portaient le costume traditionnel. Même si l'anglais, le français et l'espagnol étaient les langues officielles, les participantes ont été au-delà des barrières linguistiques et ont créé de nouvelles façons de communiquer. Des infirmières provenant des pays développés et des pays en voie de développement, ainsi que de régions urbaines et rurales, ont échangé leurs adresses électroniques, ainsi que leurs numéros de téléphone et de télécopieur.

L'avènement des nouvelles technologies de télécommunication a donné lieu à la «mondialisation» de plusieurs aspects, conférant au domaine une dimension universelle. Ce qui a sans doute été le plus touché par ce phénomène est l'information. La mondialisation de l'information présente de nouveaux défis et ouvre des horizons au sein de la profession infirmière.

L'avantage le plus évident généré par l'Âge de l'Information et dont bénéficient les infirmières est l'accès rapide aux résultats de recherche et aux théories de soins infirmiers, une première dans l'histoire. Toutefois, chaque infirmière aura à faire un tri parmi les données. La plus grande part des recherches et des théories en soins infirmiers traitent de la réaction des personnes face à la maladie et à la santé. Même si plusieurs réponses sont déterminées par le culturel et le contextuel, il existe une tendance à appliquer les résultats de recherche et les théories sans tenir compte de leur pertinence à une culture spécifique. Nous devons faire la différence entre les principes universels de réaction humaine face à la maladie et à la santé ainsi que les croyances fondamentales de la théorie des soins infirmiers, et les réponses qui sont déterminées par des contextes précis et l'origine culturelle.

<sup>\*</sup> Note de la traductrice : Pour des raisons d'économie, l'emploi du féminin est utilisé tout au long du texte. Toutefois, le féminin inclut le masculin.

Nous devons effectuer davantage d'études interculturelles et produire un corpus générique de théories. L'utilisation d'Internet peut grandement nous faciliter la tâche dans la poursuite de recherches.

L'accès rapide à l'information représente un autre défi, celui du transfert des données. Nous avons tendance à percevoir le mouvement de transfert comme étant unidirectionnel, s'effectuant du Nord vers le Sud, des pays développés vers les pays en voie de développement. Au cours des 30 dernières années, la plus grande part des publications de soins infirmiers provenaient des États-Unis, suivis du Canada et de certains pays d'Europe. Par contre, nos nombreuses collègues infirmières du Sud et des pays en voie de développement ont beaucoup à nous apprendre. Internet transmet l'information sous bien des formes. Nous devons favoriser la participation des professionnelles des pays en développement en recueillant des données auprès de toutes les professionnelles, accordant reconnaissance et valeur à leur travail. À titre d'exemple, la profession infirmière, en tant que plus vieille profession dans le domaine de la santé, a accumulé une grande sagesse au niveau du réconfort. Plusieurs des soit-disants «traitements médicaux alternatifs» étaient déjà intégrés à la tradition infirmière et sont, en partie, pratique courante dans plusieurs régions du globe. Les infirmières de l'Amérique du Nord reprennent possession de cet aspect de la profession. Nous avons donc beaucoup à apprendre de nos collègues d'autres pays sur les nombreuses stratégies de réconfort. Nous avons à notre portée l'occasion de développer des consortiums qui permettent de vérifier des stratégies de soins infirmiers.

Un autre sujet de réflexion est celui du contrôle de la qualité. Présentement, toute personne ayant accès à Internet peut diffuser toutes sortes de données. Les questions qui évidemment en découlent sont les suivantes : Comment discerner les données de bonne qualité de celles qui sont de piètre qualité? Qui effectuera le contrôle de la qualité de l'information diffusée? La communauté infirmière internationale doit immédiatement étudier la possibilité d'établir des structures permettant de contrôler la qualité de l'information.

Enfin, nous devons nous pencher sur la question de l'organisation de l'information. Les chercheurs ont tendance à travailler seuls ou dans le cadre de petits groupes et sont enclins à percevoir la propriété des résultats de recherche comment étant la leur ou celle de leur organisme de financement. Nos collègues oeuvrant en sciences médicales et en biologie reconnaissent, depuis longtemps, la nécessité d'effectuer la collecte de réponses aux questions de recherche à partir d'un plus grand échantillonnage provenant d'un éventail de sources. Ils ont amorcé

#### Éditorial d'été

l'élaboration de bases de données qui favorisent la mise en commun de l'information provenant de différents chercheurs à travers le monde. L'avènement d'Internet à permis une telle réalisation. Cette tendance se répandra sans aucun doute dans le domaine des sciences infirmières. Nous devons envisager la nécessité d'organiser l'information en bases de données viables et accessibles.

Les défis et les possibilités générés par la mondialisation de l'information exigent, de la part des infirmières-chercheures, l'adoption d'une « pensée mondiale, s'inscrivant dans des actions à échelle régionale » (Naisbitt, 1995). Les nouvelles technologies des télécommunications appellent la création de nouvelles règles pour la poursuite de travaux scientifiques. Plusieurs infirmières ont commencé à se doter de matériel et utilisent ces nouvelles technologies qui leur ouvrent les portes de l'Âge de l'Information. Toutefois, elles ne doivent pas s'arrêter là. Les sciences infirmières ont fait de grands pas au cours des 30 dernières années. Nous devons maintenant contribuer à leur avancement en utilisant les technologies de télécommunication de façon nouvelle et créative. Nous devons nous ouvrir à ces nouvelles possibilités. Sinon, notre pratique deviendra désuète.

Laurie N. Gottlieb Rédactrice en chef

#### Références

Naisbitt, J. (1995). Global Paradox. New York: Avon.

#### Note de la rédactrice

Nous avions l'intention de consacrer ce numéro à la question des jeunes familles. Nous avons donc fait appel à des articles traitant de ce sujet. Toutefois, même si nous avons reçu du matériel d'un grand intérêt, la diversité et la qualité des manuscrits ne suffisaient pas pour élaborer ce thème dans ce numéro. La question des jeunes familles est un sujet qui m'est cher et qui est d'une importance vitale, si l'on s'appuie sur les recherches publiées traitant de l'influence de la jeune famille sur la santé de ses membres, notamment sur les enfants qui sont âgés de moins de trois ans. Nous avons donc prévu la parution d'un autre numéro portant sur le thème de la jeune famille, lequel comportera une collaboration éditoriale spéciale de l'éminente infirmière-chercheure, Kathryn Barnard, Ph. D., de l'Université de Washington. Le numéro sera publié le 15 décembre 1998, vol. 30, n° 3.



# Research in Nursing and Cultural Diversity: Working with First Nations Peoples

#### Heather F. Clarke

Le profil démographique du Canada aujourd'hui trace le portrait d'une société plurielle du point de vue ethnique, culturel et racial (Masi 1993). Il est probable que l'immigration multiethnique vienne accroître cette diversité; cependant, les questions que cela soulève n'ont pas fait l'objet de discussions satisfaisantes en nursing et au sein du domaine de la santé. Alors que les infirmières, infirmiers et autres professionnels de la santé doivent désormais prêter attention aux dimensions culturelles de la santé et du processus de guérison, peu d'études solides et fiables ont été publiées en la matière, particulièrement en ce qui concerne des populations spécifiques. Les cadres de recherche et les schémas expérimentaux doivent être adaptés aux besoins de chaque groupe étudié; c'est ce qui permettra d'accumuler des connaissances solides sur les groupes concernés, et d'élaborer des théories qui pourront à leur tour être traduites dans des pratiques taillées à leur mesure. Dans le passé, plusieurs des ces populations ont fait l'objet d'études qui se sont avérées non pertinentes, paternalistes, culturellement déstabilisantes, et menant à une perte de pouvoir. Le présent essai se penche sur l'ethnographie critique, en tant qu'outil propice à l'élaboration de méthodes de recherche faisant état des différences ethnique et culturelles; il offre également des exemples de sa mise en application dans des études portant sur les peuples des Premières Nations. Des questions telles que le partenariat, les préoccupations d'ordre éthique et la propriété morale, vues comme des éléments essentiels à la conduite d'études appropriées, sont également mises en relief.

The current Canadian demographic profile indicates a society that is ethnically, culturally, and racially plural (Masi, 1993). Such diversity in our population is likely to increase with broad-based immigration, the implications of which have not been well addressed in nursing and health care. While nurses and other health-care professionals must attend to understanding the cultural aspects of health and healing, there is little published valid and reliable research to assist with this, especially with respect to specific populations. Research approaches and designs must be culturally suitable to the specific population, to generate valid knowledge about their culture and to develop theory, and to translate that into culturally suitable nursing and health care. In the past, many culturally diverse groups have been the subject of research that has been culturally inappropriate, patronizing, culturally threatening, and disempowering. This paper discusses critical ethnography as a culturally suitable research method and describes its application to studies involving First Nations (FN) peoples. Important issues in doing culturally suitable research, such as partnerships, ethical concerns, and ownership, are also discussed.

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#### Introduction

Canada's current demographic profile indicates a society that is ethnically, culturally, and racially plural (Masi, 1993), and such diversity is likely to increase with broad-based immigration. The implications of this have not been well addressed in nursing and in health care. The relationships among individual behaviour, values, beliefs, and perceptions about health and experiences of health and illness are culturally determined (Mensah, 1993). The challenge for health-care professionals is to understand the cultural aspects of health and healing in order to work with culturally diverse population groups for the improvement of their health and the care they receive. Competent1 nurse practitioners, educators, managers, and researchers are required to provide culturally suitable care.2 While the goal of culturally suitable care is consistent with the principles of primary health care (World Health Association, 1987), espoused as the foundation of health care in Canada (Canadian Nurses Association, 1995a,1995b), there has been little increase in health research addressing ethnic and cultural pluralism to assist nurses in their practice, especially in their work with specific populations (Anderson, 1993).

Research approaches, besides being appropriate in order to elicit proper responses, must be culturally suitable to the specific population in order to generate valid knowledge about their culture, to develop theory, and to translate this into culturally suitable nursing and health care. "Dominant cultural models that underlie our research approaches have failed" (Jackson, 1992, p. 14). It is becoming apparent that just as we need culturally sensitive instruments of measurement, responsive research designs, and appropriate analysis of results, we need the results to be interpreted within the cultural milieu and context of the groups being studied (Jackson). This paper will discuss critical ethnography as a culturally suitable method of doing research with people from ethnocultural and linguistic groups that are different from that of the researcher. Issues are identified in case examples of working with First Nations (FN) peoples. As background, a brief overview is provided of who FN peoples are, their changing health care, and the basis of nursing knowledge in working with them.

 Competence is the ability to integrate and apply the knowledge, skills, attitudes, and judgements required to perform safely and effectively (RNABC, 1996).

<sup>2.</sup> Culturally suitable care is care that is responsive to the preferences of client(s)/patient(s), such as practitioners' knowledge of and respect for cultural values, beliefs, and practices; similarity of cultural background of the health-care provider; integration of traditional healing systems and contemporary health-care systems; and resources available.

#### Background

#### First Nations Peoples — Who Are They?

FN peoples are aboriginal peoples of Canada with Indian ancestry. Status Indians are registered as Indians under the *Indian Act* of 1876; non-status Indians are not registered under the Act. There may be changes in the future, but currently status recognizes aboriginal heritage and entitles Indians to certain benefits. The legislation has also had detrimental effects; it denies benefits to some — the non-status Indians. While they share many values and beliefs, FN peoples are culturally and politically diverse and geographically dispersed.

## First Nations Health Care — Whose Responsibility Is It?

In the past, the federal government of Canada was responsible for providing primary health-care services to status Indians and provincial governments for providing hospital, ambulance, and other medical services, as well as all health care for non-status Indians. These responsibilities are changing, however. Federal responsibilities are being transferred to Indian Bands, and provincial ministries of health are decentralizing and delegating many responsibilities to regional and community health councils/boards. The aims of both federal transfer and provincial regionalization reflect principles of primary health care: greater public participation and responsibility, community-based programming, and more effective management of health-care systems. Thus FN peoples have to take on more health-care responsibilities themselves, by participating in band, regional, and community health planning and managing health-care services.

#### Nursing Knowledge — Where Is It?

Nurses are ideally situated to assist with planning for and implementing culturally suitable nursing and health programs, because they provide the majority of health services to FN peoples (CNA, 1993, 1995b). Where is the knowledge to guide the nurses in this role? While FN peoples, like other aboriginal peoples, have often been the subject of research, the results have rarely been a valid source of cultural knowledge and theory (Jackson, 1992). On the other hand, this population has often been excluded from research studies involving the general Canadian population. Valid knowledge, generated through culturally suitable research, is urgently needed.

Based on more than 30 years working with FN peoples in the areas of health care, research, and policy development, and having been mentored by the Arizona Native American Research and Training Center, I have found that feminist perspectives and critical ethnography methods are culturally suitable approaches for understanding the issues of FN peoples' health and working with them to bring about the changes they desire in nursing and health care. Knowledge generated through such research can help inform nursing involvement with FN peoples as they strive to improve their health.

#### Critical Ethnography

#### Historical Context

Ethnography, a classic research method for the study of cultures, provides a social-scientific description of a people and the cultural basis of their peoplehood (Spradley, 1980). However, it has distinct limitations, because observations that inform the description of and decisions about the saliency of data are always guided by the ethnographer's world images. In the past, descriptions and evaluations of races and cultures were provided by Western missionaries, explorers, buccaneers, and colonial administrators. Their reports were written from the perspective of a conquering civilization. It is understandable, then, that cultural groups such as FN peoples are sceptical, if not negative, about researchers coming in to study them and their culture, then leaving nothing, but taking away a biased interpretation of reality.

Critical theorists have challenged the positivistic paradigm to which traditional ethnography belongs, proposing that reality is shaped by an aggregation of social, political, cultural, economic, ethnic, and gender factors (Guba & Lincoln, 1994). Feminist researchers base their work on the assumption of intersubjectivity between researcher and participant and the mutual creation of data (Olesen, 1994). In a sense, participants are always "doing" research, for they, along with the researchers, construct the meanings that become data for later interpretation by the researcher. Anderson (1991) notes that over a decade some nursing scholars moved away not only from logical positivism, but beyond phenomenology and hermeneutics into a more critical theory paradigm and feminist form of reasoning. It has been my experience in doing research with FN people in British Columbia and Native Americans in Arizona that designs based on critical and feminist theories are most culturally suitable, acceptable, and productive.

My research with FN women started with an ethnographic study on childbearing issues with Coast Salish women. The results provided a classification of the sources of teaching/learning about childbearing and described ways in which women of a particular Band coped with the dilemmas they faced during childbearing. However, the research did not include a critical reflection of the findings or action, although Jordan (1990) comments on the utility of bringing together both emic (medicine-wheel) and etic (nursing) perspectives to inform the interpretation. It was not until the research was completed and I was in another role that I facilitated change in prenatal-care opportunities for the women.

Because there had been no significant involvement of the participants as researchers in this early study, and because no contract had been negotiated for ownership of data, only a general overview, rather than detailed results, were ever published (Clarke, 1990). Once again, research had been undertaken that failed to address factors perhaps more influential to women's childbearing practices than just teachings and experiences: social, political, economic, gender, and racial factors. Would publishing the specific results only serve to further marginalize these women, since there was potential for misinterpretation of health and health-care responsibilities? I thought so. Had I used a critical ethnography approach, the research would have had far greater potential to effect change and facilitate empowerment.

#### **Key Concepts**

Critical ethnography, an application of critical theory, is a style of inquiry, analysis, and discourse embedded in conventional ethnography (Thomas, 1993). Advocacy and activism are key concepts of critical inquiry. The researcher is cast in the role of instigator and facilitator, leaving judgement about needed transformations to those whose lives will be most affected by them. Critical ethnography is a reflective process "of choosing between conceptual alternatives and making value-laden judgements of meaning and method to challenge research, policy, and other forms of human activity" (Thomas, p. 4). Reflexivity involves a dialectical process involving the researcher's constructs and (a) the informant's common-sense constructs, (b) the research data, (c) the researcher's ideological biases, and (d) the structural and historical forces that informed the social construction under study (Anderson, 1989). Critical ethnography thus differs from conventional ethnography: "Conventional ethnography describes what is; critical ethnography asks what could be" (Thomas, p. 4).

Critical ethnography is a culturally suitable research method to inform nursing practice, based on the assumption that one of the aims of nursing in a context of cultural diversity is to transform social, political, cultural, economic, ethnic, and gender structures that constrain and indeed are at times detrimental to one's health (CNA, 1993, 1995b; RNABC, 1990). The concepts of advocacy, activism, reflexivity, participation, collaboration, and transformation resonate with the principles of primary health care (WHO, 1987) and assumptive premises of the culture caring theory (Leininger, 1991).

#### Research Methods

The cornerstone of critical ethnography is participation with the aim of bringing about action. The subjects are primarily those individuals who are significantly affected by the required transformation and whose level of knowledge needs to be expanded. The increasing use of participatory (action) research owes much to feminist researchers who have critiqued the aloofness and distancing methods of traditional maleoriented research (Anderson, 1989; Macguire, 1993; Thomas, 1993). The two terms participatory research and participatory action research, although they are seen as distinct methods of critical ethnography by some authors, are considered synonymous by others (Fals-Borda, 1992; Karlsen, 1991; Reason, 1994). The participatory approach in critical ethnography can be defined as "systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting social change" (Green et al., 1995, p. 4).

#### Case Examples

Following the childbearing study among the Coast Salish women, as a member of a multidisciplinary research team I was involved in two studies with FN women around cervical cytology screening. In one study the women resided on coastal and interior band reserves, while in the other they lived in a large city. The participatory research designs of both studies were informed by the critical theory paradigm and critical ethnography. As well, I incorporated lessons learned during my earlier research experiences with FN peoples and work with the Native American Research and Training Center.

#### The Problem

FN women experience a four to six times greater mortality rate from cervical cancer than the general population in the province of British Columbia (Band et al., 1992). They participate in the provincial Cervical Cytology Screening Program (CCSP) less regularly and less frequently than other women in BC (Hislop, Deschamps, Band, Smith, & Clarke, 1992). Furthermore, they are likely to have more difficulty than other women obtaining culturally suitable and consistent health-care services from respectful professionals (AMC Cancer Research Center, 1995). The first two facts above are readily available to health-care professionals and researchers, but the FN women are most familiar with the third fact. Thus what is likely to be defined as a problem by health-care professionals is not likely to be defined as such by FN women or their people.

Consistent with participatory research, defining the problem and research question(s) from an FN perspective was the first task I addressed. From previous experience I knew it was also important to address, in the early phases of project development, the following issues: partnerships and collaborative relationships between and among researchers and participants; ethical concerns related to access to women, points of entry into various systems, and confidentiality of names and data; ownership of data, results, presentations, and publications; and a culturally suitable research design that reconciles multiple scientific and community needs. These issues have been recognized by others as critical to the conduct of research with culturally diverse populations (Becker et al., 1992).

Our research team of nurse researchers and epidemiologists sought guidance from the FN peoples to determine how best to address the needs of the FN communities, whether reserves or urban communities, and yet maintain the necessarily scientific quality of the research. Meetings were held with FN agencies with an interest in or responsibility for health care to inform them of the inequities in the health status of FN women and to determine their perspective on and interest in addressing the problem. Eventually, for the two studies, a partnership was established between the research team and an FN agency. Based on the principles of critical ethnography, partnerships and collaboration were deemed essential to the advocacy and activism that would be required to make a difference in mortality and morbidity rates for cervical cancer among FN women in BC.

## Aim/Purposes of the Studies

Collaboratively, but at different times, the aim of both the reserve study and the urban study was determined to be reduction in the mortality and morbidity rates from cervical cancer among FN women through early and regular participation in the provincially funded CCSP. Direct cost was not a factor in non-participation. Based on our partner's perspectives and my research on childbearing among Coast Salish women, I felt confident that ethnocultural and health-care provider factors influenced the women in their decision on whether to have a Pap smear test. Therefore, it was decided the immediate purposes of the studies would be as follows: to understand the values, beliefs, and experiences of FN women related to health promotion and Pap smear tests; to understand factors influencing their health-promoting behaviour, including whether or not to have the Pap smear test; and to design and implement culturally suitable interventions to reach the long-term objective.

Both studies were based on critical ethnography concepts of participation, respect and valuing, empowerment, and interpreting the social realities of FN women. While this approach was appreciated by the women, they and the Band Councils expressed fears that identifying cervical cancer as a problem would result in its being labelled a "Native problem" — another in the litany of health problems stigmatizing FN peoples. Considerable discussion between researchers and community representatives centred around the fact that while the most critical factor in preventing cervical cancer mortality is early detection through regular Pap smear testing, some people believe FN women are prone to the disease because of beliefs that stereotype the FN lifestyle (e.g., early intercourse, numerous partners) — lifestyle factors whose relationship to "causing" cervical cancer is equivocal. The FN partners feared the women would be further marginalized by racist perspectives.

Maintaining collaborative relationships with the Band Councils, FN agencies, FN health-care workers, and the women themselves was an ongoing challenge in both studies. Project partners' level of participation varied; some left, others joined. Frequent re-defining of the problem was required. While time-consuming, this helped to educate and involve more people than just the initial partners, reinforcing the aims and purposes of the studies. Macguire (1993) experienced a similar need to frequently re-define the "problem" when she initiated her participatory research project with Navajo women, and suggests that the male-centred aspects of participatory research may account for this issue. Do some of the unique characteristics of participatory research (participation, organization creating, action aimed at structural change) place different demands on women and on men? Has this been accounted for in the research process? As did Macguire, our research team found that resources (e.g., child care, transportation, honoraria) and organization structures (e.g., supportive Band and employer policies) are absolutely necessary to sustain collective participation and action over time.

#### Method

Similar critical ethnography data-collection and analysis methods were used in both the reserve study and the urban study. Individual interviews, focus groups, and community meetings were used with women and with care providers - FN women collecting the data after having been trained by the nurse researchers. These data-collection methods were deemed by the partners to be culturally suitable. Principles of "Talking Circles," consistent with the principles of critical ethnography, guided the discourse: respecting silence, listening without interrupting, taking turns — with everyone eventually having something to say and accepting what is offered. Guiding questions for each of the datacollection methods were developed in conjunction with FN women, with reflections on previous work carried out by myself (Clarke, 1990) and other researchers (Dignan et al., 1990; Hall & Branstetter, 1990). Data analysis, initially conducted by the nurse researchers, was discussed with FN women in community meetings, as well as with FN women acting as advisors. Challenges in data collection and analysis related to the researchers not living in the community of study, difficulty accessing and recruiting subjects, and making and maintaining contacts with all partners.

#### Location

Entering into true collaboration and partnership with participants who will benefit from the research is a challenge when the researchers do not live in close proximity to the communities in which the research is being conducted. An ethnographic approach, particularly one that is critical, demands that the investigator be there, exposed to the various factors to be critiqued — social, racial, cultural, and gender. Collaboration cannot develop if the researcher visits the reserve on a sporadic basis only. The women, except for the Community Health Representative, participated primarily as subjects and advisors. Although participation was apparent in the latter part of the project when interventions were being implemented and evaluated, it never truly reached the guideline criteria for participatory research as outlined in the Report of the Royal Society of Canada (Green et al., 1995). However, the interventions requested by the women, such as onreserve regular Pap smear clinics performed by nurses and production

of a video and a flip chart during the study, have been maintained as provincial responsibilities.

The urban study had the advantage of bringing FN women and the researchers together on a regular and ad hoc basis for community advisory committee meetings, program management, data collection and interpretation, and publicity. The community advisory committee of elders, women from FN agencies, and women from the city's health and social services department collaborated with the research team from the moment funding was obtained. The more participatory nature of the urban study facilitated the recruitment of a very difficult-toaccess population, promoted the health issue in the wider FN community, enhanced the relevancy of data-collection instruments and methods, increased the validity of data analysis and interpretation, and resulted in a wider range of proposed interventions. However, participation requires time, and the women, already busy with their daily lives, could not always participate to the degree and with the regularity that was anticipated. FN women who were not employed received honoraria for their participation.

#### Access and Recruitment

Gaining entry to the population of FN women and their environment differed according to study location. Park's (1993) description of the organizer or mobilizer role of the participatory researcher became reality to different degrees. One of the determining factors in access and recruitment in studies with FN women has been the gatekeeper function. For on-reserve studies, it is the Band Chief and Council initially, followed usually by the Community Health Representative (CHR). The Band Chief and Council have responsibility for determining who has access to the reserve and the records, including Band lists, while the CHR has responsibility for making contact with the individual Band members on behalf of the researchers and following up on requests for information. In an urban setting, gatekeepers are primarily FN agencies and health-service providers. They determine whether the researchers can speak to their groups, advertise, or seek the participation of their members or clients. Furthermore, they interpret the research study to potential subjects/participants and seek their consent to be approached.

Thus access and recruitment is often carried out by a third party, who perceives one of their primary responsibilities to be ensuring that an ethical approach is maintained: that informed, non-coercive consent is obtained; that no harm will be done, but that benefits will be maximized; and that justice will be given to the voices of FN women, yet in a

confidential manner. These ethical principles of respect, beneficence, and justice are as critical to participatory research as they are to health care (Jecker, Carress, & Pearlman, 1995). At the request of the FN partners themselves, they were visited many times during studies in which I was engaged, even though ethical approval had been given by the ethics review committees of local universities.

#### Gaining and Maintaining Contacts

The most obvious aspect distinguishing participatory research from the more traditional research mode is that community people participate in the research process (Park, 1993). This demands interpersonal and political skills on the part of the researcher(s) as organizer(s), as well as the collaborator(s). In addition, with FN peoples one must appreciate intervening factors such as past negative experiences with researchers, exclusion from general population research, and male-centred aspects of FN life. Paradigm shifts must occur with the researcher(s) as well as the participants.

To facilitate the contact process of gaining entry and making contacts, I and others (Dressler, 1992; Frate, 1992) have found it helpful to:

- · locate some project offices in the community
- hire staff from the community
- make project resources available to the community for purposes defined by the community
- use jargon-free descriptions of the proposed research in any discussions with the community
- incorporate a health benefit within the research design for those participating and possibly others.

#### Research to Action

"The path from knowledge generation to knowledge utilization is direct in participatory research, since the same actors are involved in both activities" (Park, 1993, p. 3). In the studies with FN women, the participatory approach assisted women who have little power, or at least little perceived power, to change the complex health-care system (Hislop, Clarke, Deschamps, Band, & Atleo, 1995). As well, they became more aware, more creative, and more active in changing health-care services for Pap smear testing for FN women. They debated interpretation of the data and relevance to different intervention approaches.

The most controversial proposed intervention was public advertising (e.g., public transit posters). Although this strategy was based on the finding that in general FN women were not aware of the Pap test — purpose, relationship to cancer detection and infections, recommended schedule — some felt public advertising would stigmatize FN women, while others believed they had a responsibility to all FN women to ensure they were aware of this cause of unnecessary death. It was decided to abandon this strategy. Thomas (1993) refers to our difficulty reconstructing knowledge as a defamiliarization process, revising what we have seen and translating it into something new. Reconstructing knowledge of a health-care system is a complex process.

On the other hand, there was general agreement about the interpretation of findings related to health promotion, choices, and caring for oneself or others, and there was general agreement that these findings could be reflected in a cultural visual image. An FN woman artist was contracted to develop such an image, which was subsequently used on posters, brochures, and follow-up pamphlets. The text of all print material was based on research findings, critiqued, and revised by FN women and subsequently subjected to further evaluation by a larger audience of FN women and health-care providers.

In translating knowledge generation to knowledge utilization, the research team was primarily responsible for listening, respecting advice/decisions, facilitating required actions, and ensuring that an evaluation component was included. It was at this stage that requests for project information came from the larger community. Who was to be spokesperson? Who would write articles? Who would be acknowledged in presentations and publications? While these issues were resolved among the research team in a written agreement of principles of publication, informal approaches were taken with the other research partners. On reflection, agreement about publications and other means of sharing knowledge should have included all project partners. Guidelines are urgently needed for these types of agreements and for determining how to present appropriate acknowledgements.

#### Summary and Discussion

In summary, using critical ethnography and a participatory research approach with FN women has many advantages, especially with respect to action outcomes. While engaging and invigorating, critical ethnography is likewise exhausting. But that is the beauty of it (Macguire, 1993). You cannot be detached. Critical ethnography is not only about trying to transform social structures and people, it is about

being open to transforming ourselves and our relationships with others. It is about becoming a learner rather than being the voice of authority. Nursing in our increasingly culturally diverse society requires new approaches to research, to ensure that health and nursing care are culturally appropriate and that they provide relevant choices.

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## Acknowledgements

The author acknowledges the contributions of the FN women, partners, and participants in all studies referred to in this paper, and of the Pap Smear research team (Drs. G. Hislop, M. Deschamps, M. Band, R. Atleo, & R. Joseph). However, the perspectives put forward are the responsibility of the author.

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Date accepted: November 1996



# Évaluation psychométrique d'un instrument mesurant la motivation

# Anne Desmarais et Sylvie Robichaud-Ekstrand

McEwen's Health Motivation Assessment Inventory (HMAI) (1993) tool was developed to assess the motivation of patients with coronary artery disease to initiate and sustain healthy habits. Because of its measurement difficulties, it was modified and translated into French. The purpose of this methodological study was to examine the psychometric properties (content validity, internal consistency, and test-retest reliability) of the modified HMAI on 255 normal subjects. The average proportions of the items, rated congruent by the three raters, were 0.99 for clarity and 0.95 for relevancy. The final Cronbach's alpha coefficients for the six subscales ranged from 0.08 to 0.67. Confirmatory factor analysis provided evidence that the majority of the items were moderately independent of each other. Also, temporal stability coefficients ranged from 0.49 to 0.81. Finally, the modified HMAI was found to be free of social desirability bias. Although the modified HMAI appears to be a promising tool for future research, further refinement is needed to improve its validity.

Le Health Motivation Assessment Inventory (HMAI) de McEwen (1993) est un instrument de mesure évaluant la motivation des coronariens à entreprendre et à maintenir de saines habitudes de vie. Puisqu'il possède certaines lacunes, il fut modifié et traduit en français. Le but de cette étude méthodologique était d'examiner les propriétés psychométriques (validité de contenu, consistance interne et vérification contre-vérification) du HMAI modifié auprès de 255 sujets normaux. Les proportions moyennes d'accord entre les trois informateurs clés étaient de 0,99 pour la clarté et de 0,95 pour la pertinence des énoncés de l'instrument. Les coefficients alpha de Cronbach finaux pour les 6 sous-échelles variaient entre 0,08 et 0,67. L'analyse factorielle confirmatoire révélait que la majorité des variables étaient modérément indépendantes entre elles. De plus, les coefficients de stabilité temporelle variaient entre 0,49 et 0,81. Finalement, nous avons constaté que les énoncés du HMAI modifié étaient exempts de biais de désirabilité sociale. Bien que le HMAI modifié pourrait être un outil utile en recherche, certaines modifications doivent être apportées afin d'améliorer sa validité.

Depuis quelques années, plusieurs auteurs ont évalué l'efficacité des programmes de réadaptation cardiaque en utilisant des indicateurs de taux de mortalité (Collins, Yusuf & Peto, 1984; Oberman, 1988;

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O'Connor et al., 1989). Oberman (1988) rapporte que les programmes incluant un entraînement physique supervisé offrent des taux d'efficacité entre 21 % et 43 % (mortalité du groupe témoin — mortalité du groupe expérimental / mortalité du groupe témoin x 100). De plus, Collins, Yusuf et Peto (1984) et O'Connor et al. (1989) ont conclu que les programmes d'exercices chez les cardiaques réduisent en moyenne le taux de mortalité de 20 %. Cependant, plusieurs cardiaques ne bénéficient pas des effets de ces programmes de réadapation en raison d'un faible niveau de fidélité (Comoss, 1988; Dishman, 1982; Mullinax, 1995; Oldridge, 1982; Radtke, 1989). Dans cette perspective, Oldridge (1982) a observé que le taux moyen d'abandon aux divers programmes de réadaptation destinés aux usagers cardiaques est de 50 %.

Les cliniciens et les chercheurs affirment que la motivation semble être le facteur qui explique le mieux le degré d'engagement des usagers dans le maintien des comportements de santé (Cox & Wachs, 1985; Fleury, 1992; McEwen 1993; Kelly, Zyzanski & Alemagno, 1991). En effet, la motivation influence non seulement le processus de prise de décision de l'usager à vouloir changer ou modifier ses anciennes habitudes de vie reconnues comme étant nuisibles pour sa santé, elle influence aussi le degré d'engagement de l'usager dans le maintien de ses saines habitudes de vie (Marlatt & Gordon, 1985). Bref, la motivation est un des facteurs les plus importants à considérer lors de la réadaptation des usagers cardiaques (Oldridge & Stoedefalke, 1984), car leur persévérance en est la clé du succès (Rhodes, Morrisey & Ward, 1992).

Il est intéressant de constater que plusieurs auteurs ont observé une corrélation positive entre la motivation ou l'auto-motivation et la fidélité des usagers cardiaques à un programme d'exercices physiques (Dishman & Ickes, 1981; Oldridge & Stoedefalke, 1984; Ratdke, 1989). Kelly (1988) affirme que les usagers qui sont motivés font plus de changements dans leurs habitudes de vie que ceux qui ne sont pas motivés. En effet, selon l'étude de Kelly, Zyzanski et Alemagno (1991), les usagers qui sont motivés présentent des changements de comportements significatifs en ce qui a trait à l'usage de la cigarette, à la qualité et à la quantité d'aliments ingérés et à l'exercice physique. Par contre, une faible relation a été établie entre la motivation et la gestion du stress.

Par ailleurs, Derenowski (1988) a étudié les relations entre le soutien social, le foyer de contrôle, l'orientation de la valeur accordée à la santé et la motivation du bien-être auprès des usagers ayant subi un IM. Cette étude révèle qu'il existe une corrélation positive entre chacune de ces variables. Ainsi, un usager qui croit avoir le contrôle sur

sa vie (foyer interne) sera plus motivé à améliorer son état de santé que s'il a peu ou aucune maîtrise sur sa vie (foyer externe) (Comoss, 1988). Kelly, Zyzanski et Almagno (1991) ont démontré, auprès d'une clientèle diversifiée, qu'il existe une relation entre les croyances relatives à la santé, le soutien social, l'auto-efficacité et la motivation. Ainsi, un usager qui croit en sa capacité d'accomplir une certaine tâche ou action (auto-efficacité) sera plus motivé à changer ses comportements à long terme qu'un usager qui ne croit pas en ses habiletés (Comoss, 1988).

Le modèle de la Motivation Relative à la Santé (MMRS) (Health Motivation Model) de McEwen (1993) a été développé spécifiquement afin d'expliquer, chez les usagers, la cause de la motivation ou du manque de motivation par rapport à une amorce et au maintien de changements positifs dans leurs comportements. Les sous-concepts que l'on retrouve dans le MMRS sont : les connaissances antérieures, la perception de la sévérité et la perception de la susceptibilité à un problème de santé, la perception de la valeur accordée à l'action, les variables socio-démographiques, les aides/obstacles internes, les aides/obstacles externes et le catalyseur. Malgré le fait qu'une relation entre la motivation et le foyer de contrôle ainsi qu'une relation entre l'auto-efficacité et la motivation aient été établies, ces deux variables n'ont pas été considérées dans le cadre de cette étude.

Ce modèle est une modification du modèle des Croyances Relatives à la Santé (MCRS) (Health Belief Model) de Becker (1974). Contrairement au MCRS qui ne conçoit que les actions préventives des individus sous l'angle exclusif des croyances liées à la santé ou à la maladie, le MMRS considère, en plus, les autres motifs associés aux changements de comportements. Par exemple, un individu peut initier des changements dans son alimentation dans le but de perdre du poids, mais son intention de vouloir perdre du poids n'est peut être pas nécessairement due à des raisons de santé. Le désir d'améliorer son appparence et de vouloir plaire aux autres peuvent être d'autres motifs importants qui peuvent jouer un rôle primordial pour influencer un tel changement de comportement (McEwen, 1993).

Durant l'hospitalisation des usagers, les infirmières doivent être capable d'identifier et de reconnaître les usagers qui ne sont pas ou qui sont peu motivés à adopter des comportements de santé en plus d'explorer et de cerner l'origine de cette force qui crée une certaine résistance aux changements. Les usagers qui ont une faible motivation ont tendance à vouloir que les gens de leur entourage prennent les décisions concernant leur santé et assument la responsabilité du maintien de leur bien-être (Graw, 1992). Ainsi, les inhibiteurs aux changements

doivent être examinés et minimisés, alors que les stimulateurs (aides) aux changements requièrent une attention et un soutien particulier (Frenn, Borgeson, Lee & Simandl, 1989). Afin de faciliter cette tâche, l'utilisation d'un instrument de mesure axé sur la motivation relative à la santé serait considéré approprié et pertinent.

Selon les écrits élaborés jusqu'à présent, quatre instruments de mesure examinent des concepts qui sont reliés à la motivation relative à la santé (McEwen, 1993). The Health-Promoting Lifestyle Profile (HPLP) de Walker, Secrist et Pender (1987), The Health Self-Determinism Index (HSDI) de Cox (1985), l'instrument de Champion (1984) et The Health Motivation Assessment Inventory (HMAI) de McEwen (1993). Parmi ces instruments, le HMAI semble être le plus cohérent pour expliquer ce qui motive ou ce qui ne motive pas les usagers cardiaques à initier et à maintenir de saines habitudes de vie. La version originale anglaise du HMAI comporte cependant certaines lacunes (McEwen, 1993). D'abord, 13 énoncés de la deuxième partie sont à rejeter ou à reformuler, car ils ne saturent pas sur leur propre facteur (McEwen, 1993). Des énoncés additionnels sont à rajouter en regard de la perception de la sévérité, de la perception de la susceptibilité, des aides/obstacles internes et des aides/obstacles externes afin qu'il y ait cinq à six énoncés par sousconcept (McEwen, 1993). Pour ce qui est des énoncés déjà existants qui font référence aux aides / obstacles internes et externes, ils ne tiennent pas compte de tous les facteurs de risque; ce n'est que l'obésité et la sédentarité qui ont été considérés. La question de la troisième partie qui fait référence au catalyseur est aussi à reformuler, étant donné qu'elle ne considère qu'un seul comportement de santé entrepris par l'usager dans le passé. Aucun barême de codification des données a été établi pour pouvoir comptabiliser et interpréter plus facilement les résultats obtenus. De plus, la consistance interne de la deuxième partie du questionnaire est faible. Seuls les variables telles la valeur accordée à l'action  $(\alpha=0.76)$  et les connaissances antérieures  $(\alpha=0.73)$  ont démontré des coefficients alpha de Cronbach acceptables. Enfin, aucun test de stabilité dans le temps n'a été fait (vérification contre-vérification) et l'instrument n'a jamais été validé auprès d'une clientèle cardiaque et/ou francophone.

Il existe trois principales raisons pour vouloir développer ou modifier un instrument de mesure. (1) Le concept est nouveau et aucun instrument n'existe pour le mesurer (Streiner & Norman, 1991). (2) Il existe une erreur de mesure appréciable entre le concept théorique et la réalité empirique. L'erreur de mesure est la différence entre ce qui existe dans la réalité et ce qui est mesuré par l'instrument de l'étude (Burns & Grove, 1993; Nunnally, 1978; Polit & Hungler, 1991). Un

instrument qui possède un faible niveau d'erreur de mesure est plus utile, car il est précis dans ce qu'il évalue (Nunnally, 1978). 3) On a l'impression que certains éléments du concept ont été omis dans l'instrument (Streiner & Norman, 1991). C'est principalement pour cette dernière raison que la version originale du HMAI fut modifiée. Pour contrer la pénurie d'instruments de mesure développés en français, ce dernier a aussi été traduit. La première étape à suivre lorsqu'on procède à une évaluation psychométrique d'un instrument est d'évaluer celuici auprès d'une population normale et ce, afin de connaître certaines de ses qualités psychométriques. Une fois les critères de bases établis, l'instrument peut par la suite être utilisé auprès de la population ciblée. Bien que le HMAI modifié soit conçu pour les coronariens, l'instrument a initialement été évalué auprès d'une population francophone normale.

La validité d'un instrument se rapporte à sa capacité de mesurer le construit théorique attendu. Un instrument est alors considéré valide lorsqu'il mesure bien le ou les concept(s) qu'il est sensé mesurer (DeVellis, 1991; Fortin, Taggart, Kérouac & Normand, 1988). D'après DeVellis (1991) et Nunnally (1978), il existe essentiellement trois types de validité : la validité de contenu, la validité de construit et la validité de convergence. Pour des raisons de faisabilité, la validité de contenu de l'instrument a été la seule qui fut évaluée en profondeur, alors que la validité de construit n'a été évaluée que partiellement à l'aide de l'analyse factorielle. Waltz, Strickland et Lenz (1991) affirment que l'approche la plus fréquemment utilisée pour évaluer la validité de contenu est celle qui nécessite l'aide d'informateurs clés. La technique du coefficient d'objectivité (interrater) fut par conséquent utilisée pour cette étude. Pour ce qui est de la fiabilité, celle-ci permet de déterminer à quel point la technique de mesure utilisée est conforme au concept mesuré (Waltz, Strickland & Lenz, 1991). Afin de procéder à l'évaluation de la fiabilité d'un instrument, l'investigateur doit examiner la consistance interne des énoncés et la stabilité temporelle du questionnaire en procédant soit par la méthode de vérification contre-vérification (test-retest) ou par la méthode du split half technique (Burns & Grove, 1993; Nunnally, 1978; Polit & Hungler, 1991). Dans le cadre de cette étude, le split half technique n'a pas été utilisé, car il n'y a que sept à neuf énoncés par sous-concept.

À la lumière des présentes considérations, le but de cette étude était d'examiner les propriétés psychométriques (validité de contenu, consistance interne et vérification contre-vérification) du HMAI modifié.

#### Les questions de recherche

Quelles sont les propriétés psychométriques (validité de contenu, consistance interne et vérification contre-vérification) du HMAI modifié auprès d'une population francophone exempte de problèmes cardiaques?

- 1. Quelle est la validité de contenu de l'instrument?
- 2. Quelle est la consistance interne de l'instrument?
- 3. Quelle est la fiabilité temporelle de l'instrument?

#### La méthode

#### Devis de recherche

Cette étude est de type méthodologique. Elle vise à évaluer la validité et la fiabilité d'un instrument de mesure, centré sur la motivation relative à la santé, auprès de sujets francophones n'ayant aucun problème cardiaque.

#### Définitions opérationnelles des variables

La motivation relative à la santé est définie comme étant la volonté de vouloir persévérer ainsi que l'importance qu'attribue un individu à cette volonté affectant positivement ses choix et son ou ses comportement(s) ou action(s) en regard de sa santé. Les connaissances antérieures, la perception de la sévérité, la perception de la susceptibilité, la valeur accordée à l'action, les variables socio-démographiques, les aides/obstacles internes, les aides/obstacles externes et le catalyseur influencent individuellement ou conjointement la motivation relative à la santé. Toutes ces sous-échelles sont mesurées par le HMAI modifié (McEwen, 1993).

Les connaissances antérieures sont définies comme étant la quantité d'information reçue concernant la maladie coronarienne (MC) ou le niveau d'information ou de compréhension que l'usager possède sur la MC (McEwen, 1993).

La perception de la sévérité d'un problème de santé est définie comme étant les convictions ou les émotions engendrées à la pensée que la MC est une menace sur sa santé et l'influence que l'intensité de cette menace a sur la vie d'un individu (McEwen, 1993).

La perception de la susceptibilité à un problème de santé est définie comme étant la compréhension que se fait un individu de la MC qui menace sa santé ainsi que de la probabilité d'une récidive au cours de sa vie (McEwen, 1993).

La perception de la valeur accordée à l'action est définie comme étant la croyance en l'efficacité d'une action, d'une réponse ou d'un traitement particulier sur sa santé pour réduire sa prédisposition à la MC (McEwen, 1993).

Les variables socio-démographiques sont l'âge, le sexe, la race, l'ethnicité, le niveau d'éducation, le revenu familial, le statut marital et le type d'emploi (McEwen, 1993).

Les aides/obstacles externes sont définis comme étant des événements externes propres à chaque individu tels les interdictions, les empêchements et les renchérissements qui favorisent ou qui inhibent une action ou une réponse (McEwen, 1993).

Les aides/obstacles internes sont définis comme étant des sentiments de l'individu (attitudes, pensées et croyances) qui favorisent ou qui inhibent une action ou une réponse (McEwen, 1993).

Le catalyseur est défini comme un stimulus interne ou externe qui permet de promouvoir le changement sur une ou plusieurs variables du modèle (McEwen, 1993).

#### Le milieu et l'échantillon

Les sujets furent recrutés par la technique boule de neige dans divers milieux tels un centre pour personnes âgées autonomes, des édifices à bureaux, des écoles et à domicile. Les critères d'inclusion étaient d'être Québécois francophone, âgé de plus de 30 ans et de ne pas être diagnostiqué comme ayant une maladie coronarienne (angine de poitrine et/ou infarctus du myocarde avec ou sans angioplastie coronarienne et/ou pontage des artères coronaires). Après avoir été avisés du but et du déroulement de l'étude, les sujets qui acceptaient de participer à l'étude devaient signer une formule de consentement. Le questionnaire fut distribué à 275 sujets. Parmi ceux-ci 255 l'ont dûment rempli et retourné. L'échantillon réunit 102 hommes (40 %) et 153 femmes (60 %) âgés principalement entre 30 et 59 ans (91 %). La majorité des sujets sont sur le marché du travail (82 %), détiennent au moins un diplôme collégial (71 %) et ont un revenu familial de 40 000 \$/an et plus (64 %).

#### La description et les propriétés psychométriques de l'instrument

Le questionnaire modifié par l'investigatrice incorpore des énoncés provenants du HMAI de McEwen (1993) et de l'instrument de Champion (1984) (version traduite en français et adaptée auprès de pontés aorto-coronariens par Richard (1988)). Enfin, certains énoncés du HMAI modifié furent formulés d'après notre expérience clinique auprès d'usagers cardiaques. Une des limites du HMAI modifié est que la majorité de ses questions sont de type fermé. Les questions fermées ne permettent aux sujets que l'option de choisir parmi l'une des réponses proposées. Afin de permette une certaine flexibilité d'expression de la part des répondants, 4 questions ouvertes furent formulées.

L'instrument modifié comprend 80 questions réparties en 4 parties. La première partie regroupe 19 questions dont 15 sont à choix multiples alors que les 4 autres sont des échelles de valeur. Les questions à choix multiples permettent de découvrir les actions et les comportements entrepris par le sujet en vue de promouvoir sa santé. De plus, elles aident à déterminer l'origine de la motivation pour adopter et maintenir divers comportements de santé. Elles nous permettent aussi de découvrir si l'intention du sujet est de changer ses habitudes de vie pour des raisons de santé ou pour d'autres raisons non reliées à la santé. Pour ces 15 questions à choix multiples, aucun barême de codification des données n'a été établi, car les résultats de cette partie servent uniquement de comparaison statistique avec les autres résultats de l'instrument. Les 4 autres questions, appelées échelles de valeur, mesurent le niveau de motivation (de 1 à 10) à vouloir entreprendre un changement de comportement (ex. : réduire ou arrêter de fumer, réduire ou arrêter de comsommer de l'alcool, augmenter la fréquence et la durée des activités physiques et suivre une diète). Le sujet est très peu motivé à adopter de saines habitudes de vie s'il choisit les chiffres 1 à 4; moyennement motivé s'il encercle les chiffres 5 à 7 et très motivé s'il choisit les chiffres 8 à 10.

La deuxième partie du questionnaire est constituée de 47 énoncés mesurés à l'aide d'échelles de Likert variant de 1 (fortement en accord) à 5 (fortement en désaccord). Les 47 énoncés répartis au hasard sont représentés par les 6 sous-concepts suivants : (1) les connaissances antérieures, (2) la perception de la sévérité, (3) la perception de la susceptibilité, (4) la perception de la valeur accordée à l'action, (5) les aides/obstacles internes et (6) les aides/obstacles externes. Parmi tous les énoncés, 18 d'entre eux ont aléatoirement été sélectionnés pour être transformés sous la forme négative. Le fait d'avoir inséré certains

énoncés formulés négativement permet d'éviter que le sujet choisisse constamment la même réponse.

La troisième partie de l'instrument fait référence à la variable catalyseur. Cette partie est constituée de 4 questions ouvertes permettant au sujet d'expliquer brièvement ce qui l'a amené à adopter des comportements de santé ou ce qui l'en a empêché. Les réponses sont classées et analysées selon leurs similarités et leurs différences.

La dernière partie, composée de 10 questions à choix multiples, regroupe certaines données socio-démographiques. La dernière question diffère cependant des 9 autres, car elle nous informe sur le genre de problème cardiaque que le sujet a eu dans le passé.

Afin de déterminer si les sujets de l'étude ont tendance à répondre au HMAI modifié de façon biaisée (réponses qui reflètent des comportements socialement valorisés et acceptables), nous nous sommes servies de la version abrégée de l'échelle de désirabilité sociale de Marlowe et Crowne (1960), construite par Strahan et Gerbasi (1972) et traduite par Cloutier (1993). DeVellis (1991) et Nunnally (1978) considèrent pertinente l'utilisation de cette échelle afin de détecter la présence de lacunes et de problèmes dans un questionnaire et conséquemment, éviter que les énoncés de l'instrument soient dominés par la désirabilité sociale. Les 20 énoncés de la version abrégée sont des questions fermées à choix dichotomique vrai ou faux; 10 énoncés sont vrais alors que les 10 autres sont faux.

Afin d'établir la validité de contenu du HMAI modifié, le questionnaire a été présenté à trois infirmières ayant une expérience d'au moins trois ans auprès d'usagers cardiaques. Chaque énoncé a été révisé selon les aspects suivants : 1) La clarté, qui se réfère à la précision et au vocabulaire utilisés dans l'énoncé. La clarté était mesurée à l'aide d'une échelle de type Likert variant de 1 (clair) à 4 (incompréhensible); 2) La pertinence, qui est le degré de concordance entre le contenu de l'énoncé et le sous-concept qu'il est supposé représenter. La pertinence était mesurée à l'aide d'une échelle de type Likert variant de 1 (très pertinent) à 4 (non pertinent). Après avoir obtenu une validité de contenu acceptable (voir la partie des résultats), les questionnaires furent distribués aux sujets de l'étude. La participation des sujets consistaient à répondre au HMAI modifié et à la version abrégée de l'échelle de désirabilité sociale. Pour pouvoir procéder à une vérification contre-vérification de l'instrument, 50 sujets avaient préalablement été sélectionnés de façon aléatoire pour répondre une seconde fois au questionnaire deux semaines plus tard. Parmi les 50 contre-vérifications distribuées, 47 ont pu être utilisées pour évaluer la stabilité temporelle de l'instrument. Les

données furent par la suite recueillies dans le logiciel Excel et analysées à l'aide du SPSS. La consistance interne ainsi que la méthode de vérification contre-vérification ont été utilisées de façon à évaluer la fiabilité de l'instrument. Une analyse factorielle ainsi qu'une corrélation entre les énoncés du HMAI modifié et les résultats de la version abrégée de l'échelle de désirabilité sociale ont aussi été effectuées.

#### Les résultats

Pour répondre à la première question de recherche, nous nous sommes servies de l'index de validité de contenu (IVC) de Waltz et Bausell (1981). L'IVC permet de déterminer la proportion d'énoncés ayant reçu un score de 1 (très pertinent) ou 2 (pertinent) par chacun des informateurs clés. Comme le critère de clarté des énoncés a aussi été pris en considération, l'IVC nous a permis de déterminer la proportion d'énoncés ayant reçu un score de 1 (clair) ou 2 (légèrement ambigu) par chacun des informateurs clés. Toute proportion moyenne d'accord entre informateurs clés qui est supérieure ou égale à 0,90 (moyenne obtenue des trois IVC) en ce qui à trait à la pertinence et à la clarté de l'instrument, signifie que la validité de contenu est acceptable (Waltz, Strickland & Lenz, 1991). Initialement, la proportion moyenne d'accord entre informateurs clés en ce qui à trait à la clarté des énoncés était de 0,92 et de 0,91 pour la pertinence des énoncés. Bien qu'après cette première évaluation la validité de contenu était acceptable, nous avons considéré important de reformuler 5 énoncés, suite aux commentaires pertinents des informateurs clés, pour améliorer davantage leur clarté. Ces énoncés ont par la suite été réévalués par les trois informateurs clés. Finalement, nous avons obtenu des proportions moyennes d'accord entre informateurs clés de 0,99 pour la clarté et de 0,95 en ce qui a trait à la pertinence des énoncés.

Une distribution des fréquences pour les facteurs de risque reliés à la maladie cardiaque nous a permis de constater qu'il y a 215 sujets (85 %) qui ne fument pas, 130 sujets (51 %) qui boivent de l'alcool plus d'une fois/semaine, 175 sujets (69 %) qui font de l'exercice physique au moins une fois/semaine et 128 sujets (50 %) qui considèrent que leur poids est trop élevé. Comme il y a plusieurs sujets de l'étude qui ne fument pas, qui ne boivent pas et qui ont un poids santé, 8 énoncés principalement relatifs aux facteurs de risque tels la cigarette, l'alcool et l'obésité ont été retirés d'emblée vu qu'ils ne s'appliquaient qu'à un nombre restreint de participants. Conséquemment, l'évaluation psychométrique qui suit s'est faite sur 39 énoncés au lieu de 47.

 Tableau 1
 Le nombre d'énoncés retenus, les coefficients de consistance interne du HMAI de McEwen, du HMAI-traduit et du HMAI-modifié (moyennes et écart types par sous-échelles)

sous-échelle	HMAI de McEwen n = 285		$HMAI$ -traduit <sup>a</sup> $n = 234^d$			HMAI-modifié <sup>b</sup> n = 234 <sup>d</sup>		
	nb d'énonces	alpha	nb d'énonces	alpha	nb d'énonces	alpha	х	e.t.
Connaissances antérieures	6	0,73	5°	0,59	8	0,67	2,57	0,39
Perception de la sévérité	3	0,58	3	0,42	7	0,35	3,01	0,64
Perception de la susceptibilité	4	0,56	4	0,48	4	0,48	3,20	0,55
Valeur accordée à l'action	7	0,76	7	0,62	7	0,62	1,62	0,20
Aides/ obstacles internes	3	0,63	3	-0,13	5	0,11	2,40	0,62
Aides/ obstacles externes	4	0,60	2°	-0,70	3	0,08	3,21	1,05

a) HMAI traduit = Énoncés du HMAI de McEwen traduits en français. Certains énoncés ont été formulés négativement.

b) HMAI modifié = HMAI traduit + énoncés tirés de Champion (1984) + énoncés formulés d'après notre expérience personnelle.

c) Ces sous-échelles ont un nombre inférieur d'énoncés, puisque trois énoncés ont dû être retirés suite à un taux de réponses insuffisant.

d) Pour certaines sous-échelles, le nombre de sujets varie entre 195 et 234.

Dans la deuxième question de recherche, nous nous questionnions à savoir le niveau de consistance interne de l'instrument. Nous avons donc utilisé les coefficients alpha de Cronbach. Dans le cas d'un nouvel instrument de mesure, un coefficient alpha de Cronbach de 0,70 est jugé acceptable (Burns & Grove, 1993; Nunnally, 1978). Après avoir révisé la matrice de corrélation, nous avons constaté que 5 énoncés semblaient avoir une influence négative importante sur la consistance interne de l'instrument. Ces derniers ont alors été exclus du HMAI modifié. Les coefficients alpha de Cronbach finaux pour chacune des six sous-échelles varient entre 0,08 et 0,67. Le tableau 1 présente ces coefficients détaillés de même que les moyennes et les écarts types des sous-échelles lors de cette épreuve.

L'utilisation d'une analyse factorielle en composantes principales avec rotation varimax s'avère pertinente pour étudier les regroupements possibles entre les énoncés et pour tester la validité de construit de l'instrument (McEwen, 1993). Une première analyse factorielle de type exploratoire (laisser les énoncés se regrouper librement) nous a fait ressortir 13 facteurs. De ce nombre, six facteurs renfermaient trois regroupements ou plus d'énoncés. Une seconde analyse factorielle de type confirmatoire, ayant comme critère d'extraction six composantes, fut alors effectuée (forcer la formation de six regroupements d'énoncés). Cette structure factorielle n'a cependant pas permis de conclure à l'indépendance des variables de l'instrument. Néanmoins, les variables telles que les connaissances antérieures, la perception de la sévérité, la perception de la susceptibilité et la valeur accordée à l'action semblent être celles qui sont les plus indépendantes, alors que la majorité des énoncés respectifs à ces variables saturent à plus de 0,33 sur leur propre facteur (tableau 2).

Afin de répondre à la troisième question de recherche, nous avons utilisé le test de Kappa pour évaluer la stabilité temporelle de l'instrument (méthode de vérification contre-vérification) auprès de 47 sujets. Selon Fleiss (1981), un coefficient qui est inférieur à 0,40 reflète une fiabilité qui est pauvre, un coefficient qui varie entre 0,40 et 0,75 signifie que la fiabilité est faible à modérée, alors qu'un coefficient supérieur à 0,75 reflète une grande fiabilité. Les coefficients de stabilité temporelle obtenus dans cette étude varient entre 0,49 et 0,81.

Enfin, nous avons procédé à une corrélation entre chacun des énoncés du HMAI modifié et la version abrégée de l'échelle de désirabilité sociale (Strahan & Gerbasi, 1972). Le coefficient de corrélation (r) détermine la force de la relation qu'il y a entre chaque énoncé du HMAI modifié et le résultat de l'échelle de désirabilité sociale. Si le coefficient r

**Tableau 2** L'analyse factorielle en composantes principales avec rotation varimax pour les quatre sous-échelles reconnues indépendantes

		Facteur						
Énoncé	Sous-échelle	1	2	3	4	5	6	
18	connaissances antérieures	0,54	10					
32	connaissances antérieures	0,50						
17	aides/obstacles internes	0,47						
34	valeur accordée à l'action	0,43						
44	connaissances antérieures	0,43						
39	valeur accordée à l'action	0,43						
1	aides/obstacles internes	-0,42						
29	valeur accordée à l'action	0,40						
42	valeur accordée à l'action	0,38						
15	aides/obstacles externes	-0,38						
14	perception de la susceptibilité	-0,38						
46	perception de la susceptibilité		0,66					
37	perception de la sévérité		0,62					
43	perception de la susceptibilité		-0,55					
8	perception de la susceptibilité		-0,50					
9	valeur accordée à l'action		0,44					
10	aides/obstacles internes		0,42					
35	aides/obstacles internes		0,38					
27	aides/obstacles externes		0,37					
31	valeur accordée à l'action		0,35					
30	perception de la susceptibilité		0,33					
47	connaissances antérieures		10	0,56				
40	connaissances antérieures			0,55				
45	connaissances antérieures			0,48				
4	connaissances antérieures			0,47				
6	connaissances antérieures			0,34				
20	aides/obstacles externes			0,29				
13	aides/obstacles internes			-/	-0,48			
7	perception de la sévérité				0,40			
2	perception de la sévérité				0,38			
38	perception de la susceptibilité				0,37			
11	perception de la sévérité				-0,30			
16	perception de la sévérité				0,00	0,45		
33	perception de la sévérité					0,40		
3	perception de la susceptibilité					0;34		
26	perception de la sévérité					-0,33		
19	aides/obstacles externes					0,00	0,59	
12	aides/obstacles internes						0,48	
22	valeur accordée à l'action						-0,43	

varie entre 0,10 et 0,30, la relation est faible. De 0,30 à 0,50, la relation est modérée, alors qu'un r > 0,50 signifie que la relation linéaire est forte (Burns & Grove, 1993). Bref, plus les coefficients de corrélation sont faibles moins les énoncés du HMAI modifié sont influencés par la désirabilité sociale. Parmi tous les énoncés du HMAI modifié, aucun ne possède un coefficient de corrélation supérieur à 0,20 alors que seulement 4 énoncés sont non significatifs ( $p \ge 0,01$ ; test bilatéral). Ces résultats témoignent que les énoncés du HMAI modifié accusent une faible corrélation avec l'échelle de Marlowe et Crowne (1960).

### Discussion et interprétation des résultats

Divers motifs semblent expliquer l'obtention d'une faible consistance interne de l'instrument. D'abord, les énoncés relatifs aux six souséchelles sont pour la plupart faiblement associés entre eux. En examinant les coefficients de corrélation énoncé-total corrigés, on constate que les coefficients des sous-échelles telles la perception de la sévérité, la perception de la susceptibilité, les aides/obstacles internes et les aides/obstacles externes sont faibles et non significatifs (variants entre -0.14 et 0.28; p > 0.01). Pour ce qui est de la sous-échelle aides/obstacles internes, aucun coefficient de corrélation n'est supérieur à 0,21 alors que pour les aides/obstacles externes, les coefficients n'exèdent pas le 0,08. Ainsi, le faible niveau de consistance interne des énoncés relatifs à ces sous-échelles n'est pas attribuable à un seul énoncé, mais plutôt à l'ensemble des énoncés qui représentent ces sous-échelles. De plus, une si faible consistance interne nous porte à croire que la congruence théorique et empirique des variables aides/obstacles internes et externes ne semble pas évidente. Toutefois dans le HMAI de McEwen (1993), les résultats relatifs à ces sous-échelles semblent concorder aux écrits scientifiques. Pour éclaircir cette ambiguïté, il serait important de vérifier si l'on obtient des résultats semblables auprès d'une population qui est cardiaque, puisque le concept théorique fut élaboré initialement pour cette clientèle.

La faible consistance interne de l'instrument s'expliquerait aussi par le fait que le HMAI modifié renferme des énoncés qui sont parfois trop longs et qui sont formulés négativement ce qui, par conséquent, augmente la complexité des questions et peut confondre les répondants (DeVellis, 1991). Il est à noter qu'une compréhension erronée des énoncés ne semble pas être reliée au niveau d'éducation puisque 71 % des sujets de l'étude détiennent au moins un diplôme de niveau collégial. Par contre, le fait que les professionnels de la santé constituent une

minorité chez les participants et qu'aucun sujet n'ait jamais eu de problèmes cardiaques génère une situation où la connaissance des MC ne peut être que faible ou modérée. De plus, les informateurs clés qui, eux, possédaient de bonnes connaissances en cardiologie, ne se sont peutêtre pas rendu compte que le langage utilisé dans la formulation des énoncés ne s'apparentait pas bien à celui de la population cible.

Une telle consistance interne peut aussi s'expliquer par le fait que 8 énoncés ont dû être exclus du HMAI modifié puisque le taux de réponses à ces énoncés était insuffisant. DeVellis (1991) affirme que l'utilisation d'un échantillon qui n'est pas représentatif peut nuire aux efforts qui ont été investis lors du développement d'un instrument et peut se refléter par des valeurs psychométriques inférieures à ce que l'on avait envisagées. Comme, dans le cadre de cette étude, l'instrument est développé pour une population cardiaque mais qu'il est testé auprès de sujets exempts de problèmes cardiaques, l'interprétation des résultats doit être effectuée avec précaution.

Tel que mentionné précédemment, le HMAI modifié résulte de la traduction de tous les énoncés du HMAI de McEwen, de l'ajout de nouveaux énoncés provenants de Champion (1984) et de notre expérience personnelle et enfin, d'une reformulation sous la forme négative de certains énoncés. Afin de pousser notre réflexion, nous avons cru bon d'établir une comparaison des résultats aux questions que l'on retrouve à la fois dans le ĤMAI de McEwen (1993) et dans le ĤMAI modifié. Afin de faciliter la compréhension du lecteur, la terminologie HMAItraduit sera utilisée pour désigner les énoncés du HMAI de McEwen qui furent traduits en français et reformulés en partie sous la forme négative. Cette version exclue tous les énoncés qui proviennent des autres sources. Il faut cependant être vigilant dans l'interprétation du HMAI-traduit, car cette version diffère quelque peu du HMAI de McEwen. Entre autres, ses modalités de présentation et ses directives ne sont pas tout à fait les mêmes que celles que l'on retrouve dans la version de McEwen. En plus, trois énoncés ont dû être retirés, car ils ne s'appliquaient qu'à un nombre restreint de participants. En comparant les coefficients alpha de Cronbach du HMAI de McEwen avec ceux du HMAI-traduit, on constate que ces derniers sont inférieurs et ce, pour les six variables à l'étude (tableau 1). Vallerand (1989) affirme que dans la majorité des cas, la version dans la langue seconde possède des valeurs psychométriques un peu plus faibles que la version originale.

On observe cependant un écart important entre la version originale et la version traduite en regard des sous-échelles aides/obstacles

internes et aides/obstacles externes (tableau 1). Un tel écart s'expliquerait possiblement par la reformulation de certains énoncés du HMAI-traduit sous la forme négative occasionant une confusion chez les sujets. Le sens et la signification des questions du HMAI-traduit auraient pu également être perçus différemment par les répondants de cette étude, ce qui expliquerait la différence des résultats. Enfin, l'existence d'un écart important au niveau de la sous-échelle aides/obstacles externes pourrait s'expliquer par le fait que dans la version traduite, cette sous-échelle ne possède que deux énoncés alors que le HMAI de McEwen comprend quatre énoncés.

Les résultats de l'analyse factorielle témoignent qu'il y a certains énoncés qui saturent assez bien sur leur propre facteur alors que d'autres ne saturent pas du tout ou du moins faiblement. Comme il y a une faible homogénéité entre les énoncés de chacune des six souséchelles, les regroupements possibles se font plus difficilement, ce qui, par conséquent, amène des résultats plus ou moins concluants. Étant donné qu'il y a des regroupements d'énoncés qui ne coïncident pas avec les données théoriques, il faudrait repenser à effectuer à priori une autre évaluation de la validité de contenu de l'instrument afin de cerner et de reformuler les énoncés qui sont problématiques. Selon DeVellis (1991), pour faciliter l'émergence de regroupements possibles entre les énoncés, il faut accroître le nombre d'énoncés qui expriment et qui véhiculent des idées semblables en les formulant d'une manière différente.

Les résultats du test de Kappa nous démontrent que les réponses des sujets sont demeurées stables dans un laps de temps de deux semaines. Cependant, puisque les qualités psychométriques du HMAI modifié ont été établies comme étant faibles, nous ne pouvons pas nous appuyer sur ces résultats, car ils ne sont pas fiables. Bref, nous ne pouvons pas conclure que la motivation des participants était relativement stable dans le temps et que l'instrument démontre une fiabilité temporelle adéquate.

La corrélation entre chacun des énoncés du HMAI modifié et la version abrégée de l'échelle de Marlowe et Crowne (1960), construite par Strahan et Gerbasi (1972) et traduite par Cloutier (1993) nous a permis de conclure que les énoncés du HMAI modifié accusent une faible corrélation à l'échelle de désirabilité sociale. Ceci signifie que les réponses du HMAI modifié ne sont pas biaisées, car elles n'ont pas été influencées par la désirabilité sociale.

#### Conclusion

La mise en application de cet instrument pourrait nous permettre de faire des prédictions plus justes et plus précises concernant les raisons qui motivent ou qui créent une résistance dans l'acquisition de saines habitudes de vie. Cependant, avant de procéder à des études d'interventions, il est nécessaire d'effectuer des modifications supplémentaires afin d'améliorer sa validité.

En ce qui concerne la validité de contenu, des modifications additionnelles s'avèrent nécessaires, malgré le fait que les proportions moyennes d'accord entre les informateurs clés, concernant la clarté et la pertinence des énoncés, sont satisfaisantes. Nous recommandons que des efforts additionnels soient investis pour raffiner la formulation négative des énoncés et ce, afin de réduire la confusion des répondants. De plus, une révision de la formulation de certains énoncés devrait être effectuée afin de les rendre plus clairs et moins ambigus. Enfin, un prétest s'avère important pour s'assurer que le langage utilisé dans l'instrument s'apparente bien à celui de la population cible.

Cinq énoncés furent exclus dans le but d'améliorer les coefficients alpha de Cronbach des variables, telles la perception de la susceptibilité, les aides/obstacles internes et les aides/obstacles externes. Nous recommandons alors de reformuler et de réinsérer ces énoncés afin d'améliorer la consistance interne de l'intrument. Une révision approfondie des énoncés relatifs aux aides/obstacles internes et externes devra aussi être éventuellement entreprise, puisque l'homogénéité entre les énoncés de ces variables est faible.

Nous croyons que la consistance interne de l'instrument et les résultats de l'analyse factorielle pourraient être améliorés si le HMAI modifié était soumis à des sujets cardiaques. D'abord, parce que le taux de réponses aux énoncés portant sur la cigarette, l'alcool et l'obésité serait plus élevé ce qui, conséquement, éviterait de retirer des énoncés de l'instrument. Ensuite, parce qu'un échantillon composé de sujets cardiaques permettrait d'obtenir plus d'homogénéité entre les répondants.

Même si les résultats du HMAI modifié sont peu prometteurs, ces derniers ne devraient pas être perçus comme étant irrévocables, mais plutôt stimulants pour les recherches à venir. D'autres études pourraient être élaborées pour évaluer plus en profondeur le modèle de la motivation relative à la santé et pour tenter d'améliorer les propriétés psychométriques du HMAI modifié. Entre autre, le fait d'établir une comparaison entre l'instrument raffiné auprès des sujets normaux et

l'instrument raffiné auprès des cardiaques permettrait d'avoir une meilleure idée de la validité de construit de l'instrument. Nous suggérons aussi d'évaluer sa validité de convergence en le comparant avec un instrument similaire.

Bref, il est essentiel que le concept de la motivation soit mesuré de façon appropriée afin qu'ultérieurement, les infirmières puissent intervenir précocement en ce qui a trait à l'acquisition et la promotion de saines habitudes de vie. Cependant, si les futures recherches arrivent à des résultats peu satisfaisants et peu congruents aux écrits, de nouveaux instruments devront être mis au point afin d'obtenir des explications plus valides et des prévisions plus justes concernant les raisons qui motivent l'usager cardiaque à vouloir initier et maintenir de saines habitudes de vie.

#### Note

Le mot *compliance* a été traduit par « fidélité » et les termes *content validity, internal consistency* et *test-retest* ont été traduits par « validité de contenu », « consistance interne » et « vérification contre-vérification », suite aux recommandations de l'Office de la langue française.

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#### Remerciements

Les auteurs tiennent à remercier Carmen Loiselle Ph.D. professeure adjointe, Sylvie Lemay M.Sc. chargée d'enseignement, Madeleine Clément M.Sc. professeure agrégée, Catherine Lussier B.Sc. statisticienne à la Faculté des sciences infirmières de l'Université de Montréal et enfin, tous les participants de l'étude.

Date acceptée: Mars 1997

## Early Infant Crying: Child and Family Follow-up at Three Years

# M. Ruth Elliott, Elaine L. Pedersen, and Judith Mogan

Des enfants qui, lorsqu'ils étaient âgés de six à huit semaines, pleuraient de manière excessive, furent soumis à un examen vers les âges de deux à quatre ans, dans le but d'évaluer les effets à long terme des ces pleurs («coliques») sur l'évolution du comportement, sur les rapports parents-enfants, et sur la dynamique familiale. On a remarqué que plus les pleurs étaient fréquents lors de la période initiale, plus nombreuses étaient, trois ans plus tard, les perturbations signalées à l'intérieur de la famille (n = 0,29). Les analyses démontrent aussi qu'ultérieurement, ce comportement n'a que peu d'influence sur le développement de l'enfant concerné. Aucun effet significatif durable sur la famille n'a été détecté. Il n'y a donc pas lieu pour les familles jouissant de ressources financières et sociales suffisantes de s'inquiéter : les problèmes suscités par les pleurs excessifs d'un nouveau-né peuvent se résorber avec le temps.

Children who cried excessively at six to eight weeks of age were re-examined at two to four years of age to determine the enduring effects of excessive crying ("colic") on behavioural development, parent-child interaction, and family functioning. The more crying in early infancy, the more family disruptions occurred three years later (r = .29). Analyses showed that early crying had little impact on the children's later behavioural development. No significant major lasting effects on the family related to the infant's early crying behaviour were found. Families with sufficient social and economic resources can be reassured that problems related to early infant crying can be ameliorated over time.

Crying, the primary means by which infants communicate with their caregivers, serves the evolutionary purpose of infant survival. Fundamental exchanges between the infant and his or her immediate environment (such as is involved in becoming socialized and obtaining food and care) are regulated by crying (Lester, 1985; Newton, 1983), which has powerful effects, eliciting strong emotions from the caregiver — who is most often a parent (Murray, 1979). Because there is some evidence that infant crying, especially excessive crying, may have lasting effects on parent-offspring interaction (Bell & Ainsworth, 1972; Goldsmith, Bradshaw, & Rieser-Danner, 1986; Moss & Robson, 1968;

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Shaw, 1977), this study focused on the possible enduring effects of early infant crying on the children and their families. Our purpose was to determine whether the amount of infant crying at six to eight weeks is predictive of later problems with child behaviour, parent-child interaction, or family functioning.

#### Literature Review

### Crying Behaviour in Infancy

Although infants exhibit considerable variability in their crying behaviour (Weissbluth, 1989), important commonalities do exist. In industrialized countries the pattern for normal infants is that crying peaks to about 2 ¾ hours a day at six weeks and then decreases to approximately one hour a day at four to 12 months (Barr, 1990; Brazelton, 1962; Golton & St. James-Roberts, 1991; Hunziker & Barr, 1986; Wessel, Cobb, Jackson, Harris, & Detwiler, 1954). Still, in these countries 10–40% of infants suffer "three-month colic" or cry excessively (Illingworth, 1954; St. James-Roberts & Halil, 1991; Wessel et al.). Keefe (1988) observes that infant crying must be appropriately interpreted if parent-infant interaction is to be successfully negotiated.

### Effects on the Infant

Depending upon its intensity and duration, crying can place an infant at risk. In addition to harmful physiological effects, such as obstruction of venous return in the inferior vena cava leading to hypoxemia and intracranial hemorrhage (Anderson, 1989), heightened crying may contribute to a maladaptive mother-infant relationship (Thoman, Acebo, & Becker, 1983). In a study of 20 mother-infant pairs at two, three, four, and five weeks of age, high levels of interactional stability, a measure of consistency in the mother-infant relationship, were found to be related to low levels of social crying but not to crying in other contexts (during feeding, changing, or bathing or when the infant was alone). Because social crying took up less than 2% (five minutes) of the sevenhour day, the investigators concluded that this small (crying) component was a potent expression of the integrative processes involved in maintaining overall stability of the system. Elliott (1984) found that the amount of infant crying at four months, but not at one month, was associated with less than optimal parent-infant interaction, an unstimulating environment for the infant, and negative parental perceptions of the infant.

### Effects on the Caregiver

Excessive crying has been found to affect parents negatively (Carey, 1990, 1992; Keefe, 1988). Parents of excessive criers have reported feeling overwhelmed (Keefe & Froese-Fretz, 1989), stressed, and negative toward their infant (Wilkie & Ames, 1986). They described feeling incompetent (Beebe, Casey, & Pinto-Martin, 1993), helpless, rejected (Korner, 1974), depressed (Korner; Mayberry & Affonso, 1993; Whiffen, 1990; Wilkie & Ames), lacking confidence in their caretaking abilities and were irritable, depressed, and unresponsive to their infant (Williams, Painter, Joy, & Davidson, 1980).

### **Enduring Effects**

Sroufe (1996) notes that "many infants participate in well-regulated relationship systems and become effective in explicitly using the caregiver to modulate tension" and "are later able to manage impulses and feelings flexibly, as well as to maintain organized behaviour in the face of high states of tension, when, as young children, they operate more apart from caregivers." Sroufe states that "the secure infant-caregiver relationship, which promotes the capacity for self-modulated arousal, has its roots in the range of affective exchanges throughout early infancy." This includes the repeated arousal escalation and de-escalation in dyadic interaction (Sroufe, 1996), the frequently repeated distress-relief cycles with which the caregiver is associated (Lamb, 1981), and the continued experiences of positive affect. The roots of individual differences in the self-regulation of emotion lie within the distinctive patterns of dyadic regulation (Sroufe, 1989).

Problems in parent-infant attachment associated with infant crying may begin in the first month of life (Bell & Ainsworth, 1972; Moss & Robson, 1968) and continue into the infant's second year (Bell & Ainsworth; Goodman Campbell, 1979; Shaw, 1977). These findings support the conclusion of Ainsworth, Blehar, Waters, and Wall (1978) that patterns of parent-infant interaction, even in the first three months, may predict patterns of subsequent attachment behaviour, such as promptness of response to infant crying. Acebo and Thoman (1992) found the structuring of a mother-infant relationship to be reflected in the amount of crying that occurred while mother and infant were in close physical contact but not while there was no physical contact. Thomas and Chess (1977) interviewed urban, middle-class parents and recorded their comments (N = 138) over time. Infant fussiness was a major concern, along with ease of feeding, regularity of sleep, fearfulness, and reciprocity. They reported that "psychological characteristics

cannot be expected consistently to show linear continuity over time" (p. 266). Further, patterns of temperamental difficulty may be associated with environmental instability.

Negative effects of infant temperament, particularly infant distress, on later parent-infant attachment have been reported by Belsky, Rovine, and Taylor (1984) and Goldsmith et al. (1986). Several studies (Cutrona & Trautman, 1986; Mayberry & Affonso, 1993) have found that infants with more difficult temperaments had parents who were more depressed. Koniak-Griffin and Verzemnieks (1994) studied 49 mother-child dyads for the role of temperament in infancy, subsequent child behaviour problems, and mother-infant interaction. Their results suggest that continuity of infant temperament rating is an important factor in subsequent maternal identification of behaviour problems in toddlers, but that difficult temperament alone may not predict such problems. The child's early development may therefore be negatively affected in an environment in which the major caregiver is depressed or less than optimally responsive.

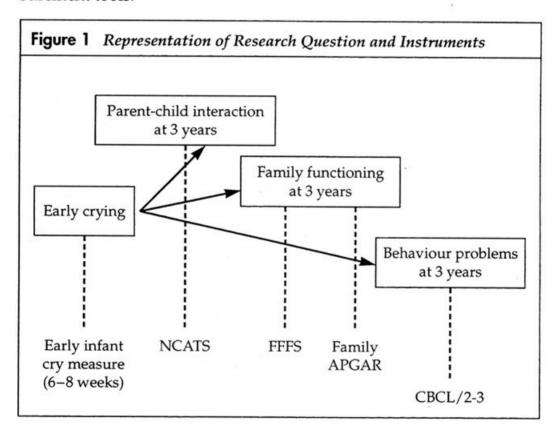
Hammond, Bee, Barnard, and Eyres (1983) link excessive crying in infancy to decreased cognitive performance in eight-year-olds. In contrast, Stifter and Braungart (1992) report no lasting effects. Pinyerd and Zipf (1989) hold that neither the short-term nor long-term consequences of infant "colic" have been adequately explored.

While the evidence remains inconclusive about the long-term effects of early infant crying on the family, Keefe and Froese-Fretz (1991) point out that "only a few studies address the impact of an irritable infant on family dynamics." Thompson, Harris, and Bitowski (1986) report that excessive infant irritability represents a crisis situation, with ramifications for the parent-infant relationship, the marriage, and family dynamics, while St. James-Roberts (1989) states that the effect of crying on parent-infant interaction is the most pressing issue. Rautava, Lehtonen, Helenius, and Sillanpaa (1995) found that families of colicky infants demonstrated more dissatisfaction, three years later, with arrangement of day-to-day family responsibilites, amount of leisure time, and number of shared activities. Researchers have established strong relationships between specific elements of early caregiverinfant interaction and the child's qualities and skills later in life. Highquality interactions early in the infant's development have been linked' to intellectual and language abilities and more secure attachments to major caregivers (Sumner & Spietz, 1995).

#### Research Question

The children in this study, some of whom cried excessively as infants, were involved in crying studies when they were six to eight weeks of age (Elliott, Fisher, & Ames, 1988). All were healthy, term infants from healthy, intact families. In this follow-up study, the children and their families were re-examined when the children were between two and four years old.

The following research question guided the study: Is infant crying at six to eight weeks of age associated with parent-reported child behaviour problems, parent-child interaction, or family functioning? Figure 1 illustrates the research question and its relationship to the measurement tools.



#### Method

### Sample

Parents of 118 infants (67 males and 51 females) who had taken part in previous cry-related studies (1986, 1987) at the Infant Development Research Laboratory of Simon Fraser University, Vancouver, were sent a letter describing the follow-up study. Of the original sample, 82 (70%) agreed to participate. Initially, these families had been recruited from

postpartum units at the Greater Vancouver hospitals that offered maternity services. Upon the infant's discharge, stamped, pre-addressed postcards were distributed to each family, requesting their participation as volunteers in one of the university's ongoing studies of child development. Newspaper and television advertisements were also placed. Parents provided informed, written consent for their child to participate. The final sample included 45 males and 37 females who were now between two and four years of age (M = 3.8, SD = 0.65). Subjects were largely from intact, two-parent families (84%). About 10% of the sample parents reported being separated and 5% were divorced. There was one single parent.

#### Instruments

The Cryscore, a single composite measure of crying, was established for each infant at six to eight weeks of age. This score was based on the caregiver's responses to three questions in a questionnaire developed in 1983 by Dr. E. Ames of the Infant Development Research Laboratory: (1) "Approximately how many times a day does your baby cry?" (2) "How long does the single, longest crying episode last each day?" (3) "How long does the average crying episode last?" In three previous studies, the variables showed satisfactory intercorrelations (from r = .20to r = .61), with mothers and fathers responding similarly to the questions about their infant's crying (Ames & Bradley, 1983; Elliott, 1985; Wilkie & Ames, 1986). The Cryscore was used to distinguish the normal criers from the excessive criers according to Wessel et al.'s (1954) definition of excessive crying (three or more hours per day, three or more days per week, during three or more weeks in the first three months of life). This measure was the independent variable used in all the analyses to categorize the children and to determine whether relationships could be found by the selected study measures.

The Child Behavior Check List [for ages] 2–3 (CBCL/2–3) (Achenbach & Edelbrock, 1986) is designed to record child behavioural problems as reported by the caregivers. This standardized scale has been used on a large population of both normal and clinically referred children, with demonstrated test-retest reliability of .87 at one week. The CBCL/2–3 discriminates between children referred for mental health services and non-referred children, showing good construct validity (Speer & Sachs, 1985). Achenbach (personal communication) approved its use with the four-year-old children in this study.

The Nursing Child Assessment Teaching Scales (NCATS) (Barnard & Eyres, 1979) measures parent-child interaction at two to four years of

age. Since the NCATS teaching tasks have been standardized only for children up to three years, we used standardized teaching tasks from Beery (1967) for the children over three. The NCATS has been tested widely and has a reported internal consistency of .83 (mother total scores) and .60 (child total scores). Test-retest reliability is .45 to .65 (mother items) (Sumner & Spietz, 1995). Construct validity has been reported in differentiating between abusing and non-abusing mothers (Barnard et al., 1989). The NCATS researchers achieved interrater reliability scores of at least 85% and obtained a Certificate of Reliability from the NCAST National Register (Sumner & Spietz).

Two tools were selected to measure family functioning from the perspective of the infant/child's immediate environment.

The Feetham Family Function Survey (FFFS) (Roberts & Feetham, 1982) is a 27-item questionnaire designed to evaluate relationships within the family as well as between the family and the social environment, by examining discrepancies between "what is" and "what should be" using the Porter format (Porter, 1962, 1963a, 1963b). The Porter format allows for an indirect measure, or discrepancy score (a-b), from two direct measures, which is converted to an absolute score and provides an indirect measure of satisfaction with the activity inherent in each item, such as amount of time spent with spouse. The FFFS has a test-retest reliability at two weeks of -.85 and an internal consistency of .66 to .84 (Speer & Sachs, 1985). Construct validity has also been reported (Roberts & Feetham).

The second tool used to assess family functioning, the *Family APGAR* (Smilkstein, 1978), was selected because of its ease of administration and its conceptual consistency with other study measures. The Family APGAR has demonstrated construct validity in differentiating adjusted from maladjusted families (Smilkstein, Ashworth, & Montano, 1982). Good, Arons, Good, Shaffer, and Smilkstein (1979) report internal consistency for item/total -.24 to .67; split half -.93. Test-retest reliability of .83 has been reported (Good et al.; Smilkstein et al.).

Families also completed a subject information sheet (SIS), which included demographic information, general questions about the health of the child and the family since the child's birth, number and type of family disruptions, and the caregiver's rating of the child's temperament. The question concerning temperament was originally used in a questionnaire developed by Ames (1983) and reported by Ames, Gavel, Khazaie, and Farrell (1985). Caregivers were asked to classify their three-year-old child as temperamentally "easygoing," "average," or "highstrung."

#### Procedure

In the follow-up study, parents were visited at home and asked to complete the CBCL/2–3, APGAR, FFFS, and SIS. Care was taken to present the study as an investigation on the child's *overall* development since early infancy, without specific reference to crying behaviours. Mothers and fathers were asked to complete all measures independently and to return them by mail. Reminder telephone calls were made when data had not been received. Eighty-two mothers and 78 fathers completed the questionnaires. During home visits, the trained researchers, using the NCATS, observed and recorded 81 mother-child teaching episodes.

### Analysis

Data from the completed questionnaires were analysed using SPSS for Windows Release 6.0 software (Norusis, 1993). Power analysis was completed to confirm the suitability of the proposed sample size (Cohen, 1977). With calculations based on a significance level of  $p \le .01$  and a medium effect size, a sample of 100 was expected to provide a 76% chance of illustrating a significant association, if there was one. The follow-up sample was compared with normed data where available.

#### Results

Unless otherwise stated, all results are reported at the  $p \le .05$  level of significance. Using the Cryscore measure, 10 (12%) of the 82 children in the study had been categorized as excessive criers at six to eight weeks of age, while the remaining 72 (88%) were normal criers (M = 3.97, S = 2.63). No significant differences in sex distribution or parental marital status between the normal group and the excessive crying group were found.

At two to four years of age, the child's major caregiver was the mother in 68 cases (83%) and the father in two cases; the role was shared or played by "other" in 12 cases (15%). The major caregiver was defined as the person who provided care for the majority of the child's waking hours.

No significant differences were found between the normal crier group and the excessive crier group, and their families, with respect to health. Seventy percent of the parents (n = 57) reported no major child (subject) health problems, 22% (n = 18) reported one problem, and 8% (n = 7) reported two or more problems. The most frequently cited child

health problems were urinary tract or upper respiratory tract infections and chickenpox. Sixty percent of families (n=49) reported no other family health problems, 23% (n=19) reported one problem, and 17% (n=14) reported two or more problems; some of the most frequently reported problems were allergies, herniated disc, chronic back problems, gynecological problems, and alcoholism/codependency.

The CBCL/2–3 was administered to address the question of whether infant crying at six to eight weeks of age is associated with parent-reported child behaviour problems at two to four years of age. Results showed no relationship between early Cryscores and mother-reported total child behaviour problems at two to four years (t = 0.61, df = 80) (Table 1). There was no significant difference between scores of the crying groups and Achenbach's (1992) non-referred sample (t = 1.05, df = 401), although there were significant differences when the normal criers' and the total criers' scores were compared with Achenbach's clinically referred sample scores. It is interesting to note that scores of the excessive crier group, when compared with Achenbach's referred sample, approached statistical significance (t = 1.94, df = 329).

To investigate whether infant crying at six to eight weeks was associated with parent-child interaction at two to four years, *t*-tests were used to compare parent and infant subscale scores and total scores on the NCATS with early infant crying scores (Table 2). Although the Sensitivity to Cues and Response to Distress subscales resulted in significant *t* values, further non-parametric analysis revealed that the distributions were not normal, rendering the results meaningless. No significant differences were seen between the normal criers and the excessive criers for any of the NCATS subscales. This suggests that parent-child dyads whose infants cry excessively at six to eight weeks and parent-child dyads whose infants cry a normal amount do not differ in their interactions when the child is two to four years of age.

When data were compared against the NCATS Database (Sumner & Spietz, 1995), t-tests revealed significant differences between the follow-up sample and the database for many of the subscales, but not for the Parent Total Score or NCATS Total Score (Table 2). Both mother and child contingency scores (items on the NCATS that specifically deal with reciprocal dyadic interaction between caregiver and child) were found to differ significantly from the database scores. Mothers' mean contingency scores in the follow-up sample were higher than those in the database, while the children's mean contingency scores in the follow-up sample were lower than those in the database.

Summary Statistics and *t*-test of Difference in Means between (1) Infant Follow-up Sample (Normal and Excessive Criers) and (2) Infant Follow-up Sample (Normal, Excessive, and Total Criers) and Norms (Achenbach's Non-referred and Clinically Referred Samples)

Tools	# of Children	Mean	Standard Deviation	Difference	t Value	Degrees of Freedom	P
Child behavior profile (CBCL/2-3) Total Behavior Problems		16					
1. Infant Follow-up Sample							
(a) Normal Criers	72	35.25	44.59				
(b) Excessive Criers (compared with Normal)	10	44.20	32.36	8.95	0.61	80	0.54
(c) Total Criers	82	39.73	38.48				0.01
2. ~Achenbach's Non-referred Sample	321	33.80	19.90				
(a) compared with Normal Criers				1.45	0.27	391	ns
(b) compared with Excessive Criers				10.40	1.02	329	ns
(c) compared with Total Criers				5.93	1.40	401	ns
3. +Achenbach's Referred Sample	321	64	26.60	***************************************			
(a) compared with Normal Criers				28.75	5.47	391	≤0.05
(b) compared with Excessive Criers				19.80	1.94	329	ns
(c) compared with Total Criers				24.27	5.71	401	≤0.05

<sup>~</sup> From raw scores, Achenbach's sample of non-referred (normal) children (Achenbach, 1992)

<sup>+</sup> From raw scores, Achenbach's sample of clinically referred children (Achenbach, 1992)

<sup>\*</sup> t value shows significant difference if  $t \ge 1.96$ ,  $p \le .05$ 

ns = no significant difference (p values reported where available)

 Table 2
 NCAST Teaching Scale, Feetham Family Functioning Survey, and Family APGAR

Summary Statistics and *t*-test of Difference in Means between (1) Normal and Excessive Criers and (2) Total Follow-up Sample (Total Criers) and Norms (where available)

			Difference	t Value	Freedom	P
71	9.49	1.13				
10			0.81	2 19	70	0.03
81	9.12		0.01	2.17	73	0.03
2123	9.38	1.57	0.26	3.30	2202	≤0.05
71	10.96	0.26				
10			0.36	2 14	70	0.04
81	10.78		0.00	2.17	79	0.04
2123	10.20	1.60	0.58	6.77	2202	≤0.05
71	8.72	1.29				
10	8.50	1.08	0.34	0.51	79	0.61
81	8.61	1.19	5.62	OloI	,,	0.01
2123	9.22	1.69	0.61	4.61	2202	≤0.05
)	10 81 2123 71 10 81 2123 71 10 81	10 10.30 81 9.12 ) 2123 9.38 71 10.96 10 10.60 81 10.78 2123 10.20 71 8.72 10 8.50 81 8.61	10 10.30 0.68 81 9.12 0.71 2123 9.38 1.57 71 10.96 0.26 10 10.60 1.27 81 10.78 0.77 2123 10.20 1.60 71 8.72 1.29 10 8.50 1.08 81 8.61 1.19	10 10.30 0.68 0.81 81 9.12 0.71 2123 9.38 1.57 0.26 71 10.96 0.26 10 10.60 1.27 0.36 81 10.78 0.77 2123 10.20 1.60 0.58 71 8.72 1.29 10 8.50 1.08 0.34 81 8.61 1.19	10       10.30       0.68       0.81       2.19         81       9.12       0.71       0.26       3.30         71       10.96       0.26       0.26       0.36       2.14         81       10.78       0.77       0.36       2.14         81       10.78       0.77       0.58       6.77         71       8.72       1.29       0.58       6.77         71       8.50       1.08       0.34       0.51         81       8.61       1.19       0.61       4.61         2123       9.22       1.69       0.61       4.61	10     10.30     0.68     0.81     2.19     79       81     9.12     0.71     0.26     3.30     2202       71     10.96     0.26       10     10.60     1.27     0.36     2.14     79       81     10.78     0.77       2123     10.20     1.60     0.58     6.77     2202       71     8.72     1.29       10     8.50     1.08     0.34     0.51     79       81     8.61     1.19

<sup>59</sup> 

Analysis of the total discrepancy scores of the FFFS was carried out to determine whether infant crying at six to eight weeks was associated with family functioning at two to four years. This revealed no differences between the two groups of families. No significant differences were noted between mothers' and fathers' scores when the two groups of criers were compared. However, results revealed a greater discrepancy for mothers between "what is" and "what should be" regarding the amount of help from relatives and friends with family tasks such as care of children, house repairs, household chores, etc. Mothers were shown to be more dissatisfied (M = 8.33, SD = 1.9, Range = 0-10) than fathers (M = 5.89, SD = 3.96, Range = 0-10). These discrepant scores correlated positively with the number of child health problems (r = .27) and major family disruptions (r = .27).

Results from the Family APGAR showed no significant differences in any of the family interaction and support items when families of early excessive criers were compared with families of normal criers.

Major family disruptions were reported on the SIS by 44% of the families (n = 36). The number of reported family disruptions showed a significant positive relationship with the Cryscore of the child (r = .29). The families of excessive criers reported more major family disruptions (such as divorce or death of a grandparent) by the time the child was two to four years than did the families of normal criers.

#### Discussion

This follow-up study of child and family characteristics related to early infant crying behaviours found no major lasting effects on the child, the family, or parent-child relationships, apart from mothers' dissatisfaction with the amount of help they received from their spouses and friends. Rautava et al.'s (1995) findings of more dissatisfaction with arrangement of day-to-day family responsibilities, leisure time, and shared activities were surprisingly similar to ours. We surmise that patterns of responding to daily tasks may well be influenced early on by time constraints imposed by an excessive crier. The majority of our results supported those reported by Stifter and Braungart (1992). We attribute this in part to the volunteer nature of our study population. Most of the subjects were partnered, reasonably healthy, middle- to upper-middle-class Caucasian families. In addition, they proved highly committed to this follow-up study, as evidenced by an impressive follow-up rate of 70% of the original sample from three years earlier. Families with fewer problems and more supportive, stable environments (as was the case

with the participants in this study) are better equipped to meet developmental challenges.

Comparison of our results on the CBCL/2–3 with those of Achenbach's (1992) normal (non-referred) sample revealed no differences between groups (t = 1.05, df = 401). Scores for the excessive crier group did not differ significantly from Achenbach's clinically referred sample, although they approached clinical significance. This latter finding is intriguing and invites further detailed analyses of our results using the Achenbach tool. However, the findings suggest that our total sample, comprising both normal and excessive criers, likely represents a normal population. Future longitudinal research should include a larger, randomized controlled trial, to determine whether long-term effects of excessive crying persist, particularly in a population of reduced psychosocial and environmental assets.

An examination of our NCATS results comparing excessive crier and normal crier groups revealed that later parent-child interaction was not compromised. The groups did not differ in responsiveness to their distressed child. These findings are inconsistent with those of Bell and Ainsworth (1972) and Shaw (1977), who found later decreased parental responsiveness, although their subjects were younger (up to 12 months and 14 months, respectively). Our results showed higher mean contingency scores for mothers, but lower mean scores for children, when compared with the NCAST database. Other differences were mixed. These results may reflect cultural and/or socioeconomic differences between samples. For example, Sumner and Spietz (1995) found consistent differences among ethnic groups. After controlling for mother's education and child's age, their Mother, Child, and Total Teaching Scores were higher for Caucasian dyads (N = 963) than for African-American (N = 467) and Hispanic dyads (N = 311).

Abundant research evidence supports the claim that infant crying, especially excessive or "colicky" crying, is a risk factor in the early post-partum months. With sufficient and effective family resources, the long-lasting negative effects of crying can be forestalled. Our sample of 85% two-parent, educated families was able to cope with infant crying. When resources are not available, or when the family's psychosocial assets are limited (such as in the case of single parents with limited finances), such a combination of risks could pose a substantial threat to a developing "reciprocal, symbolic interaction that is realized through behaviours that indicate a nurturing commitment on the part of the parent and a loving-like response from the infant" (Thompson et al., 1986).

Our findings are consistent with those of Stifter and Braungart (1992), who studied parents' ratings of infant temperament and found that colicky and comparison infants were similar, by the age of five and 10 months, in terms of both behaviours exhibited in the laboratory and behaviours rated by mothers. We found no significant differences between groups of criers in temperament ratings by parents of three- to four-year-olds. We identified a tendency for more children rated by their parents as "highstrung" to be in families reporting more disruption. This poses the question: Are "highstrung" infants reflecting the emotional climate in which they are reared, or are they contributing to a less ordered family environment? This question invites more longitudinal research.

### Clinical Implications

Although we found few lasting problems connected with early excessive infant crying, these results may not apply to all family situations. Most parents continue to express extreme anguish when their attempts at soothing are unsuccessful. We recommend that parents of excessive criers be identified and supported as an integral part of follow-up health care, to offset the possibility of continuing unresolved, unhealthy parent and family behaviours. Families with reduced psychosocial assets, such as limited knowledge or support or financial problems, where major family disruptions or child health problems co-exist, are particularly vulnerable. Offering help in applying more effective soothing techniques directed at increasing their infant's control of his or her own arousal should be part of all parent-information sessions in the perinatal period.

On a positive note, parents of excessive criers can be reassured that infant crying decreases with age and that long-term outcomes, reflected in child behaviours, interaction between caregiver and child, and family functioning, are not likely to be compromised.

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### Acknowledgements

This research was made possible by a project grant from the Alberta Foundation for Nursing Research (AFNR). AFNR does not necessarily support the ideas or findings associated with the project.

The assistance of Dr. Elinor W. Ames and Trisha Ackland of Simon Fraser University was invaluable to the successful completion of this project, as was the cooperation of the following research assistants in Vancouver: Jane Critchley, Kristy Gash, Andy Gotowiec, Lisa Jung, Laurie MacWilliam, Colleen McCartney, Gail McKnight, Laura Parsons, and Cathy Thorton. Thanks are also extended to statistics consultant Dr. Terry Taerum, Pauline Naykalyk of the University of Alberta, Edmonton, and the following research assistants in Edmonton: Rose Boyle, Caron Bright, Christene Evanochko, Nicole Letourneau, Cara Mallett, Jo-Anne Parsons, and Marilyn Woolley.

### Early Infant Crying: Child and Family Follow-up at Three Years

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Date accepted: December 1996



# Strategies to Address the Methodological Challenges of Client-Satisfaction Research in Home Care

### Dorothy A. Forbes and Anne Neufeld

Alors que les études récentes en satisfaction de la clientèle abondent, les difficultés d'ordre méthodologique persistent. Les obstacles les plus courants font l'objet du présent essai, notamment la possibilité de recueillir des informations pertinentes de la part des clients âgés recevant des soins à domicile. La tendance à la désirabilité sociale, la crainte de représailles, la tendance à l'acquiescement, et la formulation négative ou positive des items sont quelques-uns des obstacles notés. Ils peuvent rendre difficile la tâche de cerner quelles sont les modalités importantes de la satisfaction et de l'insatisfaction chez la clientèle des soins à domicile. Plusieurs stratégies de collecte de renseignements sont ici proposées : réaliser des entrevues interactives dirigées, raconter des histoires, élaborer des scénarios, de même que classer selon leur importance les modalités de satisfaction et d'insatisfaction, sur la base des données résultant des entrevues. Chacune de ces stratégies fait l'objet d'une discussion, à l'aide d'exemples tirés d'une enquête sur la satisfaction de la clientèle âgée recevant des soins à domicile. Les infirmières, infirmiers et autres dispensateurs de soins doivent pouvoir s'appuyer sur des données fiables pour que des principes directeurs soient élaborés, et que des services mieux adaptés et efficaces soient offerts à la clientèle des soins à domicile.

While there is an abundance of recent client satisfaction research, methodological difficulties continue. This paper addresses common methodological challenges in securing useful feedback from elderly clients receiving home-care services. The methodological challenges include socially desirable response sets (SDRS), fear of reprisal, acquiescent response sets (ARS), and negative or positive wording of items. These contribute to an inability to capture salient dimensions of satisfaction and dissatisfaction important to home-care clients. Several data-collection strategies are proposed: guided interactive interviews, story-telling, scenarios, and rating of the importance of the dimensions of satisfaction and dissatisfaction identified from interview data. Each strategy is discussed using illustrations from a study on elderly clients' satisfaction with home-care services. Nurses and other health-care providers require credible feedback about client satisfaction in order to develop policy and to provide more appropriate and effective services to home-care clients.

With the current emphasis on fiscal cutbacks and outcome measurement, there is an increased interest in consumers' views. Concepts such as Continuous Quality Improvement, which focus on meeting and

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exceeding customer satisfaction, have been flourishing. Indeed client satisfaction with care has become a valued outcome indicator, even an element of health status itself (Donabedian, 1988). While there is an abundance of recent client-satisfaction research, however, there continues to be disagreement about the definition of the construct of client satisfaction, the dimensions and determinants of client satisfaction, and the absence of reliable and valid instruments to measure client satisfaction. Two issues contribute to this lack of agreement: the complexity of the construct of client satisfaction and methodological difficulties of client-satisfaction research.

This paper will address common methodological challenges in securing credible and useful feedback from home-care clients. To do so, we propose several strategies that proved useful in a study of elderly clients' perceptions of satisfaction with home-care services. We will summarize the methodological challenges identified in the literature. Then we will propose strategies to address these challenges, offering examples from our research experience.

### Methodological Challenges in Satisfaction Research

The challenges in securing useful data in satisfaction research are well documented (Bond & Thomas, 1992; Carr-Hill, 1992; French, 1981; Petersen, 1988). Frequently cited challenges include: (1) socially desirable response sets (SDRS), (2) fear of reprisal, (3) acquiescent response sets (ARS), and (4) negative or positive wording of items. These challenges contribute to an inability to capture salient dimensions of satisfaction and dissatisfaction, which are important to home-care clients.

SDRS, in which individuals give answers consistent with the prevailing social norms rather than accurate personal responses, are common to all types of research but are particularly relevant for satisfaction research. Hays and Ware (1986) found that rating an item that asked for a personal response was consistently biased upward for those subjects who manifested SDRS. The rating item requesting the participant's view of most people's perceptions, however, was found to be unbiased. These results may explain why score distributions for satisfaction items requesting a personal response tend to be more skewed than score distributions for similar items referring more generally to the perceptions of others.

Fear of reprisal may be a concern for elderly individuals receiving home-care services. Clients may "fear repercussions from staff"

(French, 1981, p. 21) or fear losing some or all of their services if they give negative responses (Nehring & Geach, 1973).

Additional challenges include an ARS and negative or positive wording of items. ARS is the tendency to agree with statements regardless of the content (Ventura, Fox, Corley, & Mercurio, 1982). Ware (1978) demonstrated that 40% to 60% of respondents of satisfaction questionnaires manifest some degree of ARS and from 2% to 10% demonstrate noteworthy ARS tendencies. Occurrences of ARS accounted for significant upward bias in satisfaction scores computed from favourably worded questionnaires and significant downward bias in scores computed from unfavourably worded items. La Monica, Oberst, Madea, and Wolf (1986) posit that although the use of positively and negatively worded items reduces ARS, it may create a problem with socially desirable responses. For example, patients who are uncomfortable disagreeing with a positively worded statement may be comfortable agreeing with a negatively worded item, because they view the presence of such statements as acknowledgement that negative things can and do happen. Thus a negative statement may permit or sanction an honest response in a way that a positive statement does not.

# Strategies to Address the Challenges in Satisfaction Research

Several strategies are proposed to address these challenges in securing useful data in satisfaction research: guided interactive interviews, story telling, scenarios, and rating the importance of the dimensions of satisfaction and dissatisfaction. Each strategy will be discussed in turn within the context of satisfaction research with elderly home-care clients.

The guided interactive interviews held early in the study consisted of conversations to elicit the salient parameters of client satisfaction. As the research proceeded, the interviews became more focused, in order to explore areas of special interest, to begin to verify preliminary findings, and to start looking for areas of commonality and difference in participants' stories (May, 1991). Guided interactive interviews may decrease SDRS, ARS, and fear of reprisal by enabling the researcher to establish personal rapport with the participant. Rapport is established by ensuring that the participant is comfortable with the interviewing process; pointing out that the researcher is not interested in making judgements; affirming that the participant's identity will not be revealed and that all information will be kept confidential; and communicating that the participant's contribution is crucial to a better understanding of the meaning of client satisfaction and that the research is important and

useful (French, 1981). Fitzpatrick (1984), in a study of satisfaction with health care, found that participants are more likely to be candid if they are interviewed by a researcher who is independent of the health-care agency. Participants may fear reprisals when the researcher is also a service provider.

An additional advantage of the guided interactive interview is the ability to capture spontaneous comments about issues that clients consider important. Research reveals that salient dimensions important to clients may be considerably different from the dimensions identified as important by health-care professionals (Raphael, 1967). Other investigators have found that the results of unstructured questions about client satisfaction are different from results in response to direct questions (Carr-Hill, 1992). Open-ended questions that encourage clients to talk about the care they have received elicit a descriptive account from which satisfaction or dissatisfaction can be inferred. If a study involves only direct questions about satisfaction with aspects of care, evaluative comments may be generated without the researcher's knowing the referent or the context of the response. However, by following indirect questions with more specific inquiries, the investigator may elicit comments on additional issues that did not arise in the spontaneous response to an open-ended question (Locker & Dunt, 1978). An initial focus on demographic and health-status information clarifies the participant's point of reference, as it has been shown that clients with a chronic disease may become "experts" in their own condition and more critical of and less satisfied with their care (Carr-Hill). These interview strategies can be useful in decreasing the incidence of SDRS and ARS.

Inviting participants to tell their personal life stories, including specific events and experiences, provides access to concrete details that might otherwise not be known (Van Manen, 1990). Participants can then be encouraged to elaborate so that a fuller, more detailed understanding is reached. The stories could reflect what is important, notable, strange, or worrisome to the client (Carr-Hill, 1992). Indeed these accounts can enable researchers to access realities that may be outside the realm of their own personal life experience.

The vignette technique, often employed in survey research, can also be adapted for use in satisfaction research. Finch (1987) refers to vignettes as "short stories about hypothetical characters in specified circumstances" (p. 105) and suggests that an advantage of this technique is the ability to incorporate characteristics of the situational context into the vignette. This technique provides a concrete, specific description to which elderly clients may respond more easily. One way to adapt this

technique for use in satisfaction research is to create hypothetical scenarios that reflect the characteristics of care known to be important to elderly clients.

Satisfaction research has been insensitive to the specific dimensions of satisfaction that are important to clients. Client responses tend to fall into narrow bands that are superficially indicative of high satisfaction levels (Carr-Hill, 1992). One way to identify and incorporate clients' perspectives on the most important characteristics of care is to invite them to indicate their personal priorities by rating the importance of specific characteristics. This approach facilitates consideration of the importance of each characteristic on its own merit, without the need to rank characteristics hierarchically.

In summary, use of the guided interactive interview method combined with open-ended questions, an invitation to clients to "tell their story," and use of hypothetical scenarios (vignettes) can elicit useful, detailed information about client satisfaction. An understanding of the characteristics of care most important to clients can be reached when clients rate the importance of these elements. Next we will discuss the use of these strategies in a study of client satisfaction with home-care services.

#### Using the Proposed Strategies

The proposed strategies were successfully employed in a qualitative descriptive study of elderly clients' satisfaction with home-care services. The descriptive mode provided access to rich detail about the topics of interest and the meaning of the experience for clients involved (Artinian, 1988). The study was conducted in two western Canadian small urban centres and surrounding rural areas. Letters describing the study were mailed to 120 home-care clients. Twenty clients responded to the letter and six women and four men were selected to participate. These were at least 65 years of age; able to speak English; oriented regarding person, place, and time; and willing to discuss their thoughts and feelings about their experience with home care. Their ages ranged from 68 to 89 years and their health status varied from functional independence and requiring some assistance with homemaking to terminally ill and requiring 24-hour care. Prior to the start of the interview, a signed consent form was obtained from each participant. As well as describing the study, the consent form stated that the participants were free to withdraw from the study at any time and that their decision on whether to participate had no bearing on their eligibility for services through the home-care program. Each participant was interviewed

twice. The interviews were tape-recorded, transcribed, and analyzed using hierarchical thematic analysis (Colaizzi, 1978). Findings are reported elsewhere (Forbes, 1996). Strategies proposed to elicit useful feedback are illustrated with examples from the study.

Participants were interviewed in their homes. During the first interview, rapport was developed by creating a permissive atmosphere, by assuring the participant of his or her anonymity, and by making it clear that the researcher had no affiliation with the home-care agency. Biographic and demographic data, including the participant's health condition, were elicited at the beginning of the interview to clarify his or her point of reference. Ability to capture the *client's perspective* was facilitated by use of open-ended guiding questions such as "Tell me what it is about home care that you find satisfying."

Clients were invited to relate personal stories of experiences with home care which were satisfying as well as stories of dissatisfying experiences. Having the same personal care aide (PCA) was very important to one elderly client:

P: You know yourself you get a little shy with strangers coming in to wash your body. You feel better...a little freer, with the regular lady [PCA].

The satisfying reciprocal nature of an elderly client's relationship with her PCA was illustrated as follows:

P: She [the PCA] understands my situation and she does her best to do what she is able to do for me. And she knows that I don't expect her to do something that is not right — like I wouldn't ask her to clean up the kitchen or something like that, never.

Elements of dissatisfaction reflecting a nurse's failure to listen or insensitivity to the client's needs are revealed in this comment:

P: One nurse kept on saying, "Oh, you should see the palliative care unit they have in R. It's gorgeous!" Lord! That's the last thing I want to hear about.

Upon completion of the first 10 interviews, the following strategies were utilized in the second round of interviews. Ten scenarios were developed that portrayed satisfying or dissatisfying experiences, based on analysis of data from the first interviews. Face validity of the scenarios was established by a panel of experts. The scenarios were then shared with the participants in order to further explore personal meanings and to validate the dimensions of satisfaction or dissatisfaction. The following are examples of the scenarios and the associated questions:

1. Mrs. B. is 89 years of age. She receives homemaking service and a bath assist every week. Frequently her worker is replaced by a different worker and Mrs. B. finds she has to explain to each new worker what it is she wants done.

How would you feel about having your workers changed frequently?

2. Mr. E. has a daughter and a son who live in the same part of town as he does. Mr. E. has difficulty walking and is unable to do the housework. However, he is reluctant to ask his daughter or son for help as he does not want to become a burden to them. He finds it easier to ask the homemaker for assistance rather than a family member.

Do you ever feel this way? Please explain.

Lastly, the participants were asked to rate in importance the dimensions of satisfaction and dissatisfaction that had been identified during analysis of the first 10 interviews. This approach provided information about the relative importance of characteristics of care to clients. For example, clients indicated that a cheerful manner and trustworthiness were important characteristics in PCAs, whereas the ability to listen to clients and a cheerful manner were important characteristics in nurses.

#### Conclusion

Strategies such as the use of guided interactive interviews, storytelling, scenarios, and ratings of dimensions of satisfaction can enhance the credibility and utility of feedback from home-care clients when conducting satisfaction research. Previous research has revealed that satisfied clients are more likely to participate in their own care and to cooperate with their home-care workers by disclosing relevant information (Petersen, 1989). Dissatisfied clients are more likely to reject advice from the health-care worker, fail to attend a service for treatment, and are less likely to show improvement in symptoms (Fitzpatrick, 1990). Additionally, the satisfied client is a major "marketer" for the health-care agency, as it has been reported that satisfied customers will relate their satisfaction to four or five people; dissatisfied customers will relate their dissatisfaction to nine or 10 people (Meisenheimer, 1991). Incorporating strategies to enhance the credibility and utility of feedback from clients ensures that nurses and other health-care providers are better able to provide more appropriate and effective services to home-care clients.

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#### Acknowledgement

This research was supported by a grant from the Alberta Foundation for Nursing Research.

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Date accepted: November 1996



# Patterns of Caregiving Following the Institutionalization of Elderly Husbands

# Margaret M. Ross, Carolyn J. Rosenthal, and Pamela Dawson

Le but de cette étude était de se pencher sur le rôle de dispensatrice de soins assumé par les femmes âgées dont le mari a été placé en établissement de santé. S'inspirant de l'approche interprétative en sociologie et du concept de «carrière» élaborée par Hughes (1971), l'étude se fonde sur un schéma expérimental longitudinal, prospectif et descriptif, alliant les approches quantitative et qualitative. Les données utilisées dans cette analyse ont été puisées dans une étude plus étendue dans laquelle la transition des femmes mariées vers un quasi-veuvage était étudiée sous tous ses aspects, de même que les réactions de ces dernières, suite au placement en établissement de leur conjoint. Des visites fréquentes et une participation croissante aux soins : voilà le mode de vie qui se dégage pour les femmes engagées dans un tel processus. Deux types de prestation des soins se sont dessinés au cours des neufs mois de l'étude, et ils sont caractérisés par des circonstances et des interactions variées. En général, les femmes ayant renoncé à donner certains types de soins s'occupent d'un conjoint atteint dans une large mesure de troubles cognitifs. Elles avaient bon moral et manifestaient peu de symptômes dépressifs; elles s'étaient rapprochées de leur conjoint et se sentaient satisfaites, sous divers aspects, des soins en établissement. De leur côté, les femmes ayant continué à participer de manière intensive à la prestation des soins avaient, pour la plupart, un conjoint souffrant de troubles physiques. Les résultats des tests révélaient chez elles des symptômes de dépression allant de modérés à graves; rien n'avait changé dans leur rapport intime à leur conjoint, et elles s'avouaient insatisfaites, sous certains aspects, des soins en établissement.

The purpose of this study was to examine the caregiving career of older women following the institutionalization of their husbands. Informed by the interpretive perspective in sociology and Hughes's (1971) concept of career, the study employed a longitudinal, prospective, and descriptive design and combined the quantitative and qualitative approaches. The data used in the analysis were drawn from a larger study designed to explore the transition to quasi-widowhood and wives' responses to their husbands' institutionalization. The caregiving career of wives was seen as a pattern of frequent visiting and increasing involvement in the provision of care. Over the nine-month period of the study, two caregiving patterns emerged that were distinguished by a variety of circumstances and interactions. Wives who relinquished aspects of caregiving were more likely

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to be caring for husbands who were, in large measure, cognitively impaired. These wives reported good morale, few symptoms of depression, change in marital closeness, and satisfaction with aspects of institutional care. Wives who continued to be heavily involved in caregiving were more likely to have husbands who were physically impaired. They had depression scores indicative of moderate to severe depression, reported no change in marital closeness, and were dissatisfied with aspects of institutional care.

There is anecdotal and scientific evidence that the provision of care forms a central component of women's lives. Indeed, caregiving can be considered a career that spans the life course of many women, the phases of which are heralded by marriage, the arrival of children, the onset of dependency of parents, the deteriorating health of husbands, and the admission of husbands to long-term care in an institution (Pearlin, 1992; Ross, 1991; Suiter & Pillemer, 1990). While an extensive body of literature focuses on caregiving in later life, the recent literature chronicles the experience of elderly women who provide care to community-dwelling husbands. Less is known about the experience of those who continue to provide care to husbands who have been admitted for long-term institutional care. For these women, the provision of care to their spouse represents a major change in their caregiving career and a first step in the transition to widowhood. Little is known about this phase of their life — the shifts they experience in the provision of care, their emotional responses, and the restructuring of their lives. The purpose of this paper is to examine the caregiving career of elderly wives following admission of husbands for long-term institutional care.

#### Caregiving in Later Life

Several characteristics of the research literature on caregiving in later life provided direction for this study. With few exceptions, researchers have emphasized the provision of care that occurs prior to the institutionalization of elderly and impaired persons. Their research also focuses on the experience of adult children who provide care to elderly parents (Lichtenberg & Barth, 1989; Mui, 1995; Wolfson, Handfield-Jones, Glass, McClaran, & Keyserlingk, 1993). The experience of spouses, who may be especially vulnerable to the challenges of caregiving because of their own advancing age, particularly wives who continue to provide care to husbands following their admission to an institution for long-term care (Gladstone, 1995; Rosenthal & Dawson, 1991), takes up a very small proportion of the literature on caregiving in later life.

Substantively, researchers, with few exceptions (Aronson, 1991; Bowers, 1988; Guberman, 1992), have focused on the performance of tasks, an approach that may be particularly inappropriate for an activ-

ity dominated by women (Abel, 1990). Caregiving functions do not exist in a vacuum. Rather, they are embedded in personal relationships. Whereas men are likely to take an instrumental approach to caregiving, women are more apt to emphasize the relational aspects of care. Knowledge of both dimensions is necessary for a comprehensive understanding of caregiving (Lewis & Meredith, 1988).

Methodologically, researchers have emphasized cross-sectional studies. While this approach may be understandable, given the difficulty of gathering longitudinal data, the snapshot view of caregiving that it provides tends to portray caregiving as a static phenomenon rather than as a process that may shift over time in response to particular or changing circumstances. Studies also tend to be quantitative in nature; an approach that provides little information about the affective and cognitive aspects of caregiving.

Conceptually, the focus on stress, resources, and recovery (George & Gwyther, 1986; Knight, Lutzky, & Macofsky-Urban, 1993; Pearlin, Mullan, Semple, & Skaff, 1990; Williamson & Schulz, 1993; Zarit & Whitlach, 1992) restricts the range of other possible responses to caregiving. While researchers have correlated stress with the degree of intimacy between givers and receivers of care (Cantor, 1983; Miller, 1989), they offer little indication of whether a strong sense of affiliation and attachment simultaneously imbues caregiving with meaning and purpose (Abel, 1989). Any investigation of informal caregiving should understand the motivation to care and the meaning of caregiving as defined by the parties involved.

This study built upon and strived to move beyond previous research on caregiving in later life.

# Purpose and Objectives

The purpose of this study was to examine the caregiving careers of elderly women following the admission of their husbands to an institution for long-term care. More specifically, the research was designed to answer the following questions:

- (1) How frequently do wives visit their husbands following admission to an institution for long-term care? Does the frequency of visiting change over time, and, if so, how?
- (2) What caregiving tasks do wives carry out during their visits? Does task performance change over time, and, if so, how?

- (3) What are wives' thoughts and feelings about visiting and task performance?
- (4) Do patterns of caregiving emerge following the institutionalization of husbands?
- (5) How are patterns of caregiving associated with factors of an intrapersonal, interpersonal, and institutional nature?

#### Conceptual Framework

This study was informed by the interpretive perspective and the concept of career (Hughes, 1971). The interpretive perspective "emphasizes the human capacity to construct and share meaning and the human tendency to attempt to control, through symbolic interaction, situations in keeping with biographically meaningful intentions" (Marshall, 1979, p. 35). The concept of career was useful because of its focus on objective and subjective reality as used in sociological analyses and because it provided a way of looking at the experience of people over time, including the experience of women who provide care to family members. Hughes (p. 137) defines objective career as "a series of statuses and clearly defined offices held throughout the life course, in which there are typical sequences of position, achievement and responsibility." In addition, the concept is congruent with the hypothesis that becoming a caregiver involves a status acquisition similar to other social statuses precipitated by socially recognized events, such as marriage, motherhood, and becoming a professional (Suiter & Pillemer, 1990). Objectively, the notion of career can be seen to incorporate the activities and responsibilities associated with a particular status or position that are carried out and change over time. This study focused on visiting and task performance. Hughes (p. 137) defines subjective career as "the moving perspective in which people see their lives as whole and interpret the meaning of various attributes, actions and the things that happen to them." In other words, the ways in which the objective properties of career are viewed by those persons experiencing them constitute the subjective aspects of career (Marshall, 1980). In this study, feelings and perceptions about visiting and task performance constituted subjective aspects of the caregiving career. This study built on the work of Spence and Lonner (1978-79), Marshall (1980), Martin-Matthews (1980, 1987), Suiter and Pillemer, and Pearlin (1992), who used the interpretive perspective and the concept of career to study motherhood, aging and dying, women's experience of migration, widowhood, and family caregiving, respectively.

#### Methods

#### Design

The data were both quantitative and qualitative and were derived from a larger study that investigated the transition to quasi-widowhood i.e., "the period of time when women find themselves still married but living alone and in many respects without the mate they once had" (Rosenthal & Dawson, 1991, p. 317). The study was conducted in the Extended Care Department of Sunnybrook Health Science Centre at the University of Toronto. Many patients in the hospital's 400-bed chroniccare unit were elderly; 90% were male veterans, about half of whom had wives. Patient-related costs were covered by a combination of provincial health insurance and benefits from the federal Department of Veterans' Affairs. As a result, there were no direct charges to patients and families. The wives of all married male patients admitted to Extended Care (excluding thosed admitted for intermittent respite care or palliative care) were invited to participate in the study. The design was longitudinal, prospective, and descriptive in nature and involved six interviews over an 18-month period.

#### Sample

Seventy-eight wives were entered into the original study. Attrition was caused primarily by the death of husbands (n = 23), discharge home or to an acute-care setting (n = 2), or refusals (n = 7). Initially, wives were interviewed about their pre-admission situation. Since some researchers suggest that family members usually adjust to a relative's placement within a year, it was felt that the most turbulent time for these wives would be the six to nine months following their husband's institutionalization. Consequently, data analysis for this study involved selected variables from three interviews: the background interview conducted at admission, which inquired about the wives' pre-admission situation, and two process interviews conducted at months one and nine, which inquired about their post-admission situation; this resulted in a time span of nine months. Forty-six wives participated. There were no statistically significant differences on socio-demographic variables between the sub-sample used for this study and the parent sample used for the original study. Respondents were fairly representative in terms of income (Statistics Canada, 1987, p. 22-23) and the proportion born in Canada (Ontario Ministry of Citizenship and Culture, 1981). For the year prior to the study, 24% reported a family income under \$15,000; 34% between \$15,000 and \$19,000; 17% between \$20,000 and \$29,000; and 24% a family income of \$30,000 or more. The proportion of the sample that was of British ancestry was somewhat higher than that in the Canadian population (Dreiger & Chappell, 1987), although it was similar to that in Ontario (Gerber, 1983).

#### Measures

The demands of caregiving prior to admission derived from fixed-choice questions about the amount of help husbands required with personal care and instrumental activities of daily living (adapted from Lawton & Brody, 1969). Response categories were: no help needed, some help needed, a great deal of help needed, and unable to do without help. Wives were also asked to identify the main reasons for their husband's institutionalization.

The Zarit Burden Interview (Zarit, Reever, & Bach-Peterson, 1980), a widely used measure in social gerontology, was used to measure feelings of burden prior to admission. The reliability for all 29 items resulted in a Cronbach's alpha of 0.94.

Visiting was assessed by asking how often wives visited their husbands. The six response categories ranged from every day to once a year or less. Motivation for visiting and feelings about visiting were measured with open-ended questions asking why wives visited as often as they did, how much they enjoyed their visits, and whether they felt a sense of satisfaction with visiting.

Task performance was assessed by using a list of 27 items adapted from an inventory developed by Rubin and Shuttlesworth (1983). Each item referred to a task that a wife might perform for her husband, including aspects of grooming, personal care, caring for room and clothing, outings, diet, providing emotional support, maintaining family connectedness, monitoring medical care, providing "extras," enlisting family support, maintaining security, and arranging for counselling. Wives were asked to identify which of the tasks they were performing at each measuring point. An open-ended question asked wives to identify the most important thing they did for their husbands.

Husbands' health was assessed by a single-item question asking whether the condition for which the husband had been institutionalized was mental, physical, or both. An open-ended question inquired about other difficulties that had led to the husband's institutionalization.

Wives' self-rated health was measured using single-item questions asking them to rate their own health as excellent, good, fair, or poor and

to compare their current health to that of three years earlier as better, the same, or worse.

*Morale* was assessed using a single-item indicator asking whether wives were very happy, pretty happy, or not too happy (Sauer & Warland, 1982).

Depressive symptomatology was measured with the widely used Centre for Epidemiological Studies Depression (CES-D) scale (Radloff, 1977). A Cronbach's alpha of 0.90 was achieved.

*Marital closeness* was measured using a single-item question asking wives: "Since your husband entered the hospital, taking everything into consideration, how close is the relationship between you and your husband?" Five response categories were used ranging from extremely close to not close at all. Wives provided additional responses to this question.

Satisfaction with aspects of institutional care was measured using three single-item questions. The first asked how well staff were treating their husbands (very, fairly, not too, not at all). The second inquired whether they liked the unit on which their husband resided (very much, fairly well, so-so, not at all). The third asked whether they were satisfied with the overall arrangements (very, fairly, not too, not at all) (Benjamin Rose Study, 1982). Wives also provided responses to these questions.

# Analysis

The analysis employed in this study comprised three aspects. Univariate statistics were used initially to examine the distribution of responses to the study variables. The qualitative data were examined for emergent categories and themes (Berg, 1989) reflecting the meaning of messages provided by wives in their comments. Data reduction involved coding and clustering of data. Data reconstruction and synthesis involved identification and verification of patterns and themes. Bivariate analysis, using *t*-tests and Kendall's Tau measure of association, was conducted to examine relationships between intrapersonal, interpersonal, and institutional varibles and patterns of caregiving.

#### **Findings**

To establish a contextual basis from which to understand wives postadmission experiences, findings are presented regarding their ages, the duration of their marriages, their self-rated health, the demands of their caregiving, and their feelings of burden prior to the admission of their husbands.

#### Age of Respondents and Duration of Marriages

At the time of admission, wives were well on in years. Their mean age was 70 and their modal age, or the most frequently occurring age, was 78. Husbands were on average three years older than their wives. The duration of their marriages ranged from four years to 62 years; however, the vast majority had been married for 40 years or more. Most couples had children and grandchildren.

#### Self-Reported Health

In tandem with husbands' deteriorating health, wives had to deal with their own medical problems. They were almost evenly divided in their evaluations of their own health, as excellent/good (52%) and fair/poor (48%), at the time of admission. However, when asked to compare their health to what it had been three years prior to admission, a substantial minority (41.3%) felt their health had worsened. Deteriorating health and bad nerves were frequently mentioned as the outcomes of years of caregiving. At the time of admission, the majority of wives (78.4%) reported a wide range of medical problems for which they were receiving treatment.

# Demands of Caregiving

Husbands' health problems were physical (26%), mental (37%), and both mental and physical (37%). Typically, they were quite dependent on their wives prior to admission. The majority needed a great deal of help with handling finances (94.6%), transportation (91.9%), shopping (83.8%), taking medications (76.7%), and bathing (54%). A substantial minority required a great deal of assistance with grooming (45.9%), dressing and undressing (43.2%), and going to the bathroom (32.4%). Wives reported coping with problems related to falling, incontinence, seizures, dysphasia, memory loss, confusion, wandering, and behaviour of an aggressively disruptive nature, which were the major reasons for the institutionalization.

# Feelings of Burden

Wives' scores on the Zarit Burden Interview ranged from a low of 0 to a high of 71, with a mean of 32, indicating a moderate level of burden.

Their accounts confirmed this finding and provided a graphic sense of the desperation they felt during the year prior to their husband's admission. One wife referred to the year as "devastating." "I realized that he would never be the same again and I was constantly tired, worried, and concerned." Wives were generally worn out at the time of admission, after a year of being essentially housebound. One wife said she was tired and didn't know which way to turn. She was both exhausted and overwhelmed. It is within this context that wives continued their involvement in caregiving following the admission of their husband.

#### Post-Admission Experience

Post-admission data were gathered about the behavioural, cognitive, and affective dimensions of caregiving. As mentioned previously, objective dimensions of the caregiving career were conceptualized as visiting and task performance, subjective dimensions as reasons for and feelings about the provision of care.

#### Visiting

The pattern of visiting that emerged over the nine-month period was one of consistent and frequent visiting. The vast majority of wives (80%) visited several times a week or daily at the first interview and continued to do so over the nine months. Their reasons for visiting, in descending order of frequency, were: devotion to spouses (78.3%), duty and obligation (54.3%), to provide assistance to husbands (43.5%), to monitor husbands' well-being (41.3%), and to provide assistance to staff (26.1%). Although the majority of wives expressed some degree of satisfaction (80.4%) and enjoyment (67.4%) with visiting, many qualified their responses by stating that these descriptors did not really capture the essence of their visiting experience. Satisfaction with visiting was linked with feeling useful or with their husband's mood and behaviour. The wives who stated emphatically that they did not feel satisfied with their visits attributed their dissatisfaction to feelings of depression or a sense of futility following their visits. Enjoyment was linked with activities carried out while visiting, rather than the visit itself. Wives who clearly did not enjoy visiting expressed serious difficulties communicating and interacting with their husbands, a lack of resources or things to do during the visit, and disagreement with certain practices regarding the provision of care by staff. Just over half of the wives reported other, more negative, emotional responses to visiting. Some of these feelings derived from a sense that they had abandoned their husband to the institution. Others resulted from their husbands' frequent and

repeated requests to return home. Parting was at times problematic and it generated negative feelings. One wife reported that she had to lie to her husband in order to be able to leave, which made leaving dreadful for her.

#### Task Performance

Wives engaged in a variety of tasks related to personal, instrumental, relational, recreational, and spiritual care (Ross, Rosenthal, & Dawson, forthcoming). At the one-month interview they reported carrying out an average of 9.7 tasks for their husbands, at the nine-month interview an average of 11.3 tasks. The increase in the number of tasks over time, while small, was statistically significant (t = 4.37, p = .00). Task performance was further analyzed by using the median (10) number of tasks that wives performed at the one-month interview as a criterion for indicating "high" versus "low" involvement. At both the one-month and nine-month interviews the majority of wives (54% at the one-month interview; 76% at the nine-month interview) were heavily involved in providing care for their husbands. In addition, for a small proportion of wives (n = 10) level of involvement increased over time, whereas for the majority of wives (n = 36) level of involvement remained the same.

Wives considered visiting to be the most important function they performed for their husbands. They also viewed the provision of love, support, and companionship as important — as well as the fulfilment of specific tasks. In addition, they described the "little things" that staff could not do, but that they could, as reinforcing their husband's individuality and creating a more personalized socio-emotional and living environment for him. Monitoring their husbands' well-being was the task least frequently mentioned. It may be that for them monitoring was such an unconscious or taken-for-granted function that it was not readily articulated in response to an open-ended question.

# Patterns of Caregiving

Patterns of caregiving derived from frequency of visiting, level of task performance, and responses at the nine-month point indicated how wives were coping with life on their own and whether they were adjusting to the institutionalization of their husband. Analysis revealed two patterns. At the nine-month point, a little over one third of the wives continued to be heavily involved, both emotionally and behaviourally, in caring for their husbands. For example, one wife stated: "I have no life of my own... I can't start any projects... I can't leave him."

Another said her life continued to revolve around her husband's illness. With one exception, all of these wives visited at least several times a week and continued to feel responsible for the well-being of their husbands. These wives were categorized as "holding on to the past."

Close to two thirds of the wives were less involved in providing care at the nine-month point. These were catagorized as "embracing new realities." One of these wives stated: "It takes time to get used to the changes... I felt that I still had to check on the care that he was getting rather than letting the nurse do it. I've learned to give up some of the control... I now have more freedom." Another wife said: "I'm now a visitor... I don't have the strain or the responsibility any more... I now have more peace of mind... he's being properly taken care of and it's a big relief." These wives engaged in significantly fewer visits and appeared to be coming to terms with their new way of living, compared with those holding on to the past.

#### Factors Associated with Emergent Patterns

The above data were examined cross-sectionally and longitudinally for similarities and differences that may have led to one caregiving pattern over the other. Wives who were holding on to the past were more likely to be caring for husbands who were physically impaired, whereas those who were embracing new realities were more likely to have husbands who were cognitively impaired (Tau = 26., p = .04). Patterns of caregiving also differed on the following variables: change in feelings of marital closeness, depressive symptomatology, morale, and satisfaction with aspects of institutional care (Table 1).

*Marital closeness*. Feelings of marital closeness at each of the measuring points did not distinguish between the patterns of caregiving; however, *change* in marital closeness since admission, either for the better or for the worse, did distinguish between the two patterns. The majority of wives who were embracing new realities said their feelings of closeness to their husbands had changed, either for the better or for the worse; the majority of wives who were holding on to the past reported no change in feelings of closeness (Tau = .29, p = .02).

*Depressive symptomatology*. A significantly greater proportion of wives who were holding on to the past had scores indicating symptoms of depression, both at the time of admission (Tau C = .38, p = .00) and at the nine-month interview (Tau C = .46, p = .00), than wives who were embracing new realities. Furthermore, there was no significant change in their mean CES-D scores over the nine-month period (22.29 at one

2 2	Embracing New Realities $N = 29$				Holding on to the Past $N = 17^d$			
	Mo	onth 1	Mo	onth 9	Month 1		Month 9	
	N	%	N	%	N	%	N	%
Change in Marital Closeness*								
Stable			12	41.7			12	70.6
Closer			10	37.9			4	23.5
More distant			6	20.3	*		1	5.9
Depressive Symptomatology								
0-15 (none)	19	65.5	23	79.3	5	29.4	6	35.3
15-20 (mild)	3	10.3	4	13.8	3	17.6	0	00.0
21-30 (moderate)	6	20.7	1	3.4	5	29.4	4	23.5
31+ (severe)	1	3.4	1	3.4	4	23.5	7	41.2
Morale								
Very happy	3	10.3	4	13.8	0	0.00	0	0.00
Pretty happy	17	58.6	21	72.4	2	11.8	2	12.5
Not too happy	9	31.0	4	13.8	15	88.2	14	87.5
Satisfaction with the Unit								
Very	25	86.2	18	62.0	6	35.2	4	28.6
Fairly	4	13.8	11	37.9	8	47.0	9	64.3
Not really	0	0.00	0	0.00	3	17.6	1	7.1
Satisfaction with Staff								
Very	17	58.6	26	89.6	1	7.1	9	52.9
Fairly	10	34.5	3	10.4	12	85.7	7	41.2
Not really	2	6.9	0	0.00	1	7.1	1	5.9
Satisfaction with Care								
Very	22	75.8	21	72.4	3	17.7	5	29.4
Fairly	5	17.3	6	20.6	13	76.5	7	41.2
Not really	2	6.9	2	6.9	1	5.8	4	29.4

month and 23.81 at nine months). In contrast, wives who were embracing new realities had mean scores indicating little depressive symptomatology, and their mean scores on the CES-D scale decreased significantly, from 12.72 at the one-month interview to 9.03 at the nine-month interview (t = -2.0, p = 0.05).

*Morale*. The findings were somewhat similar with respect to morale. Wives who were holding on to the past scored significantly lower on morale at both interviews than wives who were embracing new realities (Tau C = -.54, p = .00 at one month; Tau C = -.69, p = .00 at nine months). Over 90% of these wives continued to experience low morale nine months following their husband's institutionalization.

Satisfaction with aspects of institutional care. Caregiving patterns were distinguished by satisfaction with the unit (Tau C = .56, p = .00 at one month; Tau C = .35, p = .01 at nine months), satisfaction with the staff (Tau C = .34, p = .01 at one month; Tau C = .52, p = .00 at nine months), and satisfaction with the overall arrangements for care (Tau C = .52, p = .00 at one month; Tau C = .42, p = .00 at nine months). At the nine-month interview the majority of wives who were embracing new realities expressed positive feelings about aspects of institutional care. These feelings were reflected in their comments. One wife stated: "The staff are wonderful... they always have patience... they couldn't do any better." Another commented: "They are friendly and kind to my husband." A third remarked: "The staff do a good job of taking care of him... they deserve a medal." Wives who were holding on to the past, however, were very dissatisfied with the unit on which their husband resided. They were also unhappy with the staff and with the overall care provided. Examples of their comments are: "They certainly don't look after him like I do," "They don't have the time that is needed... they are run off their feet," and "I don't think that they are too crazy about my husband... there are so many changes of nurses and he becomes frightened and then they get angry."

#### Discussion

Wives' caregiving career emerged as a pattern of frequent visiting and increasing involvement in task performance. Visiting was both the context within which task performance occurred and a task in itself. Indeed, wives considered visiting to be the most important task they carried out for their husbands. The care they provided served a variety of purposes, including maintaining husbands' sense of personhood, preserving family ties, and redressing the rather impersonal and standardized nature of institutional care.

Over the nine-month period of the study, two patterns of caregiving emerged. The majority of wives relinquished responsibility for aspects of caregiving and began to reshape their lives while living apart from their husbands. They were conceptualized as "embracing new realities." A substantial minority, however, continued to feel responsible for the overall well-being of their husbands and to be heavily involved in the provision of care. They were conceptualized as "holding on to the past." Wives who were embracing new realities experienced fewer symptoms of depression, had better morale, and were generally more satisfied with institutional aspects of care. Wives who were holding on to the past had depression scores indicative of moderate to severe depression. Their morale was poor and they were dissatisfied with many aspects of institutional care.

In interpreting these findings, it is interesting to note that a significantly greater proportion of wives who were embracing new realities had husbands who were cognitively impaired. Many husbands had become merely shells of their former selves, following a process that had occurred over a period of years. As a result, many of these wives felt they had already lost their husbands to illness prior to admission. Following admission, their husbands deteriorated even further, often recognizing the wife as simply another caring person. It may be that for such wives the process of adjustment to a new caregiving relationship begins prior to admission, as marital expectations change. It may be that wives find it easier to relinquish caregiving responsibility when husbands have become totally different personalities, no longer recognizing them nor interacting with them as wives because of the changes associated with mental impairment. Factors of an institutional, intrapersonal, and interpersonal nature also served to distinguish the caregiving patterns.

With respect to aspects of institutional care, wives who were embracing new realities reported satisfaction, for the most part, with the unit, the staff, and the care. Wives who were holding on to the past were generally dissatisfied with care. The association between caregiving patterns and the nature of husbands' impairment may be useful in understanding these findings. It may be that wives who have lost their husbands to mental impairment are more ready to turn over caregiving responsibilities to staff than are wives of husbands with physical impairment. Because of their desire to relinquish responsibility for caregiving, they may view the care provided by others more favourably than those who continue to feel a sense of responsibility for the provision of care. It may also be, however, that because they visit less fre-

quently wives who are embracing new realities have less contact with the institution and less opportunity to be involved in situations that warrant criticism. Wives who are holding on to the past spend more time at the institution and consequently have more opportunity to be involved in care-related situations, which they then may evaluate as less than optimal. For example, several of these wives referred to the shortage of staff in their responses, whereas none of the wives categorized as embracing new realities did so. Wives who were holding on to the past evaluated the staff very specifically and negatively, as opposed to those who were embracing new realities, who used global and positive terms when referring to the staff.

Intrapersonally, the caregiving patterns were distinguished by wives' emotional health as measured by the CES-D depression scale and morale. It must be noted that more depressive symptomatology and lower morale were found in the total sample when compared with what would normally be found in community populations. It seems that the admission of husbands to an institution for long-term care is an emotionally distressing experience for all wives and leads to elevated levels of depressive symptoms in many. George and Gwyther (1986) suggested that it is primarily the characteristics of the caregiving situation that most affect caregiver well-being. This may also be the case with wives of institutionalized husbands. There was a significant and inverse relationship between wives' level of depressive symptoms and their satisfaction with aspects of institutional care. These findings are congruent with and extend those of Brody, Dempsey, and Pruchno (1990), who found that negative perceptions of staff were predictive of depression in adult caregivers of elderly parents who resided in nursing homes. In this study, negative views of the unit, the staff, and the overall arrangements for care were found to be associated with higher depression scores when the total sample was included in the analysis. This relationship, however, did not hold when controlled for the different caregiving patterns. Other factors must be implicated as contributing to the differences in depression scores between the patterns of caregiving. It seems reasonable to suggest that a diminished involvement in caregiving and the embracing of new realities serve to create a distance between wives, and what is for them an emotionally distressing situation. Turning over responsibilities to staff also relieves them of some of the demands of caregiving and allows them to recover from the fatigue associated with high levels of caregiving and to focus on other activities in building a life apart from their husbands. These outcomes may be restorative in nature and thus serve to ameliorate

feelings of depression and poor morale. Wives who hold on to the past and continue their heavy involvement in caregiving are not afforded these opportunities. As well, they are continually confronted with their husband's deteriorating health and requests or demands for assistance with activities of daily living. They are also in frequent contact with other patients, in similar or worse circumstances than their husbands. Continued dissatisfaction with institutional aspects of care might contribute to feelings of emotional distress.

Interpersonally, the caregiving patterns were distinguished by change in feelings of marital closeness. These feelings remained stable for the majority of wives who held on to the past and changed for the majority of wives who embraced new realities. Continuity in feelings of marital closeness was also related to feelings that they were still married. It seems reasonable to suggest that those who perceived little change in marital closeness over time continued to hold the same expectations regarding their responsibility for the provision of care and thus continued their heavy involvement in caregiving following admission.

#### Limitations of the Study

Implications of the study must be considered within the context of its limitations. Generalization of the results beyond the study population is limited by the non-random sampling design and the size of the sample. The approach to analysis of the numeric data assumed that parametric tests are generally robust to violations of normality (Polit, 1996). Nevertheless, some researchers would argue that if the assumptions for such tests are not met, then non-parametric tests should be selected. Although the exploratory and correlational nature of the analysis rendered the attribution of causation problematic, insight into the direction of influence was provided by wives' qualitative responses. Generalization of the results beyond the study population was also limited by the nature of the setting from which the respondents were drawn. The life course of wives whose husbands have served in the Canadian armed forces and for whom the experience of war has touched their lives in a very personal way can be expected to differ from that of other wives. Nevertheless, findings from this longitudinal study should be regarded as transferable; it is likely that other wives who continue to provide care to husbands following their admission for long-term care will identify similar experiences and responses.

#### Implications for Nursing

The significance of this research lies partly in the identification of behavioural and affective changes that occur over time and that may signal the increasing vulnerability and potential for breakdown in elderly wives coping with the institutionalization of their husbands. It also lies in the need to recognize elderly wives as both clients of and resources to the institution, and in the development of strategies that will assist in their adjustment to the new realities of their caregiving careers. At a more global level, a better understanding of the informal health-care system and its relationship to the formal system is essential if each is to maximize this relationship, only improving the delivery of health care to people in their later years.

Over time, some wives are better able to cope with their new realities than others. Nurses need to be observant of and responsive to signs of depression, low morale, and dissatisfaction with institutional aspects of care as indicators of distress. Wives who are having difficulty with the institutionalization of their husbands and its consequences may view caregiving as a way of coping, albeit an unsuccessful one. They require support in learning to turn over responsibility for care to health-care workers. Nursing strategies that result in the provision of care to husbands that is both technically and interpersonally excellent may infuse wives with confidence in the system and allow them to concentrate on other aspects of their lives rather than on the provision of care. Nevertheless, wives who wish to and are able to remain involved with caring for their husbands should be encouraged to do so in whatever ways are conducive to the maintenance of positive and health-promoting caregiving and marital relationships.

#### Conclusion

This longitudinal study of the caregiving careers of elderly wives revealed the different directions that their lives can take following the institutionalization of their husbands. Further research employing larger samples, from a variety of sites, and a longer time period will more definitively examine the experience of continuing to provide care to elderly husbands within an institutional setting. Such research should inform the development of strategies to ensure that the health and well-being of elderly wives, who are themselves experiencing the health and social consequences of advancing age, is not compromised because of the continuation of their caregiving career.

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### Acknowledgements

This study was conducted with the assistance of a grant from the Social Sciences and Humanities Research Council of Canada and doctoral fellowships from the Social Sciences and Humanities Research Council of Canada and the Ontario Ministry of Health. This manuscript was prepared with the assistance of a Career Scientist Award from the Ontario Ministry of Health.

Date accepted: October 1996

# Fraying Connections of Caring Women: An Exemplar of Including Difference in the Development of Explanatory Frameworks

# Judith Wuest

La recherche qui s'intéresse à une diversité de groupes mène à une meilleure compréhension des expériences et des optiques de ces derniers, mais elle contribue également à en accentuer l'exclusion plutôt que de favoriser l'accès aux courants dominants et aux solutions en place. Une méthode fondée sur la théorie féministe peut davantage rendre compte des groupes marginalisés grâce à l'ouverture qu'elle prône; elle permet d'élargir le cadre d'analyse et l'échantillonnage. Le présent essai tente de démontrer comment une telle démarche aboutit, dans le cadre d'une étude sur les soins donnés par les femmes, à un schème explicatif qui tient compte des réalités diverses. Ainsi, des dissonances dans la vie des femmes dispensatrices de soins ont été identifiées comme étant une réaction initiale à la concurrence et au changement en matière de prestation des soins. Les modalités et les caractéristiques de ce phénomène ont pu être mises en lumière grâce à un procédé d'échantillonnage et à une orientation théorique qui tiennent pleinement compte de facteurs tels que le sexe, l'origine culturelle, la capacité, la classe sociale et l'orientation sexuelle.

While research exploring diverse groups enhances understanding of their unique perspectives and experiences, it also contributes to the exclusion of such groups from mainstream frameworks and solutions. The feminist grounded theory method allows for inclusion of marginalized groups through theoretical sensitivity to feminist theory and theoretical sampling. This paper demonstrates how this approach results in an explanatory framework that accounts for diverse realities in a study of women's caring. Fraying connections were identified as women's initial response to competing and changing caring demands. The range of dimensions and properties of fraying connections was identified through theoretical sampling guided by the emerging themes and theoretical sensitivity to issues of gender, culture, age, ability, class, and sexual orientation.

Much of the research that addresses the health of populations delineated by such characteristics as gender, culture, or socio-economic status focuses on detailed exploration of issues of difference. While the knowledge gained from this research contributes immeasurably to our understanding of the needs of such aggregates, inherent in this approach are the hazards of stereotyping, marginalizing, and victim blaming attendant in setting a group apart. Moreover, such research

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commonly assumes homogeneity within heterogeneous populations. A central concern, then, is how to address differences within and among groups without contributing to marginalization. I submit that the feminist grounded theory method allows for the inclusion of difference in the development of explanatory frameworks useful for nursing (Keddy, Sims, & Stern, 1996; Stern & Pyles, 1986; Wuest, 1995a). Theoretical sampling and theoretical sensitivity, particularly to issues of gender, culture, class, ability, age, and sexual orientation, allow for the uncovering of variation in the emerging concepts that contributes to the relevance of the resulting framework for a diverse society. Because this research process is consistent with feminist principles of being useful to participants, avoiding oppression, and reflecting on both intellectual traditions and the research process (Acker, Barry, & Essevald, 1991), groups who are frequently marginalized in research are more likely to be treated respectfully as partners and to have their perspectives and concerns reflected in the findings.

In this paper, I will discuss how the feminist grounded theory method was used in a study of New Brunswick women's caring. In the literature, caring is depicted as fundamentally good and enriching for both the provider and the recipient (Bevis, 1981/88; Mayeroff, 1971; Ray, 1981/88; Roach, 1992) and as fundamental to human existence and well-being (Leininger, 1993). Feminist analysis puts forward two contrasting views (Baines, Evans, & Neysmith, 1991). One is that women's caring is an outgrowth of an oppressive family structure that socializes women to assume caring roles despite their increased responsibilities outside the home. The other is that women have unique caring talents and take satisfaction in assuming nurturing roles. Two key dimensions of caring are labour and love (Graham, 1983). The literature on family caregiving conceptualizes problematic aspects as caregiver burden and strain, especially when caring for the elderly and demented (Given & Given, 1991; Montgomery, 1989), a conceptualization that denotes a negative experience in which there is little likelihood that the caregiver will find any meaning (Farran & Keane-Hagerty, 1991). A final critical issue is the influence on caring behaviour of social and structural factors (Leininger, 1991). This paradoxical picture of caring, combined with current health reform that is resulting in greater demands placed on women to take on caring roles, led me to undertake a grounded theory study of women's caring. The goal was to discover what is problematic for women about caring and to generate a theory that explains how the central problem was resolved or processed (Glaser & Strauss, 1967).

#### The Emergent Design

The research question in grounded theory research emerges through analysis of data collected via dialogue with participants, observation, and/or literature review; the researcher does not impose her or his notion of what is most significant (Glaser, 1978). Sampling is theoretical.

Theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyses his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges. This process of data collection is controlled by the emerging theory... (Glaser & Strauss, 1967, p. 45)

This sampling may be incidents, events, activities, or populations (Strauss, 1987). Participants are selected, therefore, because they are good sources of information for a specific analytic goal, rather than because they will allow the researcher to generalize to others of similar age, sex, or race (Sandelowski, 1995).

Glaser (1978) indicates that analysts must possess theoretical sensitivity in order to "render theoretically their discovered substantive, grounded theories" (p. 1). Theoretical sensitivity is enhanced by "disciplinary or professional knowledge, as well as both research and professional experiences" (Strauss & Corbin, 1994, p. 280). My theoretical sensitivity, particularly to feminist thought and cultural diversity, guided my response to the emerging theoretical concepts and directed the theoretical sampling. Constant comparison of themes emerging from each interview led to new questions and hypotheses, and my decisions regarding data collection were guided by consideration of where the answers might be found. For example, initial interview subjects were white, middle-class women keenly interested in caring optimally for their children as evidenced by breastfeeding, prenatal preparation, and participation in playgroups. They spoke of feelings of frustration and conflict in their caring and in their communication with lay and professional helpers. These women had time, energy, and financial resources to invest in their caring. I wondered whether women with less to invest might also experience this dissonance. What might I learn about the variation in the dimensions of fraying connections from women experiencing more difficulty providing basic needs and possessing fewer resources to invest in their caring — perhaps working-class or poor women? How would communication with helpers be influenced by cultural differences or limited English-language skills? Theoretical sampling took several forms: choosing new participants on the basis of

what they could contribute, seeking comparisons in data already collected, returning to participants to ask new questions, participant observation, and examining the literature and other written data.

#### Data Collection

Twenty-one women participated in this study. They were a convenience sample recruited for what they could contributre to the emerging framework. Letters describing the study were given to potential participants by key community people. Those who wished to participate contacted me. Fifteen women participated in individual tape-recorded unstructured interviews lasting one to two hours. Thirteen of the 15 were interviewed twice.

Two groups, one of two women and one of four women, each participated in two tape-recorded interviews. Group interviews were used to gather diverse perspectives for theoretical variation and also to learn about shared perspectives (Frey & Fontana, 1993). In the group interviews, women's comments triggered further thoughts, resulting in rich data for comparison. Participants enjoyed the group discussion but demonstrated no interest in continuing beyond the two meetings. Participant observations occurred when the investigator attended community events of particular interest to women, such as the screening of a National Film Board release on home birth, or social and support group meetings such as those of breastfeeding women or immigrant women. Field notes were taken to reflect these observations and the nature of informal discussions.

# Characteristics of Participants

The women ranged in age from 20 to 64, lived in rural, suburban, and urban areas, and ranged in level of education from elementary schooling to doctoral degree. They included the employed and the unemployed; lesbian and heterosexual women, presently with and without a partner; and physically able and disabled. The women were of diverse socio-economic circumstances: welfare recipients, working poor, middle class, and pensioned on fixed income; with and without children of various ages and abilities. The women who agreed to be interviewed were from the dominant Anglo-Canadian culture. Data collected in participant observation focused on immigrant women and specific groups such as young, working mothers or breastfeeding women. Data from previously conducted interviews with members of First Nations and

Caucasian families of children with middle-ear disease, caregivers of family members with Alzheimer's disease (AD), and women who had left abusive conjugal relationships were theoretically sampled for further variation in concepts and further development of conceptual links.

#### **Findings**

Competing and changing caring demands from partners, children, extended family, and self, within the existing environment, emerged as the greatest problem for caring women. Precarious ordering is a dynamic, recursive, two-stage process women use to manage this problem (Wuest, 1995b). In the first stage, women's connections with others become frayed in the process of reacting to competing and changing demands. Fraying connections are evident in daily struggles with caring work, relationships, and adversity with helping systems; in altered prospects for future employment, parenting, and relationships; and in ambivalent feelings engendered in the responses to caring demands. In the second stage of precarious ordering, women become proactive using the intuitively and consciously acquired strategies of setting boundaries, negotiating, and repatterning care to reduce demands, change the environmental conditions, or manage more effectively. In this discussion, I report the findings of the first stage of precarious ordering named fraying connections, demonstrating how attention to difference in theoretical sampling resulted in the identification of variation in the emerging concepts such that the emerging framework is relevant to a wide range of New Brunswick women.

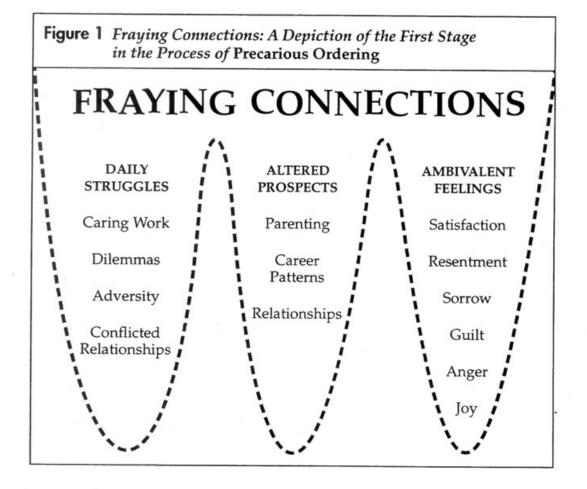
#### Caring Demands

Faced with multiple caring demands, women took diverse actions inherent in which was a sense of dissonance or conflict, eventually named *fraying connections*. The source of *fraying connections* was women's inability to deal with each demand in a singular and linear fashion, and their inexperience with particular demands. Analysis of the properties of caring demands revealed that it was the *changing* and *competing* nature of demands that imbued the caring responses with struggles, conflicts, and mixed emotions that were frequently at odds with women's caring ideals, that is beliefs about how caring should be. Individually, the two properties of caring demands each contributes to the development of *fraying connections*; however, when demands are both competing *and* changing, the intensity of fraying connections is

likely to increase. In addition, environmental conditions interact with caring demands to intensify or moderate *fraying connections* (Wuest, 1995b).

#### Fraying Connections

Fraying connections refers to the emotional, cognitive, relational, and material disorder and dissonance inherent in reactive responding to caring demands. Relationships between women and care recipients, helpers, and family members are vulnerable. Fraying connections fluctuate in intensity and manifest differently, according to the complexity, familiarity, quantity, and intensity of competing and changing demands and the intervening environmental conditions. Fraying connections can be transient or long-term. The three categories of fraying connections identified in this study are daily struggles, altered prospects, and ambivalent feelings (see Figure 1). The following discussion of the properties of fraying connections will delineate the ways in which theoretical sampling and sensitivity to feminist thought allowed for expansion of variation in emerging concepts.



#### Daily Struggles

Struggles, the first category of *fraying connections*, are material, moral, and relational difficulties evident in caring work, dilemmas, adversity with systems, and conflicted relationships. *Fraying connections* exist both in the process of struggling and as an outcome of the struggle.

Caring work. The work of caring for health involves meeting such basic needs as nutrition, hygiene, sleep, comfort, transportation, and safety for self and others. Fraying connections are inherent in responding to the competing and changing demands that arise from these basic health needs, and they vary in intensity. Initially, in interviews with young, middle-class mothers the labour of caring for preschoolers and newborns and its resultant fatigue were evident. This led me to consider other groups who might find caring physically taxing. Theoretical sampling revealed that the most physically and mentally taxing form of caring work for women was with infants and young children, the mentally and physically disabled, the sick, and frail elders. All fraying connections rooted in caring work can be intensified or reduced by environmental conditions, particularly financial resources, substitute care, professional assistance, informal support, and transportation.

Caring work results in fatigue. Fatigue ranged from weariness to extreme exhaustion, according to the intensity and predictability of the demands and whether other demands had to be met as well. Physically demanding work, such as bathing and toileting elders or disabled adults, overcoming personal disabilities in activities of daily living, or caring daily for preschoolers, is extremely tiring. Daisy faced competing caring demands, with resultant discord, because her daughter had costly health needs that forced Daisy to work outside the home:

Oh I hate that . . . every morning. Oh, I hate it, I hate it. Before going out the door, it is like, "This is packed, this is packed, this is packed." Packing and everything doesn't bother me too much, but when it is like minus 20 outside and the car is cold, and then I go over to my friends [the sitter] and they live on the top floor of the building. Lug everything up the steps, you know. It is like, "Why the hell do I do this?"

When caring work is unpredictable, fatigue can intensify. The data suggest that women's rest and sleep were regularly disturbed by children needing attention for feeding, or because of bad dreams, asthma attacks or ear infections, a teenager's late-night comings and goings, or a demented elder's wandering. Under these conditions, women are prone to exhaustion. I queried whether First Nations women, who had spoken of responding to their children's rhythms rather than to rigid

routines, would have similar experiences. Theoretical sampling of data previously collected revealed that the night-time demands of children were equally exhausting for First Nations women.

Fraying connections related to caring work are further evident in physical injury or stress-related illnesses such as hypertension. Physical health problems were found to be most common under conditions of intense caring demands of long duration, such as women caring for people with disabilities or dementia. Limited financial support and rigid criteria for access to services intensified the fraying connections for Gert, whose husband developed AD at 55 and was therefore too young to qualify for elderly support services. Gert, who had not been employed for 20 years, supported them with a minimum-wage cleaning job that did not pay enough for her to hire a caregiver. Gert left her husband alone, ran home at noon, phoned often, and got neighbours to keep watch. She worried constantly and eventually developed an ulcer. This variation in the data identified the disadvantaged position of caring women who have been outside the workforce.

Caring work also produces the "Empty Teapot Syndrome," described by Gina:

I do find that I refer to myself as a teapot. And I think all women do. And I think what happens is that we pour out all the time, that we pour out and suddenly the heat under the griddle is boiling the pot dry and there is no water left. And that's when we get fried.

While fatigue and health problems may be a part of this phenomenon, the Empty Teapot Syndrome included a sense of physical and emotional bankruptcy that often accompanied having to deal with intense demands or with frequent, changing demands over a long period. The major consequence of fatigue, illness, and Empty Teapot Syndrome is that women are alerted to the toll of caring, and begin to think about setting boundaries.

Caring dilemmas. Caring dilemmas begin with competing demands to which women want, or feel they should, respond. Dilemmas occur when responding to one caring demand precludes responding to another or when there are several available courses of action, none of which is totally satisfactory. The outcome is that women perpetually "feel torn." A common dilemma was having to choose between caring for an ill or dying parent and caring for dependent young children; the dilemma intensified if the parents were far away or if the children were very young, and became complicated when women faced additional burdens such as job demands, financial concerns, or personal health problems. Dilemmas were harder to solve when one of the demands

was socially unacceptable, such as the woman's commitment to a lesbian partner or to an abusive partner.

A central dilemma was that of working outside the home versus caring for family. The decision to stay home and care for children, dependent others, or both, as opposed to using substitute care and taking a job outside the home, involves consideration of personal needs, financial needs, and the needs of the person(s) requiring care. Financial needs are a major consideration, and the decision is influenced by whether the woman has a partner, whether the partner has an adequate income, and cultural values about lifestyle and income. In single-parent families or in traditional families where both partners earn the minimum wage, a woman's income may be vital for subsistence living. Immigrant women face multiple dilemmas when a spouse who has been the traditional wage-earner cannot find employment and the woman can. Partner and family ideals about necessary lifestyles can push women to work outside the home even when personal ideals would dictate staying home. The level of dependency and complexity of the needs of the person requiring care, the financial drain of that person, and the likelihood of finding suitable substitute care are additional factors.

### Adversity with Systems

Fraying connections were apparent in the conflict between women and the health, social, education, religious, and legal systems, which left them disillusioned. Women generally expect to find help from these systems. Erica had a hyperactive son.

All I got from professionals was "You don't discipline him enough, you let him get away with too much." Like, "You're doing this wrong, do it that way." I had social workers knocking at my door saying, "Are you abusing your children"? for years and years . . . And I'm saying, "Sure I need help, but so does my son." Oh, no, no, no, I couldn't get anyone to step in and help my son.

Adversity is inherent in the process of seeking and obtaining help. Systems failed to help, provided inadequate help, or made things worse. These outcomes were associated with the availability and suitability of resources, and cultural gap between the professionals and the caring women.

Demeaning process. The process of accessing resources is demeaning for women when they feel devalued in their interactions with helpers — a situation that stems from both the behaviour of individual profes-

sionals and the structure of systems. Theoretical sensitivity to issues of respect, control, and power facilitated theoretical sampling to uncover dimensions of this process. The extent of disillusionment varied with the extent of the discrepancy between the behaviour of the professionals and the women's expectations of their relationships with them.

All women felt some degree of powerlessness in their interactions with professionals, associated with their vulnerability at the hands of the expert and the failure of professionals to demonstrate respect for the woman's potential contribution. Because most professionals tend to view themselves as better informed than caring women, they frequently failed to value women's observations, knowledge, and concerns. The use of medical or legal terminology was intimidating and hampered women's participation in decision-making. Physicians frequently used language suggesting that the processes of birth, menopause, and breastfeeding were risky ones requiring expert medical intervention. When professional attitudes conveyed the message that problems such as infant feeding difficulties were the woman's fault, she was discouraged from asking questions. Cultural variations in beliefs about such routine issues as nutrition, discipline, and communication between women and helpers served to intensify the difficulty. Women were intimidated by insinuations that issues were too complex for them to understand.

He told me all the time, "You're putting on too much weight." I said, "How much am I supposed to put on with twins? I gained 40 pounds with my first baby and I'm kind of small to start with." He mumbled, "Well, I don't know how much is normal for twins, but you're putting on too much."

Professionals regularly deceived women, by misrepresenting policy, by giving them inadequate and wrong information, by behaving in an obstructive manner, and even by lying.

Women's accounts revealed that the attitudes of professionals varied according to how they viewed the woman seeking assistance. Women of difference frequently had their perspectives negated by professionals because they came from a different culture, failed to speak English, or were poor, lesbian, or developmentally or physically handicapped. The unspoken attributes attendant to labels, such as battered woman, disabled, single mother, and poor, intensified women's humiliation. Meeting criteria often required women to explain their particular circumstances repeatedly, a potentially mortifying experience. To obtain a peace bond, Astrid had to tell her story of physical and sexual abuse to the police, then to the crown prosecutor, and finally to the

judge. Her attempt to care for herself became self-abusive because of the system.

System structure contributes to women feeling demeaned. The lack of central coordination necessitates time-consuming phone calls to numerous agencies and departments to discover available resources. For women with poor language or social skills, or without access to a telephone, this presented a formidable task and further eroded their sense of competency. Gaps in the system were hazardous for women seeking help. In communities where access to a family physician required a referral, refugee and other immigrant women found it impossible to see a family practitioner.

Unsuitable help. Disillusionment can set in when the quality and nature of a service is unsatisfactory. Disrespect, the iatrogenic effects of medications, incorrect diagnosis, insufficient nursing care, inaccurate information about the legal system, and insufficient social-service support were examples of unsatisfactory assistance. A major concern for isolated women, such as rural women without access to transportation, was speed of response. Often as much as an hour elapsed before police responded to calls from abused women still in danger. The lack of knowledge among professional helpers of how to manage specific conditions, such as the aftermath of torture or war, left some refugee women with few resources for dealing with their own health or that of their children.

# Conflicted Relationships

Conflict ranged from minor disagreements to physical battering, from occasional flare-ups to insidious persistence. Differences among women and recipients of care, family members, and employers about the extent and nature of caring, and about priorities and decisions, led to friction and strife. Caring relationships became tense when the woman failed to meet the recipient's expectations, or when her own expectations differed from those of the recipient. Men often failed to participate or even be aware of the complexity of caring demands of their children and neglected responsibilities to their aging parents, assuming that their partners would do it. Cultural incongruence between women and their partners or care recipients can increase such conflict.

Having to handle demands from more than one person forces women to prioritize responses — and disagreement can be the result. Partners sometimes resented women's attention to children or elders.

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Jocelyn's lesbian partner resented her attention to her children, from whom Jocelyn was hiding her sexual orientation.

...her jealousies of what I was doing for my kids, and I just, you know, was in the middle — if my kids were around — trying to make sure that everybody was taken care of.

In abusive relationships, the demands of others often triggered a physical beating or a verbal assault.

Conflict frequently developed in the workplace when women needed flexibility to attend to their families' needs. Because Kate's coworkers thought she should have weaned her 14-month-old child, she received little support when she was running home to breastfeed at noon. Even when cultures and values are in accord, conflict arises if interference with employment is of long duration. Women facing long-term, high-demand needs, such as caring for demented elders or demanding special-needs children, often developed serious conflicts with both employers and coworkers that resulted in their being fired or quitting. Conflict is exacerbated by an unpleasant, resentful, or irritable nature in carers, care recipients, or other family members. Mothers of infants with persistent colic and daughters of elders resentful of their dependency had to deal with strained relationships over long periods. Conflict in relationships resulted in the loss of necessary supports for caring. Fraying connections increased because women had to deal with conflict as well as the original caring demand.

# Altered Prospects

The second category of fraying connections, altered prospects, occurs when the direction of women's lives is unexpected and substantially changed because of competing and changing demands. The salient altered prospects that emerged in this study were parenting, relationships, and career patterns.

# Parenting

Altered prospects related to parenting are associated with unanticipated caring demands. In the extreme, a child may be born with a physical or mental handicap or may develop health or social problems that require more care than had been anticipated. Caring demands associated with parenting undergo major alterations when a woman moves to a new environment and can no longer rely on old patterns. Nora moved to a low-cost housing area and found there was no safe place for her son to play. Ara, an immigrant woman, found that her disciplinary

methods were considered unacceptable in Canada and had to learn new ways of managing her children. Prospects are also altered when a woman changes attitudes about mothering after becoming a parent. Aline said, "I was Miss Career. Now I don't want to return to work. I want to be with my baby." This was an unexpected deviation from an expected life course requiring discovery of different ways to meet personal needs, those of the child, and those of the larger family unit.

#### Career Patterns

Career patterns often change or are relinquished in the face of caring demands from children, the disabled, the elderly or partner career demands. "I was brought up to believe I could have everything," said Hilary, who was coming to terms with the fact that she could not be both a mother and a career scientist.

...there's no way I can have my father's career. One, I'm a female; two, I don't have a wife like he did. It's their career... and there's no way I would leave my kids for three months every year to go and do research.

Women who found alternative ways to progress along planned life paths continued to experience altered prospects: it took longer for them to complete their education, and job opportunities were often relinquished in favour of caring demands.

### Relationships

Altered prospects are sometimes played out in the changing scope of women's lives when caring is very demanding. When caring is intense, there are few opportunities for personal activities and little time to cultivate relationships. The outcome can be isolation. Because people tend to avoid or withdraw from awkward or uncomfortable situations, isolation was intensified for some women, such as those caring for a demented parent. A significant altered prospect results when caring relationships do not meet a woman's expectations. Spousal relationships changed following the birth of a child. Abuse distorted images of caring relationships as women discovered that their expectations of reciprocal caring and commitment would never be realized: "I was just a piece of ass to him."

Significant reduction in caring demands also frays connections. Women who had responded to such demands all their lives suddenly faced completely altered prospects. When 80-year-old Marie placed her demented husband in a nursing home, she said, "I am no good for

nothing. Nobody needs me now." Women whose children had grown up and left home had periods of feeling similarly bereft. Altered prospects can create fraying connections that require minor adjustments or major transitions. Altered prospects result in challenges to women to modify or create new goals and to develop new skills.

### **Ambivalent Feelings**

The final category of fraying connections is ambivalence stemming from competing and changing demands in the context of women's beliefs about how caring should be. Ambivalence is related to the contradictions between the realities of caring relationships and work, and beliefs about caring. Women identified caring as positive, connecting, and fundamental to their roles as mothers, daughters, and partners, and they experienced feelings of satisfaction and joy. However, the demands of caring also produced many discordant emotions such as guilt, resentment, anxiety, anger, fear, helplessness, and sorrow that were difficult to reconcile. The greater the imbalance between caring ideals and caring realities, the more ambivalent felt the women in the study.

Although this ambivalence was implicit in many of the feelings expressed by participants, the women began to talk openly about such feelings only after trust had been built with the interviewer. One woman, who had been very optimistic about her caring, asked toward the end of the second interview, "Did any of the other women you interviewed speak about resentment?" Brown and Smith (1993) found that women who express such ambivalent feelings about the arduousness of caring even when caring demands are patently unreasonable are generally made to feel they are going against the norm. This may account for women's difficulty articulating such feelings, and it supports the feminist process of involving women in analysis in the second interview.

Competing demands produced feelings of guilt when choices inevitably had negative consequences in the form of demands being unmet. Failure to measure up to personal caring ideals contributes to feelings of guilt: "I still go to bed most nights thinking that I didn't do enough that day." Guilt also arose from feelings of inadequacy when women compared themselves with other individuals in similar situations, or judged themselves against community norms and found themselves lacking. This guilt is associated with both quantity and quality of caring.

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My parents are in their 70s and they live about 50 miles from here, and I get up there as much as I can but I am self-supporting and do not earn a great salary. My mother's an invalid. I guess it's just more like moral support for them that I can give at this point. My only sibling, my sister, lives up there... she's the one that's there all the time. I have gone through periods of feeling guilty about that, but it was her choice to move back there. I guess I kind of talked to myself, figured it out, because it is kind of hard. I don't think I could do it on a full-time, everyday basis.

Sometimes the anger and resentment were directed at the person being cared for, especially when demands were cumulative and exhausting. Anger also sprang from feelings of injustice. Lana anticipated a time when she would no longer be able to care for her mentally challenged daughter:

But she will have to be kept the way I want her to be. I will want her kept clean and I would want her just like she is here. I just make her look normal for a 25-year-old girl. Well, why shouldn't she have her legs shaved every time she takes a bath? And why shouldn't she have her underarms shaved? And why shouldn't she have a little bit of rouge on her face and her hair curled every morning? Why shouldn't she? I do it for myself.

Diane was angry about her mother's AD: "She doesn't deserve this." Often the anger is accompanied by sorrow and by resentment regarding the increasing demands. Women suffered when they felt their caring interventions had little effect. "It breaks my heart to see her this way. I can't do anything to help." This sense of helplessness was prevalent among women who were caring for those whose conditions could not improve.

#### Conclusion

The present findings make visible the complexity that originates from competing and changing demands of caring and from *fraying connections* at the emotional, relational, moral, and material level. Caring demands are not limited to women caring for family members with specific health problems. Caring is complex. Changing and competing demands are pervasive in the lives of all women as they care for themselves and others. The literature on caring pays scant attention to its competing and changing nature. Mayeroff (1971) tended to treat competing demands as an occasional problem to be overcome. In contrast, the present findings suggest that incompatibility of demands is pervasive in the lives of most women and that the changing nature of demands makes resolution exceedingly difficult. Noddings (1984) was

more realistic about sources of conflict in caring, but does treat such conflicts as singular problems and fails to identify the complex consequences of demands that are not only competing but changing. Such perspectives discount the complexity of competing and changing demands and can contribute to the marginalization of women for whom *fraying connections* are an everyday problem. Thus this study, by demonstrating the complexity of caring demands for women, highlights the need for nurses to carefully assess the competing and changing demands facing women carers and to consider how women might be supported in the process of *precarious ordering*.

Because the feminist grounded theory method permitted theoretical sampling guided by theoretical sensitivity, in order to uncover variance in emerging concepts, the discovered substantive theory reflects a central process that is common to the lives of diverse women. Rather than focus on a narrow view of caring for someone with a specific illness or disability, or caring by a specific group of women, this study illuminates the dimensions and properties of fraying connections as they have meaning for women in a wide variety of circumstances. Walters (1991) suggests that "It is only when women's concerns are documented that there is any possibility of taking them into account in policy making" (p. 33). These findings may be useful for policy-making because of their inclusiveness. They apply to women across the lifespan, from a wide range of cultural, educational, and socio-economic backgrounds, who care for the sick, the elderly, and the disabled and whose caring is directed at keeping families healthy. They draw attention to the importance of considering the ways in which women's response to caring demands is informed at a personal and community level, by culture, class, ability, age, and sexual orientation.

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### Acknowledgements

This research was supported by a Dorothy J. Kergin Research Grant in Primary Health Care, Canadian Nurses Foundation. Doctoral studies at Wayne State University, which led to this research, were funded by the Canadian Nurses Foundation, the University of New Brunswick, and St. John Ambulance. The author thanks the women who gave so generously of their time and energy to participate in this study.

Date accepted: September 1996

# Book review

Fading Away: The Experience of Transition
in Families with Terminal Illness
Betty Davies, Joanne Chekryn Reimer, Pamela Brown, and Nola Martens
New York: Baywook Publishing, 1995. 137 pp., index
ISBN 0-89503-127-2

### Reviewed by Ariella Lang

Fading Away: The Experience of Transition in Families with Terminal Illness examines how patients with advanced cancer and members of their family experience the process of "fading away": the transition from living with cancer to experiencing a death from cancer. This book is based on a prospective qualitative study that, unlike most research done in this domain, included the patient and did not rely on a family member's recollection of the palliative-care situation. It is one of the first publications to maintain a family perspective that focuses on the palliative-care experience of the patient, the spouse, and the children as they describe it both individually and as a family.

Using a grounded theory approach, the authors interviewed 71 family members in 23 families with a member who had lived with cancer between a few months and four years prior to the interview. Patients and their family members were interviewed individually and as a unit. Analysis of the data resulted in a theoretic scheme. To scrutinize the rigour of these findings, the conceptualization of this transitional process was tested with five additional families, who reported that the description of the phenomenon of "fading away" made sense to them.

The book has a unique structure. The first chapter is an overview of the construct of "fading away" and its components (i.e., redefining, burdening, struggling with paradox, contending with change, searching for meaning, living day to day, preparing for death). Subsequent chapters describe in greater depth the different perceptions of the patient,

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spouse, and children regarding each component of this transitional process. Although these components do not necessarily fall in any particular sequence, the authors propose that over time they accumulate, overlap, and recur, beginning with the patient's redefinition of self and the family's redefinition of the patient.

The strength of this book lies in its exploration of this experience from the separate perspectives of the patient, spouse, and children as well as the family as a unit. Together, these various perspectives describe what it is like for a family to cope with advanced cancer. The authors suggest that individual variations can be better understood when viewed from the perspective that the family unit is different from, but closely related to, the separate lives of its members. Guidelines for the care of the patient and the family can be found at the end of each chapter. Finally, a section is devoted to the challenges of conducting research in palliative care as well as the specifics of the qualitative study on which the book is based.

This book makes an important contribution to existing knowledge about how patients and families make the transition from living with cancer to experiencing a death from cancer. It is an excellent resource both for its rich descriptions and its care guidelines. It is also invaluable to practitioners who work with patients requiring palliative care and to their families, as well as to the public at large. For educators, particularly in nursing, the book will be an important resource in both undergraduate and graduate curricula. Indeed, it has much to offer to clinicians, educators, and researchers alike in developing their expertise and increasing their understanding of how patients and families experience the transition of "fading away."

# Happenings

# The National Forum on Health

# Judith A. Ritchie

The National Forum on Health, chaired by the Prime Minister of Canada, was launched in October 1994 and presented its final report, Canada Health Action: Building on the Legacy (National Forum on Health, 1997a), in February 1997. The Forum's mandate was "to involve and inform Canadians, and to advise the federal government on innovative ways to improve our health system and the health of Canada's people."

I was privileged to be one of the 24 members of the Forum. We were volunteers from across Canada with varied backgrounds: small and large business; labour; health-policy research; health and health care, as practitioners, researchers, or volunteers; health advocacy and activism; and political-party policy development. Our work was supported by a secretariat in Ottawa that included an Executive Director, policy analysts, and communications experts.

While the Forum met regularly in plenary sessions, the major background work was carried out in four working groups: Values, Striking the Balance, Determinants of Health, and Evidence-Based Decision-Making. We were determined not to repeat work already completed by various commissions, task forces, and studies. We consulted widely with experts in various fields and with groups and councils working on similar issues, commissioned papers, accepted letters and briefs, conducted polls, and held two series of public consultations. Our meetings always included observers from provincial governments, Health Canada, and the offices of the Prime Minister and the Minister of Health.

Following our analysis of the very diverse data, we concluded that our recommendations should be addressed more broadly than just to

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the federal government. Our report calls for action from all levels of government, the private sector, and the people of Canada. The recommendations take a medium- to long-term view and have considerable implications for nursing and nursing research. The major recommendations are built on the values that the Canadian people expressed to us: equity, compassion, collective responsibilities, individual responsibility, respect for others, efficiency, and effectiveness.

The key recommendations fall into three broad categories: preserving the health-care system while doing things differently, acting on our knowledge about what makes people healthy, and using better evidence to make better decisions. Because the report is readily available from the Publications Distribution Centre at Health Canada Communications, I will merely highlight the directions within each of these areas, and then comment on the issues to which I believe nurses and nursing researchers should pay particular attention. A detailed analysis of these issues is available in a separate volume as synthesis reports from the working groups and discussion papers on key issues (National Forum on Health, 1997b). The papers commissioned by the Forum will be published in the fall of 1997.

# Preserving the System by Doing Things Differently

Canadians are very concerned about the state of their health-care system. They are responding with fear to the marketing, by health-care professionals, of a "crisis" in health care. They are concerned that, despite their strong support for the principles of the Canada Health Act, it may no longer be feasible for us to maintain a system of universal health care that assures them both accessibility and quality. The evidence does not support this view; indeed, we concluded that the system is fundamentally sound and sufficiently funded, but it is clear that things must be done differently in terms of preserving the system and making it more integrated.

# Preserving the System

The Forum concluded that it is possible to preserve the Canadian system while ensuring that is it more comprehensive. We concluded that full public funding of "medically necessary services" is fundamental to preserving and protecting Medicare. We also found that the amount spent on health and health care at present is appropriate. However, the current balance of public and private funding should not be altered in a way that increases the proportion of private funding.

We also concluded that the federal role in preserving the system requires a significant and stable financial contribution. Therefore, we reiterated our 1996 recommendation that the Canada Health and Social Transfer (CHST) not be decreased beyond \$12.5 billion.

### Making the System More Integrated

The media have attended most to the Forum recommendations on improved integration of health-care services. A key principle underlying these recommendations is that "medically necessary care" should be a part of publicly financed health services no matter where, or by whom, it is delivered. The particular services we addressed were primary care, pharmaceuticals, and home care. Moreover, we recommended — and the 1997 federal budget established — that \$50 million be designated annually, for three years, in transition funding to establish and evaluate pilot or existing projects consistent with these directions, and to promote the implementation of the best models.

*Primary care.* We found that there is no one perfect model of primary care. Each province must determine the system that best fits its communities. However, an effective model of primary care will include multidisciplinary teams of providers and offer a continuum of preventive and treatments services; it will not provide remuneration based on volume of services.

*Pharmaceuticals.* We concluded that our national system of health insurance should include pharmaceuticals. Implementation of this recommendation will require careful planning, but it is the only way to ensure both universal access to and control of the costs of pharmaceuticals. Implementation must be preceded by many steps, including the creation of automated, interactive decision-support and drug-management systems.

Home care. During our consultations, the public made clear that they fully support the notion that people should receive care at home rather than in hospitals or chronic-care institutions. However, they are unwilling to be conscripted to provide that care. We recommended that home care be an integral part of publicly funded health services.

### Impact on Nursing and Nursing Research

From a nursing perspective, these initiatives have major implications, both for the individuals, families, and communities with whom we work and for the nature of our work. Reformed systems of primary care

— including expansion of a number of excellent systems that exist in some provinces — will significantly improve the integration of assessment and care of individuals and families and will foster better use of a range of nursing skills. Public financing of pharmaceuticals will mean one less barrier those with chronic conditions will have to face in managing their care according to the recommendations of their physicians. Inclusion of home care as a publicly funded service is expected to reduce the demands on family caregivers (mainly women) and increase the number of positions for nurses.

A major challenge, however, will remain in determining the "nurse dose" required in each of these services. Such questions will likely set the agenda for nursing researchers. Nurses and nurse researchers must play an active role in influencing how the \$50 million in transition funding is allocated in each of the three years. For instance, we may wish to ensure that the allocation includes both pilot projects that are consistent with nursing's vision and evaluations of nursing's contributions to the outcomes.

### From Knowledge to Action: What Makes People Healthy?

There is a strong, growing information base demonstrating that what makes people healthy has little to do with health care. Canada has focused for many years on issues related to individuals taking responsibility for their health by such means as adopting healthy lifestyles. As powerful as some of those strategies are, other forces — including social and economic ones — also determine health outcomes. We must initiate broad and specific actions that will implement change in accordance with this knowledge base. In particular, we recommended actions in four areas: investing in children and families, strengthening community action, creating an Aboriginal Health Institute, and addressing employment policies. Additionally, we called on federal granting agencies to broaden the research agenda: in order to strike a better balance between research into non-medical determinants of health and basic and clinical research; and to create an annual fund of \$5 million for research into the determinants of health.

### Investing in Children and Families

We live in an era of rapid social change — with nearly 20% of Canadian children living in poverty, dramatic changes in family life, increased patterns of parental employment outside the home, and limited access to early-childhood care and education. In such a context, we were par-

ticularly struck by the research evidence demonstrating causal links between the social environment and the pattern of growth in the brain of the young child, and the degree to which children develop resilience. Taking action to support children and families requires a comprehensive and integrated child and family strategy of programs and income support. We recommended that such a strategy include the following components: an integrated child-benefit program; community-based programs with a home-visiting component for specific populations of pregnant women and their children; access to affordable, high-quality child care and early childhood education, funded by a sliding scale of fees based on ability to pay; "family friendly" policies and programs in the workplace; and taxation policies favouring horizontal equity for families.

### Community Action

When we analysed the "success stories" described in a series of papers on various health issues (National Forum on Health, 1996), we discovered that nearly all of the approaches or programs that were successful in creating positive health outcomes featured three elements in a "winning combination." These were: strong community involvement in initiating or planning the approach; involvement of multiple sectors from the community in implementing the approach; and inclusion of multiple actions, directed at multiple issues, in developing the approach. Because communities play an enormous role in influencing health, we sought ways in which to promote a renewed partnership of communities, governments, and the private sector. We recommended the creation of a national foundation for community action, which would promote community integration, involvement, and control, as well as recognize the contribution of communities to health.

# Aboriginal Health Institute

The health issues facing the Aboriginal communities require comprehensive approaches. While we recommended that special attention be paid to Aboriginal health issues within many other recommendations, we also recommended that an Aboriginal Health Institute be established. Among the Institute's many functions would be identifying culturally relevant, appropriate approaches to disease management, conducting health research to meet the needs of Aboriginal people and communities, sharing information, and supporting Aboriginal health workers and students in the health professions.

### **Employment**

The health impact of economic policies that negatively influence employment — such as by creating involuntary transitions in employment — is widespread and devastating. Meaningful work and income security are essential to health and well-being. Our recommendations in this area focused on recognition of the health impact of economic policy and — besides advocating the lowest possible rates of unemployment — urged immediate attention to youth unemployment.

### Impact on Nursing and Nursing Research

Many of our recommendations pertaining to what makes people healthy require actions beyond the health-care system. However, they have important implications for nursing and nursing research. While evidence in this arena provides a perspective on the relative contribution of health care to the overall health of the population, implementation of some recommendations, such as community-based programs with a home-visiting component for specific populations of pregnant women and their children, would extend the potential community role of nurses. A number of community-action initiatives require the community-development and partnerships skills that many nurses bring to multisectoral and interdisciplinary teams. Again, movement in this area will bring additional opportunities for nurses.

A major implication for nursing, however, is that we must take an advocacy position, to ensure that the recommendations remain part of the public debate. It would be easy to limit the debate to the issues of primary care, pharmaceuticals, and home care. Given nursing's understanding of and commitment to health, we must play a major role in dealing with employers and all levels of government to maintain the pressure for action to improve the health of Canadians. Each new funding allocation for research on key determinants of health has major implications for the nursing research agenda.

# Using Better Evidence to Make Better Decisions

There is general agreement that a large portion of what we do in health care is not based on good evidence. In addition, it is now acknowledged that even good evidence is not readily accessible to decision-makers—that is, providers, administrators, policy-makers, and people making personal decisions about their own health and health care. Finally, there is concern in all arenas that, frequently, for many reasons, decisions are made that do not use the existing evidence — even when the informa-

tion is accessible. Our analysis of these issues led us to the conclusion that the health sectors depend on rapid development of an evidence-based system. We recommended that the federal Minister of Health take leadership in that development, that a comprehensive health-information system be established, and that Canada develop a comprehensive research agenda to address knowledge gaps and facilitate dissemination and use of evidence in the health system.

### Comprehensive Health-Information System

A nationwide, comprehensive health-information system will require major initiatives by provincial ministers of health and involvement of provincial and territorial agencies to foster linkages among governments and agencies. We require standardized and longitudinal data on both health status of the population and performance of the health system. A key component of such a nationwide health-information system would be a National Population Health Institute with a mandate to aggregate and analyse data, report on national trends and comparisons, and act as a resource for developing and evaluating public policy.

### Research Agenda

Our recommendations concerning a strategic and focused research agenda were intended to enhance the potential of a nationwide health-information system. Moving the agenda forward requires several steps, including careful analysis of the state of health-related knowledge and identification of gaps in knowledge. We identified several such gaps: non-medical determinants of health and the effectiveness of strategies for ameliorating the negative determinants; alternative and complementary health practices; women's health issues; and Aboriginal health issues. Other recommendations concerning the research agenda referred to the issues of promotion of uptake of research knowledge, human-resource planning and development, and foci for research funding.

### Impact on Nursing and Nursing Research

The recommendations in this section of the report are relevant for nurses, in many ways. Any recommendations concerning evidencebased decision-making may be seen as relevant only for researchers and administrators, but the kinds of changes recommended in setting the research agenda and focusing research funding are consistent with the interests of nurse researchers. For example, we must be clear about the specifics of an agenda that we know will achieve the goals. We must be persistent in influencing local representatives to research policymaking bodies, federal, provincial, and territorial ministers of health (and their staffs), and national granting agencies.

As well, there are signals in the discourse around the issues of using better evidence to make better decisions that might lead us to consider carefully how much of our practice is evidence-based. How high on the nursing research agenda are questions related to research utilization and outcomes of nursing approaches? In addition, it is my hope that nurses in all areas of practice and in policy-setting positions will act to influence the way in which these recommendations are implemented. We must all consider very carefully the kinds of information that we need in order to make decisions in our everyday work. What kind of information do we believe decision- and policy-makers should consider in their work? What kinds of information do individuals and communities need when they are considering personal or aggregate options? Unless nurses are involved in advocating for certain types of information, and explaining how such information would be useful, it is unlikely the key information that we and our clients or patients need will be available. Now is the time for focused thinking on this issue. The work on these initiatives is already underway.

# What Happens Next?

The question I was asked most frequently over the two-year period in which the Forum met was "What will happen — will the report just sit on the shelf?" The Forum's report has a clear vision for medium- to long-term health policy in this country, and there are indications it will not just sit on the shelf. It has been well received overall, although some of the recommendations have been highly criticized. The federal government took action on the report within weeks of its release, when allocations to support some recommendations were included in its 1997 budget. During the 1997 election campaign, the Liberal Party of Canada addressed its plans for action on several recommendations.

There can be no doubt that some of the recommendations have generated national debate. The Forum's final meeting was held at the time of the report's release. It is now up to nurses, and Canadians in all walks of life, to ensure that the debate continues and that the more popular recommendations are acted upon. Work has already begun around the issues of a health-information system and a Population Health Institute, and three conferences are being planned around the

issues of primary care, pharmaceuticals, and home care. However, other issues seem to be less clearly understood or of lower priority for policy-makers. For example, initiatives addressing an integrated child benefit have been announced; yet there is little indication that the vision of an integrated child and family strategy that includes both programs and income support has been understood. The actions underway at the federal level in response to the report, however, do suggest that this is one report that will actually have some influence.

Given the track record of implementing the recommendations of reports, one may ask why there has been such acceptance. I believe the answer lies in the processes of the Forum's work and provides an indicator for new ways of influencing health policy. The Forum was gender balanced. Its members came from diverse backgrounds and very few had any clear political party affiliation. Several had extensive research backgrounds and links with groups that worked on some of the issues under discussion. The credibility of other members sprang from their involvement in and knowledge of the community. While we shared strong commitment to our national system of health insurance and the principles of the *Canada Health Act*, we were a group of very independent thinkers who frequently debated diverse perspectives with vigour.

Although Prime Minister Chrétien was official chair of the Forum, he did not attend our meetings. However, his office was kept informed of our progress and we communicated our recommendations regularly. We also engaged regularly in informal communications to ascertain the perspectives of provincial governments on some issues, and in formal communications to brief provincial departments of health on the directions of the Forum. A key strategy in our work on some areas, such as child and family issues, was to meet with groups or councils working on similar issues. We determined whether their assessments and solutions were in accord with those of the Forum. These consultations resulted in more unanimity in the voices from various sectors and, I believe, added to the power of all the voices to influence policy. Our extensive public-consultation processes ensured that we knew the views of the Canadian public and key stakeholders. Those consultations influenced our thinking: we altered some of our directions and modified some of our recommendations as a result of our final public and stakeholder consultations in late 1996. Finally, we used a variety of evidence from around the world, and were careful to base our analysis and recommendations on the best evidence available while taking into account the current Canadian context. We made clear choices about priorities and were specific in our recommendations so that the content itself is highly credible, focused, pragmatic, and therefore, I believe, difficult to ignore.

"What's next" for nursing, considering the directions of this report? How will our practice be affected by implementation of the Forum's call for changes in health-care policies, action on our knowledge concerning the determinants of health, and creation of an evidenced-based health system with different emphases in funding research? How will we shape our work to influence the directions taken in implementing the recommendations? How can we use the lessons of the Forum to influence public policy? It is up to everybody to keep the debate alive and to create the impetus for action.

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#### Systems Research Spring 1998 (vol. 30, no. 1)

The aim of this issue is to make a contribution to our knowledge of nursing and/or patient-care systems and their application to the organization, delivery, and evaluation of care. Topics with potential for enhancing the development and implementation of information systems as well as reports of testing and implementation are of particular interest.

Guest Editor: Dr. Phyllis Giovannetti Submission Deadline: October 15, 1997

## Gerontology Summer 1998 (vol. 30, no.2)

This edition will feature research that focuses on older people. Studies that increase our understanding of what people experience and perceive as needs as they age are of interest. Research studies that contribute to our knowledge of how to care for or assist older people and their informal caregivers are also sought. Papers that describe new ways of conceptualizing nursing of older people and research that is needed within these frameworks are also welcome.

Guest Editor: Dr. Dorothy Pringle Submission Deadline: January 15, 1998

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#### Articles à publier

#### La recherche sur les systèmes Printemps 1997 (vol. 30, no. 1)

L'objectif du présent numéro est de participer à l'approfondissement de la connaissance en sciences infirmières sur les différents systèmes de soins prodigués aux usagés ainsi que leur mis en pratique au niveau de l'organisation, de la prestation et de l'évaluation des soins. On recherche surtout les sujets qui permettraient d'améliorer le développement et la mis en place de systèmes d'information ainsi que des études d'utilisation et d'implantation de tels systèmes. Ces sujets présentent un très grand intérêt.

Rédactrice invitée : Dre Phyllis Giovannetti Date limite pour les soumissions : le 15 octobre 1997

#### Gérontologie Été 1998 (vol. 30, no. 2)

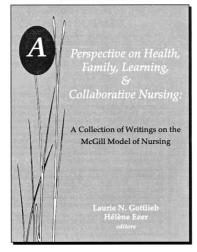
Ce numéro traitera de la recherche consacrée aux personnes âgées. Les études qui nous permettent d'acquérir une meilleure compréhension de ce que les gens développent et perçoivent comme besoins au fil du processus de vieillissement s'inscrivent dans notre champ d'intérêt. Nous sommes aussi intéressés aux recherches qui contribuent à approfondir nos connaissances en matière de soins des aînés et du soutien des proches qui leur administrent des soins. Nous invitons la soumission d'articles traitant des nouvelles approches conceptuelles en soins infirmiers auprès de personne âgées et de la recherche à poursuivre dans ces cadres.

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#### Dean, Faculty of Nursing

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The University of Alberta has a clear vision: to be indisputably recognized nationally and internationally as one of Canada's finest universities. The University plays an integral role in the educational, business and cultural life of Alberta through the impact of its integrated mandate of teaching, research and community service. In excess of 4,500 courses are offered in 16 Faculties at the University of Alberta where more than 29,000 students are enrolled.

The Faculty of Nursing is one of five Health Science Faculties at the University of Alberta, and is a member of the Coordinating Council of Health Sciences whose goal is the development of interdisciplinary opportunities for students and faculty. We offer three undergraduate programs leading to a BScN. At the graduate level, we offer an Advanced Nursing Practice Master's program with thesis and non-thesis routes, and a PhD in Nursing program. A complement of 61 full-time faculty, engaged in more than 75 funded research projects, offers approximately 70 courses to over 1050 undergraduate students and 128 graduate students. For further information about the Faculty of Nursing please view our

home page on the World Wide Web at http://www.quasar.ualberta.ca/nursing.

The Dean is responsible to the Vice-President (Academic) for the supervision and administration of academic programs, budget and all activities of the Faculty. Candidates should have proven administrative experience, welldeveloped leadership skills, a strong cademic background, and be committed to excellence in teaching and research. The appointment will take effect July 1, 1998 or as soon as possible thereafter.

Written nominations for the position, or applications supported by a curriculum vitae and the names of three referees, should be submitted by December 1, 1997 to:

Dr. Doug Owram, Vice-President(Academic) Third Floor, University Hall University of Alberta Edmonton, Alberta Canada 16G 2J9

The University of Alberta is committed to the principle of equity in employment. As an employer we welcome diversity in the workplace and encourage applications from all qualified women and men, including Aboriginal peoples, persons with disabilities, and members of visible minorities.





# The University of Manitoba Faculty of Nursing

#### TENURE-TRACK POSITIONS

Palliative Care & Oncology Nursing Nursing Care of Families & Maternal/Newborn Nursing Administration & Health Services Research

> Advanced Nursing Practice Mental Health Nursing

The Faculty of Nursing invites applications for five tenure-track positions to begin July 1, 1998. Rank will be at the Assistant or Associate Professor level depending on qualifications.

DUTIES include teaching nursing courses at the undergraduate and graduate levels in the area of expertise; participating in the thesis/ practicum supervision of graduate students in the Master of Nursing program; maintaining an ongoing program of research and scholarship; participating in faculty, university and professional activities; and, where relevant, tractising in area of clinical expertise.

QUALIFICATIONS: Ph.D. (earned or near completion) for Palliative Care, Care of Families, Administration, and Mental Health nursing positions; Ph.D. preferred for Advanced Nursing Practise position; consideration will be given to non-Canadian applicants who hold an earned Ph.D.; evidence of advanced research training and development of an ongoing research and publication program; effective teaching and communication skills; clinical experience where relevant; eligibility for registration in the Manitoba Association of Registered Nurses; and demonstrated ability to establish collegial relationships.

The University of Manitoba encourages applications from qualified women and men, including members of visible minorities, Aboriginal peoples, and persons with disabilities. This advertisement is directed primarily to Canadian citizens and permanent residents.

The salary range for Assistant Professor rank is \$40,868 - \$62,509 and for Associate Professor is \$52,718 - \$80,638; starting salary dependent on qualifications and experience.

Please send a curriculum vitae and the names, addresses and telephone and fax numbers of three references by December 15, 1997 to:

Dr. Janet Beaton, Dean, Faculty of Nursing, University of Manitoba, 246 Bison Building, Winnipeg, Manitoba, R3T 2N2 Fax: (204) 474-7500.

Visit our Website at: www.umanitoba.ca/faculties/nursing.

#### Information for Authors

The Canadian Journal of Nursing Research is a quarterly journal. Its primary mandate is to publish nursing research that develops basic knowledge for the discipline and examines the application of the knowledge in practice. It also accepts research related to education and history and welcomes methodological, theory, and review papers that advance nursing science. Letters or commentaries about published articles are encouraged.

Procedure: Three double-spaced typewritten copies of the manuscript on 8 %" x 11" per are required. Articles may be written in French or English. Authors are requested not to put their name in the body of the text, which will be submitted for blind review. Only unpublished manuscripts are accepted. A written statement assigning copyright of the manuscript to the Canadian Journal of Nursing Research must accompany all submissions to the journal. Manuscripts are sent to: The Editor, Canadian Journal of Nursing Research, School of Nursing, McGill University, 3506 University Street. Montreal, OC H3A 2A7.

#### Manuscripts

All manuscripts must follow the fourth edition of the Publication Manual of the American Psychological Association. Research articles must follow the APA format for presentation of the literature review, research questions and hypotheses, method, and discussion. All articles must adhere to APA guidelines for references, tables, and figures. Do not use footnotes.

Title page: This should include author name(s), degrees, position, information on financial assistance, acknowledgements, requests for reprints, address, and present affiliation.

Abstract: Research articles must include a summary of 100–150 words containing information on the purpose, design, sample, findings, and implications. Theory and review papers must include a statement of the principal issue(s), the framework for analysis, and a summary of the argument.

Text: The text should not exceed 15 double-spaced typed pages. References, tables, and figures should follow the text.

References: The references are listed in alphabetical order, double-spaced, and placed immediately following the text. Author names and journal citations must be spelled out in full.

Tables and figures: Tables and figures should appear only when absolutely necessary. They must be self-explanatory and summarize relevant information without duplicating the content of the text. Each table must include a short title, omit abbreviations, and be typed on a separate page. Figures must be in camera-ready form.

Review process and publication information: The Canadian Journal of Nursing Research is a peer-reviewed journal. Manuscripts are submitted to two reviewers for blind review. The first author will be notified following the review process, which takes approximately 12 weeks to complete.

**Electronic copy:** Authors must provide satisfactory electronic files of the accepted final version of the manuscript.

#### Renseignements à l'intention des auteurs

La Reuse canadienne de recherche en sciences infirmières paraît quatre fois par année. Son mandat est de publier la recherche en sciences infirmières qui a trait au developpement des connaissances dans la discipline et l'analyse de la mise en pratique de ces connaissances. La revue accepte également des articles de recherche reliés à l'éducation, à l'histoire de même que des articles reliés à la méthodologie, la héroire et l'analyse critique qui permetent le développement des sciences infirmières. Des lettres et commentaires sur des articles publiées son écalement encouragés.

Modalités: Les textes doivent être soumis en trois exemplaires, être dactylographiés à double interligne sur des feuilles 2 línm x 27 pm et être adressés à la rédactrice en chef, à la Reux camadiemne de recherche en sciences infirmières, Université McGill, École des sciences infirmières, 306 rue Université, Montréal, QC, H3A 2A7. Il est entendu que les articles soumis n'ont pas été simultanément présentés à d'autres revues. Veuillez également inclure lors de la soumission, une déclaration de propriété et de cession de droits d'auteurs. Finalement, afin de garder l'anonymat lors du processus de révision, veuillez ne pas inclure les nom des auteurs dans le texte.

#### Manuscrits

La présentations du manuscrit doit respecter les normes du Publication Manual of the American Psychological Association, 4ºme édition, 1994. Particulièrement, les figures, tableaux, illustrations et références doivent suivre ces normes de présentation. Il est suggéré de ne pas utiliser de notes au bas de la page.

Page titre: Pour assurer la lecture anonyme des textes soumis, seule la page titre du manuscrit comprendra le nom, l'adresse et l'affiliation de(s) auteur(s), les diplômes obtenus ainsi que l'aide financière reçue, les remerciements et une demande de copies.

Résumé: Un résumé en anglais et en français d'environ 100 à 150 mots chacun doit précéder le text. Ce résumé devrait comprendir Objectif, la méthode, les résultats et les retombées de la recherche. Les manuscrits qui concernent la théorie et les analyses critiques doivent inclure une identification des objectifs principaux, le cadre conceptue utilisé pour l'analyse des données et un résumé de la discussion. La qualité du français est primordiale; le style doit être clair concis et doit éviter un langage seviste ou discriminatoir.

Texte: La longueur totale d'un manuscrit incluant les tableaux, les figures et les références, ne doit pas dépasser 15 pages, dactylographiées à double interligne. Les articles peuvent être rédigées soit en anglais ou en français.

Références: Les références doivent paraître en ordre alphabétique, à double interligne et faire suite au texte. Les noms des auteurs de même que les citations de revues doivent être écrites au long.

Tableaux et schémas : Les tableaux et schémas doivent paraître seulement si nécessaire. Ils doivent résumer des informations pertinentes sans redire le contenu du texte. Chaque tableau doit comprendre un titre, ne pas comprendre d'abréviations et être dactylographié sur une page à part. Vous devez remettre les originaux des schémas dessinés à l'encre de Chine et prés à être photographiés.

Examen des manuscrits et renseignements reliés à la publication: Lorsqu'un manuscrit est soumis pour publication à la Revue canadienne de recherche en sciences infirmières, le comité de rédaction débute le processus de lecture: il envoie à un minimum de deux réviseurs, spécialistes du sujet dont traite le texte, une copie anonyme du manuscrit ainsi que la grille d'avaluation des manuscrits. Sur réception des évaluations des réviseurs, le comité de rédaction prend la décision de publier ou non le texte et en informe l'auteurle/ responsable en lui faisant part des évaluations des réviseurs. Ce processus prend habituellement douze semaines. Si la décision est favorable, le comité peut proposer des corrections que [les] auteurle/) devra (ont) effectuer avant que le texte ne soit publié.

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The Canadian Journal of Nursing Research/Revue canadienne de recherche en sciences infirmières est publiée quatre fois par année par l'École des sciences infirmières de l'Université McGill, 3606 rue University, Montréal, Québec H3A 2A7. Tel: 514-398-4160. Téléc: 514-398-8455. Courrier élec: czji@musica.mcgill.ca. Veuillez vous adresser au directeur de la diffusion pour les abonnements, chaneement d'adresse, et d'autres questions d'affaires.

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This issue has been supported by an SSHRC (647-95-0048) grant. Nous avons reçu les subventions du CRSHC (647-95-0048) pour ce numéro.

#### ISSN 0844-5621

The Canadian Journal of Nursing Research is indexed in /La Revue canadienne de recherche en sciences infirmières se retrouve dans les indexes suivants:

CINAHL; Health Care Management Studies; Hospital Abstract; Index de la santé et des services sociaux; Micromedia's Canadian Business & Current Affairs (CBCA) database; Nursing Abstracts; Sociological Abstracts (SA); Social Planning/Policy and Development Abstracts (SOPODA).

Dépot légal – Bibliothèque Nationale du Québec, 1997 © Copyright: McGill University, School of Nursing, 1997

Cover, design & layout/Couverture, design & mise en page : Résolutique Globale, Montréal

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