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## SUMMER EDITORIAL

# **The Impending Nursing Shortage: A Case for Raising — Not Lowering — Education Standards**

It's been quite a year. In early February the Quebec ministers of education and health announced that in future there would be only one access route to nursing, the CEGEP (or technical college) level — implying that access to nursing via the university route would be closed, university education reserved for specialization. In November 1997 the Canadian Nurses Association (CNA) released a long-awaited report predicting that by the year 2011 there will be a serious shortage of nurses, estimated between 60,000 and 113,000; these Canadian findings confirmed those of earlier nursing studies conducted by provincial manpower departments. And in May the premier of Nova Scotia, in a Speech from the Throne, announced his government's intention of re-introducing hospital schools of nursing.

The Nova Scotia decision appeared to be directly linked to the nursing shortage. The reason for the Quebec announcement was less clear, although it did relate in part to the job market. During the past few years of severe job shortages, CEGEP-trained nurses have experienced difficulty finding employment, and it has become patently clear that their preparation is inadequate to meet the needs of an increasingly complex health-care system.

Whatever the reasons underlying the Quebec ministers' announcement, the affected community reacted to it with disbelief and outrage. Reaction came from all sectors of the nursing community, the health-care system, and the education system. It came from all corners of the province and from across Canada. Even the American Nurses Association communicated its dissatisfaction with the plan.

The government was surprised and overwhelmed by the response. The nursing community was even surprised by its own reaction. Nurses spoke up in a loud and clear voice and, for once, were heard. In June the Quebec government issued a communiqué reversing its intention to close direct access to nursing via the university. All is calm — for the moment. (The community is still reacting to the Nova Scotia decision.)

These are defining moments in Canadian nursing history. The profession was able to make its case because, as a community, it has developed a clear vision for itself. Over the past 30 years, nursing has clarified its mandate and developed an impressive body of knowledge. It has created an education system to realize its vision.

We are at a precarious point in our history. How we respond to the nursing shortage will define the future of the profession. The estimated shortages are based on an aging population who will require nursing care, a large number of nurses retired or at the point of retiring, and a diminishing pool of young nurses. During the past 20 years the number of individuals who have selected nursing as a career has fallen by nearly 50%. In other words, nursing has not been replenishing itself.

There are many reasons for this alarming state of affairs. Each of us has our own favourite explanation. We can blame the feminist movement, particularly in its early years, for devaluing the "pink professions" and rejecting anything associated with traditional women's roles. The message conveyed to a whole generation of young women was that to make it in the health-care field you had to be a doctor. The nurse was a symbol of subservience to men. We can blame the media for portraying nurses as either saints, sluts, or dimwits. We can cite the endless tensions between physicians and nurses and the lack of appreciation on the part of physicians for nursing's critical contribution to the well-being of patients. We can cite difficult working conditions. We can cite nursing's failure to recognize the complexities of its own work and its failure to communicate what nurses do — to make its work visible. The list goes on.

At the end of the day, however, we are responsible for our own state of affairs. Nursing has important choices to make in attracting and keeping its future practitioners. The CNA and the Canadian Association of University Schools of Nursing (CAUSN) have made the nursing shortage their priority.

At the most immediate level, nursing will have to resist the pressure to find quick and easy solutions to the nursing shortage. We are already witnessing one response — a solution that I predict will be disastrous for the profession in the long term — fewer entrance requirements and shorter programs. While these measures are intended to make nursing more accessible and attractive, they will have the opposite effect: They will discourage the best and the brightest students from applying. With the many career choices available to young people today, bright students are attracted to professions they perceive to be difficult and challenging; these are the professions that are awarded

status. By lowering standards we are conveying the message that nursing requires little substantive knowledge and that its skills can be learned quickly. In effect we are, once again, denying the complexity of nursing, denying that quality care requires vast stores of knowledge. And in effect we are guilty of exactly the type of thinking behind the recent Quebec and Nova Scotia proposals: We are failing to recognize the vital link between quality health care and quality education.

We should in fact be raising entry requirements and extending the length of programs. The students we attract into nursing today will be determining the nature of the profession 30 years from now. It is from this pool that our practitioners, researchers, educators, and leaders will be drawn.

We were able to win this round against the governments because nursing had invested in education, and therefore its leaders, practitioners, and scholars could articulate our mandate and knew what was at stake for the health-care system. They had the knowledge and the empirical evidence to back up the vision.

To help realize the vision and realize the dream of quality health care, nursing must continue to attract the best and the brightest. If we fail to invest in high-quality nursing education now, who will be around to fight for quality health care in the next round?

**Laurie N. Gottlieb**  
**Editor**



## ÉDITORIAL D'ÉTÉ

# **Le manque imminent en personnel infirmier : un plaidoyer en faveur de la hausse et non de la réduction des normes de formation**

Cette année en fut toute une pour nous. En début de février, les ministres provinciaux de l'éducation et de la santé firent une déclaration à l'effet que le cégep (collège de formation technique) deviendrait la seule institution à dispenser une formation en soins infirmiers — ce qui signifie que l'accès à la profession ne se ferait plus par la voie universitaire, qui elle, ne serait empruntée que pour acquérir une spécialisation. En novembre 1997, l'Association des infirmières et infirmiers du Canada (AIIC) publia un rapport longuement attendu, dans lequel on prévoyait une grave pénurie en personnel infirmier, un manque se chiffrant entre les 60 000 et 113 000, d'ici à l'an 2011. Ces résultats à l'échelle canadienne confirmèrent ceux issus de recherches antérieures menées par les ministères provinciaux de la main-d'oeuvre. De plus, au mois de mai, le premier ministre de la Nouvelle-Écosse annonça, dans un discours du Trône, que son gouvernement avait l'intention de réintroduire les écoles de soins infirmiers en milieu hospitalier.

La décision de la Nouvelle-Écosse semble être directement liée à la pénurie de personnel infirmier. Les raisons qui motivent celle de Québec ne sont pas aussi limpides, quoiqu'elles sont partiellement liées à la situation sur le marché du travail. Dans le contexte de pénurie d'emplois des dernières années, les infirmières formées dans les cégeps ont éprouvé des difficultés à trouver de l'emploi. Il est donc très évident que leur formation ne répond pas aux besoins d'un système de santé qui se complexifie de plus en plus.

Quelles que soient les raisons qui motivent la décision des ministres québécois, la communauté concernée fut surprise et outragée par cette déclaration. Les réactions fusèrent de tous les secteurs de la communauté infirmière, ainsi que du système de santé et d'éducation, de toutes les régions du Québec et d'un bout à l'autre du pays. Même



l'association américaine des infirmières et infirmiers exprima son insatisfaction face au projet.

Le gouvernement fut stupéfait et dépassé par l'ampleur de la réaction. La communauté infirmière fut même étonnée de sa propre réaction. Les infirmières se prononcèrent publiquement avec force et clarté, et pour une fois, leurs propos furent reçus. En juin, le gouvernement du Québec émit un communiqué à l'effet qu'il renversait sa décision de couper l'accès direct à la profession par voie universitaire. Tout est calme — pour l'instant. (La communauté mène toujours une lutte contre la décision de la Nouvelle-Écosse.)

Les enjeux qui se jouent sont de la plus haute importance dans l'histoire des soins infirmiers au Canada. La profession a pu mener sa plaidoirie parce qu'elle a élaboré, en tant que communauté, une vision claire de ses objectifs. Au cours des 30 dernières années, elle a précisé son mandat et développé un impressionnant bloc de connaissances, tout en créant un système d'éducation qui permet de mener à terme cette vision.

Nous sommes à un moment précaire de notre histoire. Notre réaction face à la pénurie de personnel infirmier définira l'avenir de la profession. Les prévisions de pénurie sont fondées sur le phénomène de vieillissement de la population, laquelle nécessitera des soins infirmiers. Il y a aussi le grand nombre d'infirmières et infirmiers qui sont retraités ou au bord de la retraite, ainsi que la baisse du nombre de jeunes dans la profession. Au cours des 20 dernières années, le nombre d'individus qui choisissent une carrière en soins infirmiers a diminué de près de 50 %. En d'autres termes, les effectifs de la profession ne se renouvellent pas.

Voilà autant de raisons qui expliquent cette situation alarmante. Chacun de nous possède sa propre explication. Nous pouvons reprocher au mouvement féministe, surtout dans ses premières années, d'avoir dévalorisé les « professions roses » et rejeté tout ce qui était associé aux rôles traditionnels féminins. Le message véhiculé auprès de toute une génération de jeunes femmes était qu'il fallait être médecin pour percer dans le domaine de la santé. L'infirmière était le symbole de la soumission face aux hommes. Nous pouvons pointer aussi du doigt les médias pour avoir présenté les infirmières comme des saintes, des prostituées ou des imbéciles. Nous pouvons citer sans fin les éternelles tensions entre les médecins et le personnel infirmier et l'absence de reconnaissance, de la part du corps médical, de la contribution vitale des infirmières et infirmiers au bien-être des patients. Nous pouvons



faire référence aux conditions de travail difficiles, ainsi qu'à l'incapacité de la profession de reconnaître la complexité de son propre travail et de rendre public les réalisations du personnel infirmier, soit de visibiliser son travail. La liste de raisons est longue.

Toutefois, en bout de ligne, c'est nous qui menons notre barque. La profession doit procéder à d'importants choix si elle veut attirer et conserver dans ses rangs de futurs praticiens. L'AIIC et l'Association canadienne des écoles universitaires de nursing (ACÉUN) ont choisi d'accorder la priorité à ce dossier.

À court terme, la profession devra résister aux pressions qui l'incitent à trouver des solutions rapides et faciles, face à cette pénurie. Déjà, nous sommes témoins d'une certaine approche, soit une diminution des conditions d'entrée et l'instauration de programmes plus courts. À mon sens, une telle solution s'avérera, à long terme, désastreuse pour la profession. Ces mesures visent à rendre la profession plus accessible et attirante, mais elles produiront l'effet contraire. Elles auront un effet dissuasif auprès des meilleurs étudiants, lesquels ne s'inscriront pas. Dans un contexte actuel où les jeunes ont accès à un vaste choix de carrières, les étudiants doués sont attirés par les professions qu'ils perçoivent comme étant exigeantes et riches en défis. Ces professions sont celles qui décernent un statut dans la société. En diminuant les normes, nous véhiculons le message comme quoi la profession requière peu de connaissances approfondies et que les compétences pour l'exercer sont rapidement acquises. En fait, nous nions, une fois de plus, la complexité de la profession et le fait que des soins de qualité nécessitent un vaste savoir. De plus, nous adhérons à cette même pensée qui anime les projets récemment proposés au Québec et en Nouvelle-Écosse. Nous ne reconnaissons pas le lien vital entre des soins de qualité et une solide formation.

En fait, nous devrions plutôt hausser les conditions d'entrée et la durée des programmes. Les étudiants que nous recrutons aujourd'hui définiront, dans 30 ans, la nature de la profession. C'est de ce bassin que seront issus nos praticiens, chercheurs, formateurs et porte-parole.

L'investissement de la profession dans le domaine de l'éducation nous a permis de remporter cette ronde contre les gouvernements. Grâce à cet investissement, les meneurs, praticiens et chercheurs ont pu articuler notre mandat et cerner les enjeux quant au système de santé, puisqu'ils possédaient la connaissance et les preuves empiriques pour défendre la vision.

## *Éditorial d'été*

Pour concrétiser la philosophie et le rêve qui préconisent des soins de santé de qualité, la profession doit continuer à exercer un attrait auprès des étudiants les plus brillants et doués. Si nous ne réussissons pas, aujourd'hui, à investir dans un solide programme de formation en soins infirmiers, qui se portera à la défense des soins de qualité lorsque la prochaine ronde du combat aura lieu ?

**Laurie N. Gottlieb**  
**Rédactrice en chef**

## LETTER TO THE EDITOR

# Predicting Fall Risk

In their article "Falls risk factors in an acute-care setting: A retrospective study," Stevenson, Mills, Welin, and Beal (1998) comment on use of the Morse Fall Scale (MFS) (see Morse, Morse, & Tylko, 1989). I quote: "McCollam found that the MSF did identify those most at risk of fall [sic], *but* also found that the cut-off score for risk of fall had to be modified for different types of patient-care units" (p. 99, italics added). It is important that the following points be noted about McCollam's testing of the scale and its use:

(1) Fall risk varies with patient populations. While my research has done much to identify normative scores for various populations, it is recommended that scores for determining risk be established for each patient-care unit. Setting the scale at a level that will determine those most at risk of falling on a stroke unit will be virtually useless in determining fall risk on a general medical or surgical unit, psychiatric unit, or maternity unit, where there is a greater proportion of the normal and weak scores and the distribution of the fall scores is quite different. Recommendations for determining risk is an *administrative* decision, made according to the level of risk to be assumed by the institution, resources available for fall prevention programs, and so forth. Full instructions for determining level of risk ("cut-off scores") have been published (Morse, 1986, 1997), as have the distribution of scores for several types of patient populations.

(2) In her study, McCollam (1995) did not use the MFS scale according to instructions. For determination of high risk she selected a score of 55. This score is *off the scale* according to any of the published data and any published instructions regarding the calibration and use of the MFS. This is a serious concern, for both research replication and patient safety. Following the publication of her results, I requested that McCollam rerun her data according to published guidelines and republish, but she did not respond and has not, to my knowledge, corrected her analysis.

(3) Researchers continue to ignore the fact that there are *different causes* of patient falls (see Morse, Tylko, & Dixon, 1987). The MFS predicts *anticipated physiological falls* (i.e., 90.1% of falls in my study). The MFS cannot predict *accidental falls* or *unanticipated physiological falls*.

Therefore, the predictive ability of the MFS scale will never be 100%. In order to determine "success," fall programs must analyze their results according to this classification scheme.

I remain puzzled that, given the interesting predictive ability of the MFS and the reliability and validity data available for the scale, researchers waste their time on retrospective studies. Stevenson et al. (1998) are aware of and acknowledge these limitations. The MFS was developed from a controlled study using a large number of variables and multivariate and computer modelling. It has been extensively trialled and is quick and easy to use. All of the publications from this research program have now been brought together in a single volume written to the level of implementation for clinicians, so let us do just that: implement.

One other point. In their discussion, Stevenson et al. (1998) suggest that "misperceptions of functional ability" may be important. This factor is already included in the MFS (developed more than 13 years ago) as the means of measuring the variable *mental status*.

Please, let us do our homework before beginning a project, and let us calibrate assessment scales according to published instructions. We must evaluate the literature fairly, replicate responsibly, and spend our limited research energies and resources wisely.

Janice M. Morse  
University of Alberta

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GUEST EDITORIAL

## **Gerontological Nursing Research: Lessons in Clinical and Service Relevance**

**Dorothy M. Pringle**

Twenty-five years ago it was possible to count on one hand the number of nurse researchers in Canada investigating questions related to the health of older people, their care, or the well-being of their family caregivers. This field was not viewed as exciting or intellectually stimulating. How things have changed. Today, research on the elderly is one of the most dynamic research areas in nursing and, for that matter, in any health-science discipline. The clinical challenges that confront practising nurses in the field of elder care make wonderful research challenges as well.

These dual challenges are well represented in this issue of the journal. This issue also offers samples from the great range of research topics currently being explored by nurse researchers: clinical problems, behavioural problems, caregiver needs and services, and quality of life.

When I was examining the manuscripts to be published in this issue, four lessons struck me as particularly relevant.

The first lesson is the role of clinical judgement in the application of research findings. In this era of evidence-based practice — or at least exhortations to use evidence in practice — the role of clinical judgement in determining what evidence to use, and when and how to use it, has received little emphasis, in fact too little emphasis. At times, it seems, we think that having evidence is sufficient, that the application to practice is self-evident. Not so. Two articles make this point particularly well. Goodridge and colleagues report on a study evaluating the risk of pressure-ulcer development in older adults. The assessment used the Braden Scale, the gold standard for risk assessment, but these authors found that the Braden Scale identifies only the sub-population of patients at risk, not which patients will actually develop ulcers. The experienced clinical nurse must take the score on the Braden Scale and put it in the context of the individual patient, consider all the factors

that are likely to influence the risk, and decide which preventive actions must be taken. The article by Dorothy A. Forbes also demonstrates this point. Research is demonstrating that a range of interventions have the potential to reduce behavioural difficulties, but, in practice, it is the nurse who must use clinical judgement in deciding which intervention is likely to be effective for a particular patient.

The second lesson in this issue is the imperative for nurses to be experts in working with the cognitively impaired elderly. Forbes outlines the epidemiology of dementia and discusses Alzheimer's disease as one cause of this condition. Because we are aging as a society, the number of people who develop dementia will increase dramatically over the next decade. Not only will these people require assistance from family members in the early and middle stages of their illness, and from nurses in facilities for long-term care in the later stages, but nurses who work in acute-care hospitals, emergency rooms, and primary-care and ambulatory clinics will have to be experts in working with patients who are cognitively impaired and have a range of behavioural disturbances. People with cognitive impairment will require all types of health services during the long course of this terrible disease, and the nurses who care for them will have to be informed about the research findings that could affect their care. Pamela Dawson's Discourse contribution in this issue is reassuring: It demonstrates that clinical research programs are concentrating on ways of working with cognitively impaired people to support their level of functioning and reduce the stress they experience when they are unable to understand what is happening to them.

The third lesson involves knowing what services are needed by individuals with dementia and their family caregivers. The article by Pamela Hawranik is very instructive in this regard. She found that the cognitive status of recipients of home-care services was not predictive of their use of most services — homemaking, home-delivered meals, and, importantly, inhome nursing — but was predictive of their use of personal care. This is distressing news from two perspectives. Nurses have an enormous contribution to make to the care of cognitively impaired persons, through education of family members who provide ongoing care and through direct support to family caregivers. It is not an overstatement to say that home-care programs across Canada are not providing the assistance that family caregivers require and deserve.

Research in which I was involved almost a decade ago (Mohide et al., 1990) demonstrated the tremendous value that family caregivers attach to support by visiting nurses. Specially prepared nurses worked directly with caregivers and took direction from them as to what they



found helpful; in most home-care programs, in contrast, the primary role of nurses or other caregivers was simply to provide a service to the cognitively impaired individual, support to the caregiver being of secondary concern. The results of that 1990 study support what Hawranik points out in her article: When formal services are available, family caregivers do not abuse them by making excessive demands or withdrawing their assistance. Nurses should take a leadership role, by offering services that help family caregivers and by informing caregivers about available services and encouraging caregivers to use them.

An example of this type of service is described by Stewart and colleagues. Although their study focused on a service for caregivers of persons who had experienced stroke rather than cognitively impaired persons, it demonstrates the value of individual peer support for family caregivers. This innovative approach offers an alternative to the more widely researched peer-support group. This article provides other important lessons. It is difficult to conduct research demonstrating the value of a new service. Despite a huge recruitment effort, Stewart and colleagues could not find the numbers of caregivers at an early stage in their careers sufficient to meet many of the research objectives. This despite the fact that stroke accounts for an unbelievable 40% of inpatient hospital days. Why didn't the nurses of these patients inform their caregivers about the opportunity to participate in this research? We need many more studies of the effectiveness of new services for family caregivers. And we must find ways to get practising nurses to take a real interest in these studies by recruiting subjects for them, to ensure that the research is conducted with adequate sample sizes.

The fourth and last lesson I found in these articles relates to quality of life. The measurement of quality of life has already received some attention in this journal (Harrison, Juniper, & Mitchell-DiCenso, 1996). However, it is impossible to publish an issue devoted to gerontological nursing research without addressing quality of life, because quality of life has become the driving force behind the care of older people. As discussed by Dawson in the Discourse article, Mitchell and colleagues conducted a series of studies on the meaning of quality of life for persons living in facilities for long-term care. This is powerful research. It tells us what matters to people in circumstances very different from our own, and it provides direction for nurses in their day-to-day practice. In contrast, J. Ivan Williams contributes to the debate on *how to measure* quality of life. For all its limitations and challenges, measurement of quality of life is critical, particularly in evaluating the effectiveness of services and programs designed to improve the quality of life of elderly persons. A research challenge for years to come will be to deter-

mine when (time) and where (space) and how to capture change (motion) in the attributes of quality of life that qualitative research is uncovering.

Research in gerontological nursing is alive and well in Canada and internationally. The research is clinically relevant, and it addresses issues that are significant for nurses and the people in their care. The groundwork we are laying now will help us respond to demands that are bound to escalate dramatically over the next decade, as more Canadians reach a stage in their lives when they will need to rely on nurses to help them live meaningful and happy lives.

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COLLABORATION SPÉCIALE

## **Recherche en soins infirmiers gérontologiques : préceptes acquis sur la pertinence des interventions cliniques et des services**

**Dorothy M. Pringle**

Il y a vingt-cinq ans, nous pouvions compter sur les doigts d'une main le nombre d'infirmières et infirmiers chercheurs qui, au Canada, menaient des recherches sur les questions liées à la santé de personnes âgées, aux soins prodigués ou au bien-être des soignantes naturelles. Ce domaine n'était pas considéré comme palpitant ni stimulant sur le plan intellectuel. La situation a bien changé. Aujourd'hui, la recherche menée sur les personnes âgées constitue l'un des champs d'études les plus dynamiques de la profession, voir même des sciences de la santé. Les défis cliniques qui s'offrent au personnel infirmier praticien du domaine des soins aux aînés constituent également d'excellents défis de recherche.

Ce numéro de la revue illustre bien le double défi qui s'offre. On y présente également un grand éventail de sujets de recherche qui sont présentement explorés par les infirmières et infirmiers chercheurs : les problèmes cliniques, les problèmes de comportements, les besoins des soignantes naturelles et les services, ainsi que la qualité de vie.

En révisant les manuscrits qui devaient être publiés dans ce numéro, j'ai relevé quatre nouveaux préceptes qui me semblaient particulièrement pertinents.

Le premier de ces préceptes est la place du jugement clinique dans l'application des résultats de recherche. Dans un domaine qui s'appuie sur des preuves, lesquelles déterminent la pratique — du moins en principe — le rôle du jugement critique dans le choix des résultats qui seront utilisés, ainsi que le choix du moment et de la méthode d'utilisation sont des facteurs qui n'ont pas été assez relevés. Il semble qu'à certain moment, nous croyons que le fait de posséder des preuves est suffisant et que l'application va de soi. Tel n'est pas le cas. Deux articles

illustrent très bien ce point. Goodridge et ses collègues présentent une étude portant sur l'évaluation du risque d'ulcères de pression chez les adultes vieillissants. L'évaluation a été faite selon l'échelle de Braden, la norme par excellence pour évaluer les risques. Toutefois, les auteurs ont constaté que cette échelle n'identifie que la sous-population de patients à risque, et non les patients qui en sont vraiment atteints. L'infirmière et infirmier cliniques compétents doivent prendre la cote obtenue sur l'échelle Braden et la mettre en contexte en tenant compte du patient et de tous les facteurs influant sur le risque, pour ensuite décider des actions préventives à entreprendre. L'article de Dorothy A. Forbes illustre également ce point. La recherche démontre que l'application d'un éventail d'interventions entraîne une réduction potentielle des problèmes de comportement. Toutefois, dans la pratique, l'infirmière et infirmier doivent procéder à un jugement clinique pour décider du choix d'intervention qui s'avérera efficace pour un patient en particulier.

Le deuxième précepte qui ressort dans ce numéro est l'importance du fait que les infirmières et infirmiers doivent être des experts pour oeuvrer auprès des aînés qui affichent des troubles cognitifs. Forbes présente l'épidémiologie de la démence et traite de la maladie d'Alzheimer, laquelle est présentée comme l'une des causes de cette condition. Parce que nous vivons dans une société vieillissante, le nombre de personnes qui seront atteintes de démence augmentera de façon importante au cours de la prochaine décennie. Les personnes requerront de l'aide de la part des membres de leur famille au cours des phases primaires et secondaires de leur maladie, et de la part d'infirmières et infirmiers pour les soins prolongés en phases ultérieures. De plus, le personnel infirmier qui travaille dans les hôpitaux de soins actifs, dans les salles d'urgence et dans les cliniques de soins primaires et ambulatoires devront posséder une expertise pour travailler auprès de patients atteints de troubles cognitifs et d'un éventail de problèmes de comportement. Les personnes atteintes sur le plan cognitif nécessiteront une gamme de services de santé au cours de cette longue et terrible maladie, et le personnel infirmier soignant devra être mis au courant des résultats de recherche qui peuvent influencer sur la pratique de son travail. La contribution de Pamela Dawson, dans la rubrique « Discours » de ce numéro, est rassurante. Celle-ci démontre que les programmes de recherche clinique visent à trouver des façons d'intervenir auprès des personnes atteintes de troubles cognitifs pour renforcer leurs habiletés de fonctionnement et réduire le stress qu'elles peuvent éprouver lorsqu'elles sont dépassées par ce qui leur arrive.

Le troisième précepte est d'identifier, en matière de services, les besoins des individus souffrant de démence et ceux des soignantes naturelles. L'article de Pamela Hawranik est très révélateur à ce sujet. Selon ses conclusions, l'état cognitif de la clientèle bénéficiant de services de soins à domicile n'était pas un facteur à partir duquel on pouvait prédire l'utilisation de la plupart des services, soit les services d'entretien ménager, de repas et surtout de soins à domicile. Toutefois, ce facteur permettait de prédire leur utilisation des services de soins personnels. Ces résultats sont alarmants, sur deux plans. Le personnel infirmier doit jouer un rôle important dans les soins prodigués aux personnes atteintes de troubles cognitifs, notamment en effectuant un travail de conscientisation auprès des membres de la famille qui prodiguent des soins prolongés, ainsi qu'en fournissant un soutien direct aux soignantes naturelles. Il n'est nullement exagéré de dire qu'à travers le Canada, les programmes de soins à domicile ne satisfont pas les besoins des soignantes naturelles, qui méritent un appui.

Une recherche à laquelle j'ai participé il y a près d'une décennie (Mohide et al., 1990) démontrait la grande importance que revêtait la visite du personnel infirmier pour les soignantes naturelles. Des infirmières et infirmiers dotés d'une formation spéciale travaillaient directement avec les soignantes naturelles et ajustaient leurs interventions pour répondre aux besoins de celles-ci. Toutefois, dans la plupart des programmes de soins à domicile, le rôle principal du personnel infirmier ou d'autres intervenants était tout simplement d'administrer un service à la personne atteinte de troubles cognitifs. L'appui que nécessitait la soignante naturelle était secondaire. Les résultats de l'étude menée en 1990 soutiennent les arguments que présente Hawranik dans son article, à l'effet que les soignantes naturelles n'abusent pas des services officiels disponibles en effectuant des demandes excessives ou en retirant leur participation. Les infirmières et infirmiers doivent devenir des chefs de file en offrant des services qui apportent une aide aux soignantes naturelles, en plus de les informer sur les services disponibles et les encourager à les utiliser.

Un exemple de ces services est présenté par Stewart et ses collègues. Quoique leur étude se penchait spécifiquement sur les soignantes naturelles qui prodiguaient des soins à des personnes ayant vécu un accident cérébrovasculaire plutôt que des personnes atteintes de troubles cognitifs, celle-ci démontrait l'importance, pour les soignantes naturelles, du soutien individuel provenant des pairs. Cette approche innovatrice offre une alternative au groupe de soutien de pairs, lequel bénéficie d'une plus grande attention de la part des chercheurs et chercheuses. Il est plus difficile de mener des recherches

qui démontrent la valeur d'un nouveau service. Malgré d'importants efforts de recrutement, Stewart et ses collègues ne purent trouver, pour atteindre plusieurs de leurs objectifs, un nombre suffisant de soignantes qui étaient en début de « carrière », et cela malgré le fait que les victimes d'accidents cérébrovasculaires occupent 40 % du temps d'hospitalisation. Pourquoi les infirmières et infirmiers qui prenaient soin de ces patients n'ont-ils pas avisé les soignantes naturelles de la possibilité de participer à cette recherche? Nous avons besoin davantage de recherches sur l'efficacité des nouveaux services destinés aux soignantes naturelles. De plus, nous devons susciter un réel intérêt chez le personnel infirmier praticien quant à ces recherches en recrutant, pour lui, des sujets, ce qui assurerait un échantillonnage adéquat.

Le dernier précepte que j'ai relevé dans ces articles traite de la qualité de vie. La question de l'évaluation de la qualité de vie a déjà été abordée dans cette revue (Harrison, Juniper et Mitchell-DiCenso, 1996). Toutefois, nous ne pouvons consacrer un numéro à la recherche en soins infirmiers gériatologiques sans aborder la question de la qualité de vie, en raison du fait que ce facteur constitue maintenant le fondement même des soins aux personnes âgées. Dans la même veine que les propos présentés par Dawson à la rubrique « Discours », Mitchell et ses collègues ont mené une série d'études sur la définition du concept de qualité de vie auprès de personnes demeurant dans des institutions de soins prolongés. Cette recherche est riche en apprentissages. Elle nous révèle ce qui est important pour les personnes qui vivent dans un contexte très différent du nôtre et indique, au personnel infirmier, une voie dans sa pratique quotidienne. D'un tout autre point de vue, J. Ivan Williams contribue au débat sur la *manière de mesurer* la qualité de vie. Malgré toutes ses limites et ses défis, le mesurage d'une qualité de vie est vital, notamment pour évaluer l'efficacité des services et des programmes conçus pour améliorer la qualité de vie des personnes âgées. L'un des défis de recherche qui se présente dans les années à venir est de déterminer le « quand » (le temps) et le « où » (l'espace), ainsi que la façon de saisir les changements (le mouvement) dans les aspects qui caractérisent la qualité de vie, telle qu'identifiée par la recherche qualitative.

La recherche dans le domaine des soins infirmiers gériatologiques se porte très bien au Canada et à l'étranger. La recherche est pertinente sur le plan clinique, tout en abordant des questions qui sont d'importance pour le personnel infirmier, ainsi que pour les gens dont ils prennent soin. Le travail de fond que nous effectuons présentement nous permettra de répondre aux demandes qui ne peuvent que grandement s'accroître au cours de la prochaine décennie, puisque davantage de

Canadiennes et Canadiens atteindront une étape où ils devront s'appuyer sur les infirmières et infirmiers pour vivre une vie épanouissante et heureuse.

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# **Risk-Assessment Scores, Prevention Strategies, and the Incidence of Pressure Ulcers among the Elderly in Four Canadian Health-Care Facilities**

**Donna M. Goodridge, Jeff A. Sloan,  
Yvonne M. LeDoyen, Jo-Ann McKenzie,  
William E. Knight, and Michele Gayari**

Prévoir avec précision l'apparition des ulcères de pression (UP) chez les personnes âgées hospitalisées est une entreprise complexe. Une étude prospective, longitudinale, portant sur une cohorte de 330 patients âgés de plus de 65 ans dans deux hôpitaux d'enseignement de soins tertiaires et dans deux établissements de soins de longue durée du Canada, a porté sur les liens qui existent entre les résultats de l'évaluation des risques, les stratégies de prévention et l'incidence des UP. L'incidence globale des UP s'est établie à 9,7 %, la moitié des sujets ayant développé des UP pendant la première semaine d'hospitalisation. Le taux d'incidence chez les patients à risque s'est établi à 10,1 %, comparable au taux enregistré auprès des patients non à risque (9,3 %). Il se dégage un rapport entre le nombre de stratégies de prévention déployées d'une part et les résultats de l'évaluation des risques et l'apparition des UP d'autre part. Paradoxalement, le taux d'incidence augmente avec le nombre de stratégies de prévention mises en oeuvre. Le score total à l'échelle d'évaluation des risques qui semble être le plus sensible (69 %) et le plus spécifique (55 %) est 19. Quatre des six sous-échelles d'évaluation des risques ont un rapport avec l'apparition des UP. La modélisation de la régression logistique confirme les résultats à une variable voulant que le nombre de stratégies de prévention déployées est le meilleur facteur de prédiction de l'apparition d'ulcères de pression. Les données confirment qu'il est difficile de prédire si tel ou tel patient développera des ulcères de pression. Les résultats donnent à penser que l'utilisation d'une échelle d'évaluation des risques ne suffit pas à elle seule à prédire avec exactitude s'il y aura ou non des ulcères de pression. Le jugement clinique et l'expérience des infirmières s'imposent et complètent les instruments de mesure standards.

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The accurate prediction of pressure ulcer (PU) development among hospitalized elderly patients is a complex endeavour. A prospective, longitudinal, cohort study of 330 patients over age 65 in 2 Canadian tertiary-care teaching hospitals and 2 long-term-care facilities examined the association between risk-assessment scores, prevention strategies, and PU incidence. The overall PU incidence rate was 9.7%, with half of the subjects who developed a PU doing so in the first week of hospitalization. The incidence rate for "at risk" patients (10.1%) was similar to the rate for "not at risk" patients (9.3%). The number of prevention strategies used was related to risk-assessment scores and to PU development. Paradoxically, the incidence rate increased with the number of prevention strategies employed. The total risk-assessment score that appeared to have the best balance of sensitivity (69%) and specificity (55%) was 19. Four of the 6 risk-assessment subscales were associated with PU development. Logistic regression modelling confirmed the univariate results that the number of prevention strategies used was the best single predictor of PU development. The data confirm that predicting PU development for individual patients is difficult at best. Results suggest that use of a risk-assessment scale alone is not sufficient to accurately predict PU development. The clinical judgement and experience of nurses are required in providing supplementary information to standard measurement instruments.

## **Introduction**

Pressure ulcers (PU) are a significant clinical problem among hospitalized elderly patients, in spite of the fact that they are largely preventable. It is a high-volume, high-risk problem in many health-care settings and is often used as an indicator of quality of care (Frantz, 1997). Increasing in-patient acuity levels and the aging of the population have the potential to lead to an increased incidence of skin breakdown in hospitalized individuals (Harrison, Wells, Fisher, & Prince, 1996). Substantial resources are expended in efforts to prevent the development of PU. Myriad risk factors have been identified in the literature as contributing to the development of PU, but, unfortunately, conflicting evidence regarding precise delineation and articulation of the most relevant risk factors make identification somewhat problematic.

Accurate identification of the at-risk patient is an ongoing challenge. Practical constraints preclude the possibility of collecting all potential covariates in every patient. Nurses often independently assume responsibility for assessing patient risk for PU and implementing appropriate prevention strategies. Clinical practice guidelines from the Agency for Health Care Policy and Research (AHCPR) strongly promote the use of risk-assessment instruments, and strong support for the clinical use of these tools is indicated by the results of numerous studies (Bankert, Daughtridge, Meehan, & Colburn, 1996; Bergstrom & Braden, 1992; Foltz-Gray, 1997; Langemo et al., 1991). Accurate assess-



ment of PU risk will allow for the appropriate allocation of physical and human resources.

This paper reports on a cohort study that attempted to address these issues by investigating the association between PU incidence, prevention strategies, and risk-assessment scores in a geriatric in-patient population of four Canadian health-care facilities. The findings are part of a larger study examining prevention strategies and treatment trajectory related to PU (Goodridge, LeDoyen, Sloan, McKenzie, & Knight, 1997). Specific research questions investigated for this manuscript were: (1) *Can risk-assessment scores alone accurately predict the development of PU in older adults?* (2) *Can prevention strategies alter the risk, and therefore the ultimate incidence rate, of PU?*

### **Review of the Literature**

Predicting the development of PU in an individual patient presents a daunting challenge (Bergstrom & Braden, 1992; Burd, Langemo, & Olson, 1992; Harrison et al., 1996; Norton, 1996). A number of studies have identified the factors associated with PU development. It is a different and more difficult matter, however, to collate these risk factors into a practical prognostic index capable of predicting individual patient illness trajectory and identifying which patients will develop PU.

The evidence supporting the contribution of specific risk factors in PU is inconclusive. Age was initially identified as an important risk factor by Bergstrom and Braden (1992) and Spector, Kapp, Tucker, and Sternberg (1988), but was found not to be significant in a large epidemiological study by Brandeis, Ooi, Hossain, Morris, and Lipsitz (1994). Male gender has been implicated as a risk factor in some studies (Brandeis et al., 1994; Spector et al.), but not in others (Guralnik, Harris, White, & Coroni-Huntley, 1988; Smith, Winsemius, & Besdine, 1991; Verdery & Mittlemark, 1990). Maklebust and Magnan (1994), in a study with 2,189 patients, examined a series of risk factors: fecal incontinence, urinary incontinence, malnutrition, impaired mobility, decreased mental status, diabetes mellitus, peripheral vascular disease, spinal cord injury, multiple sclerosis, and metastatic carcinoma. Fecal incontinence was associated with a 22-fold increase in PU and was the second most frequently occurring risk factor. Stepwise logistic regression resulted in a model that included fecal incontinence, impaired mobility, malnutrition, decreased mental status, and an interaction effect between fecal incontinence and impaired mobility. Patients with both fecal inconti-

nence and impaired mobility were 37.5 times more likely to develop PU than patients with neither.

Increasingly sophisticated analyses of large data sets have produced alternative models of PU development specific to various populations. Brandeis, Berlowitz, Hossain, and Morris (1995), using data on 2,011 patients in 270 nursing homes across 10 American states, determined that dependence in transfer or mobility, being bedfast, having diabetes mellitus, and having had a PU in the past were the only factors significantly associated with the development of Stage 2–4 ulcers.

To date, impressive work in this area has included the development of prognostic indices such as the Braden and Norton scales (Harrison et al., 1996; Norton, 1996). These assessment instruments are easy to use and represent minimal clinical intervention. They take a subset of the factors known or widely believed to be involved in PU development and assign the patient numeric scores for presence of risk (Buhrer & Mitchell, 1996). A summative risk score serves as a basis for prediction and prescription of prevention strategies. Clinical use of these risk-assessment instruments is recommended in the AHCPR guidelines (Panel on the Prediction and Prevention of Pressure Ulcers in Adults, 1992).

The Braden risk-assessment tool is widely identified as one of the leading instruments prognostic for PU development (Harrison et al., 1996). It identifies six variables traditionally associated with PU development: sensory perception, moisture, activity, mobility, nutrition, and friction and shear (Bergstrom, Braden, Laguzza, & Holman, 1987). Each variable is rated from 0 to 3 or 4, for a possible total of 23 points, with higher scores indicating low risk. The predictive ability of the Braden Scale has been examined in a number of studies via alternative approaches, with varying results. Sensitivity (the percentage of persons correctly predicted to develop PU) and specificity (the percentage correctly predicted to not develop PU) have varied substantially among studies. Sensitivity has been reported from as low as 40% and 53% (Oot-Giromini, 1993; Salvadalena, Snyder, & Brogdon, 1992) to as high as 100% (Bergstrom, Braden, et al., 1987). A number of studies found more moderate sensitivities, ranging from 67% to 83% (Barnes & Payton, 1993; Bergstrom, Demuth, & Braden, 1987; Braden & Bergstrom, 1994; Capobianco & McDonald, 1996; Harrison et al.) using cut-off scores of 16 or 18. Reported specificity has ranged from 50–59% (Braden & Bergstrom; Oot-Giromini) to 91% (Barnes & Payton). The variation in sensitivity and specificity appears to be due, in part, to the different risk

cut-off points and populations studied. The majority of the cited studies used sample sizes of 60–100.

The quality or type of care provided by a particular agency may also influence the relative significance of individual risk factors, rendering a standardized tool for PU development ineffective across multiple settings. Brandeis et al. (1994), in reviewing data on more than 4,232 nursing-home patients, found differences in the variables associated with PU development in high-incidence (19.3%) and low-incidence (6.5%) nursing homes. In high-incidence homes, fecal incontinence and diabetes mellitus were significantly related to the development of PU. In low-incidence homes, in contrast, risk factors included male gender but not fecal incontinence or diabetes mellitus. In both settings, difficulties with ambulation and self-feeding were significant factors. Age, BMI, transfer ADL, and facility size were not significantly associated with the incidence of PU in either group. These authors suggest that there may be an unknown or unmeasured facility effect on the risk for PU development in addition to the characteristics of a given resident in a particular home. These results corroborate the findings of Rudman, Mattson, Alverno, Richardson, and Rudman (1993), who compared clinical indicators in two nursing homes. Residents of one nursing home were significantly less likely to develop PU than those of the other. The authors attribute the difference to exogenous (environmental and quality-of-care) causes such as higher staffing and greater expenditures on clinical care.

A danger inherent in using risk-assessment scales is oversimplification of a very complex set of interacting factors that produce ulcers in some patients but not in others. A qualitative study conducted with nurses expert in the prevention of PU (Buhrer & Mitchell, 1996) demonstrated the complexity of parameters that expert nurses take into account when determining risk. The nurses included such factors as particular medical conditions (chronic illness, local and systemic infection, respiratory diseases, diabetes), age, serum albumin, and hypotension in their judgement regarding the patient's risk status. They likewise gave preferential consideration to nutrition and activity/mobility as critical elements. While formalized risk-assessment tools often emphasize levels of consciousness, the expert nurses tended to focus on mood, motivation, and social support as key factors in risk status. There remain many unanswered questions about the association between risk-assessment scales and PU prevention strategies.

## Methods

### *Subjects and Settings*

For this prospective, single-arm, longitudinal, observational study, a convenience sample of 330 patients was drawn from patients 65 years of age and older consecutively admitted, within the preceding 48–96 hours, to the medical and geriatric units of two tertiary-care hospitals ( $n = 222$ ) and two long-term-care facilities ( $n = 108$ ) in a large western Canadian city. Exclusion criteria were: pre-existing dermal ulcers, the terminal stages of cancer, and acute or chronic renal failure.

### *Procedures*

Ethical approval was received from the Faculty of Nursing, University of Manitoba, and access approval was received from each of the participating facilities. Research assistants were given both didactic and clinical training in the use of the Braden Scale and the use of demographic, prevention-strategy, and other research instruments. Several meetings were held with staff nurses and the head nurse of each participating unit to inform them of the study protocol.

Potential subjects were identified through daily contact with the head nurse of each participating unit to determine whether eligible patients had been admitted. Patients were given a brief written disclaimer by the research assistant. The disclaimer stated that a project on skin care was being conducted, that data would be gathered from the health record only, and that confidentiality and consistency of care were guaranteed.

If the patient agreed to participate, the research assistant gathered data from the health record within 48–96 hours of admission, employing demographic, medical, risk-assessment (Braden Scale), and prevention-strategy data-collection instruments that had been pilot-tested by the investigators to ensure validity and interrater reliability.

Data were collected bi-weekly for a period of 3 months or until the patient was discharged or transferred from the participating unit, in order to assess the accuracy of the risk-assessment method prospectively. The data were gathered from a health-record review and verified clinically by the nurse who provided care to the subject on the day of collection. The data included medical, demographic, prevention-strategy, and Braden Scale information. Nurses were kept blinded to the Braden Scale information to avoid the possibility of Hawthorne effect. Medical and demographic data included age, medical diagnoses, labo-

ratory values (WBC, hemoglobin, albumin, zinc), height, weight, and medications. Prevention strategies included turning schedule, ambulation schedule, range-of-motion exercises, assistive positioning/moving devices, protective padding, seating assessments, pressure-reducing mattress, pressure-relieving mattress, use of emollients/lubricants/barriers, incontinence management, nutrition management, and patient/family teaching. While many of these strategies serve other purposes in addition to PU prevention, it was considered important to include them as prevention strategies.

Research assistants monitored the subjects for PU. In the case of patients who developed an ulcer, the skin was evaluated a second time after 20 minutes had elapsed to confirm the initial indication. The research nurse at each institution verified the findings of the research assistant; there was 100% agreement between the research nurses and research assistants in terms of PU identification and assessment. Written consent was obtained to continue with the second phase of the study. The research assistants arranged to be present during regularly scheduled dressing changes on a weekly basis in order to visually assess the wound. They continued to collect medical and prevention-strategy data for subjects with PU.

### *Statistical Methods*

Data were analyzed by the research team in collaboration with the Health Services Research Division of the Mayo Clinic in Rochester, Minnesota. Descriptive statistics were used to summarize the incidence of PU and related patient characteristics. Hypothesized differences in subjects with PU and without PU were tested using a variety of parametric and non-parametric tests appropriate for the level of data under consideration. These are detailed under Results. Comparisonwise type I error rates were set at 5%. The sample of 330 provides 80% power to detect small-effect sizes across most subsets, so statistical significance must be interpreted along with a consideration for clinical relevance. For example, comparing the average of two groups of 165 patients on any continuous variable would provide 80% power to detect a small-effect-size difference of 0.33 standard deviations (Cohen, 1988). Sensitivity, specificity, positive and negative predictive values, and performance of the Braden Scale were calculated.

Larson (1986) defines the various parameters typically used to evaluate screening tests such as the Braden Scale. Sensitivity refers to the extent to which a true characteristic is classified correctly (rate of true positives), while specificity indicates the extent to which the absence of



a characteristic is classified correctly (rate of true negatives). A highly sensitive test will identify the majority of individuals who have a given disease or characteristic; a highly specific test will correctly identify individuals who are free of a given characteristic. Both parameters are necessary for a measure of validity. The test that is chosen must provide the best balance between sensitivity and specificity. Since sensitivity and specificity are inversely related, increasing the sensitivity of a test by lowering the point at which it is considered positive (the cut-off point) decreases its specificity.

The predictive value of a positive test is the probability that when it is positive the characteristic is truly present; in other words, those who test positive are the proportion who have the condition. The predictive value of a negative test is the probability that when it is negative the characteristic is truly absent; those who test negative are the proportion who do not have the condition.

Simple correlation measures (Pearson's *r*, Spearman's *rho*) were used to assess the relationship between the Braden score and associated covariates such as age and number of prevention strategies used. A sample of 330 observations provides 80% power to detect a true correlation of 0.16 with a 5% type I error rate and one-sided testing (Cohen, 1988).

Logistic regression modelling procedures were used to examine the relative prognostic value of selected sociodemographic and clinical variables for predicting PU development in individual patients. Variables were selected by univariate associative testing involving Fisher's exact test for categorical predictors (e.g., gender) and Wilcoxon procedures for continuous variables (e.g., age). The dependent variable was the presence or absence of PU for each patient.

## Results

Subjects ranged in age from 65 to 101 years ( $\bar{x} = 78.6$ ,  $SD = 8.53$ ). The average number of medical diagnoses was 5.86 ( $SD = 2.47$ ), the most common diagnoses being cardiac disease (55.9%), arthritis (25.6%), and fractures (23.5%). Mean WBC was 13.9 and hemoglobin 126.2 was g/dl. The most frequently prescribed medications were non-narcotic analgesics and laxatives.

Comparisons of average scores of the 298 patients who did not develop PU and the 32 who did develop PU have 80% power to detect a moderate-effect size of 0.5 standard deviations (Cohen, 1988). A total of 1,251 observations was obtained for the 330 patients. Subjects were



assessed an average of eight times (over 2 months), with a range of 2–14 observations per subject. Only two subjects were assessed for less than 1 month.

### *Pressure Ulcer Development*

Of the 330 subjects, 32 (9.7%) developed a total of 62 ulcers within 3 months of admission. Most of these (73.8%) had only one ulcer, 11.9% had two ulcers, and 14.4% had three or more ulcers. Of the 32 subjects who developed PU, 23 were acute-care patients and nine were long-term-care patients. The incidence rate of 10% (95% C.I. of 6.7%, 13.5%) was not significantly different for the two settings. By the end of the first week of hospitalization, 15 subjects had developed ulcers. By the end of the first month, 75% of all ulcers had developed. The mean number of days in which subjects developed an ulcer was 18.5 ( $SD = 21.27$ ). The sacrum/coccyx was the most frequent site of PU, at 27%. The heel was the next most frequent site, at 20.3%. More than half (57.1%) of the total ulcers were Stage 1, while 31% were Stage 2. Stages 3 and 4 ulcers each accounted for 4.8% of the total ulcers in the sample.

Subjects with PU did not weigh significantly less (58.99 kg) than subjects without PU (66.83 kg) (two-sample  $t$  test  $p = 0.09$ ). Subjects with PU did have a significantly greater number of medical diagnoses (6.2) than subjects without PU (5.4) (two-sample  $t$  test  $p = 0.01$ ).

### *Braden Scale Risk Assessment*

For the sample, the mean Braden score on admission was 18.0 ( $SD = 2.75$ ) with a range of 6–24. For those who developed PU, the mean Braden score on admission was 18.0 ( $SD = 2.75$ ) with a range of 6–24. The average Braden score on admission for those who developed PU (mean = 17.5, median = 18) was roughly one point lower than that for patients who did not ultimately develop PU (mean = 18.8, median = 19, Wilcoxon  $p$  value = 0.002). According to the Braden Scale, on admission 172 subjects (52.1%) were assessed as *no risk* ( $\geq 19$ ), while 107 (32.5%) were assessed as *low risk* (16–18) and 39 (11.8%) as *moderate risk*. Only 12 (3.6%) were assessed as *high risk* ( $< 12$ ). Of the *high risk* subjects, nine were from acute-care facilities. Significantly more long-term-care than acute-care patients were classified as *at risk* (chi squared = 10.09,  $df = 1$ ,  $p < .001$ ), although the prevalence rate of PU was marginally lower in the long-term-care setting.

The incidence of PU development was very similar for *at risk* ( $< 19$ ) and *not at risk* ( $\geq 19$ ) patients (Table 1). Furthermore, although a greater

proportion of long-term-care patients were classified as *at risk*, the incidence of PU was similar for the two groups. While 10.1% of the *at risk* subjects went on to develop an ulcer, a similar proportion (9.3%) of the *not at risk* subjects also developed PU. Only 50% of subjects who developed PU had a Braden score indicative of increased risk. Of the 158 subjects with a Braden score less than 19 (*at risk*), 16 (10.12%) went on to develop PU. One might speculate that the prevention strategies instituted at the point of care were thus effective for the majority of subjects. The degree of risk, however, was not associated with frequency of PU. Four (25%) of the 12 *high risk* subjects developed PU, while four (10%) of the *moderate risk* group and eight (7.5%) of the *low risk* group likewise developed PU. Of the 172 subjects classified as *not at risk* (Braden score >18), 16 (9.3%) developed an ulcer (Table 1). The stage distribution for development of PU was the same for *at risk* and *not at risk* patients.

<b>Table 1</b> <i>PU Incidence Rate Classified by Braden Score Risk Status</i>		
<b>Risk Status</b>	<b>Proportion of Subjects (N = 330)</b>	<b>Proportion of Subjects with PU (N = 32)</b>
Not at risk (Braden Score >18)	172 (52%)	16 (50%)
Low risk (Braden Score 16–18)	107 (33%)	8 (25%)
Moderate risk (Braden Score 12–16)	39 (12%)	4 (25%)
High risk (Braden Score <12)	12 (4%)	4 (25%)
Overall	330	32 (10%)

The average Braden score immediately prior to development of PU (17.42) was typically lower by about two points than the scores of subjects without PU (19.33) (two-sample *t* test  $p<0.0001$ ). There was no change in Braden scores for individual patients over the duration of the study from baseline measurements. The score did not change significantly when the PU appeared. The Braden scores of very few subjects dropped immediately preceding PU appearance to indicate increased risk.

Table 2 illustrates the differences in mean Braden score for patients with and without PU at the four sites, using standard one-way ANOVA

testing. In both acute-care facilities, subjects with PU had significantly lower Braden scores ( $\bar{x} = 18.1$ ) than subjects without PU ( $\bar{x} = 19.9$ ). In the long-term-care facilities, there was no significant difference in scores for subjects with and without PU; the mean Braden score was actually higher for subjects with PU (18.4) than for subjects without PU (18.1).

**Table 2** *Mean Braden Scores for Subjects With and Without PU*

	Mean Braden Score (298 Subjects Without PU)	Mean Braden Score (32 Subjects With PU)	One-way ANOVA F-test <i>p</i> value
Acute Care A	20.4	18.9	0.001
Acute Care B	19.5	17.4	0.01
Long-Term Care A	18.1	17.4	0.64
Long-Term Care B	18.2	19.4	0.27

### *Braden Subscale Items*

The Braden subscale items of sensory perception, nutrition, and moisture were not problematic for this sample. In 70.2% of subjects, sensory perception was unimpaired. More than three quarters of the sample (83.7%) were rated as having either excellent or adequate nutrition. However, 69.0% were assessed as having problems with moisture. In contrast, only 38.2% of subjects were free of mobility limitations and only 18.1% walked frequently. Long-term-care subjects were significantly more impaired than acute-care subjects in terms of mobility and activity (chi squared  $p < .001$ ). Almost half (47.2%) of the subjects experienced no apparent problem with friction and shear, although in 43.9% of cases a potential problem was noted.

Differences in factors associated with increased risk for the acute-care subjects were examined via Wilcoxon rank sum testing (Table 3). Nutrition and activity scores were similar for the two groups, but comparison of the remaining Braden subscale scores demonstrated that the long-term-care subjects were more impaired in sensory perception, moisture, mobility, and friction/shear. However, the differences were once again small in terms of clinical significance. The sample size had sufficient power to detect small differences, so that even though statistical significance was observed the differentials were quite small and perhaps clinically insignificant.

**Table 3** *Braden Subscale Means in Acute Versus Long-Term Care*

	Acute Care ( <i>n</i> = 232)	Long-Term Care ( <i>n</i> = 108)	<i>p</i> value
Sensory Perception	3.9	3.5	<0.0001
Moisture	3.7	3.4	<0.005
Activity	2.9	3.0	0.23
Mobility	3.9	3.0	<0.0001
Nutrition	3.0	3.0	0.38
Friction/Shear	2.6	2.2	<0.0001

Table 4 presents the differences between subjects with and without PU in terms of Braden subscale means. Four of the six Braden subscale means (nutrition, activity, mobility, and friction/shear) were statistically associated with PU development, while no relationship with incidence was demonstrated for sensory perception and moisture. Again, the sample size allowed for detection of all but the smallest of differences, so statistical significance should be interpreted with caution.

**Table 4** *Relationship of Braden Scale Items to PU Development*

	Mean (Subjects Without PU) ( <i>n</i> = 298)	Mean (Subjects With PU) ( <i>n</i> = 32)	Wilcoxon rank sum <i>p</i> value
Nutrition	2.9	2.4	0.0003
Sensory Perception	3.7	3.6	0.61
Moisture	3.6	3.4	0.13
Activity	2.8	2.3	0.0001
Mobility	3.4	2.9	0.0003
Friction/Shear	2.4	2.0	0.0003

#### *Sensitivity and Specificity of the Braden Score for PU Development*

Only half of the 32 subjects with PU had Braden scores indicative of increased risk. Sensitivity, specificity, and positive and negative predictive values of the Braden Scale in predicting all stages of PU were infe-

rior to that previously reported (Table 5). Overall sensitivity in this sample using the recommended cut-off of 16 was 22%, while specificity was 86%. The positive predictive value of the Braden Scale using the recommended cut-off was 15%, while the negative predictive value was 91%. Table 5 provides these predictive values at various Braden scores. The Braden score found to have the best balance of sensitivity (69%) and specificity (55%) was a cut-off of 19, although even this cut-off provided relatively weak performance characteristics for predicting PU in individual patients.

**Table 5** *Sensitivity and Specificity of the Braden Scale for Varying PU Risk Cut-Off Values*

Braden Score PU Risk Cut-off	Sensitivity (%)	Specificity (%)	Positive Predictive Value (%)	Negative Predictive Value (%)
20	81	46	14	96
19	69	55	14	94
18	47	68	14	92
17	38	80	17	92
16	22	86	15	91
15	9	91	10	90
14	9	94	15	91
13	9	97	23	91
12	9	98	22	91
11	0	98	0	90

### **Prevention Strategies**

An average of 3.3 PU prevention strategies were used for patients classified as *no risk*, while significantly (*t* test,  $p < .001$ ) more strategies (6.4) were used for patients with scores of  $< 19$  on the Braden Scale (up to a maximum of 11 strategies per subject). The number of prevention strategies used was correlated (Pearson  $r = -.596$ ,  $p < .001$ ) to Braden scores. Patients with a minimum Braden score indicating *risk* for PU development ( $\geq 19$ ) averaged twice as many prevention strategies as patients *not at risk* (4.0 versus 2.0, respectively, Wilcoxon  $p$  value  $< 0.0001$ ). The mean number of prevention strategies per subject increased by approximately one, from 5.2 to 6.3, following the development of an ulcer.



The number of prevention strategies used tended to be greater for older patients ( $r = .24$ ,  $p < .001$ ). Patients aged 75 or older had slightly more prevention strategies (2.7) than patients under age 75 (2.2) (Wilcoxon  $p$  value = 0.01). The number of prevention strategies used was comparable across genders (Wilcoxon  $p$  value = 0.49).

Prevention strategies were ranked in order of frequency of use. Those most frequently documented were (in descending order): use of a pressure-reduction mattress, use of a barrier cream, diapering, and use of a walker. Frequencies were the same regardless of whether the patient's Braden score indicated risk or whether the patient had a ulcer. A turning schedule was documented for only 38.6% of the *at risk* subjects. Patient and family teaching regarding PU was documented in only 4.4% of cases. A greater number of prevention strategies per subject was documented in the long-term-care settings ( $\bar{x} = 3.7$ ) than in the acute-care settings ( $\bar{x} = 2.7$ ).

A logistic regression modelling process was undertaken to examine the prognostic power of the collected variables for predicting PU in individual patients. From the above-reported univariate analyses, the variables recording the patient's age and total number of prevention strategies used prior to PU observation would seem to be useful supplements for the minimum Braden score in predicting which patients would develop PU. The Braden score at admission was also included, as suggested in the literature. The modelling results are not sufficient for practical purposes, because 90% of the subjects did not have PU. No model produced predicted more than 75% of the cases. Hence, if we just assumed no patients would develop PU we would be correct more often than any of the models constructed empirically. The knowledge derived from this modelling process was therefore used to produce a relative ranking of association of the variables with PU development. Models were run both with and without the gender variable, as the literature suggests that gender may be an important covariate. In none of the models did gender appear to be a useful prognostic factor for PU development. Stepwise modelling resulted in a model that incorporated only the total number of prevention strategies used prior to PU appearance as a prognostic factor for PU development. The odds ratio of PU development was 1.35 per prevention strategy used (chi square  $p$  value = 0.0005). This result supports our contention that the prevention strategies were used more as a prophylactic measure than as a reaction to PU development. None of the other variables (minimum Braden score, Braden score at admission, age) contributed significantly to the predictive power of the model, which correctly predicted 75% of the cases. A saturated model was subsequently used to force the entry of all vari-



ables into the model. The saturated model estimate for the effect of the number of prevention strategies remained unchanged and produced a lower correct prediction percentage. Hence the Braden score and age collectively had lower predictive power for PU than the number of prevention strategies implemented. If the number of strategies used was removed from the model, both age and Braden score became useful predictors. This model correctly predicted only 68% of the cases. The Braden score upon admission added no prognostic value to the modeling process.

### **Discussion**

The incidence of PU (9.7%) in the present study is comparable to that reported for other studies. Overall incidence rates among various sites range from 9.0% to 12.0% (Bergstrom, Braden, Kemp, Champagne, & Ruby, 1996; Langemo et al., 1991). The acute-medicine and geriatric units of the tertiary-care facilities in this study had an incidence of 10.36%, while the long-term-care settings had an incidence of 8.0%. Tertiary-care incidence rates range from 7.4% to 15.0% (Bergstrom et al., 1996; Langemo et al.), while rates in skilled-care facilities and nursing homes are reported to be between 3.4% and 28% (Bergstrom et al., 1996; Langemo et al.; Leshem & Skelskey, 1994).

Thirty-two subjects developed a total of 62 ulcers within 3 months of admission. By the end of the first week, almost half of all subjects who would eventually develop PU had done so, making this first week of hospitalization an especially critical period for both skin assessment and implementation of prevention and treatment measures. Three quarters of the ulcers that were present over the 3-month data-collection period had developed by the end of the fourth week. The time frames for PU development suggested by the present study are somewhat different from those reported by Bergstrom and Braden (1992) and Langemo et al. (1991), who found that 77–80% of subjects developed ulcers within 2 weeks of admission. In the study by Bergstrom and Braden, 92% of the ulcers had developed by the third week.

In terms of ulcer characteristics, our findings are consistent with the ranking of the most common PU sites reported in a recent national prevalence study with 39,874 patients (Barczak, Barnett, Childs, & Bosley, 1997). Sacral ulcers comprised 39% of the total ulcers reported for that study, followed by heel ulcers at 28%. In their study, Bergstrom et al. (1996) found that sacral/coccygeal PU comprised almost 60% of ulcers. More than half (57%) of the ulcers detected in the present study were classified as Stage 1. This is a higher proportion than the previ-

ously reported range of 29.8% to 38% (Barczak et al.; Bergstrom et al., 1996; Maklebust & Magnan, 1994). Stage 2 ulcers were the next most common, at 30%, while stages 3 and 4 accounted for only 4.8% each. The incidence of Stage 2 ulcers in the present study was markedly lower than the 67.3% reported by Bergstrom et al. (1996) but was similar to the 37.5% reported by Maklebust and Magnan and the 39% reported by Barczak et al. The remaining 10% of ulcers in the present study were classified as stages 3 and 4, falling within the range of the 0% reported by Bergstrom et al. (1996) and the 17% cited in the national prevalence study.

Nine of the 12 subjects categorized as *high risk* were acute-care patients. However, a significantly higher proportion of *moderate* and *low risk* subjects, and fewer *no risk* subjects, were in long-term care than in acute care. This finding may reflect the relative stabilization in health status that has occurred by the time a patient enters a long-term-care facility.

Our results support the use of risk-assessment instruments such as the Braden Scale in differentiating between groups of patients in terms of indicating PU development. We found that patients who developed PU did have a lower average risk-assessment score, and the scores did dip slightly just before the PU appeared. The collective average Braden score immediately prior to PU development was almost two points lower on average than the scores of patients who did not develop ulcers. A similar difference in scores is reported by Bergstrom and Braden (1992): mean score of 16.3 for subjects without PU; between 14.1 and 14.5 for subjects with PU.

However, the risk-assessment scores were not successfully prognostic in predicting ulcer development in individual patients. Only half of the patients classified as *at risk* actually developed PU. The scores of the individual subjects changed only very minimally over time, and, furthermore, did not change when a PU developed. These findings suggest that risk-assessment scales alone may not be sensitive to the changes in status that can predispose a patient to an ulcer. Collectively, our results produce an answer for research question #1, indicating that it is not reasonable to expect a simple risk-assessment score to accurately predict PU in individual patients. Risk-assessment scores, then, would seem to have an associative rather than a prognostic role in PU. As such, they can be useful in the context of a comprehensive prevention strategy, in identifying patient subpopulations that may be at greater risk for PU.

In the acute-care setting the mean Braden scores were significantly lower for subjects with PU ( $\bar{x} = 18.1$ ) than without PU ( $\bar{x} = 20.0$ ). This difference disappeared, however, in the long-term-care setting, where the mean Braden scores were actually marginally higher for subjects with PU ( $\bar{x} = 18.41$ ) than without PU ( $\bar{x} = 18.13$ ). It may be that an exogenous variable was especially significant in the development of ulcers in the long-term-care population.

In terms of the relationship of subscale means to PU development, four of the Braden subscales (nutrition, activity, mobility, and friction/shear) were associated with PU development, although the magnitude of the differences was of questionable clinical value. The sensory perception and moisture subscales did not demonstrate an association with PU development. This may reflect the fact that only one third of the sample were impaired in either risk factor, although it seems more likely that these findings support the possibility that models of PU development containing alternative variables are better predictors (Brandeis et al., 1994, 1995; Maklebust & Magnan, 1994; Rudman et al., 1993).

In the current study, the total Braden score that appeared to have the best balance of sensitivity (69%) and specificity (55%) was 19. These results are somewhat lower than but comparable to those of Harrison et al. (1996) and Salvadalena et al. (1992). Langemo et al. (1991) reported that optimal sensitivity (64%) and specificity (87%) were attained at a score of 15 for acute-care settings. For the current study, sensitivity was 9% with a specificity of 91% at a score of 15. This is an unacceptably low rate of accuracy in predicting PU, with the results of the current study being less favourable than those of previous studies using the Braden Scale (Bergstrom, Braden, et al., 1987; Bergstrom, Demuth, et al., 1987; Capobianco & McDonald, 1996).

Harrison et al. (1996) identify a number of factors that could account to some extent for the poor sensitivity and specificity of risk-assessment scores in their study: a large range of patient ages, diagnoses, and severity of condition; cross-sectional design; and varying levels of nursing care and staff between units ranging from critical to long-term care. Similar issues arise in the current study with respect to range of diagnoses, severity, and varying levels of nursing care, but not for age or cross-sectional design. Any of these issues may have contributed to the results. It may, however, be simply an unreasonable expectation for a simple single associative index to have substantial prognostic power.

Capobianco and McDonald (1996) found that the Braden Scale failed to identify four of 14 patients who developed ulcers. They suggest that patients with poor nutrition may be missed by the Braden Scale. In the present study, only three of the 15 subjects who developed ulcers were considered to have poor nutrition, so the poor sensitivity and specificity of the Braden Scale cannot be attributed solely to problems with the nutrition subscale.

In the present study, patients who were *at risk* according to the Braden Scale were found to have significantly more prevention strategies in place than patients who were *not at risk*. In fact, the number of preventive strategies increased upon appearance of the ulcer; this might indicate that the prevention strategies were sometimes used in reaction to the development of PU rather than as a prophylactic measure. It may be that prevention strategies were used to prevent secondary ulcer development, and that these strategies were highly effective in this group, thus possibly accounting for the low sensitivity of the Braden Scale in accurately predicting PU. However, it is difficult to account for the *not at risk* subjects developing ulcers other than by suggesting that fewer prevention strategies were in place for *not at risk* than for *at risk* subjects. This type of reasoning tends to become circular and is not helpful in the clinical setting. The reality is that in terms of our second research question the use of prevention strategies is related to PU incidence rates, although the directionality of the relationship in the clinical settings studied is in question.

A limitation of the study may be the reliance upon staff nurses' identification of new ulcers, particularly Stage 1 ulcers. However, as more than half of the ulcers identified were Stage 1, this does not represent a large concern.

Another limitation relates to interrater reliability testing. Interrater reliability between the three research assistants was not formally assessed, but the 10 patient assessments of each research assistant were reviewed and approved by an expert nurse (YL) prior to data collection.

A further limitation is the lack of availability for some of the potentially concomitant confounding influences. The prevalence of protein-calorie malnutrition is as high as 50% in some health-care settings (Strauss & Margolis, 1996), yet albumin levels (a valuable gauge of nutritional status) were not ordered for the vast majority of patients in this study. Strauss and Margolis note that in multiple cross-sectional and longitudinal studies demonstrating that malnourished people are at greater risk for PU, zinc levels were absent for all subjects. Albumin levels were absent in 88.2% of cases, but the average for available sub-

jects was 32.3 g/l ( $N = 33.45$  g/l). Data on height and weight were not present in the health-care record for half of the subjects. While these data represent potential sources of bias, and while they may have been helpful in building a more comprehensive prognostic model for PU development, there is no evidence to suggest that their inclusion would have altered the basic findings.

A brief comment on the choice of assessment tool is in order to clarify our purpose in this study. It was our goal to examine the degree to which a risk-assessment tool, in concert with prevention strategies and associated demographics, could predict PU. We chose the Braden Scale because it is recognized as one of the best instruments available for PU risk assessment. The primary point to be made here is that our findings indicate the need for a comprehensive approach to predicting PU rather than relying on a simple single index. It is doubtful that our results would be different had we used any other risk-assessment tool. The data indicate the context within which risk-assessment tools such as the Braden Scale can be applied to aid in PU prevention. The results are not an indictment of the Braden Scale, nor do the data suggest that the tool itself is flawed in any way. As per the AHCPR guidelines, the data indicate that risk-assessment tools are an important *part* of a prevention program but cannot stand alone in predicting PU in individual patients.

### **Conclusions**

Accurate prediction of PU is a highly complex endeavour. This conclusion was borne out strongly by our data. In terms of our specific research questions, it is clear that a simple risk-assessment tool alone cannot accurately predict ulcer development. Further, while prevention strategies may indeed alter the incidence of PU, it may well be that many prevention strategies are not employed until PU is imminent and are applied more as a reactive rather than as a prophylactic intervention.

It is not surprising that a simple index encounters difficulty in accurately predicting the development of PU. Besides the patient's functional characteristics described by risk-assessment scales, it may be that variables such as medical status, social support, environment, and quality of care need to be entered into the predictive equation. No doubt there are many individualistic variables that confound the prediction effort. Further work along this line to supplement risk assessments in the development of a reliable, sensitive, and specific prognostic model for PU development in individual patients is indicated.



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# **The Role of Cognitive Status in the Use of Inhome Services: Implications for Nursing Assessment**

**Pamela Hawranik**

Le lien entre l'état cognitif et l'utilisation des services de soins à domicile par les aînés et par leurs soignantes naturelles a reçu peu d'attention sur le plan de la recherche. L'objectif de cette étude était de déterminer s'il existe une association entre l'état cognitif et l'utilisation des services de soins à domicile par les aînés et par leurs soignantes naturelles identifiées ( $N = 380$ ). Une version modifiée du modèle d'utilisation des soins de services conçu par Andersen-Newman a été élaborée dans le but de faciliter l'analyse des données et leur comparaison aux résultats d'autres recherches. Des données provenant du Manitoba Study on Health and Aging-1 (MSHA-1) ont été analysées, en utilisant la modélisation hiérarchique de régression logistique. Des aînés appartenant à trois catégories d'états cognitifs — un état de démence, une perte cognitive sans troubles de démence, et un état libre de troubles cognitifs — ont fait l'objet d'une étude. Quatre types de services à domicile ont également été examinés, soit des services d'entretien ménager, de soins infirmiers, de soins personnels et de repas à domicile. L'étude a démontré qu'il existait peu de lien entre l'état cognitif et l'utilisation de soins à domicile. Les résultats soulèvent des implications en ce qui a trait à l'évaluation menée par les infirmières quant à l'admissibilité, telle qu'établie par les politiques de soins à domicile.

The link between cognitive status and use of home-care services by elders and their informal caregivers has received limited research attention. The purpose of this study was to determine whether an association exists between cognitive status and inhome service utilization by elders and their identified informal caregiver ( $N = 380$ ). A modification of the Andersen-Newman health service utilization model was constructed to facilitate analysis and comparison with other studies. Data from the Manitoba Study on Health and Aging-1 (MSHA-1) were analyzed using hierarchical logistic regression modelling. Elders of 3 types of cognitive status — dementia, cognitive loss without dementia, and no cognitive impairment — were studied; 4 different inhome services — homemaking, inhome nursing, personal care, and home-delivered meals — were examined. The study revealed a weak association between cognitive status and use of inhome services. The findings raise implications for eligibility assessment by nurses and home-care policy.

Research suggests that the problems experienced by caregivers of an elder with cognitive impairment are unique to the memory-impaired and cannot be generalized to caregivers of an elder with no cognitive

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impairment (George & Gwyther, 1986; Issacs, Livingston, & Neville 1972). The behavioural manifestations, the unpredictability of the behaviour, and the progressive global deterioration can affect the caregiver-elder relationship and increase several forms of caregiver strain, including psychological distress and physiological problems (Clipp & George, 1990; Collins, Stommel, Wang, & Given, 1994; Diemling & Bass, 1986; Kiecolt-Glaser et al., 1987; Moritz, Kasl, & Berkman, 1989; Vitaliano, Scanlan, Krenz, Schwartz, & Marcovina, 1996).

In spite of the apparent psychological and physiological strain many experience when caring for an elder with cognitive impairment, relatively little is known about whether cognitively impaired elderly persons and their caregivers use formal services differently from those who are not cognitively impaired and their caregivers. Several studies comparing elders with dementia and elders with no cognitive impairment have found that those with dementia are likely to use a greater number of services (Bass & Noelker, 1987; Beattie, Tuokko, & Hertzman, 1994; CSHA, 1994; Penning, 1995). However, these studies do not differentiate dementia from cognitive loss without dementia.

There is a paucity of literature on the association of use/non-use of inhome services and cognitive status, particularly as influenced by dementia. The findings of this present study raise questions pertaining to the targeting of services, the nature of assessment, and family needs.

### **Review of the Literature**

Studies examining the association of cognitive status with use of home-care services are limited in number, and their findings do not provide direction for policy-makers and nurses. Results are inconsistent. Nonprobability sampling techniques of people presently enrolled in a health or social program, differing measurements of community services, and the variation in measuring "use" are some of the issues limiting adequate comparisons across studies (Collins et al., 1994; McAuley & Arling, 1984; Wan & Arling, 1983). Furthermore, there are challenges to the standardization of cognitive impairment, such as lack of consensus on the signs of age-associated memory changes and those of mild or early cognitive impairment, the diagnostic criteria used, and the discrepant views of dementia across clinicians and researchers (Biegel, Bass, Schulz, & Morycz, 1993; Branch et al., 1988; Jeans, Helmes, Merskey, Robertson, & Rand, 1987; Plugge, Verhey, vanEverdingen, & Jolles, 1991).

The role of impaired cognition in the use of community services is unclear. Cognitive status has been a predictor of use of community services when the outcome variable is operationalized as "volume" — for example, in the number of services used or the number of service hours used once formal care has been instituted (Bass & Noelker, 1987; Bass, Looman, & Ehrlich, 1992; Hanley & Wiener, 1991; McAuley & Arling, 1984). Cognitive impairment is significantly associated with increased likelihood of using more types of service (McAuley & Arling) or using a greater number of services (Bass & Noelker; Hanley & Wiener). Bass et al. found that cognitive status did not have a direct effect on the number of hours of health-service use during a 2-month period, but that it exhibited a modifying effect by interacting with five variables: living arrangement, secondary helpers, depression, emotional strain, and task burden.

Clearly, the findings are inconsistent regarding the influence of cognitive status when service use is defined as use/non-use. Several studies found that cognitive impairment was significantly associated with use of services (Branch et al., 1988; Ganguli, Seaberg, Belle, Fischer, & Kuller, 1993; Penning, 1995; Soldo, 1985). Branch et al. found that the greater the number of errors on the mental-status instrument, the greater the likelihood of home-care use. In their study, home care included the services of nurses, social workers, physicians, therapists, and homemakers/home-health aids.

In contrast, Penning (1995), using data from the national component of the Canadian Study of Health and Aging-1 (CSHA-1), studied use of specific services among cognitively impaired elder respondents. Those with higher levels of impairment (a score of 77 or less on the Modified Mini-Mental Status Examination [3MS] [Teng & Chiu, 1987]) were less likely to use homemaking than those with lower levels of impairment. Penning speculates that cognitive impairment may act as a barrier (due to the behaviour manifestations) and consequently the elder or their family may not seek help.

A number of other community service studies found no significant association between cognitive status and use of services (Coulton & Frost, 1982; Grabbe et al., 1995; Hanley & Wiener, 1991; Wan & Arling, 1983). All of these studies aggregated a number of different services into one outcome variable. All of the studies measured cognitive status differently, but each utilized one question or a single tool to determine the presence of cognitive impairment. Penning (1995), who utilized CSHA-1 data from the screening phase, constructed separate logistic

models for four services. Use of three of the services — nursing, personal care, and therapy — was not significantly associated with cognitive status. Cognitive status was determined by the score on the 3MS.

The physical needs of the elder are included as independent variables in most of the studies. Functional status, often measured as limitations in basic or instrumental activities of daily living (ADLs or IADLs), has been identified as a strong determinant of service use even when cognitive status is one of the independent variables (Branch et al., 1988; Coulton & Frost, 1982; Crowell et al., 1996; Penning, 1995; Wan & Arling, 1983).

### **Conceptual Framework**

The Andersen-Newman model (Andersen, 1968; Andersen & Newman, 1973) for health-service utilization was adapted for this study in order to provide a structure for the organization of the variables and analysis of the data. The Andersen-Newman model is the most frequently applied utilization framework. It theorizes that health-service use is dependent on: (a) the predisposition of the family to use services (predisposing factors), such as age, sex, education, or health beliefs; (b) the family's ability to secure services (enabling factors), such as income or geographic location; and (c) the family's illness level (need factors), such as self-rated health or objective means; for example, diagnostic test results or functional assessments.

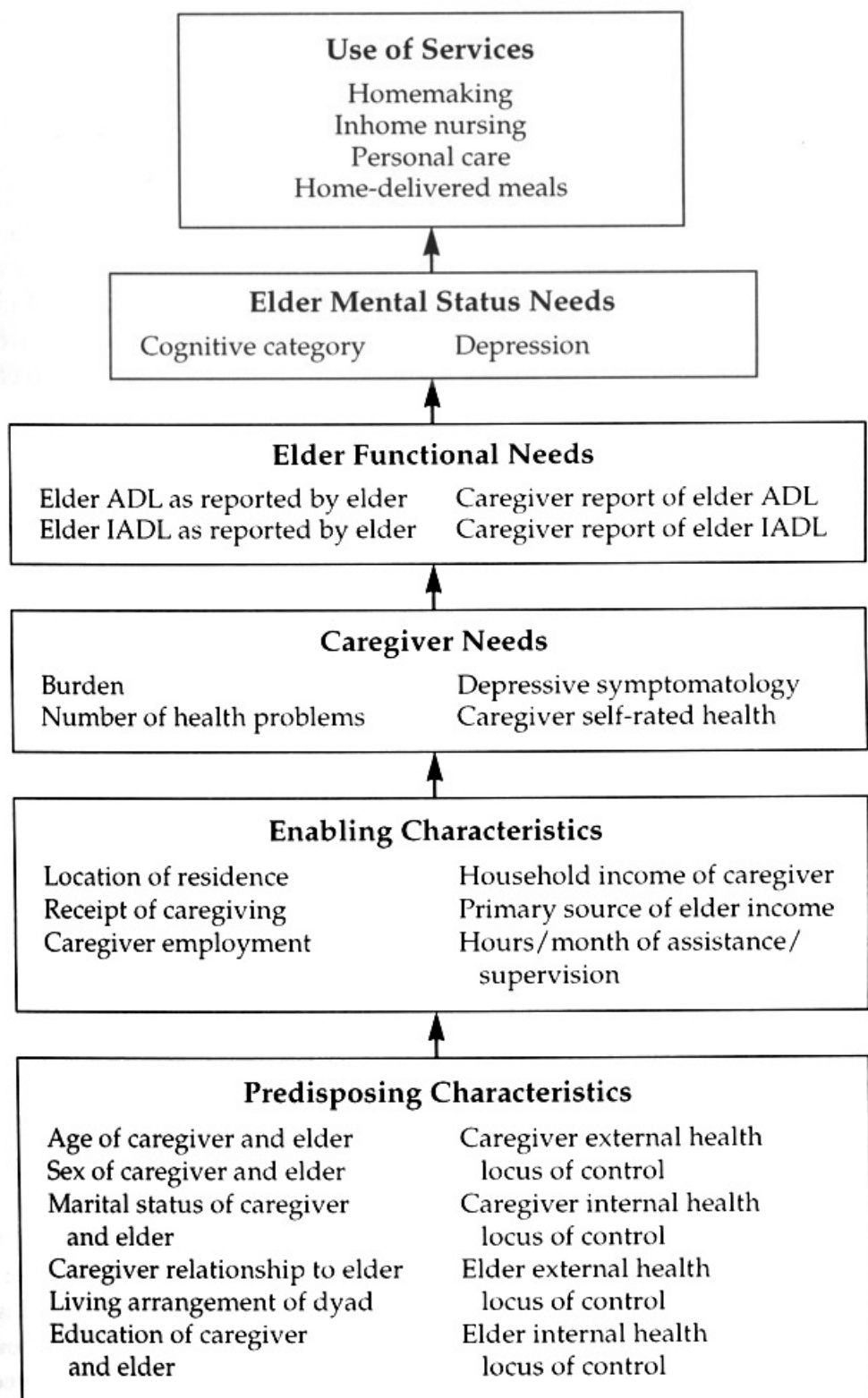
For this study, several adaptations were made to the Andersen-Newman model as a result of limitations cited in the literature (Figure 1). These comprised: (a) the addition of variables measuring aspects of social support, including characteristics of the elder's informal caregiver; (b) the formation of three needs categories — elder mental-status needs, elder functional-status needs, and caregiver physical and psychological needs; and (c) a focus on both the elder and the caregiver.

### **Research Questions**

1. What categories and variables within each category of the adapted Andersen-Newman model are significantly associated with the use of each inhome service — homemaking, inhome nursing, personal care, and home-delivered meals?
2. Is cognitive status significantly associated with the use of each of the four inhome services?



**Figure 1** *Adapted Andersen-Newman Model*



Adapted from: Andersen & Newman (1973).

Homemaking included assistance with cleaning, laundry, or meal preparation. Nursing included care provided by a professional nurse such as changing dressings and monitoring blood pressure. Personal care included assistance with bathing, dressing, grooming, toileting, and other personal functions. Home-delivered meals were meals delivered to the person's home such as provided by Meals-on-Wheels. The definition of the elder's "identified informal caregiver" was based upon the definition used by the CSHA-1 and the Manitoba Study of Health and Aging-1 (MSHA-1): an unpaid person, either a family member or a friend, who "was perceived by the subject (elder) or his/her family as ordinarily being the most responsible for day-to-day decision-making and provision of care to the subject" (MSHA-1 screening questionnaire), though not necessarily providing care or supervision on a daily basis currently.

### **Manitoba Home Care Program**

Manitoba Home Care is a province-wide, no-cost-to-consumer program initiated by the provincial government in 1974 (Havens, 1996). Eligibility is based on assessment by a nurse or social worker to determine if home care is the most appropriate form of care or whether placement in a facility is indicated. No charges are levied for homemaking, personal care, or inhome nursing provided by Manitoba Health. A small user fee is charged for home-delivered meals. The four inhome services under examination were provided largely by public rather than private sources.

### **Data and Methodology**

This study utilizes data from the MSHA-1 (MSHA Aging Research Group, 1995). This was an expansion of the CSHA-1, a national study of Canadians 65 years and older that focused on the prevalence, causes, and patterns of caregiving associated with dementia; 18 study centres in 10 Canadian provinces, including Manitoba, collaborated. The Manitoba sample used by the CSHA-1 was expanded for the MSHA-1, both to increase the sample size and to collect additional data on a number of other variables for subanalysis on the Manitoba population. The MSHA-1 sample consisted of a random sample of people 65 years and older, stratified by health region and age group with over-sampling in the older age groups. The sample was selected from those registered with Manitoba Health, which administers a provincial health-insurance program for all permanent residents of the province.

The data-collection process in the MSHA-1 consisted of four steps: a screening interview with the elderly person, a clinical assessment, a community-caregiver phase, and a risk-factor study phase. Data for this study were drawn from the first three steps.

The data of the caregiver were linked with those of their elder, as follows: (1) those who had completed the screening interview and scored 78 or greater on the 3MS examination (considered noncognitively impaired,  $n = 255$ ); (2) those who had been categorized in the clinical assessment as having dementia ( $n = 50$ ); and (3) those who had been categorized in the clinical assessment as having cognitive loss without dementia ( $n = 75$ ). Dementia included Alzheimer's disease, vascular dementias, and other dementias. Cognitive loss without dementia included depression, delirium, age-associated memory loss, and other forms of cognitive loss.

### *Measurement and Data Analysis*

Independent variables for this study were selected based on the utilization literature. The operationalization of the variables reflected forms of measurement used in previous research. Table 1 illustrates the scoring for all of the independent variables that were considered for the four dependent variables.

Descriptive statistics of all variables were obtained to provide a profile of the elders and caregivers. Multivariable analysis included a logistic regression modelling process to analyze the relationships between the independent variables and the outcome variables. Variables were considered for inclusion in the model-building based on two criteria: (a) a significance level of  $\leq 0.25$  from the  $t$  tests, chi-square, or Mann-Whitney  $U$  tests when the independent variables were compared with each of the outcome variables, or (b) a theoretical significance of the variables as indicated in the literature.

Separate bivariate comparisons were conducted between each of the independent variables and each of the four outcome variables. It was assumed that each type of service would have different predictors. It was necessary to perform separate tests for each outcome variable, since each dependent variable represented a different configuration of services comprising different activities intended to support specific needs. The significance level of  $\leq 0.25$  was based upon Hosmer and Lemeshow's (1989) suggestion that such a  $p$  value may be appropriate when models containing more variables are required to provide a more complete picture of possible models. Mickey and Greenland's (1989)

work on logistic regression indicates that 0.05 is too low and can exclude important variables from the model. They suggest that a larger level may include variables that individually have a weak association with the outcome variable but that could, when the influences of other variables are controlled for, become important predictors of the outcome.

<b>Table 1</b> <i>Operationalization of Variables for Hierarchical Logistic Regression Modelling</i>	
<b>Variables</b>	<b>Scoring</b>
<i>Elder Mental Status Needs</i>	
Cognitive category	
no cognitive impairment	0 = no cognitive impairment
dementia	1 = dementia
cognitive loss	2 = cognitive loss
<i>Elder Depressive Symptoms</i>	1 = high depressive symptomatology
<i>Elder Functional Needs</i>	
ADL limitations as reported by elder	1 = 1 or more ADL limitations
IADL limitations as reported by elder	1 = 1 or more IADL limitations
ADL limitations of elder as reported by caregiver	1 = 1 or more ADL limitations
IADL limitations of elder as reported by caregiver	1 = 1 or more IADL limitations
<i>Caregiver Needs</i>	
Burden	Zarit burden scale (0 to 55)
Number of health problems	actual number (0 to 10)
Depression	1 = high depressive symptomatology
Self-rated health	1 = not too good, poor, very poor
<i>Enabling Characteristics</i>	
Location of elder residence	1 = urban
Source of caregiving	1 = assistance received from caregivers or others
Caregiver employment	1 = works for pay
Household income of caregiver	1 = medium (\$1,500–2,599) 2 = high (\$2,600–9,996) 3 = missing/don't know
Primary source of elder income	1 = other than Old Age Security & supplement
Number of hours/month of ADL/IADL supervision by caregiver	0 to 720

**Table 1** (cont'd)

Variables	Scoring
<i>Predisposing Characteristics</i>	
Age of caregiver	years (26–86)
Age of elder	years (64–97)
Sex of caregiver	1 = female
Sex of elder	1 = female
Marital status of caregiver	1 = married
Marital status of elder	1 = married
Years of education of caregiver	actual number (2 to 24)
Years of education of elder	actual number (0 to 20)
Caregiver relationship to elder	1 = spouse
Living arrangement of caregiver and elder	1 = same household
Caregiver health beliefs	
Internal health locus of control	score (10 to 25)
External health locus of control	score (4 to 17)
Elder health beliefs	
Internal health locus of control	score (3 to 19)
External health locus of control	score (2 to 19)
<i>Dependent Variables</i>	
Homemaking services	1 = used
Inhome nursing services	1 = used
Personal-care services	1 = used
Home-delivered meals	1 = used
Note: ADL = activities of daily living; IADL = instrumental activities of daily living	

Hierarchical logistic regression was used to introduce the conceptual sections of the adapted Andersen-Newman framework into the models. According to Stoller (1992), this strategy reflects a decision-making process in which individuals must first perceive a need for service, then possess the ability to use the service (which can be considered enabling factors), and, finally, be predisposed to use the service (the predisposing characteristics).

The independent variables were entered in blocks. Elder Mental Status Needs were entered first, followed by Elder Functional Needs, Caregiver Needs, Enabling Characteristics, and finally Predisposing Characteristics. All variables pertaining to a particular category of the model, such as Elder Mental Status Needs, were entered simultaneously. The model chi-square and *p* values were observed. The fifth stage of the model included all five categories of the adapted Andersen-Newman model. After the fifth stage, tests for two-way interaction terms were conducted. The next stage in the model-building process included reduction of the model, using backwards stepwise

logistic regression, to include only the significant main-effects variables and the significant interaction term(s). The criterion for the removal of a variable from the model was a log likelihood ratio  $p$  value of  $\leq 0.05$ . Variables that did not meet this level of significance were considered to be not significant characteristics of the caregivers and their elders for that particular dependent variable.

The Final Model comprised the significant main effects and interaction terms, using the maximum number of cases for which there were no missing values for the relevant variables. Missing cases for variables that were not significant were added (for example, this still excluded missing cases for significant variables), resulting in an expanded number of cases in the model.

## Results

An overview of the use of inhome services by cognitive status is presented in Table 2. A greater proportion of dyads with elders with dementia were users of all four types of services than dyads with no cognitive impairment or cognitive loss without dementia. Of the three categories of cognitive status, dyads with elders with no cognitive impairment used services the least frequently.

Overall, homemaking services were the most frequently used of all inhome services, while home-delivered meals were the least frequently used except for those dyads with an elder with dementia. Inhome nursing was used the least frequently by this latter group. The results of the hierarchical logistic regression analysis are reported in Table 3, with the beta and the log likelihood significance for the final stage for each of the four models.

<b>Table 2</b> <i>Percentage of Users of Inhome Services by Cognitive Status (N = 380)</i>			
<b>Services</b>	<b>No Cognitive Impairment (n = 255) %</b>	<b>Cognitive Loss (n = 75) %</b>	<b>Dementia (n = 50) %</b>
Homemaking	29.80	45.30	56.00
Inhome Nursing	5.90	14.70	24.00
Personal Care	11.80	17.30	42.00
Home-Delivered Meals	5.10	9.30	28.00



Consistent with the literature, cognitive status emerged as only weakly related to use of services, but it was significantly associated with the use of personal-care services. Dyads with an elder with dementia were more likely to use personal-care services than those with a noncognitively impaired elder. There was no significant difference in the likelihood of using personal-care services between elders with cognitive loss without dementia and those with no cognitive impairment. Cognitive status was not significantly associated with the use of homemaking, inhome nursing, or home-delivered meals.

The category of the modified Andersen-Newman model that demonstrated the most powerful effect on use of services was Elder Functional Needs. This finding confirms results of previous studies that found functional status of the elder to strongly influence use of community services (Chappell & Blandford, 1987; Coulton & Frost, 1982; Crowell et al., 1996; Shapiro, 1986). At least one of the functional-status variables was significant for each of the outcome variables. The greater the number of ADL or IADL limitations in the elder, as reported by the elder or the caregiver, the greater the likelihood of using the specific service.

The Caregiver Needs category was significantly associated with the likelihood of using homemaking, inhome nursing, and personal care. However, overall it was a less powerful indicator of inhome service use than the Elder Functional Needs category. Each of the caregiver-need variables was significantly associated with only one of the outcome variables.

Enabling characteristics refers to the resources of the dyad, which can inhibit or promote service use. Employment status of the caregiver, availability of assistance for the elder, and number of hours of care provided by the identified caregiver to the elder were each significantly associated with only one of the inhome services. Three Predisposing characteristics were significantly associated with the use of the four inhome services: elder age, living arrangement of the elder, and caregiver health beliefs, specifically internal locus of control. These three categories of variables did not emerge as powerful determinants of inhome service use.

One interaction term was significantly associated with use of personal-care services: elder self-report of one or more ADL limitations and caregiver level of burden. The impact of the level of caregiver burden on the likelihood of use of personal-care services was influenced by the elder's self-report of ADL limitations. The level of burden affected the likelihood of this service being used less when the elder reported one or more ADL limitations than when the elder reported no ADL limitations.

**Table 3** *Logistic Regression of Use of Each Inhome Service by Significant Variables in Final Models*

Variables	Homemaking			Inhome Nursing			Personal Care			Home-Delivered Meals		
	B	Log LR sig.		B	Log LR sig.		B	Log LR sig.		B	Log LR sig.	
<i>Elder Mental Status</i>												
Cognitive status		ns			ns			.01			ns	
Dementia vs. no cognitive impairment							1.44					
Cognitive loss vs. no cognitive impairment							-.04					
Depression		ns			ns			ns			ns	
<i>Elder Functional Status</i>												
ADL limitations according to elder	1.23	.00		1.86	.00		4.03	.00			ns	
IADL limitations according to elder	.86	.01			ns			ns			ns	
ADL limitations according to caregiver		ns			ns			ns		1.50	.00	
IADL limitations according to caregiver		ns		7.38	.00			ns		6.93	.01	
<i>Caregiver Needs</i>												
Burden		ns			ns		.10	.00			ns	
Number of health problems	.20	.00			*			ns			ns	
Depression		ns		1.07	.01			ns			ns	
Self-rated health		*			*		-2.26	.01			ns	
<i>Enabling Characteristics</i>												
Urban or rural		*			ns			*			ns	
Source of assistance/supervision	1.75	.00			ns			ns			ns	
Number of hours of assistance/supervision by caregiver	-.01	.02			*			ns			*	
Caregiver household income		ns			ns			*			ns	
Elder primary source of income		*			*			*			ns	
Caregiver employment		ns			ns		-1.10	.01			ns	

**Table 3** (cont'd)

Variables	Homemaking		Inhome Nursing		Personal Care		Home-Delivered Meals	
	B	Log LR sig.	B	Log LR sig.	B	Log LR sig.	B	Log LR sig.
<i>Predisposing Characteristics</i>								
Caregiver age		ns		ns		ns		*
Elder age	.06	.00		ns		ns	.10	.00
Caregiver sex		*		*		*		*
Elder sex		ns		ns		ns		ns
Caregiver marital status		ns		*		ns		ns
Elder marital status		ns		ns		ns		ns
Caregiver years of education		*		*		ns		*
Elder years of education		*		*		ns		*
Living arrangement of elder		.01	-1.23	.01	-2.54	.00	-1.02	.03
Caregiver external health locus of control	-.85	*		*		*		*
Caregiver internal health locus of control		*		ns	.17	.01	.22	.00
Elder external health locus of control		*		ns		ns		ns
Elder internal health locus of control		*		*		ns		*
<i>Interaction Terms</i>								
Source of assistance/supervision by living arrangement of elder	none sig.		none sig.		-.08	.01	none sig.	
<i>Model Chi-square</i>	133.98		64.12		153.45		58.53	
<i>d.f.</i>	7		4		9		5	
<i>p value</i>	<.001		<.001		<.001		<.001	
<i>n</i>	378		377		378		377	

Note: "ns" refers to those variables that were not significant after the stepwise backwards logistic regression was conducted to reduce the model to its significant main effects and interactions; \* refers to those variables that did not meet the inclusion criteria for the logistic modelling process.

## **Discussion**

This study sought to examine the relationship between elder cognitive status and the use of inhome services by the elder and their identified informal caregiver. Overall, the cognitive status of the elder was not a predictor of use of homemaking, inhome nursing, and home-delivered meals. It was, however, significantly associated with the use of personal-care services. It is interesting to note that those with dementia were more likely to use personal-care services than those with no cognitive impairment. A number of researchers have acknowledged that the personal-care needs of a cognitively impaired elder are one of the most stressful demands for caregivers. A survey of caregivers providing care to a family member with dementia (Chenoweth & Spencer, 1986) found that assistance with physical care and/or constant supervision was identified the most frequently as a major problem. Particularly troublesome were physical-care problems associated with feeding and eating, incontinence, and sleep disturbances. The literature describes bathing as a confusing event that can precipitate catastrophic reactions (substantive emotional reactions) in dementia patients (Foltz-Gray, 1995; Mace & Rabins, 1981; Namazi & Johnson, 1996; Sloane et al., 1995). Because of the agitated behaviour that can be exhibited by an elder with dementia when receiving personal care, family members may request assistance from people trained to deal with such situations.

No difference in use of personal-care services was identified between dyads with elders with cognitive loss without dementia and dyads with elders with no cognitive impairment. This may be due to the nature of the diagnoses that make up the cognitive-loss-without-dementia category. Cognitive loss may include mild cognitive impairment or forms of cognitive impairment, such as depression, without behavioural manifestations. In such cases, the elder may still be able to carry out personal-care functions.

The lack of significant association of cognitive status with the three remaining outcome variables confirms the findings of several previous community service utilization studies (Bass & Noelker, 1987; McAuley & Arling, 1984; Montgomery, Kosloski, & Borgatta, 1988–89). There are several possible explanations for the lack of association. These relate to methodological issues and previous research citing reasons families have given for not using services.

One explanation for lack of a strong association between cognitive status and use of services may relate to the diagnosis or categorization

of respondents according to a disease state, and the possibility that cognitive test score or diagnosis are not the most accurate methods for measuring cognitive status when studying its impact on use of services. A more appropriate means might be a tool for measuring the behavioural manifestations associated with cognitive status as well as the effects on caregivers such as how they handle the elder's reduced communications skills and the disruption in family routine.

A second explanation may be that the services studied do not respond to the needs of a dyad when the elder has cognitive impairment. The services that have been studied tend to be directed toward physical or functional problems rather than cognition ones. Certainly these services are relevant for a cognitively impaired individual, since these abilities are affected by cognitive status; however, they do not directly address cognitive-impairment needs, such as supervision or diversion from repetitive or harmful activities.

A further consideration is the sensitivity of the cognitive testing used in the MSHA-1. The testing conducted in the CSHA-1/MSHA-1 to arrive at a cognitive categorization can be considered close to the "gold standard." The majority of the studies that have included cognitive status as a factor have not demanded such a rigorous process. However, despite the rigorous testing in the clinical phase for those with cognitive impairment, some false positive cases will exist. False negative scores will also be present for those who underwent the single cognitive test during the screening phase.

Other reasons for non-use of community services have been identified by caregivers or elders themselves. Caserta, Lund, Wright, and Redburn (1987) found that the most frequently offered reason was lack of need at the time. In a descriptive study exploring reasons for non-use of community health services, conducted with informal caregivers of elders with Alzheimer's disease (Hamilton, Braun, Kerber, Thurlow, & Schwieterman, 1996), one of the reasons caregivers gave for not using a home-health agency or Meals-on-Wheels was that they did not require the services.

Researchers and other professionals have reported a reluctance by families to use community services until the elder's health is so severely limited that care can no longer be handled by the informal support system alone (Chappell & Guse, 1989; Soldo & Manton, 1985; Stone, Cafferata, & Sangl, 1987); families view formal services as a last resort (CSHA, 1994). Other reasons cited in the literature include: the family's perception that caregiving is a familial responsibility, the unavailability of trained personnel, the embarrassment of having a cognitively

impaired family member, and lack of knowledge of available services or how to access them. A final speculation of the author is that behaviour related to cognitive impairment is unpredictable, with specific events sometimes acting as stimuli to create a behavioural disturbance. The unpredictability of the symptoms may influence the types of services that are used, and when they are used.

### **Implications for Nursing**

The services under study were functionally oriented, and functional status was a strong predictor of these services. However, they do provide assistance with some of the functions that elders with cognitive impairment may have difficulty with. It is hard to know whether the weak association between cognition and use of inhome services rests primarily with policy or with family concerns.

Do families know the services are available? Silverstein (1984) found that respondents who had learned of the services through formal supports were more likely to use them than respondents who had learned of the services informally. The nurse has an important role to play in informing people about resources, those available through voluntary organizations as well as services available through publicly funded bodies. Health teaching on the benefits of such services should be incorporated into the nurse's initial family assessment.

If services are not being used because of lack of awareness, wider dissemination of information about the services, their purposes, their benefits to the family, and access to them may be warranted. Such strategies tend to raise the anxiety level of policy-makers, who fear that "advertising" the services will transfer responsibilities from the family to the public domain. However, the evidence from Manitoba, the United States, and Europe is that the amount of care provided by the informal system does not decrease with the introduction of a no-cost-to-user home-care service (Havens, 1996).

There is some suggestion in the literature that families believe they do not need these services. Caserta et al. (1987) asked caregivers of elders with dementia to identify their reasons for not using available services. The most frequently given reason was lack of need. Is this because the services were not relevant for them? If so, perhaps nurses should be asking families, "How can I help you most in caring for your spouse (or parent)?" This might inform the nurse of the family's perceived needs and help guide the nurse in planning interventions.



When a family hesitates to obtain formal assistance, or refuses assistance, the nurse should carefully and thoroughly determine whether the caregiver or elder has a realistic perception of their stress level and coping abilities. Does the family understand the progressive nature of the cognitive impairment and the extent to which it can interfere with the caregiver's physical and mental health? Is the family aware of the dependency needs and safety issues that will arise? Discussions with the family about their coping methods should be included in all caregiver and elder assessments. Discussion of possible scenarios, and the strategies the caregiver or elder would use in coping with them, might be helpful to the family in considering the future and helpful to the nurse in determining the family's problem-solving abilities.

In their decisions to enlist clients for home-care services, nurses are influenced by the policies of their employer. If the agency's mandate is to provide a minimal amount of assistance to help the elder remain in the community, the nurse needs to consider the implications of this minimal support for both the caregiver and the elder. The expectation that the family provide most or some of the care could jeopardize the health of the caregiver or elder. The responsibility may place greater stress on the informal support system and create a demand for other family members to assume a caregiving role. Family members may be providing moderate-intensity or high-intensity care. Periodic assessment and ongoing support is crucial. Information about other available services, strategies for dealing with behavioural manifestations, and anticipatory teaching are also important. Nurses could maintain an "at risk" file of families who refuse services or who, in the estimation of the nurse, will have difficulty managing with minimal formal assistance. Such elders would not be formally admitted to a home-care program, but their name would be retained in a file so that the nurse could contact the family in future to see how they are coping. The aim would be to prevent the family from becoming burnt out and entering a crisis, by offering support and reminding them that services are available.

Flexibility may be required to let the system respond to sporadic behavioural disturbances. Rather than having to arrange for respite several days or weeks in advance, families should have access to services on short notice and intermittently, according to need. Services should be based on client need rather than on the planning and structural needs of the organization.

Does the nursing assessment for home-care eligibility include an adequate assessment of cognitive status? The use of a single mental-

status test to determine cognitive impairment is inadequate, according to this author. Questions regarding the behaviour of the elder and the onset and progression of symptoms should be included in the interview. The effects of the behaviour on the elder's ability to perform basic functions should be determined. The effects of the behaviour on the informal caregiver cannot be overlooked.

In conclusion, home-care services must be tailored to the requirements of families of elders with cognitive impairment. The majority of these families do not use formal services. The small number of families that do use them are utilizing one of the cheapest forms of health-care services available. The fear of extensive overuse and abuse of health-care services is not substantiated in the literature. Nursing has an important role to play in promoting the caregiving relationship and reducing the stress and strain that accompany it.

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# **Strategies for Managing Behavioural Symptomatology Associated with Dementia of the Alzheimer Type: A Systematic Overview**

**Dorothy A. Forbes**

L'objectif de ce survol systématique est de résumer les résultats de recherches sur les stratégies de prise en charge de la symptomatologie comportementale liée à la démence de type Alzheimer. Un total de 265 articles publiés et non publiés ont ainsi été recensés, parmi lesquels 45 ont été jugés adéquats. L'application de critères de validité a permis de dégager un « bon » article, six articles « moyens », 20 « très moyens » et 18 « médiocres ». Les stratégies comme les promenades à heure fixe, la zoothérapie, un programme destiné à canaliser l'attention, l'acquisition de compétences fonctionnelles, la musique et les obstacles visuels ont donné des résultats prometteurs, puisqu'ils ont permis d'améliorer : a) les comportements agressifs, agités et perturbateurs, b) les interactions sociales, c) la faculté de s'occuper de soi, d) les perturbations jour-nuit ou e) le vagabondage. Ces résultats indiquent qu'il se fait des recherches, même si celles-ci n'en sont qu'à leurs balbutiements, sur les stratégies destinées à prendre en charge la symptomatologie comportementale liée à la démence de type Alzheimer.

The purpose of this systematic overview was to summarize research findings on strategies for managing the behavioural symptomatology associated with dementia of the Alzheimer type. A search of the published and unpublished literature resulted in 265 articles, 45 of which were judged to be relevant. Using validity criteria, 1 article was judged to be strong, 6 moderate, 20 weak, and 18 poor. Strategies such as planned walking, pet therapy, an attention-focusing program, functional skills training, music, and visual barriers demonstrated promising results in improving: (a) aggressive, agitated, and disruptive behaviours, (b) social interaction, (c) self-care ability, (d) day-night disturbances, or (e) wandering. The findings indicate that there is existing research, although in its infancy, to support the use of strategies for managing the behavioural symptomatology associated with dementia of the Alzheimer type.

The Systematic Research Overview Pilot Project was initiated in early 1997 by the Alberta Heritage Foundation for Medical Research (AHFMR) Dissemination Program, Edmonton, Alberta, to synthesize

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and assess research findings that address questions important to clinical practitioners. Four research teams were established, each to address a different research question. This article describes the systematic overview conducted by the Alberta Association of Registered Nurses (AARN) research team, which was composed of an AARN representative, a university faculty advisor, and a reference librarian.

### Problem Formulation

In order to generate their research question, the AARN team asked registered nurses in Alberta to submit questions of concern to them. The question considered to be of interest to most registered nurses, and most relevant to their clinical practice, was: *What strategies, within the scope of nursing, are effective in managing the behavioural symptomatology associated with dementia of the Alzheimer type in elderly individuals?* This question limited the overview to strategies within the scope of nursing practice and to studies with individuals 65 years of age and older diagnosed with Alzheimer's disease (AD) or degenerative dementia. "Within the scope of nursing practice" was included because, while professionals from other disciplines may have provided the interventions in the studies, registered nurses have the skills to either implement the strategies or train other care providers to provide the interventions.

In Canada, 8.0% of the population aged 65 and over and 34.5% aged 85 and over are diagnosed with dementia (Canadian Study of Health and Aging Working Group, 1994). AD, the most common type of dementia, affects 5.1% of persons aged 65 and over and 26% aged 85 and over (Canadian Study of Health and Aging Working Group). The estimated prevalence of AD in the world population is 8.5% of persons aged 65 and over and 28% aged 85 and over (National Advisory Council on Aging, 1996).

AD affects both cognition and behaviour. The former has received significant attention; the latter is only beginning to be addressed. Behavioural symptoms affect 70–90% of people with AD and may be manifest on a daily basis, affecting the quality of life of both the individual and the caregiver (Teri et al., 1992). The diversity of behavioural symptoms is well documented (Beck & Shue, 1994; Maas & Buckwalter, 1991; Teri et al.). The most common or most serious behaviours are wandering, agitation, physical violence, repetitive disruptive vocalizations, withdrawal, day/night disturbances, and difficulties related to

feeding and self-care (Alessi, 1991; Teri et al.). Behavioural symptoms are a primary source of stress for informal (Alessi; Stevenson, 1990) and formal caregivers (Hallberg & Norberg, 1993), as these affect persons with AD at various stages of the disease and in every care setting.

The purpose of the systematic overview was, therefore, to assess and summarize research evidence on the effectiveness of strategies in managing the behavioural symptomatology associated with dementia of the Alzheimer type. The overview was conducted from the beginning of March through June 1997.

### **Data Collection**

Data-collection strategies included on-line computer searches, manual searches of selected journals, and searches of reference lists. An on-line search of MEDLINE, CINAHL, PsychINFO, Sociofile, Ageline, HealthSTAR, Dissertation Abstracts, Government Documents (First Search), and Can Research Index was conducted for the period January 1985 through April 1997. Selected key words were "aged 65 and over," "dementia," "Alzheimer's Disease," "long term care," "residential care," "intervention," "strategy," "manage," "behaviour therapy," "clinical trial," "random," "outcome and process assessment," and "evaluation." Key journals such as *The Gerontologist* and the *Journal of the American Geriatrics Society* were manually searched and several key informants were contacted for their published and unpublished papers. Lastly, relevant references from each article were identified, retrieved, and reviewed. The search strategies resulted in the screening of approximately 8,000 abstracts or titles. Any article whose title or abstract suggested examination of a strategy for managing the behavioural symptomatology associated with dementia of the Alzheimer type was retrieved. This process resulted in the retrieval of 265 potentially relevant articles. *ProCite*, a reference-management computer program, was used to catalogue the 8,000 citations (Rosenberg et al., 1992).

### **Data Evaluation**

Previous systematic research overviews (Ciliska et al., 1994; Ploeg et al., 1995) and reviews of interventions to manage the symptoms of dementia (Beck & Shue, 1994; Maas & Buckwalter, 1991) guided the development of reliability and validity criteria that were used to determine whether the article would be included in the review.

### *Relevance Rating*

A relevance tool was developed, pretested, and revised. The relevance criteria determined whether the study: (a) was published or conducted between January 1, 1985, and May 31, 1997; (b) evaluated a nonpharmacological intervention directed to an individual aged 65 or older with dementia of the Alzheimer type, or to their caregiver; (c) described an intervention within the scope of nursing practice; (d) measured one of the following care-recipient behaviours: wandering, agitation, physical violence, repetitive vocalizations, withdrawal, day/night disturbances, or difficulties with feeding or self-care; and (e) incorporated a control group or a pretest-posttest design with a sample size greater than one. To be included in the validity appraisal, an article had to meet all five relevance criteria. The first 20 articles were independently reviewed by two readers, and the level of agreement beyond chance was found to be 86% ( $kappa = .857$ ); thus the second reader was not considered necessary for the remaining articles. Only 45 of the 265 articles retrieved met all five criteria.

### *External, Internal, and Statistical Conclusion Validity*

The next phase involved rating the 45 relevant studies for validity. A validity tool, dictionary, and rating scale were developed, pretested, and revised. The external, internal, and statistical conclusion validity categories, the corresponding criteria, and the rating scale are shown in Table 1.

For a *strong* rating, at least four of the criteria had to "pass" and none could "fail." For a *moderate* rating, no criteria could fail and no more than four could pass. For a *weak* rating, one or two criteria had to fail. For a *poor* rating, more than two criteria had to fail. Although the level of agreement of the two raters remained high ( $kappa = .762$ ,  $n = 20$ ), the two raters independently completed the validity ratings for all of the relevant studies. There were 13 discrepancies related to oversight or differences in interpretation of the criteria; these differences were discussed and a consensus was reached on the ratings of all articles.

To facilitate retrieval of significant data from the studies, a data-extraction tool was developed, pretested, and revised. The following data were collected: year(s) in which study was conducted, date of publication, country, setting, research design, sample size at baseline and at completion of study, characteristics of sample (e.g., gender, age, diagnoses, medications, length of hospital stay), credentials of provider,

intervention strategy, intervention intensity, co-interventions, compliance with intervention, and statistical analyses.

### **Data Analysis**

Descriptive analyses were conducted on methodological weaknesses according to the validity criteria, country, setting, provider, intervention, and outcome.

The vast majority of the relevant studies ( $N = 45$ ) were conducted in the United States (82.2%); the others were conducted in Sweden and Norway (6.7%), Canada (2.2%), Australia (2.2%), Italy (2.2%), Japan (2.2%), and the United Kingdom (2.2%). The settings were primarily long-term-care facilities (LTCFs) (41.3%), followed by AD special-care units (28.3%), psychogeriatric centres (10.9%), and day-care centres (10.9%); only three studies (6.5%) were conducted in the home. The interventions were provided primarily by registered nurses, without advanced preparation (20.8%) or with advanced preparation (14.6%), followed by other professionals (22.9%), such as gerontologists, psychiatrists, psychologists, social workers, occupational therapists, recreational therapists, or music therapists. The remaining interventions were provided by paraprofessionals (8.3%), such as nursing aides, and informal caregivers (6.3%). Some articles (6.3%) did not identify the type of provider, and in other studies (20.8%) the intervention was related to an environmental change or pet therapy.

Music (27.1%) was the most frequent form of intervention, followed by skills training (18.8%) and visual barriers (10.4%). The remaining interventions were: exercise (8.3%), bright-light therapy (6.3%), pet therapy (6.3%), sensory integration (6.3%), reality orientation (4.2%), presence (4.2%), hand massage (2.1%), therapeutic touch (2.1%), life review (2.1%), and white-noise therapy (2.1%). The most commonly addressed outcomes pertaining to the purpose of this overview concerned: social interaction (29.6%), agitation (14.8%), wandering (14.8%), self-care ability (13.0%), physically violent behaviour (9.3%), vocally disruptive behaviour (7.4%), day/night disturbances (5.6%), and eating problems (5.6%).

### **Findings**

Of the 45 articles reviewed, one was rated as strong, six moderate, 20 weak, and 18 poor. Those rated as poor were not included in the overview. Those rated as strong, moderate, and weak were described and critiqued within the following outcome categories: (a) aggressive,

<b>Table 1</b> <i>Validity Rating Tool</i>		
<b>Category</b>	<b>Criteria</b>	<b>Rating</b>
<i>External Validity</i>		
(a) Design and allocation to intervention	(1) Random	(1) Pass
	(2) Before/after or matched cohort	(2) Moderate
	(3) No control or unknown	(3) Fail
(b) Inclusion	(a) If consent to participate had been sought from subject, next of kin, or legal guardian:	
	(1) >80% participation in both groups	(1) Pass
	(2) 60–79% participation	(2) Moderate
	(3) <60% participation or level of participation not stated	(3) Fail
	(b) If consent to participate had not been sought:	
	(1) subjects clearly described	(1) Pass
(c) Attrition	(2) some detail provided but not conclusive	(2) Moderate
	(3) not described	(3) Fail
	(1) <10%	(1) Pass
	(2) 11–20%	(2) Moderate
	(3) >20%, did not indicate level of attrition, or not applicable	(3) Fail



Table 1 (cont'd)	Criteria	Rating
<b>Internal Validity</b>		
(d) Confounders controlled	<p>(1) All relevant confounders controlled (e.g., age, sex, functional ability, level of cognitive impairment)</p> <p>(2) At least three confounders controlled, or subjects acted as their own control</p> <p>(3) Two or fewer confounders controlled</p>	<p>(1) Pass</p> <p>(2) Moderate</p> <p>(3) Fail</p>
<b>Statistical Conclusion Validity</b>		
(e) Data collection	<p>(1) At least one data-collection method (self-reported, assessment/screening, or medical records/vital statistics) had all of the following criteria rated as <i>yes</i>: well described, pretested, investigator blinded to participant's group allocation</p> <p>(2) At least one data-collection method had most criteria rated as <i>yes</i></p> <p>(3) None of the data-collection methods adequately addressed</p>	<p>(1) Pass</p> <p>(2) Moderate</p>
(f) Statistical analysis	<p>(1) Multivariate</p> <p>(2) Bivariate</p> <p>(3) Descriptive or unknown</p>	<p>(3) Fail</p> <p>(1) Pass</p> <p>(2) Moderate</p> <p>(3) Fail</p>

agitated, and disruptive behaviours; (b) social interaction; (c) self-care ability; (d) day/night disturbances; and (e) wandering. Table 2 summarizes the design, setting, subjects, intervention, provider, and outcomes of the articles rated as strong and moderate. While this area of research is still in its infancy, innovative interventions and promising results have emerged from the overview.

### *Aggressive, Agitated, and Disruptive Behaviours*

Several strategies showed promise in managing aggressive, agitated, and disruptive behaviours. A study rated as moderate revealed that a planned walking program was effective in reducing by 30% the number of aggressive events on a dementia special-care unit (Holmberg, 1997). Though the methodologies were rated as weak, simulated presence therapy (SPT) — a personalized audiotape of a family member's telephone conversation about cherished memories — significantly improved problem behaviours among residents with AD (Woods & Ashley, 1995); bright-light therapy significantly reduced agitation on treatment days (Lovell, Ancoli-Israel, & Gevirtz, 1995); calming music significantly decreased agitated behaviour during and after the music intervention (Tabloski, McKinnon-Howe, & Remington, 1995); and classical and favourite music decreased the number of repetitive disruptive vocalizations in two of three LTCF residents with AD (Casby & Holm, 1994). Additionally, informal caregivers' use of written cues was shown to be effective in decreasing repetitive vocalizations (Bourgeois, Burgio, Schulz, Beach, & Palmer, 1997). The lack of a significant decrease in agitated behaviours with hand massage and therapeutic touch may have been a result of the short duration of the effectiveness of these interventions (Snyder, Egan, & Burns, 1995).

### *Social Interaction*

Several interventions were shown to improve social interaction. The only study rated as strong in the overview demonstrated that a program of walking while engaged in conversation improved communicative function (Friedman & Tappen, 1991). Two studies rated as moderate found that an attention-focusing program improved participation in group activities (Rosswurm, 1991) and that the presence of a pet dog on a special-care AD unit significantly increased social behaviours (Kongable et al., 1989). Two studies, though rated as methodologically weak, found that a life-review program increased social interaction and orientation (Tabourne, 1995) and that reality-orientation therapy appeared to increase verbal ability but not functional ability in

LTCF residents with AD (Zanetti et al., 1995). Other studies rated as weak demonstrated that participatory music caused a trend towards improved sociability (Smith-Marchese, 1994) and that small-group activities resulted in increased walking with others and increased spontaneous singing (Martichuski, Bell, & Bradshaw, 1996).

### *Self-Care Ability*

Four studies, two rated as moderate and two rated as weak, examined interventions directed at improved self-care for people with AD. Three of the studies reported significant improvements, while the fourth — one of the two weak studies — demonstrated no significant effect. A skills-training program appeared to improve self-care ability (Tappen, 1994). Soothing music had a statistically significant effect, increasing the amount of food intake and lengthening the mealtime by 22%. Additionally, soothing music resulted in the patients eating by themselves more often and being fed by others significantly more often (Ragneskog, Brane, Karlsson, & Kihlgren, 1996; Ragneskog, Kihlgren, Karlsson, & Norberg, 1996). However, a sensory-integration program demonstrated no effect on task-oriented and disruptive behaviours (Robichaud, Hébert, & Desrosiers, 1994).

### *Day/Night Disturbances*

Although all three studies that examined the effect of bright light and music on day/night disturbances were rated as weak, the results are promising. Two of these studies reported that bright-light therapy appears to normalize disturbed sleep during the treatment period, with more severe behavioural disorders at baseline predicting greater clinical improvement (Mishima et al., 1994; Satlin, Volicer, Ross, Herz, & Campbell, 1992). The third study demonstrated that music appears to increase the number of hours of productive sleep in patients with AD (Lindenmuth, Patel, & Chang, 1992).

### *Wandering*

Several studies rated as weak and one rated as moderate built on the work of Hussian and Brown (1987) and examined the effectiveness of using visual barriers to limit hazardous exiting from a facility. Hussian and Brown's study concluded that a floor grid pattern in front of a door is effective in limiting potentially dangerous exiting in many individuals with dementia. Hewawasam's (1996) study, rated as moderate, supported these findings for participants diagnosed with AD and with

**Table 2** *Summary of Strong and Moderate Articles*

Study	Design (Weaknesses)*	Subjects	Intervention & Provider	Outcomes (Measurement Tools)
<b>Social Interaction</b>				
Friedman & Tappen (1991) USA LTCF	Randomized Control Trial Strong (e)	Subjects were ambulatory. AD: NINCDS-ADRDA, McKhann et al. (1984) Mini-Mental State Exam: mean 6.47 Age: mean 72.8 years (range 60–87) Males: 57% Intervention A: $n = 15$ Intervention B: $n = 15$ No significant differences between groups on Mini-Mental State Exam scores at pretest.	Group A: <b>planned walking with conversation</b> 30 minutes 3 times a week for 10 weeks. Group B: conversation only. Providers: Authors, RN, PhD & RN, EdD. Data were collected prior to and following the intervention.	<i>Significant:</i> Increased ability to communicate in Group A (Communication Observation Scale [Hoffman, Platt, & Barry, 1985], $p = .007$ ). <i>Nonsignificant:</i> Ability to communicate (Communication Assessment Scale [Tappen, 1988], $p = .057$ ).
<b>Aggressive, Agitated, and Disruptive Behaviours</b>				
Holmberg (1997) USA Special-Care Unit	Pretest/Posttest Moderate (d, e)	Physically active patients with disruptive wandering behaviour. Mini-Mental State Exam: 8 subjects scored 0–10 3 subjects scored 11–16 Age: mean 84.6 years (range 76–92) Females: 64% $N = 11$ Participation rate on average was 91%.	<b>Walking group</b> immediately after the evening meal for 1.5 hours, 3 times a week for a period of 1 year. Retrospective aggressive incident reports were counted for each day of the year by investigators who were blind to day of the week and dates of the walking group. Providers: 2–3 lay community volunteers specifically trained in safety and group-management procedures.	<i>Significant:</i> A 30% reduction in number of aggressive events between walking group weekdays and nongroup weekdays ( $p = .03$ ). <i>Nonsignificant:</i> Number of aggressive incidents between (a) walking group weekdays and weekends, and (b) nongroup weekdays and weekends.

\* **Key:** (a) Not random allocation. (b) If consent to participate had been sought from subject, next of kin, or legal guardian, less than 80% of eligible individuals consented to participate. If subject's consent had *not* been sought (i.e., with a retrospective chart review or an examination of the impact of an environmental change), subjects were not clearly described, allowing the study to be replicated. (c) More than 11% attrition. (d) Did not control for all potentially relevant confounders. (e) Data-collection strategies did not optimize validity.

Table 2 (cont'd)

Study	Design (Weaknesses)	Subjects	Intervention & Provider	Outcomes (Measurement Tools)
<b>Social Interaction</b>				
Kongable, Buckwalter, & Stolley (1989) USA Special-Care Unit	Repeated measures within-subject Moderate (a, d, e)	Diagnosed with AD, required supervision or assistance with activities of daily living. All participants but one had owned a pet in the past. Age: range 66–88 years Males: 83% N = 12	<b>Pet therapy:</b> weekly dog visitations followed by dog becoming a permanent resident. Observations of social behaviours were made in sets of two (individual and group) pretreatment, during weekly pet visitations, and permanent placement of pet.	<i>Significant:</i> Increased social behaviours during weekly visits and permanent placement of pet ( $p < .001$ ) (checklist developed by first author). <i>Nonsignificant:</i> Between the weekly and permanent-placement phase and between the individual and group settings.
Rosswurm (1991) USA 3 LTCFs	Random allocation Moderate (e)	AD or multi-infarct-type dementia. Mini-Mental State Exam: mean 10.5 ( $SD = 5.6$ ) Age: mean 84 (range 72–96) Females: 60% N = 30 Intervention: $n = 15$ Control: $n = 15$ No significant differences between the groups on demographic variables, Mini-Mental State Exam, dementia behaviour, and visual matching tasks at pretest.	The <b>attention-focusing group (AFG)</b> consisted of 3 activity segments: (a) welcoming and relaxation exercises; (b) perceptual-matching exercises, in which each member identified 2 matching objects from 4 objects of each category: solid colours, number clusters, lengths, and patterns; and (c) reinforcement with refreshments. The control group had refreshments and the opportunity for social interaction but no program. Each group met for 30 minutes 3 times weekly for 4 weeks. The posttests were completed 2 days and 3 weeks following the AFG. Provider: Author, RN, EdD.	<i>Significant:</i> Improvement in participation in group activities ( $t = 3.81, p < .001$ ) and in the visual matching exercises ( $t = 3.81, p < .001$ ) (checklists quantified participation in group activities and performance of visual matching exercises). Improvement in completion of the perceptual-matching tasks ( $p < .01$ ) (Rosswurm, 1989); however, these gains had not persisted 3 weeks later. <i>Nonsignificant:</i> Functional ability (Dementia Behavioral Scale [Haycox, 1984]) and Mini-Mental State Exam did not improve significantly.

Table 2 (cont'd)

Study	Design (Weaknesses)	Subjects	Intervention & Provider	Outcomes (Measurement Tools)
<i>Self-Care Ability</i>				
Tappen (1994) USA LTCF	Random allocation Moderate (c, e)	Dementia: Short Portable Mental Status Questionnaire (Pfeiffer, 1975): 6 or more errors out of 10. Mini-Mental State Exam: mean 6.4 ( $SD = 6.57$ ) Age: mean 84 years (range 59–102) Females: 75% $N = 72$ at baseline $N = 63$ at completion Intervention A: $n = 21$ Intervention B: $n = 21$ Control: $n = 21$ Subjects in 3 groups did not differ significantly on these characteristics or on functional ability at pretest.	Group A: <b>Functional skills training</b> focused on regaining function in the basic activities of daily living for 2.5 hours 5 times a week for 20 weeks. Group B: General stimulation incorporated traditional recreational activities such as dominoes, bowling, music, relaxation, and interest discussion groups. Provider: Clinical Nurse Specialist in Gerontology and Rehabilitation Aide. Posttest data were collected at the end of intervention by investigators who were blind to group assignment.	<i>Significant:</i> Skills-training group had improved ability to perform basic activities of daily living (Physical Self-Maintenance Scale [Kent, Kastenbaum, & Sherwood, 1972], $F = 3.17$ ; $df = 3,59$ ; $p = .04$ ; Goal Attainment Scaling [Brody, Kleban, Lawton, & Silverman, 1971], $p = .05$ ). <i>Nonsignificant:</i> Stimulation group had no significant effect on ability to perform basic activities of daily living (Physical Self-Maintenance Scale [Kent et al.]; Goal Attainment Scaling [Brody et al.]; Performance Test of Activities of Daily Living [Kuriansky & Gurland, 1976]). Similarly, the skills-training group had a nonsignificant effect when measured by the Performance Test of Activities of Daily Living (Kuriansky & Gurland), $F = 2.16$ ; $df = 3,59$ ; $p = .12$ .



Table 2 (cont'd)

Study	Design (Weaknesses)	Subjects	Intervention & Provider	Outcomes (Measurement Tools)
<i>Self-Care Ability (cont'd)</i>				
Ragneskog, Brane, Karlsson, & Kihlgren (1996) Sweden Psychogeriatric ward	Pretest/Posttest Moderate (b, c, d, e)	Dementia: DSM-III-R (American Psychiatric Association, 1987); NINCDS-ADRDA (McKhann et al., 1984). Mini-Mental State Exam: 16 subjects scored 0-10 4 subjects scored 11-24 Age: mean 80 years (range 69-94) Females: 50% N = 25 at baseline N = 20 at completion	Music was played 5 minutes before dinner until the last resident had finished the meal. The following design was used: (a) no music for 5 days, (b) soothing music for 8 days, (c) no music for 7 days, (d) tunes from the 1920/30s for 10 days, (e) no music for 7 days, (f) pop music for 8 days, and (g) a control period for 9 days. Data were collected by a Registered Psychologist, who was blind to the interventions, following periods b, d, f, and g.	<i>Significant:</i> The residents ate more when music was played, and the difference was particularly significant for dessert ( $p < .001$ ) (meals were weighed prior to and following eating). Irritability, anxiety, and depression also improved ( $p < .05$ ) (GBS-scale [Gottfries, Brane, Gullberg, & Steen, 1982]). <i>Nonsignificant:</i> Restlessness did not improve between the music periods and the control period (GBS-scale [Gottfries et al., 1982]).
<i>Wandering</i>				
Hewawasam (1996) UK NHS trust hospital	Pretest/Posttest Moderate (d, e)	Residents who had a tendency to open the exit doors. AD: 4 subjects Parkinson's disease: 1 subject Other forms of dementia: 5 subjects Mini-Mental State Exam: mean 8 (6 subjects severe, 4 moderate) Age: mean 76 years Females: 70% N = 10	Following a 3-week period of baseline observations, eight 3.8 cm strips of black tape were applied 3.8 cm apart horizontally in front of the exit door for 1 week. Following another 1 week of baseline observations, the process was repeated with the tapes applied vertically. The two research assistants, who were blind to the subjects' diagnoses, recorded the frequency of door contacts by each subject in specified time intervals.	<i>Significant:</i> Reduction in the number of exit-door contacts by up to 97% for the subjects with AD and Parkinson's disease with the use of the grid ( $p = .01$ to .003). <i>Nonsignificant:</i> Subjects with other forms of dementia.

Parkinson's disease but did not find this strategy effective for subjects diagnosed with other forms of dementia. Namazi, Rosner, and Calkins (1989) found a cloth panel concealing the doorknob to be more effective than a taped grid in decreasing exiting in AD residents with symptoms of visual agnosia. Dickinson, McLain-Kark, and Marshall-Baker (1995) supported these results by suggesting that visual barriers camouflaging the panic bar or doorknob are effective controls for reducing hazardous exiting in residents with dementia. Chafetz (1990) found the ineffectiveness of the grid to be related to the presence of glass windows in the doors. Lastly, Namazi, Rosner, and Rechlin (1991) found that significant personal memorabilia displayed outside bedrooms was helpful in assisting some residents with mild to moderate levels of dementia to find their bedrooms.

## Discussion

### *Limitations*

Common methodological weaknesses included: (a) absence of a control group (73.3%); (b) failure to obtain resident or guardian consent for participation (64.4%); (c) attrition rate greater than 11% (48.9%); (d) inadequate control for all potentially relevant confounders (86.7%); and (e) poorly described or un-pretested method of data collection, or possible investigator bias (100.0%). Many of the studies did not use a control group and therefore could not control the effect of attention; consequently, their reported positive effect could be partly the result of the attention the subjects received by engaging in the activities.

Some of these methodological weaknesses may reflect the editorial policies and guidelines of the journal, rather than the quality of the research itself. Many journals publish nursing research for a target audience of clinicians interested in the implications of findings and the recommendations, rather than in a description of the study; such journals may omit details about the research design and the methods.

Additionally, demonstration of effectiveness could have been hindered by several factors: (a) intervention of too short a duration to produce significant change; (b) sample sizes too small to produce measurable effects; or (c) instruments insensitive to small increments of change in elderly persons with dementia of the Alzheimer type. Moreover, conducting research with cognitively impaired residents is especially challenging because of the unpredictability of their behaviour; their misunderstanding of, or their inability to understand, how to participate in an intervention; and the high levels of noise and

disruptions on the units. The findings of this examination must be considered in light of the methodological limitations found in all of the studies included in the overview.

### *Implications for Research*

The overview revealed several areas in which researchers might enhance the reliability and validity of their studies. The rigour of the research might be strengthened by the following measures: incorporating a control group or a delayed-intervention group; reporting on the level of agreement to participate and the attrition rate; collecting information on possible confounders and controlling for these; using blinded data collectors or measuring interrater reliability; describing the psychometric properties of the instruments used; and conducting analyses to determine the level of significance. The overview revealed the need for further research, to examine these and other strategies in greater depth. What is the optimal duration and intensity of interventions? What specific aspects of the interventions contribute to the outcomes? Can an organizational structure ensure that the most appropriate care provider implements the strategy? These are a few of the most pressing questions that remain to be addressed by future research in this area.

Replication of all of the studies included in the overview would promote implementation of the interventions. Specifically, replicating the studies with individuals diagnosed with a variety of dementias and with different levels of cognitive impairment would help determine which strategies are appropriate for each particular person. Conducting the studies at multiple sites would help build confidence in the generalizability of the results. Longitudinal studies would help in assessing long-term effectiveness in preventing or delaying the progression of the disease and in reducing caregiver stress. The cost-effectiveness of implementing the interventions requires further study and might be of particular interest to policy-makers and administrators.

Systematic overviews that include other research methods, such as qualitative approaches, would broaden our understanding of the meaning of the disease process and the effectiveness of the interventions from the perspective of persons with dementia and their caregivers. Quality of care and the quality of life of the recipients of care must be taken into account in designing interventions. Research funding targeting these areas will be necessary for the design and conduct of high-quality studies using samples of adequate size. Policy-makers and administrators have a role to play in supporting

additional research and in facilitating implementation of the strategies that have shown promise in managing the behavioural symptomatology associated with dementia of the Alzheimer type.

### *Implications for Practice*

Behavioural symptoms associated with dementia of the Alzheimer type — aggressive, agitated, and disruptive behaviours; poor social interaction; decreased self-care ability; day/night disturbances; and wandering — have detrimental effects on the physical and mental status of the individuals and their caregivers. The management of many of these behaviours has traditionally included chemical and physical restraints. However, concerns have been raised that such interventions may create additional adverse physical and psychological problems (Werner, Cohen-Mansfield, Braun, & Marx, 1989). Moreover, the shortage of health-care professionals in LTCFs makes it difficult to implement the high staff:resident ratio necessary to ensure the safe management of problematic behaviours (Gerdner & Buckwalter, 1996). Alternative interventions are needed to manage the behavioural symptomatology associated with dementia of the Alzheimer type. While this area of research remains in its infancy, innovative interventions and promising results have emerged from the systematic research overview.

### **Conclusion**

Studies rated as strong or moderate and demonstrating positive effects can be recommended with more confidence than those rated as weak. For example, Friedman and Tappen's (1991) study, the only one rated as strong in validity, demonstrated that a walking program increased participants' ability to communicate when measured using the Communication Observation Scale (Hoffman, Platt, & Barry, 1985). This strategy can be implemented with a fair degree of confidence that the desired effect will be produced. However, it should be noted that replicating this study in different settings would enhance the generalizability of the findings.

Although the results of the other studies are less conclusive, these other strategies are worth trying as well, as this overview has revealed the best available scientific evidence for managing the behavioural symptomatology of dementia of the Alzheimer type. The interventions are clinically safe and most can be easily implemented in a wide variety of settings: acute care, long-term care, adult day-care, home care. Although occasionally the interventions were implemented by the

researcher or by individuals with specialized training, most caregivers of people with dementia could use the strategies described.

The findings, considered in light of the various methodological limitations, indicate that research exists, although it is in its infancy, to support the use of strategies for managing the behavioural symptomatology associated with dementia of the Alzheimer type.

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## Peer Visitor Support for Family Caregivers of Seniors with Stroke

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Les objectifs de cette étude d'intervention subventionnée par de multiples organismes canadiens étaient de : (1) mettre en place un programme de soutien fondé sur des visites à domicile menées par des paires compétentes et destinées aux soignantes naturelles des personnes âgées ayant subi récemment un accident cérébrovasculaire; (2) surveiller, décrire et évaluer l'intervention de soutien; et (3) mesurer l'impact de l'intervention de soutien menée par des paires sur les perceptions des soignantes naturelles concernant le soutien qu'elles reçoivent de la collectivité, leur fardeau, leur stress et leurs compétences, ainsi que l'utilisation des services de santé par les survivants d'un accident cérébrovasculaire. Les deux premiers objectifs constituent le point de mire de cet article. Vingt soignantes naturelles ont d'abord été visitées par une professionnelle de la santé (infirmière, ergothérapeute) pour une évaluation, puis par une paire (soignante naturelle ayant vécu la même expérience), à une fréquence de deux fois par semaine, pendant 12 semaines. Les transcriptions d'entrevues enregistrées qui ont été menées auprès des participantes peu de temps après l'intervention et aussi quelque temps après (trois à six mois), et les cahiers d'écoute des professionnelles et des paires ont été soumis à une analyse de contenu. Les paires visiteuses offraient, aux soignantes naturelles, un soutien émotif, ainsi qu'un appui sur le plan de l'information et de l'affirmation. Les soignantes naturelles ont affirmé que l'intervention était satisfaisante en ce qui avait trait à leurs besoins en soutien, qu'elle contribuait à une diminution de certaines de leurs demandes en soins de santé et consolidait leur confiance personnelle et leur capacité d'adaptation.

The objectives of this nationally funded intervention study were to: (1) implement a home visiting support program for family caregivers of seniors with a recent stroke using experienced peers; (2) monitor, describe, and evaluate the support intervention process; and (3) measure the impact of the peer support intervention on caregivers' perceptions of their social support, burden, stress, and competence and the use of health-care services by stroke survivors. This paper focuses on the first two objectives. Twenty family caregivers were visited initially by a health professional (nurse, occupational therapist) for assessment, and thereafter twice weekly for 12 weeks by a peer (experienced family caregiver).

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Transcripts of audiotaped post-intervention and delayed post-intervention (3 and 6 months) interviews with participants and the diaries/logs of professionals and peers were subjected to content analysis. Peer visitors offered emotional, informational, and affirmational support to family caregivers. Family caregivers reported that the intervention met their support needs, lessened some of their caregiving demands, and enhanced their confidence and ability to cope.

Older Canadians are more likely than others to suffer from chronic conditions (Health Canada, 1997) that restrict their activities (Rosenberg & Morre, 1997). Most Canadians living with chronic conditions (Statistics Canada, 1997) and most elderly people (Canadian Study of Health and Aging Working Group, 1994) are cared for and supported by family members. Stroke is a common chronic condition that afflicts the elderly, results in disability and caregiver burden, and accounts for a significant proportion of hospitalizations and deaths among seniors. Stroke represents 19% of all deaths from cardiovascular diseases; stroke was the cause of 7% of deaths in Canada in 1994 and accounts for 40% of patient days in hospital (Heart and Stroke Foundation of Canada, 1997). Whether or not survivors are discharged to their home depends upon the severity of stroke deficits and the willingness and ability of family members to help them to live in the community (Macnamara, Gummow, Goka, & Gregg, 1990).

Studies suggest that family caregivers of elderly persons with stroke need support and guidance as they cope with the demands of the caregiving situation (Anderson, Linto, & Stewart-Wynne, 1995; Smurawska, Alexandrov, Bladin, & Norris, 1994; Williams, 1994). Demands encountered by caregivers relate primarily to the stroke survivor's behaviour and physical care (Macnamara et al., 1990; Williams). Confidence in their ability to handle the challenges of the caregiving role may diminish. Furthermore, the caregiver's relationship with their elderly relative with stroke may suffer. Caregivers face adjustment difficulties following a family member's first stroke (Schultz & Tompkins, 1990). Given the stress associated with their new caregiving role, they may experience negative mental and physical health outcomes (Canadian Study of Health and Aging Working Group, 1994; Statistics Canada, 1997; Tyman, 1994).

Given the potential deficits in support from the natural network and the need for support specific to caregiving demands, support interventions for the family caregivers of stroke survivors are important. Such interventions can modify or mobilize natural networks, create new sources of support, decrease conflict, enhance the quality of support (Barrerra, 1991; Maguire, 1991), or moderate the costs of providing and seeking support (Fisher, Goff, Nadler, & Chinsky, 1988).

Support interventions are most useful when they enhance role functioning, develop new skills, enable coping (Heller, 1990), or alleviate social isolation (Maguire).

The support portion of intervention programs for caregivers of seniors is typically not explicated and not matched to caregiving burdens or demands. Furthermore, intervention programs have emphasized professional rather than lay/peer support (e.g., Forster & Young, 1996). Finally, support intervention studies for family caregivers of the elderly have not focused explicitly on caregivers of stroke survivors.

### **Objectives**

The objectives of this nationally funded intervention study were to: (1) implement a home visiting support intervention, delivered by experienced peers, to address the caregiving demands and support needs of family caregivers of seniors with a recent stroke; (2) monitor, describe, and evaluate the support intervention processes; and (3) measure the impact of the peer support intervention on caregivers' social support, caregiving demands, stress, and competence and the use of health-care services by stroke survivors. This paper focuses on the first two objectives and the evaluation of the support intervention process.

### **Research Questions**

1. What types of social support are provided by the peer visitor intervention?
2. What are family caregivers' perceptions of the support intervention processes?
3. What are family caregivers' perceptions of the impact of the support intervention on their caregiving demands, support needs, and coping?

In order to document the caregiving demands and support needs discussed with peer visitors (intervention processes) and to provide background information for the perceived impact of the intervention on caregiving demands and support needs, supplementary research questions were posed:

4. What caregiving demands are experienced by new family caregivers of seniors with stroke?
5. How do family caregivers of seniors with stroke appraise their support needs?



### **Theoretical Context**

Partners/spouses, family members, friends, neighbours, and coworkers (House, Umberson, & Landis, 1988) may all be sources of support to those caring for elderly persons with stroke. The four specific functions or types of social support are: emotional, instrumental (practical), informational, and affirmational (House et al.). By communicating information, esteem (affirmation), aid (practical support), and emotional help, support providers may enhance the caregiver's ability to cope, moderate the impact of perceived stressors, and promote health (Stewart, 1993).

Integration in a social network and ability to draw support resources from the network can help maintain health and facilitate physical recovery (Bloom, 1990). However, not all persons caring for an elderly person with stroke have people in their social network who are willing and able to provide support. Health and illness can affect the availability and quality of social support. The continued need for social support in chronic stressful situations like illness and caregiving can deplete support and drain the social network of resources that contribute to support (Stewart, 1993).

Support functions will be most effective if they are matched to specific stressors encountered (Cutrona, 1990). Furthermore, specific types of support are most effective when they are provided by sources that are perceived by the recipient as supportive (Dakof & Taylor, 1990). Thus, even when caregivers have supportive persons in their networks, these persons may not be able to provide them with the specific support they need to manage their caregiving demands. Their support efforts may have negative effects (Brenner, Norwell, & Limacher, 1989). Indeed, most social relationships have supportive and stressful elements (Rook, 1990). Even successful relationships involve lapses in support, miscarried efforts (Sarason, Sarason, & Pierce, 1990), and failed support modes or functions (Eckenrode & Gore, 1990). These negative effects are most likely to occur when there is a continued need for social support in chronic stressful conditions such as caring for a senior with a stroke. Moreover, negative interactions are more predictive of poor emotional health than supportive interactions (House et al., 1988; Rook). These drawbacks of support affect both support providers and support recipients.

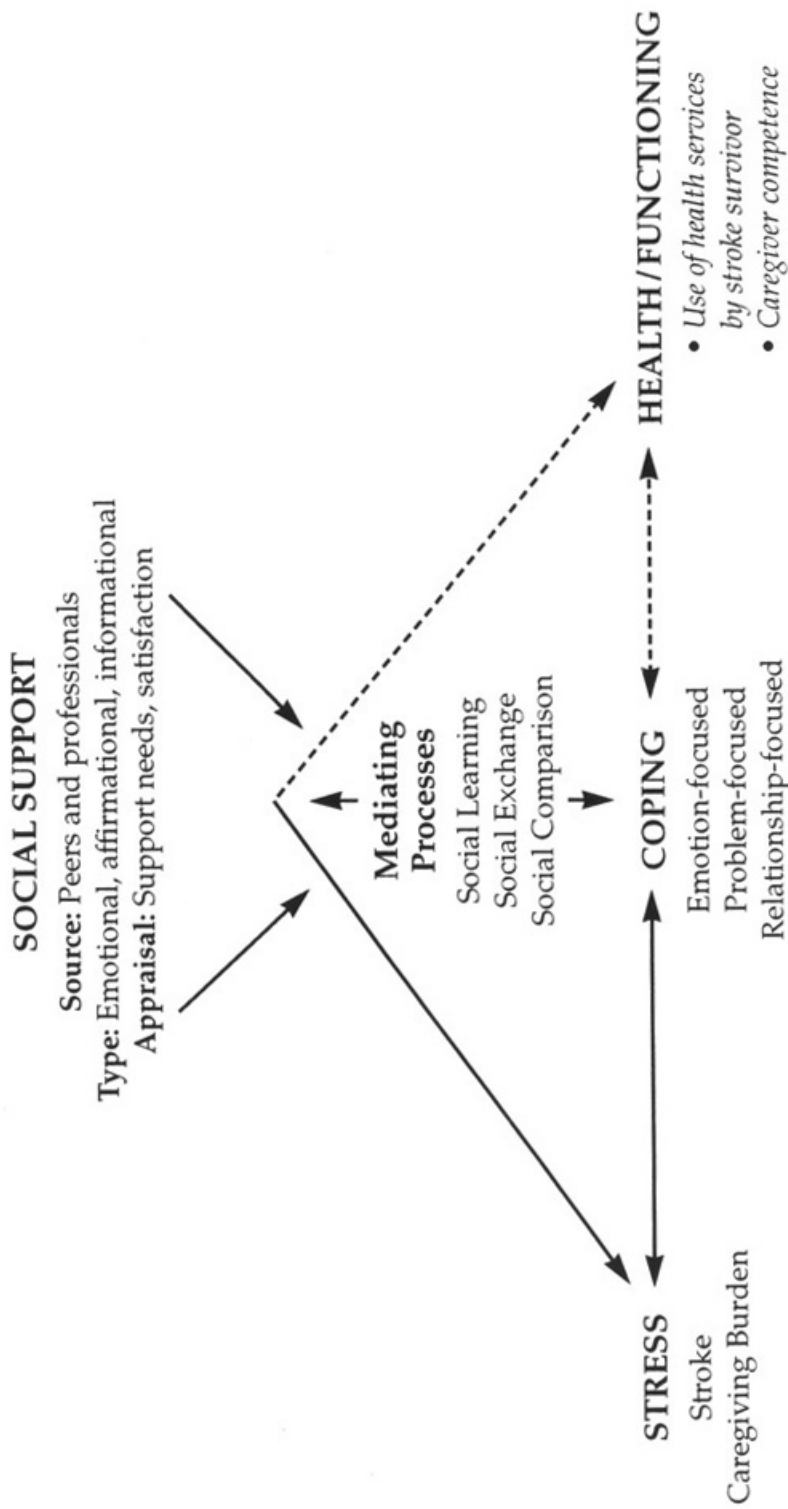


Social support is conceptualized as a coping resource or coping assistance (Thoits, 1986). Supportive persons can alter appraisal of caregiving stressors, sustain coping efforts, influence choice of coping strategies, augment coping resources available to deal with stressful encounters, and change the trajectory of coping. Moreover, perceived availability of social support has been linked to coping effectiveness (Bennett, 1993). Conversely, the ways in which the caregiver copes may provide important clues to potential supporters about whether support is needed and, if it is, about the types of support needed (Silver, Wortman, & Crofton, 1990). Coping with caregiving can be conceptualized as managing distress (emotion-focused), completing instrumental tasks (problem-focused) (Lazarus & Folkman, 1986), and attending to each other's needs in the caregiver/stroke survivor relationship (relationship-focused) (Coyne & Smith, 1991).

This intervention focused on provision of peer support to supplement the depleted or strained networks of family caregivers, by offering emotional, informational, and affirmational assistance (House et al., 1988). Peer support has a potential effect on coping efforts, and may influence the choice of coping strategies (Folkman et al., 1991). Furthermore, peer support may influence the use of health services by stroke survivors.

Three mediating processes were anticipated within this support intervention. The process of *social comparison* occurs among peers, and, depending on the direction and dimension of comparison, will influence emotions and coping effectiveness (Gottlieb & Selby, 1989). Norms of equity or *social exchange* suggest that support should be bidirectional (Tilden & Galyen, 1987). However, persons who are ill and their caregivers frequently form non-egalitarian, non-reciprocal relationships (Tilden & Galyen). As social exchange and equity theories indicate, support may involve benefits and costs for both recipients and providers. Yet reciprocity is neglected in many social-support studies (Winemiller, Mitchell, Sutcliffe, & Cline, 1993). Interventions involving peers typically promote reciprocity (Katz, 1993). *Social learning* theory posits that people's perception of their capabilities (self-efficacy) affects their behaviour, thinking, and emotional reactions in stressful situations (O'Leary, 1985) and that personal and situational influences alter coping behaviour (Bandura, 1986). Thus family caregivers may learn from peer visitors as role models.

**Figure 1** *Conceptual Framework*



(Italics = quantitative results reported in a separate paper)

## Methods

### *Intervention Design*

This intervention introduced guidance and information around caregiving within the context of a supportive relationship with an experienced peer. As family caregivers themselves, the peers had an understanding of the caregiver's situation and an appreciation of the caregiver's concerns about caregiving demands and about her/his performance. Participants received two home visits per week for a period of 12 weeks. The support intervention was implemented soon after the elderly person who had an initial stroke was discharged from hospital. This is the point at which new caregivers may be most fearful, lacking in confidence, in need of someone to ease their apprehensions about caregiving demands, and in need of ongoing reinforcement in performing specific caregiving tasks.

The professional completed a preliminary assessment of the stroke survivor's functional status in the home and accompanied the peer at the first intervention session. Once the professional withdrew, she/he was on call (as a consultant) to deal with problems or concerns raised by either the peer or the family caregiver.

The peer visitor conferred periodically with the professional; provided ongoing emotional, informational, and affirmation support; and monitored the caregiver's needs and the unanticipated effects of the intervention for both the caregiver and the stroke survivor.

The specific types of support provided by peers and professionals, and the support processes inherent in the intervention, are delineated below, in the third and fourth subsections of the Results. The conceptual underpinnings of the intervention are described above, in the section entitled Theoretical Context.

The guide for peer visitors encompassed specific issues and strategies pertaining to each of four caregiver burden domains — physical care, changes in family life, changes in caregiver roles, and emotional needs of caregivers — that might be raised in peer-caregiver interactions. The peer visitor listened carefully to the caregiver, offered suggestions concerning coping with different burden domains, encouraged problem-solving, and dealt with interpersonal tensions between the caregiver and the care recipient that might reduce the efficacy of caregiving.

Several steps were taken to control sources of bias and other potential problems. The professionals received specific project-related train-

ing in observation techniques and evaluation criteria. Both professionals and peers received empathy training. Peer visitors were taught how to document the delivery of support in diaries. All participants were encouraged to refrain from discussing details of the intervention with other caregiving families during the study period.

Family caregivers were assured that their participation was voluntary, that they could withdraw at any time, that confidentiality and anonymity would be protected, and that only group data and anonymous quotes would be presented in reports of results. The project received ethical approval from the research team's university.

### *Project Personnel*

The health professionals — nurses and occupational therapists — were recruited to provide ongoing support and guidance to the peer visitors. The health professionals used their assessment, communication, teaching, and supervisory skills to help the peer visitors to: (a) maintain the major focus on the family caregivers' needs; (b) encourage the caregivers to share their experiences; and (c) provide emotional support by listening to the caregivers' stories. By providing situation-specific feedback, the professionals enabled the peers to hone their interaction skills and boost their confidence in their ability to provide effective support.

All peers had experience caring for a relative or another elderly person recovering from stroke. Most had cared for mothers; a few had cared for husbands. Although this was not a criterion, all of the peers selected were women. All had well-developed communication skills. Selection of peer visitors was based in part on whether they lived reasonably near a caregiver.

Potential peer visitors and professionals for the intervention study were easily identified through stroke clubs and newspaper advertisements.

To prepare peers and professionals for the program, a one-day training session was held, focusing on how personal beliefs might affect peers' ability to provide support, ways of using personal strengths or obtaining assistance from professional partners, and strategies for creating supportive partnerships that might reduce caregiver isolation and build caregiver competence. Simulated situations and role playing were used. Strategies were identified for assisting individuals who might need more support than the intervention could offer.

### *Sample Selection and Recruitment*

The convenience sample was drawn from family caregivers and elderly stroke survivors across Nova Scotia and New Brunswick. The inclusion criteria for persons with stroke were: men or women 55 years or older who had experienced a stroke for the first time, had been recently discharged from hospital to the community, and continued to have a deficit or range of deficits. The inclusion criteria for family caregivers were: spouses or children who either lived with the elderly person or visited on a daily basis and saw themselves as the primary caregiver.

The convenience sample was recruited through numerous community sources, including professional associations, practitioners, consumer groups, non-governmental organizations (NGOs), and public avenues such as the media. To ensure recruitment of a sufficient number of caregivers, multiple avenues (print and electronic media, church bulletins, neurologists and family physicians, stroke clubs, hospitals, Victorian Order of Nurses, Heart and Stroke Foundation, etc.) were used. Although interest was expressed by all groups, few referrals resulted. The lack of initiative on the part of the health professionals approached for referrals may have been a result of their busy schedules and other priorities. For example, calls to 900 family physicians resulted in only three referrals.

### *Evaluation of Intervention Process: Data Collection and Analysis*

The provision or delivery of support was documented. After each visit, the peer helper recorded the diary account of the visit, describing subjects of conversation and documenting types of support provided. The professionals kept records of contacts with peers and family caregivers. The family caregiver also commented on types of support received and satisfaction with the intervention during the post-intervention interviews and interviews 3 and 6 months later.

Transcripts of the audiotaped post-intervention and delayed post-intervention (3 and 6 months) interviews of participants (family caregivers) and the peer and professional diaries/field notes were content analyzed using a category system that was developed inductively from the data by the research team. The research assistant coded the data in consultation with the principal investigator. The data were analyzed for both manifest and latent content. The units of analysis were full references to any content related to: (1) nature of the demands involved in caring for an elderly relative with a chronic condition; (2) caregivers' reactions to those demands; (3) types, sources, and appraisal of support

from social networks and from peers; (4) support intervention processes; and (5) impact of the intervention. Each category and subcategory was fully and clearly defined and categories were mutually exclusive. Frequency counts of categories and subcategories were identified using *Ethnograph*. (Five measures — social support, caregiving confidence, caregiver burden, global perceived stress, and use of health services — were administered pretest, post-test, and delayed post-test [3 and 6 months]. These quantitative results, which address the third objective, are reported in a separate paper.)

### Profile of Family Caregivers

All 20 caregivers were women, average age 58.8 years ( $SD = 10.66$ ). Most caregivers (90%) were married, and the spouse of the stroke survivor (65%). The remainder were daughters (20%), daughters-in-law (5%), and other relatives (10%) of the stroke survivor. Over half (60%) of the caregivers had not completed a high school education. Generally, the caregivers provided care to older ( $M = 70.8$  years,  $SD = 12.54$ ) males (90%) with whom they lived (85.5%). On average, those caregivers who lived with the stroke survivor had lived with them for over 30 years. The average interval between the time of the stroke and the start of the support intervention was 9 months ( $SD = 4.61$ ), although some caregivers were visited as early as 3 months following the stroke ( $range = 3$  to 18 months).

### Results

The key themes and sub-themes identified in peers' diaries, professionals' field notes, and interviews with the caregivers are summarized below. Pertinent quotations from family caregivers, peer visitors, and project professionals are interspersed throughout.

#### *Demands of Caregiving (RQ4)*

These new caregivers of stroke survivors eloquently described the primary demands of caregiving to peer visitors and during post-intervention interviews. These demands included providing physical care, managing emotional and behavioural reactions of the stroke survivor, coordinating the health care of the stroke survivor, and facilitating the occupational and social functioning of the stroke survivor.

All caregivers expressed considerable concern to peer visitors about managing the symptoms and deficits experienced by their family member with stroke. They worried about the effects of the stroke, the



**Table 1** *Primary and Secondary Demands of Caregiving*

Primary Demands	(N = 20)
<i>A. Physical Care</i>	
Managing/worrying about symptoms/deficits	20
Constancy of care/constant responsibility	15
Assisting with activities of daily living	10
Adhering to a schedule/routine of care	8
Managing crises	5
<i>B. Dealing with Emotional and Behavioural Reactions of Stroke Survivor</i>	17
<i>C. Coordinating Formal and Social Health Care of Stroke Survivor</i>	
Interacting with health professionals and/or health-care system	14
Making appointments	8
Negotiating/clarifying caretaking roles with family	5
Arranging for community services	3
Advocating for stroke survivor's care	2
<i>D. Facilitating the Occupational and Social Functioning of Stroke Survivor</i>	8
<b>Secondary Demands</b>	
<i>A. Personal Needs of Caregiver</i>	
Respite/time off	17
Fatigue — getting rest/sleep	16
Managing own illness(es)	13
Dealing with own emotional reactions or concerns	12
Planning for the future	4
<i>B. Effect on Family</i>	
Finances	9
Family relationships	8
Marital relationships where stroke survivor is a spouse	6
Housing requirements	4
Loss of friendships	3
Marital relationships where stroke survivor is not a spouse	2
<i>C. Family Caregiver Role Involvements</i>	
Other caregiving commitments	8
Paid work outside home	5
Household maintenance and responsibilities	3

deterioration of the survivor's health, and the possibility of another stroke. Many caregivers (75%) spoke of the constancy of worrying about the stroke survivor and their vigilance concerning symptoms, medication use, and other aspects of care. They were reluctant to leave the stroke survivor alone and felt "tied down." Caregivers fulfilled a variety of physical functions, including changing dressings and treating minor physical problems. Many caregivers (50%) assisted the stroke survivor with dressing, eating, getting to the bathroom, washing, and other personal activities of daily living. Other physical care demands included adhering to a routine of care (40%) and managing crises (25%). The following examples were documented in the peer visitor diaries.

*CG can't go unless stroke survivor (SS) is okay. She can't stay too long. Meals are prepared around what SS can eat and when. [peer visitor — PV]*

*CG is sure her mother is going to have another stroke as her blood is changing every test and that is what it did before. It will be a year in April and she can't shake the feeling. [PV]*

In the initial post-intervention interview, one caregiver said:

*The thing is she's on my mind whether she falls or if she has more strokes, which could happen any time... [caregiver — CG]*

Caregivers reported to peer visitors that they found it difficult to deal with the emotional and behavioural reactions of the stroke survivor (85%). Caregivers indicated that sometimes stroke survivors behaved towards them in ways that were unkind, unappreciative, and even abusive. Problems with memory presented concerns. In the first interview post-intervention, one family caregiver said:

*I shouldn't say this but I feel there is another man, another person, inside his body. [CG]*

Caregivers also reported negative experiences in their interactions with health professionals and the health-care system (70%). Other sources of stress pertaining to coordination of care included arranging for appointments (40%), arranging for community services (25%), and advocating for the health care of the stroke survivor (10%).

*CG is angry with medical professional about dumping her mother from the hospital when discharged and not telling CG what to do or how to cope. [PV]*

Caregivers indicated that they wished stroke survivors would "do more for themselves" and that they attempted to facilitate the

survivor's participation in self-care, meaningful activities, and social activities (40%).

*CG was going to get SS to help her put windshield washer fluid in the car after his nap. She tries to get him to do things like this so he'll feel like it is a help to her. [PV]*

Secondary caregiving demands described by these caregivers included the devastating impact of the stroke on their own personal needs and role involvements and on the family unit (see Table 1). In addition to their caregiving responsibilities, caregivers had to balance the demands of other roles, such as caring for elderly parents, spouses, children, and grandchildren (40%), paid work (25%), and household maintenance (20%). Family caregivers contended that the additional role of caregiver interfered with their rest. Caregivers (85%) indicated that they did not get enough time to participate in personal activities and social interactions. The types of respite activities engaged in by caregivers included hobbies, walking, going to the library, and shopping.

*Her mom thinks she should take the phone to the bathroom with her. CG was very upset... It's that she isn't getting enough time to herself. [PV]*

One family caregiver said:

*I do everything for him that I can. Many times I feel worn from it... sometimes I'm downright exhausted. [CG: Int2]*

Another caregiver commented on the need for respite:

*I started taking him to the Adult Day Care one day a week... He enjoys that in there, and I can leave him and have the day to do whatever I want to do. [CG: Int2]*

Over half (65%) of the caregivers revealed to peer visitors that they had health problems of their own (e.g., arthritis, diabetes, anxiety). Consequently, they had to cope with their symptoms and navigate the health-care system. Many caregivers were concerned about the impact of their health problems on their ability to care for the stroke survivor. They also had to deal with their own emotional reactions to their caregiving responsibilities (60%) and changes in their relationship with the stroke survivor (13%).

*CG just recently had a heart attack. She tires out quite easily and feels that sometimes she doesn't have the energy to put towards helping stroke survivor. [PV]*

A major effect on the family unit involved finances (45%). Changes in financial circumstances resulted from several factors. Income was

depleted as a result of the loss of the stroke survivor's income and/or the loss of the caregiver's income, as many caregivers quit work in order to care for the stroke survivor. New expenditures for services that the stroke survivor had formerly provided, and for respite care and medications, also placed a strain on the family finances. Caregivers expressed concerns related to family relationships and strategies for reducing and managing real or potential familial conflict (40%).

### *Caregivers' Appraisal of Support Needs (RQ5)*

Caregivers spontaneously discussed their support needs, arising from gaps and deficiencies in support, with peers. While people in their network, such as family members and friends, provided physical care of stroke survivors and transportation (instrumental support), 40% of the caregivers indicated that they did not have people available who could meet their needs for emotional, affirmational, and informational support. Even when potential support providers were available, 35% of the caregivers reported that persons in their network either were unable to provide help or provided insufficient help. Another 15% reported that they did not believe the support they received from family and friends was helpful (i.e., miscarried helping).

During caregivers' discussions with peer visitors, several referred to inadequate support and stressful interactions with family members. Support was either absent, insufficient, or miscarried. Many family caregivers referred to the absence of support during interviews:

*Don't mention Homecare... They interviewed us, and we had meetings at the hospital when [the stroke survivor] was being discharged. That was last May, and there has been nothing. Absolutely nothing. And we're just getting by. But we've had absolutely no help from all this. [CG: Int2]*

*I don't have any family so it makes it hard. And at one time we used to have more neighbours around... They had to move. And all Mom's friends are gone. And all the ones that are left here, they are never home. They are working all the time. So there isn't anybody I can depend on. [CG: Int1]*

Other caregivers indicated that network members were unable to help:

*My brothers and sisters live about 100 km from here. They are not actually able to drop in and help... And my in-laws are just too old to be helpful. [Int3]*

Some caregivers referred to insufficient support:

*When Mom came home at first, she [sister] was there two afternoons a week when she thought it was a lot. To me it was wonderful. It wasn't*

*enough but it was all I had so I would grab it... But two weeks before Christmas that ended. [CG: Int1]*

Many caregivers had experienced miscarried helping.

*She [sister] said, "Why don't you just pack him off to a nursing home? You would have a good rest." And I think, "Yes, I know. That is fine for you to say." [CG: Int3]*

Finally, caregivers encountered stressful interactions:

*You can tell family members, they don't understand. They make you feel that they don't believe you. [CG: Int2]*

Clearly, the caregivers had unmet emotional, affirmational, and informational support needs. There was a strong need for the supplementary support provided by the project peer visitors and professionals.

### *Types of Social Support Provided by Intervention (RQ1)*

Peer visitors provided emotional, affirmational, informational, and occasional instrumental support. Project professionals offered primarily informational support (see Table 2).

**Emotional support.** All caregivers indicated that they received emotional support from peers during the intervention. Listening was a central component of every caregiver/peer relationship. The presence of the peer provided caregivers with an opportunity to tell their "stories" and to vent their anger and frustrations. Caregivers confirmed that understanding was a very important element in the support provided (90%). The peers' common experience as caregivers was identified as the basis for their understanding. Aside from caregiving concerns, caregivers and peers talked about a wide variety of topics: interests, hobbies, people they knew in common, families, cooking, and work. These exchanges allowed the caregiver to build rapport and develop a foundation for the relationship with the peer. Interactions served as a point of social comparison regarding the behaviour and functioning of their relative.

*I thought she was a good listening presence. [CG]*

*Before she started coming I...didn't have anybody to really talk to that would understand. [CG]*

Peer visitors expressed concern primarily about the caregivers' own health — getting sufficient rest, exercise, and time for themselves (70%). The peer visitors attempted to create an atmosphere in which caregivers would feel comfortable expressing themselves, sometimes by asking

**Table 2** *Types of Support Provided by Peer Visitors and Professionals*

Types of Support	(N = 20)	Source of Support
<b>A. Emotional Support</b>		
Listened	20	Peer visitors
Conveyed understanding	18	Peer visitors
Provided companionship	16	Peer visitors
Expressed concern for caregiver as a person	14	Peer visitors
Encouraged expression of emotions and recounting of experiences	12	Peer visitors
Provided comfort	10	Peer visitors
Conveyed empathy	10	Peer visitors
Provided reassurance	7	Peer visitors
<b>B. Affirmational Support</b>		
Positive feedback or encouragement	18	Peer visitors
Affirmation that decisions made or strategies used are appropriate	16	Peer visitors
Sharing of feelings and experiences	16	Peer visitors
Affirmation that caregiver is not alone	12	Peer visitors
<b>C. Informational Support</b>		
Information about community resources	15	Peers & Professionals
Oral explanations about stroke	12	Peers & Professionals
Explanations about coping	11	Peer visitors
General information about caregiving	11	Peers & Professionals
Print material	6	Peers & Professionals
Access to other caregivers or self-help groups	6	Peer visitors
<b>D. Instrumental Support</b>		
Locating of equipment	8	Peer visitors
Coordination of care	3	Professionals
Transportation	1	Peer visitors



questions, other times through "active" listening (60%). Peer visitors often provided comfort (50%), in conjunction with listening, understanding, sharing similar experiences, and "just being there." Finally, peer visitors were empathetic towards the caregivers (50%); the foundations for empathy were similar experiences and having "been there."

**Affirmational support.** Most caregivers indicated that they received affirmational support from the peers. Positive feedback or encouragement sometimes focused on particular aspects of caregiving or specific caregiving activities. In addition, peer visitors offered affirmation that caregivers' decisions or strategies were appropriate and that they were not alone in their caregiving experiences and feelings. Peer visitors also related difficulties they had experienced so that caregivers could see that they were handling similar situations effectively.

*CG called homecare to talk about services available for her. I complimented her on doing this. [PV]*

*I mention it is common for caregivers to be hard on themselves and think that others would do a much better job in the situation. [PV]*

*Peer would offer advice or something that had happened in her situation that was similar. [CG]*

**Informational support.** The caregivers received informational support from peers and/or professionals. The peers provided informational support based on their own experiential knowledge (*social learning*). The professionals provided information either directly to the caregiver or indirectly through the peer. The peers offered information about local day programs, home-care or homemaker services, library resources, "friendly visiting" programs, financial assistance, transportation options, and seniors' housing (75%). In many cases caregivers were not aware of the resources available in their communities and/or how to access them. Oral explanations about stroke and treatment of stroke focused on stroke symptoms, problems associated with the effects of stroke, therapy, modifications to living spaces, and enabling self-care (60%). The peers suggested strategies for managing the emotional and behavioural reactions of stroke survivors, respite, caregiver stress, family conflict/demands, and for enhancing the self-confidence of the stroke survivor. They offered problem-specific suggestions for meaningful activities for stroke survivors and suitable "solutions" to caregiving problems or concerns (55%). Peer visitors also recommended equipment and strategies regarding the safety and comfort of the stroke survivor.

*I did not know that homecare workers would come for nominal fee. I found out through peer. [CG]*

**Instrumental support.** Project personnel offered practical/instrumental support infrequently. On a few occasions, peers assisted with housework, took the stroke survivor for an outing, stayed with the stroke survivor, checked on the stroke survivor when the caregiver was out, visited with the stroke survivor, and took the caregiver for outings. Even these small periods of respite were greatly appreciated by caregivers.

### *Caregivers' Perceptions of Intervention Processes (RQ2)*

Most support from peer visitors was viewed as supportive, reciprocal/bidirectional, appropriate, and timely.

*She was very respectful of my emotions. She didn't offer me advice except if it was solicited. [CG]*

*I almost felt like I was giving her as much as she was giving me. [CG]*

Peer visitor support increased caregivers' self-esteem and made them feel more capable (30%).

*I was feeling most inadequate.... I found her affirming. [CG: Int2]*

*Probably self-confidence. That she helps you feel that yes, you can handle this. That life goes on, and you'll be able to cope better and still have a life for yourself outside of looking after this person 24 hours a day.... I guess she gave me some self-confidence, and thinking about yourself again. [CG: Int3]*

Caregivers (30%) noted that peer support helped them to feel more confident in their role.

*I think it just made me stronger and firmer so that I don't allow her to rule me any more. [CG: Int3]*

*The main thing she did for me was to give me confidence so I wouldn't feel so guilty being away from my mother. [CG: Int3]*

*I think that she probably has made me more confident that I could get a job and carry on. [CG: Int1]*

Some caregivers (25%) explained that peer support had reduced the uncertainty they felt in their role as caregiver.

*At first, I didn't know whether I was coming or going so she told me what to expect. I'm okay now. [CG: Int2]*

## *Peer Visitor Support for Family Caregivers of Seniors with Stroke*

*[When stroke survivor had seizures] I was a little bit more prepared because [peer visitor] said that her father had had them. [CG: Int2]*

Caregivers referred to the importance of the personal characteristics of peers (60%), caregiver/peer match (50%), comfort in the relationship (50%), caregiver/peer friendship (50%), and opportunity for communication (45%). Many caregivers indicated that the personality of the peer visitor contributed positively to the relationship.

*I thought she was nice. Very caring. [CG]*

Elements contributing to the success of a caregiver/peer match included similarities in caregiving experience, personality factors, age, and interests (*social comparison*). A feeling of mutuality or reciprocity (*social exchange*) in the relationship was also important.

*You just feel connected to other people who are going through the same thing. I felt connected to peer. [CG]*

Also significant were the comfort of the caregivers in talking freely and openly with the peers and the process of establishing a level of comfort in the relationship. Trust developed over time. Many caregivers reported that they became friends with their peer visitor during the intervention. They looked forward to the visits as an opportunity to talk openly about caregiving with someone who understood their feelings and concerns. Peers' efforts to interact with the stroke survivor were very important to some caregivers.

*I felt more at ease each time she came. Because I'm not much one for talking to strangers about things. So it kind of helped a lot there after a while. I kind of opened a bit more. [CG]*

*Peer was a very good listener. ... she didn't try to interrupt or give advice. ... after you had explained things, she might have some ideas as to some other things to try but she wasn't trying to impose her solutions on you. She just let you talk. [CG]*

*I was talking to peer and she realized that I was doing more than... I expected a lot from myself. ... talking to her, I knew that I had to start taking more time for me. It was good to have somebody that wasn't in the family that you could vent your frustrations and you knew that they weren't going back and telling. [CG]*

Many family caregivers saw the professional as a source of information and liaison with the peer, although others noted that the professional's role seemed to be restricted to initial assessment. Family caregivers were asked, during the post-intervention interviews, whether they would choose a peer or a professional visitor in a future

intervention. Of those who responded, 67% indicated a preference for a peer visitor and 33% indicated a preference for both a peer and a professional, while none indicated a preference for a professional alone.

*I just think that somebody who is living with it, day in and day out, sees it on a different level because they have to experience the emotional side of it, not just the clinical side of it. [CG]*

Some peers and family caregivers found it difficult to terminate the visits. Some peers indicated that they were aware that caregivers did not have other sources of emotional, affirmational, and emotional support following the termination of the intervention program. About half of the caregivers indicated that they were not receiving any formal support services. However, in an effort to fill the void, several reported joining peer-support groups or exploring respite-care possibilities. During the follow-up interviews most caregivers said that they still kept in touch with their peer visitors.

*She keeps in contact with me though, like through the phone just to say "Hi"... It's good that you can feel that you can talk to her from time to time. [CG]*

Caregivers and peer visitors recommended that, in future projects, the peer be matched as closely as possible to the family caregiver, specifically in terms of the experience with similar stroke disability (e.g., gait impairment, aphasia, memory impairment) and the relationship of the caregiver to the stroke survivor (i.e., spouse, daughter, daughter-in-law). Peer visitors who had previously cared for persons with dissimilar levels or types of stroke disability, or who had a more peripheral relationship with a person with stroke, were uniformly viewed as being less effective than those who had similar personal experiences with a relative with stroke. This reflects the importance of *social comparison*. Caregivers also suggested that the intervention start within a month after the stroke survivor is discharged from hospital, as this was when they experienced the greatest uncertainty.

### ***Caregivers' Perceptions of Impact of Intervention on Caregiving Demands, Coping Strategies, and Support Needs (RQ3)***

Some caregivers reported lessening of burden during and after the intervention. More indicated improvement in the stroke survivor (e.g., acceptance of functional deficits, improvements in self-care, engagement in physiotherapy or speech therapy).

*Oh, easier... I would say [the peer] made it easier. [CG]*

*Yes, [the intervention] did lighten my load. [CG]*

During their discussions with peer visitors, caregivers reported using a wide array of coping strategies — help-seeking (problem-focused), protective buffering (relationship-focused), and acceptance (emotion-focused).

Caregivers sought practical and emotional support from members of their network such as family and friends. They managed their relative's behaviour with a range of verbal strategies (e.g., rational explanation, changing the subject, reassurance, use of a calm approach and instruction). Caregivers hid concerns, denied worries, and yielded to the stroke survivor to avoid disagreements (i.e., protective buffering). Caregivers accepted their relative's illness and behaviour and the necessity of caregiving.

*There are days I'm really, really nervous with him. Not that I can't care for him.... But my nights are worse. I go to bed and I wake up, and I hear him also coughing.... I'll get up and see if he's alright. That is just what goes on with me. That's the way it's going to be. [CG]*

Avoidance or escape (emotion-focused) coping was evident in a few caregivers who physically withdrew from caregiving for short periods and/or avoided thinking about the stroke survivor.

In summary, the family caregivers appeared to engage primarily in emotion-focused coping (i.e., acceptance) and relationship-focused coping (i.e., protective buffering) to manage the primary and secondary demands associated with caregiving. Some engaged in problem-focused coping (i.e., help-seeking).

When asked, at the end of the intervention and again months after the intervention had finished, whether the support program had made it easier or harder for them to care for the stroke survivor, nearly all of the caregivers responded that it had made it easier. Eight caregivers reported that the visits by peers offered a distraction from their caregiving roles.

*It made it easier because I had somebody to talk to. I didn't know where I was going from one day to another, so it was nice. It would relieve some of the pressures. I guess it helped me in different ways. It helped me to understand stroke survivors' problems. [CG]*

Other caregivers commented on changes in emotion-focused coping strategies following the intervention:

*I was certainly being very hard on myself and thinking that I wasn't doing enough or I wasn't doing it right. There were kind of negative thoughts.... I'm much more at home in the circumstances. I am much more accepting of my dad in light of how he is today. I am a little better*



*with the unpredictability of what I may encounter on any given day because I am aware now that is the disease. I am less demanding. [CG]*

### **Summary of Results**

The major burdens experienced by the family caregivers in caring for their elderly relative with stroke seemed to pertain to the cognitive and emotional impact of the stroke and the requisite constancy and vigilance in managing symptoms and deficits during everyday and crisis situations. Thus the key primary caregiving stressors appeared to be situational and derived directly from the day-to-day care of their relative. The family caregivers described the impact of caregiving responsibilities on their other responsibilities, roles, and relationships within and outside the home. The key impact of caregiving was on their ability to get enough rest and respite to fulfil their caregiving and other responsibilities. Most stressful interactions and instances of inadequate support concerned relationships with family members. These stressful situations and support deficits confirmed the need for this intervention.

In the support intervention, peer visitors provided informational support by explaining and offering information about other sources of support and resources in the community and potential coping strategies based on their experiential knowledge. Peer visitors frequently offered positive feedback and affirmed the family caregiver's decisions, actions, and perceptions. Affirmation among peers, based on social comparison, can help to diminish stigma and assure people that they are not alone in a situation. Listening was the primary type of emotional support provided by peer visitors. Other types of emotional support were understanding, sharing of feelings, and companionship. Most of the supportive interactions involving the peer visitor were considered appropriate and reciprocal. The peers also reinforced self-esteem and confidence and offered support at appropriate times in the caregiving trajectory. The intervention was designed to offer support during a particularly difficult transition, and peer visitors were trained to provide "appropriate" assistance and types of support. The family caregivers appraised their relationship with the peer visitors as very positive. Trust, closeness, and comfort level developed over time, influenced by the personal characteristics of the peers.

### **Limitations**

Some peer visitors were not as well matched with the caregiver as others, in terms of length of time since diagnosis of stroke, relationship with the



stroke survivor, and personality. Caregivers expressed a clear preference for peer visitors whose situations were very similar to their own.

The intervention was designed to reach caregivers within a year of discharge. However, because of difficulties with recruitment, participants were visited 3 to 18 months following discharge.

Some of the seniors with stroke were uncomfortable with the home visits by the peers and professionals or jealous of the attention paid to the caregiver. Although the intervention was focused on the needs of family caregivers, it became clear that the peer visitor also needed to interact with the stroke survivor, reflecting the importance of the family dyad.

The repetition of the post-intervention interview at 3 and 6 months was viewed as irritating by a few of the participants.

Finally, social-desirability bias was likely a limit, arising from the post-intervention interviews of participants and the peer visitor diaries.

### **Implications for Nursing Practice, Theory, and Research**

Recent nursing research points to the support needs of family caregivers of seniors with chronic conditions and recommends development and testing of support interventions designed to meet these needs (Adams, 1996; Dewis & Miskala, 1992; McDonald, Stetz, & Compton, 1996; Steele & Fitch, 1996). Family caregivers of seniors with stroke are in particular need of support interventions (Grant, 1996). One post hoc study evaluated the impact of existing respite programs and described clinical implications for community-health nurses (Theis, Moss, & Pearson, 1994). One pilot study examined the impact of a home-nursing intervention designed to support frail seniors and their family caregivers (Miller, Hornbrook, Archbold, & Stewart, 1996). Despite the importance for nursing practice, no support interventions focusing on family caregivers of seniors with stroke have been tested. Moreover, no support interventions have combined the expertise and knowledge of professional supporters (nurses) with lay or peer supporters.

#### ***Practice***

Nurses frequently deal with family caregivers of persons with chronic conditions in the hospital and in the community. Intervention strategies that ease stressful demands, enhance coping, and mobilize support can be informed by the lessons learned from this study. Many elderly caregiving spouses in this study were dealing with their own health prob-

lems and worried about the impact of their health on their caregiving responsibilities. Caring for individuals disabled by stroke can lead to stress-related physical and psychological health problems (Tyman, 1994). These caregivers indicated that managing the emotional and behavioural reactions of the stroke survivor was very stressful. According to Williams (1994), caregivers find irritability, dependence, and immature behaviours of stroke survivors most stressful. Caregivers in this intervention study frequently commented on their own fatigue and emotional reactions and the need for time off. Almost all the caregivers of long-term stroke survivors reported adverse effects on their emotional health, social activities, and leisure time. Caregivers often lack time for their own self-care and activities outside the home (Gottlieb, 1989; Stoller & Pugliese, 1989). Family caregivers also noted the effect on family finances and relationships. Other studies reveal adverse effects on family relationships (Anderson et al., 1995) and the need for caregivers to seek a new balance in their marriage (Robinson-Smith & Mahoney, 1995). The stroke had an impact on other role involvements for some of these caregivers. Role conflict can be experienced by family caregivers of seniors with chronic illness (Gottlieb, 1991). The stressors of caregiving increase the potential for deterioration in caregivers' health, which can have a detrimental effect on their ability to keep stroke survivors at home. Community-based support programs, such as the peer visitor program evaluated in this intervention study, offer needed support at modest cost. A peer intervention based on a combination of visits and telephone calls, or telephone calls alone, might have a similar impact at lower cost.

A growing number of caregivers are given responsibility for home care of family members with complex psychological and physical deficits. Family caregivers in the intervention study suggested that the peer visitor program should start within a month after the stroke survivor is discharged from hospital, as it was then that they experienced the greatest uncertainty. More proactive programs delivered by nurses prior to discharge from hospital settings would help reduce the uncertainty and stress experienced by new family caregivers. (Such programs could include family conferences, regular educational sessions for family members, with experienced family caregivers as resources, and pre-discharge passes to the home so that family caregivers can identify unmet learning or support needs before discharge.)

Given the current practice of early discharge from hospital, and the expectation that families will provide home-based care, nurses need to assume a more proactive role in educating and supporting family

members and other lay caregivers in their home-based care of persons with chronic illnesses and disabilities. In order to achieve this goal, nursing-education programs must assume responsibility for enabling students to play these roles in their communities.

### *Theory*

Nurses frequently invoke coping and social support theories explicitly in their research and implicitly in their practice with family caregivers and clients with chronic conditions. These caregivers used acceptance of constancy of care as a key coping strategy and were also vigilant. Caregivers of stroke survivors practise situational vigilance, create solutions to problems, and seek personal meaning in the caregiving experience (Davis & Grant, 1994). Seeking support was another significant coping strategy used by the caregivers in this study. Support-seeking has been linked to greater provision of support (Dunkel-Schetter & Skokan, 1990). According to these family caregivers of stroke survivors, the support intervention enhanced their ability to cope with the demands of this chronic health condition, because peers provided explanations about coping. Specifically, participants noted improved information-seeking and distraction from caregiving stress.

Health professionals are valued for their informational support (Dakof & Taylor, 1990). In this intervention study, professionals provided mainly informational support, while peers offered considerable affirmational and emotional support. Borkman (1990) distinguishes professional knowledge from the experiential knowledge that was offered by these peer visitors. Most informational support relayed by peer visitors was grounded in their experiential knowledge. First-hand experience also helped the peers to be empathetic and understanding in their provision of emotional support. Affirmational support among peers, based on social comparison with others in similar situations, helped to diminish stigma and assured caregivers that they were not the only ones in their situation.

Nursing interventions, which encompass support, can be informed by the theoretical underpinnings of the "mediating" processes identified in this intervention research. The importance of social comparison and reciprocity in the peer/family caregiver relationships was evident in the discussions of the similarities in their experiences and interests and of the importance of mutual exchange. This study revealed that it is important for peer supporters to be as similar as possible to recipients of support. All of these family caregivers and peer visitors were

women. Women have more complex social networks than men and are more likely to give than to receive all types of support (Belle, 1987; Shumaker & Hill, 1991). Reciprocity has a greater influence on women's support satisfaction than on men's (Antonucci & Akiyama, 1987). Almost half of the family caregivers in this study were impressed with the reciprocal nature of their relationship with the peer.

### *Research*

As support can either endure or dissipate over time, changes in individuals' social networks (Bernard et al., 1990) and changes in patterns of support in chronically stressful situations, such as caregiving, should be examined by nurse researchers. These caregivers reported that support from family members and others diminished over time. The timing of support is another critical issue. Accordingly, this support intervention was directed at new family caregivers of persons who had experienced a severe stroke for the first time and had recently been discharged from hospital. Duration of support is also an important feature in determining intervention "dose" and the stability of outcomes. In this intervention study, a peer visited the home of the new caregiver of a stroke survivor twice weekly over a period of 12 weeks, and the impact of the intervention was assessed not only at the end of 12 weeks, but also after 3 and 6 months. In the delayed post-test interviews, caregivers noted that they missed the peers when the visits terminated.

In future intervention research, the peer visitor should be matched to the family caregiver as closely as possible not only in terms of personal experience caring for a relative with stroke, but also in terms of their relationship to that relative (e.g., spouse, child). The intervention should start within a month after the stroke survivor returns home from hospital. A staggered withdrawal process that is flexible enough to meet individual needs could prepare participants for termination.

A parallel intervention for the stroke survivor may be desirable. For example, the stroke survivor could have a different peer visitor — someone who had recovered from a stroke themselves — or could join a stroke club. Peer support could also be offered by telephone.

As this low-cost intervention was perceived positively by both participants and providers (lay persons and health professionals), it should be tested in a randomized control trial with a larger sample size. Two interviews — post-test and 6 months delayed post-test — may be sufficient. Family caregivers of stroke survivors in the control condition would receive the "usual care."

## Conclusion

No studies of peer visitor support interventions with family caregivers of stroke survivors have been reported in the literature. Burden and depression among family caregivers of stroke survivors are commonly reported (Anderson et al., 1995; Schultz & Tompkins, 1990), in part because they may not seek assistance in managing the stress of their caregiving role (Macnamara et al., 1990). When a person has a stroke and becomes dependent on a close family caregiver, the loss of social support from the ill relative is added to the direct burden of caregiving. Support is likely to be most effective when it comes from other caregivers (peers) who have experienced similar losses (Williams, 1994). Indeed, peer mentoring is a potentially valuable approach requiring investigation (King, Shade-Zedlow, Carlson, & Knafl, 1995). For these reasons, this study makes a unique contribution.

The family caregivers, peer visitors, and health professionals were impressed with this support intervention and believed that it was sufficiently effective to be implemented on a routine basis for new family caregivers of stroke survivors. Support from someone who had "been there" had a significant impact on the lives of these family caregivers. Consistent with trends towards public participation and community-based care involving informal caregivers, nurses played unique consultative and facilitative roles in this support intervention. Their professional knowledge supplemented and complemented the experiential knowledge of the peers. Moreover, nurses worked in collaboration with other health professionals and with lay persons. Family caregivers of seniors with chronic conditions, such as stroke, can benefit from similar partnerships among peers and professionals. Clearly, the peer visitor model tested in this intervention study could be adapted for use in other caregiving situations.

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## Designer's Corner

### **Time, Space, and Motion: The Unanswered Challenges in Measuring Quality of Life**

**J. Ivan Williams**

By the beginning of the 18th century the measurement of longitude was one of the major challenges facing scientists. Errors in navigation resulted in wrecked ships with lives lost, failed explorations, and wasted time at sea. European powers were limited in their ability to wage war at sea, explore, discover, and claim new lands.

The Ptolemaic views of the universe and earth, with modifications, reigned for 1,400 years, and navigators charted their voyages and explorations accordingly. Claudius Ptolemaeus believed that the earth was the stationary centre of the universe, the sun, moon, and stars revolving around it. As an astronomer and mathematician he used epicycles to account for the motions of the planets, and he mapped the location of 1,020 stars. As a geographer he created a map of the world marked off in a grid of longitudes and latitudes (Chernow & Vallasi, 1993).

But the Ptolemaic system was too imprecise for use in navigation. By measuring the position of the sun, at its zenith, on the horizon, 16th-century navigators could determine their latitude if they used tables to correct for the seasonal changes in the position of the sun. Astronomers, navigators, and explorers lacked the tools for determining longitude with any reasonable degree of accuracy. Spain, France, and England offered prizes for the discovery of precise methods of measuring it. The

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major prize, established by the English House of Commons in 1714, was £20,000 to a person or persons who could measure longitude with the accuracy of half a degree at the equator, an error term of 48.3 kilometres.

Contestants in the quest for longitude determination laid claim to the prizes with competing theories and methods. The main competitors were astronomers and watchmakers. Copernicus's theory of the universe, Kepler's laws of planetary motion, Newton's theory of gravitation and mathematical discoveries, and the invention of the telescope enabled astronomers to plot the motion of the sun, moon, and planets and map the position of the stars from different locations and at different times of the year. They strived to create systems of celestial navigation and precise instruments for observing the skies that could be used to establish longitude anywhere, in any season. The Académie Royale des Sciences in France and the Royal Society in England provided support and recognition for the leading astronomers of these two countries.

Navigators determined time by the position of the sun on the horizon. A ship-board clock that could accurately give the time in home port would allow them to calculate longitude as well as latitude. John Harrison and his son William designed and produced five clocks over the course of 35 years, the later clocks keeping time at sea with the degree of accuracy required for navigation. The committee responsible for awarding the British prize was dominated by mathematicians and astronomers; they tested the clocks under questionable conditions and changed the rules of the contest. John Harrison appealed to King George III, saying that his clocks were being judged unfairly. The King agreed and the Harrisons received recognition, and the prize, in 1773. The discovery has been celebrated in a symposium, at Harvard University in 1996, and a number of books (Andrews, 1996; Sobel, 1995).

Now we have Geographical Positioning Systems linked to satellites that tell the exact latitude and longitude of a given position. They are available as hand-held devices and modules that can be installed in notebook computers and in cars.

With respect to movement across the surface of the earth, time, space, and motion are now measured precisely.

The measurement of health status and quality of life is a major challenge facing health researchers. The task is to locate individuals within life space and show how health-related events impact on their life



space. The specific quest is for measures sensitive to changes in health status/quality of life that can be attributed to health problems and interventions. Pharmaceutical companies must demonstrate, to the agencies responsible for approving drugs, the impact of their products on the quantity and quality of life. Researchers need responsive, sensible instruments for assessing the efficacy and effectiveness of interventions in randomized controlled trials and clinical studies. Providers, managers, and policy-makers need to know the cost-effectiveness of interventions and programs. Outcomes information systems are introducing measures into managed care in the United States, for purposes of both management and marketing. National organizations in the United States, such as the National Council for Quality Assurance and the Foundation of Accountability, are requiring report cards for managing care that include assessments of outcome.

The creation, adaptation, and testing of measures has been a growth industry in Europe and North America over the past 20 years, as evidenced in publications, presentations at conferences, peer-reviewed grants, industry funding, graduate theses, seminars, workshops, consulting activities, and the commercialization of specific products. International collaborations and networks of providers are being formed to create new measures. Researchers and commercial enterprises compete for their share of the academic and private markets.

One might wonder about the state of the quest for measures. There is general agreement that health should be conceptualized in terms of physical, mental, and social well-being, rather than just the absence of disease (World Health Organization, 1958). There is further agreement that quality-of-life assessments should include measures of general health status, disease-specific measures, and measures of patient preferences. Spilker's (1996) edited work covers 215 measures. Bowling (1995, 1997) and McDowell and Newell (1996) offer thoughtful guides to the use of the more established measures. An entire journal, *Quality of Life Research*, is dedicated to the subject and several major journals have published special issues on it. My bookshelves hold more than 30 volumes related to the measurement of health status and quality of life, and my holdings are by no means exhaustive.

The range of measures reflects four basic strategies in creating them: psychometric methods, clinimetric methods, deriving utilities, and Rasch modelling. In the absence of objective criteria for health status/quality of life, researchers have adapted items from existing measures and created items to reflect theoretical domains and concepts of interest. Psychometric methods are used for reducing the number of

items, identifying the factors or facets of the underlying structure of the responses, and testing the internal consistency of the responses. The measures are correlated with pre-existing measures to establish construct validity. Clinimetricians select items based on occurrences of symptoms and problems reported as important by providers and patients, or in other studies. The items are specific to the disease and interventions of interest, and they are gauged on clinical criteria. The selection and weighting of the final items are based in part on the declarations of importance. Validity is determined by how well the measures predict clinical outcomes. Researchers, working from concepts of economics and decision theory, derive utilities for given health states based on patient preferences. Typically, the methods produce a single value for each health state, ranging between 0.0 for death and 1.0 for perfect health. The standard gamble is the "cardinal method," as it is theoretically tied to the axiomatic theory of Von Neuman and Morgenstern (Drummond, O'Brien, Stoddart, & Torrance, 1997). Other measures are based on time-tradeoff methods, multi-attribute theory, and rating scales. Researchers employing the Rasch model for item-response theory focus on the scoring of responses of items, so the items can be weighted to reflect degree of health and quality and the respondents can be rated and scored on the underlying dimension of interest.

Brock (1995) summarizes the current state of the quest as follows: "While that literature provides little in the way of well-developed, philosophical accounts of the quality of life or of a good life, it is a rich body of analysis, data, and experience on which philosophical accounts of a good life can draw." The Ptolemaic conception of the universe and geography is more theoretically advanced than our theoretical and philosophical underpinnings of the concept(s) of health status/quality of life. The dimensions of longitude and latitude were correct; measuring them was the issue. While there is reference to the World Health Organization dimensions, researchers focus on the physical and mental dimensions of health, giving nominal attention to social dimension. There are attempts to broaden the definition and domains or attributes, such as the WHO Quality of Life Instrument (Szabo, 1996), and to recast the items accordingly, but this is a fledgling international collaboration. If we knew the dimensions of life, we could begin to focus on the precision with which location and motion might be measured.

The quest for longitude became important when the costs of navigational errors became intolerable. Random error in the measurement of key endpoints increases the size and costs of studies (Fleiss, 1986) and the difficulty in using the results to make key decisions in clinical policy and management of individuals (Nunnally, 1978). While authors

have defined the uses of the measures and have set stringent standards for the reliability and validity of responsiveness, most researchers ignore these and cite instead the standards of 25 years ago, for the initial development of measures (Kane & Kane, 1981; McDowell & Jenkinson, 1996; McHorney & Tarlov, 1995; Williams & Naylor, 1992; Wright & Feinstein, 1992).

Responsiveness is the Achilles' heel of measurement. A measure is responsive if it mirrors the status of individuals over time, whether it changes or not. It is difficult to identify true change and no change from random fluctuations in scores. I think this is so for two reasons. First, we drift in life; our points of view change subtly as we move through our experiences. Summary assessments of functioning, activities, moods, and feelings over the previous week or month may well shift from one time to another without assessment being either "wrong" or "unreliable." Second, as we encounter significant health events, our perspective or frame of reference may well shift. Even though a hip or knee may not work as well after total joint replacement as the normal joint, an individual can alter expectations for performance and redefine health status and quality of life accordingly. Qualitative researchers may have to provide quantitative researchers with directions as to how to reconstruct their concepts and methods (Kessler & Mroczek, 1996).

A reformulation of the theory and concepts of health status and quality of life is required, and the theory and concepts should stem from an idea of the good life. The advance of strategies and tools is contingent upon new ideas being in place rather than the constant production of new tools for old concepts. While Harrison the horologist won the prize, intelligent use of the clock was made possible by the Copernican view of the universe and the scientific theories of Kepler and Newton. This is what the quest for quality of life should be about.

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## Discourse

# **Realizing the Imperative of Clinical Nursing Research: The Experiences of a Collaborative Research Program in Long-Term Care**

**Pamela Dawson**

The demographics of Canadian society are creating at least two imperatives for nurses and all health-care providers. The first is to create services sufficient to meet the health needs of the expanding aging population. The second is to undertake relevant research sufficient to ensure that the services created are as effective as possible. Health services for the aging population are frequently interrelated with the living environments of this population — a small but significant proportion of older people require a congregate environment where health care and supportive services are provided on a 24-hour basis, while other older people depend on home-care services in order to remain in their own homes.

When older people live in long-term-care environments, the assistance they receive is frequently delivered by nonprofessional workers. In order for nursing research to meet the test of relevance, it must take into account this mix of nursing personnel, in the questions that are asked, the subjects who are recruited, and the interpretations that are drawn from the results.

This is the background that influenced the creation, 4 years ago in Toronto, of the Collaborative Research Program—Long Term Care (CRP-LTC). Three long-term-care facilities, Baycrest Centre for Geriatric Care, Queen Elizabeth Hospital (now Rehabilitation Institute of Toronto), and Sunnybrook Health Science Centre, were teaching hospi-

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tals for the University of Toronto, and the Faculty of Nursing of the U of T was deeply involved with all three facilities. Each of the three organizations had research resources and conducted some clinical research, but it became clear that if we pooled our resources each organization would benefit (and we were arrogant enough to believe that nursing research would benefit as well). Since that time, Providence Centre has joined CRP-LTC as an affiliate and is participating in the research programs.

Each partner makes an annual contribution to a central fund that allows the CRP-LTC to employ a full-time director and part-time research assistants. The nurse executives from each organization agreed to second me from Sunnybrook, where I had worked as a clinical nurse specialist in long-term care for many years and had conducted a number of research studies. The advantage to this approach was that I knew the Toronto environment and had a track record of externally funded research conducted in service settings; thus the program could start immediately, which would not have been the case if we had to undertake an external search. I am supported by a management committee consisting of the nurse executives and a research planning committee on which sit researchers from each organization.

The mission of the CRP-LTC is:

to develop nursing-specific and multidisciplinary programs of research in order to learn about the experiences of residents living in long-term care and to develop innovations in care which enhance their quality of life.

The mission is informed by the reality of the collaborating partners and the values and beliefs they share. Three of the partners provide residential care, in settings ranging from assisted-living apartments to chronic-care hospitals. Consequently, understanding how residents experience their environments, and their lives in these environments, is critical to improving the environments. Furthermore, the partners share the belief that nursing is primarily responsible for creating and maintaining environments that contribute to residents' improved quality of life, and that all innovations derived from research should have as their objective improved quality of life as perceived by the residents.

Because of the program's commitment to relevant research, considerable effort went into defining the research programs. This was a critically important undertaking: it was essential for us to identify themes and commit ourselves to conducting studies that build on each other, lest we end up undertaking a number of unrelated studies that individually might be justified but collectively would not move the science



of nursing ahead in any substantial way. Among the strategies we used in making these decisions were interviews with nurses at all levels in the participating organizations, a review of the mission statements of the organizations, and identification of the research interests of the individual researchers who would be contributing their time. Finally, a 1-day retreat was held for all participating researchers, to review the input that had been received and to come to final decisions. Four programs of research were selected, each comprising specific themes.

### **Quality of Life**

The first program, *Quality of Life*, has three themes: quality of life of persons with Alzheimer's disease, the meaning of dignity and feeling respected, and the meaning of feeling understood and listened to. It might be argued that sufficient research has already been conducted on quality of life and that the limited resources of the CRP-LTC should be directed to other, less studied areas. There is no question that quality-of-life research has become a growth industry with particular concentration on measurement (Gill & Feinstein, 1994). However, the long-term-care sector has not been the focus of the majority of this work, and the cognitively impaired have received even less attention. There are some excellent papers on individual concepts of what constitutes quality of life — for example, Schwartz's (1975) observations on self-esteem as the essence of quality of life for the aged — but there is little research that confirms or extends these individual conceptions.

Dr. Gail Mitchell, Chief of Nursing at Sunnybrook, heads the team working on quality-of-life themes. This program is central to the overall initiative, and it builds directly on work that Mitchell and colleagues had previously undertaken at Queen Elizabeth Hospital (Mitchell & Jonas-Simpson, 1995). In the earlier work, residents had identified the contributions of nurses as central to their quality of life but indicated, unfortunately, that many of these contributions led to a diminution rather than an increase in quality. A theme that emerged in this earlier work was waiting for assistance and care. Because there is very little understanding of what waiting means, Mitchell, Kolodny, et al. (1998) undertook to "explore the lived experience of waiting," using a phenomenologic approach in interviewing 45 residents of the three collaborating institutions.

Another team (Mitchell, Jonas-Simpson, et al., 1998) has just launched a study to better understand the "lived experience of being listened to." Although being listened to is critical to quality of life and interpersonal relationships (Gerteis, Edgman-Levitan, Daley, & Del-

banco, 1993; Hanestad, 1996; Mitchell & Jonas-Simpson, 1995; Webb & Hope, 1995), research indicates that patients do not frequently experience this phenomenon (Koch, Webb, & Williams, 1995; Mitchell & Jonas-Simpson). The research team was unable to locate any studies that explicate what patients mean when they say they are or are not being listened to. In order to help nurses and other health-care providers to change their practice and listen in a way that residents find meaningful, it is necessary to understand what behaviours convey true listening.

This research program and all the studies within it are guided by Parse's theory of human becoming (Parse, 1981, 1992, 1995). Briefly, the researchers search for meanings, paradoxical patterns, and plans that are linked to universal experiences.

To date, all of the studies undertaken within this program have been funded by small seed grants awarded through CRP-LTC competitions.

### Caring/Relating

The second research program, which is closely related to the first, focuses on *Caring/Relating*. Studies have shown that the most critical element in residents' quality of life is their relationships with nursing staff (Kayser-Jones, 1991). As with quality of life, there is much rhetoric about the elements of caring and relating that make a difference to patients but little in the way of research to explicate what these elements are and how they are constituted into a meaningful whole that is experienced as a fulfilling interpersonal relationship. This program has two specific themes: the participation and involvement of residents and families in the caring process, and activities and interactions that convey a spirit of caring to residents and families.

This research team is led by Dr. Diane Buchanan of the Baycrest Centre, and the studies involve both quantitative and qualitative methods. One foundational study (Dawson, Spee, et al., 1998) seeks to determine whether Resident Assessment Profiles such as the RUGS-III tool used to determine care requirements and funding levels are congruent with concerns and priorities identified by the residents and their family members. In this era of "patient-centred care," it is surprising how little research has been conducted into what residents in long-term care identify as their concerns and priorities, what they would like to participate in and have control over, and what the outcomes of this participation would be (Cahill, 1996; Davies, Laker, & Ellis, 1997; Kane

et al., 1997). This study will identify what care the residents want control over and which aspects of care they and their families wish to participate in, and it will allow both residents and providers in long-term care to challenge what funders consider important — versus what care recipients would like to see provided and paid for.

A second study in this program addresses the theme of enhancing the resident/nursing staff relationship. Kathy McGilton, a doctoral student in the Ph.D. program in nursing science at the University of Toronto, is conducting a field study based on Winnicott's (1960) theory of relationships, in which the culture and practices on a long-term-care unit will be changed to emphasize continuity of resident/health-care-aide relationships; enhanced ability of health-care aides to communicate with residents and to identify and value unique characteristics of each resident; and increased support, from registered nurses and the nurse manager, to the aides for the emotional side of their work. A particularly challenging component of this study was the measurement of the relationship, which involved translating and quantifying concepts identified in earlier qualitative work.

### **Freedom and Mobility**

The third research program asks: What knowledge, attitudes, beliefs, and practices concerning mobility, and its relationship to quality of life, do health-care providers carry, and what interventions enhance freedom and mobility? This program is headed by Dr. Cheryl Cott, a professor in the Department of Physical Therapy. While most members of the research teams are nurses, the intention of the CRP-LTC was not to focus exclusively on nursing but to involve other health disciplines concerned with quality of life.

This program was begun with an examination of the meaning of mobility for both residents and long-term-care staff, in order to provide baseline information for future interventions. While focus groups were being held to gather the data for the first study, Dawson, Cott, et al. (1998) were aware that previous research suggested that physical exercise and walking/talking programs could enhance the overall functioning of residents in long-term-care facilities. Among the benefits are improved communication (Tappen, 1988), increased independence in ambulation, improved walking endurance (McRae et al., 1996), and decreased incontinence during the day shift (Jirovec, 1991). All of these studies had paired a staff member with one resident, and some studies did not have strong research designs; hence the work suggests rather than demonstrates. A proposal was developed, funded

require during different points in the convalescent trajectory?" "What is the role of nursing within a collaborative framework of multidisciplinary practice?" "What are the indicators that nursing has made a difference to patient and family outcomes?"

The profession that has knowledge of patients' and families' needs will not only find itself in a strong position to meet the many challenges of the new health care system but will also be in a unique position to influence its direction. The right type of knowledge is dependent on asking the right set of questions. We believe that nursing has been asking the right questions. Now what we need to do is to find the answers.

cognitive impairment and dementia (Wells, Ens, Cowan, Irvine, & Rogers, 1997).

This has been a brief tour of the programs and some of the research undertaken by the CRP-LTC in its short existence. It is meant to illustrate the advantages, for the development of nursing research — in this case research focused on institutionalized older people — of collaboration across a number of organizations. While we have not accomplished all that we had hoped to do by this date, we do believe we would have accomplished less had we not been working together. The responsibility of not letting colleagues down has served as a great incentive for getting work accomplished. There is also consensus that the research we are undertaking is clinically relevant. We have the advantage of being a group of nurses who straddle the research/practice line. Our research questions are our practice questions. We experience the same frustrations as staff nurses in having to wait for research to produce the answers, but the frustration is tempered by the fact that we are aware of how all the studies are proceeding and are informed by all the literature reviews. This is a very different experience from working alone or with a sole group within one's own institution.

The collaboration is not without its challenges. It is obvious from the research programs, themes, and individual projects that there is considerable overlap across the programs. A good example of this is the study on walking/talking, which is categorized under the *Freedom and Mobility* program but could just as easily be listed under *Living with Cognitive Impairment*. Does this matter? It may be that we have too many programs and that as the whole initiative evolves the programs will be reconceptualized and reduced in number so that the entire program of research becomes more focused. A side effect of developing a collaborative arrangement such as ours is that participating individuals come with a wide range of interests and areas of special knowledge. These drive what they want to study, because they know where the gaps in research are. This is very different from building a program around a central theme and recruiting and paying researchers to focus on that theme. Rarely in nursing are we in a position to do the latter, so we must respect the interests of our colleagues who are invited to work together. Experience in working together builds common interests and facilitates agreement on what the research priorities should be. The more focused the research program, the greater the likelihood that a substantial contribution to knowledge will be made; thus the overlaps in our four programs will likely serve us well in the future.



Our team of researchers is composed of individuals with very different research training and research traditions. We do not always agree, and some of the disagreements are based on profoundly different research values. We have been able to work together, however, because we have profoundly similar values about what is important for older people, and this helps us respect each other's work in building the knowledge that will serve older people.

The CRP-LTC is an experiment, but it is also an adventure for all of us who are involved. We think we are creating a model of collaboration that can serve other groups of nurses dispersed across a number of organizations but with similar research interests. A critical and probably essential element of our collaboration is the role I play as full-time director. Knowing something of the financial circumstances of our collaborative partners, I think it is unlikely that any one of them would have the resources to fund my position and provide me with research assistants and seed money to stimulate the development of studies that are important to the success of the program. Sharing these expenses has made the collaborative program possible. Thus collaboration among the executive heads of the organizations has been and continues to be crucial.

We gave ourselves 5 years to create a program of research. We are just beginning our fourth year and have much to show for our first 3 years of collaboration. We have developed momentum in writing grant applications and abstracts for presentations and, now, articles reporting on our completed studies. These are very important indicators of success, but the most important will be change in nursing practice informed by our work.

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# **Les effets d'une intervention éducative préopératoire sur la conduite de parents d'enfants de trois à six ans opérés dans le cadre d'une chirurgie d'un jour**

**Jocelyne Tourigny**

This quasi-experimental study assessed the effects of an intervention with the parents of children aged 3-6 at 2 weeks before the child's admission for day surgery. It entailed providing the parents with an educational booklet embodying the learning theories of Gagné and of Bandura. The 150-parent sampling was randomized into 2 experimental groups (receiving the educational booklet) and 1 control group (receiving only an information leaflet). Their behaviour was observed by means of video camera at various times on the day of surgery. In addition, the subjects themselves (usually the mother) assessed their level of anxiety. The parents in the experimental groups displayed greater competence on the day of surgery, and reported less anxiety, than did the control subjects. The study underscores the effectiveness of an educational approach favouring the use of family-targeted instructional material. It also shows that parents are able to use the information they receive to effectively prepare their tots for day surgery. The implications for research and clinical practice are examined from the vantage points of benefits to parents, child, and nursing staff and implementation of new ambulatory-care strategies.

Cette étude quasi expérimentale a servi à évaluer les effets de la remise aux parents, quinze jours avant l'admission en chirurgie d'un jour de leur enfant de trois à six ans, d'une brochure éducative conçue selon les principes d'apprentissage de Gagné et de Bandura. Les parents (au nombre de 150) ont été répartis de façon aléatoire dans deux groupes expérimentaux (où on leur remettait une brochure) et un groupe contrôle (où on leur remettait un feuillet explicatif seulement). Leur conduite a été observée par le biais d'une caméra vidéo à différents moments au cours de la journée de la chirurgie et ils (le plus souvent la mère) ont eux-mêmes évalué leur degré d'anxiété. Les parents des groupes expérimentaux ont montré plus de compétences pendant la journée de la chirurgie et se sont dits moins anxieux que ceux du groupe contrôle. Cette étude a donc souligné l'efficacité d'une approche de type éducatif favorisant l'utilisation de matériel pédagogique en milieu familial. Elle a de plus démontré que les parents sont capables d'employer l'information fournie afin de préparer adéquatement leur jeune enfant à une chirurgie d'un jour. Les implications pour la recherche et la pratique clinique sont examinées tant au point de vue des bénéfices pour les parents, l'enfant et le personnel infirmier que de l'implantation de nouvelles stratégies d'intervention en soins ambulatoires.

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Les jeunes enfants ayant besoin d'une chirurgie comme une adénoïdectomie, une amygdalectomie, une myringotomie ou une herniorraphie sont maintenant admis dans des unités de chirurgie d'un jour. Les parents de ces jeunes enfants, plus particulièrement les mères, se disent très anxieux lors de cette chirurgie et leur état émotionnel peut influencer les réactions de l'enfant pendant et après la chirurgie (Johnston, Bevan, Haig, Kirnon et Tousignant, 1988 ; Tourigny, 1992). Ils admettent aussi manquer d'information sur les procédures médicales, les soins infirmiers et les moyens d'aider leur enfant tout au long du processus opératoire (Caty, Ritchie et Ellerton, 1989 ; Tourigny, 1992 ; Wolfer et Visintainer, 1975).

De nombreux types de préparation à la chirurgie ont fait l'objet de recherches ou sont appliqués présentement dans plusieurs hôpitaux pédiatriques. On utilise des stratégies comme l'information transmise verbalement et par écrit sous forme de feuillets explicatifs ou de livres à colorier, la présentation d'un modèle de conduite sur bande vidéo, l'enseignement de techniques de maîtrise du stress et le soutien psychologique fourni par le personnel infirmier. Bien que ces stratégies se soient avérées efficaces dans la réduction de l'anxiété des parents et des conduites de détresse chez l'enfant, il est difficile d'évaluer spécifiquement les effets réels de l'une ou l'autre d'entre elles, les chercheuses en ayant associé plusieurs à la fois. De plus, la plupart des programmes de préparation visent indifféremment les enfants de tous âges, sans tenir compte des différents niveaux de développement cognitif et psychosocial. En outre, on trouve très peu d'interventions s'adressant exclusivement aux enfants d'âge préscolaire.

On remarque également que l'on fait généralement peu appel aux parents dans la préparation de leur jeune enfant à une chirurgie d'un jour et que les effets d'une préparation sur leur participation réelle aux soins de l'enfant opéré n'ont presque jamais été mesurés.

Les parents étant les personnes qui connaissent le mieux leur enfant, il apparaît évident que le fait de leur fournir toute l'information nécessaire pour préparer et aider leur enfant au moment de la chirurgie devrait les inciter à intervenir efficacement pour faciliter cette expérience à l'hôpital. Ils pourraient ainsi devenir de précieux alliés et collaborateurs pour le personnel infirmier en place.

Le but de cette étude était donc de déterminer les effets, sur les parents et sur les enfants, d'une intervention destinée à préparer les parents à intervenir adéquatement auprès d'un enfant de trois à six ans en vue de son admission à court terme en chirurgie d'un jour. Cet article rapporte les résultats concernant les parents.

### **La recension des écrits**

Cette partie de la recension porte sur les réactions des parents à une chirurgie de l'enfant et sur les besoins exprimés par eux lors de l'hospitalisation. Divers types d'interventions éducatives et de programmes de préparation pré-opératoire sont examinés.

#### *Les réactions des parents*

Les mères se disent anxieuses lors d'une chirurgie mineure (Skipper, 1966) et plus particulièrement la journée de l'opération (Tourigny, 1992). Elles affirment être plus préoccupées par la peur et la douleur ressenties par leur enfant que par la crainte de complications ou l'insécurité. Pour elles, les moments les plus difficiles sont la séparation d'avec l'enfant et lorsqu'il est souffrant (Coty et al., 1989). Par ailleurs, le degré d'anxiété des mères pourrait avoir un effet sur la façon dont elles s'adaptent à l'hospitalisation de leur jeune enfant. Ainsi, les mères qui savent à quoi s'attendre durant le séjour à l'hôpital sont moins anxieuses et s'adaptent mieux à la situation (Schepp, 1991).

#### *Les besoins des parents*

Peu d'écrits se rapportent aux besoins exprimés par les parents de jeunes enfants hospitalisés. Smitherman (1979) affirme que les parents désirent comprendre le traitement de leur enfant et se sentir importants pour celui-ci et compétents en tant que parents. Certains parents dont l'enfant est atteint d'une maladie chronique disent avoir besoin de comprendre la maladie de leur enfant et de soutien face au milieu hospitalier de même que dans leur nouveau rôle (Hayes et Knox, 1984). Ils disent avoir également besoin de services dans la communauté (Graves et Hayes, 1996). Une étude qualitative menée par Kristjansdotter en 1991, jumelée à une analyse approfondie de la documentation, a permis de relever certains des besoins exprimés par les parents d'enfants de deux à six ans hospitalisés pour une chirurgie électorive. Ainsi, les parents souhaitent obtenir de l'information, sentir qu'on leur fait confiance, connaître les ressources disponibles et obtenir du soutien ainsi que des conseils. Toujours selon cette étude, les infirmières et les médecins constatent chez les parents ces mêmes besoins, auxquels s'ajoutent le besoin d'autonomie et de connaissances sur le développement de l'enfant de même que sur la façon de l'informer.

Bien qu'il n'existe aucune étude portant sur les besoins des parents ayant un enfant opéré en chirurgie d'un jour, nous pouvons présumer que ces parents ont des besoins similaires, mais font face à la difficulté



d'obtenir de l'information à l'avance et de remplir leur rôle de parents, en raison du court séjour à l'hôpital.

### *La préparation préopératoire*

Les recherches visant à évaluer les effets de divers programmes de préparation préopératoire ont été répertoriées et classées selon les personnes à qui ces programmes s'adressent : les enfants, les parents, ou les deux à la fois.

Les programmes s'adressant aux enfants comportent divers types d'interventions : de l'information transmise verbalement ou au moyen de films (Faust et Melamed, 1984; Melamed et Siegel, 1975; Visintainer et Wolfer, 1975), un soutien aux moments de stress (Visintainer et Wolfer), ou des jeux thérapeutiques (Schwartz, Albino et Tedesco, 1983). Quel que soit le type d'intervention utilisé, les enfants en ayant bénéficié montrent généralement moins de détresse émotionnelle, coopèrent davantage et sont moins anxieux que les enfants n'ayant pas reçu de préparation. Les chercheuses ne font cependant pas de distinction entre les groupes d'âge, ces programmes s'adressant indifféremment aux enfants de quatre à dix-sept ans. Johnston (1983) ainsi que Melamed et Siegel (1975) font toutefois remarquer que les enfants plus jeunes, c'est-à-dire ceux de huit ans et moins, montrent plus d'anxiété quand ils visionnent un film se rapportant à la chirurgie le jour même de l'opération.

Les programmes s'adressant à la fois aux enfants et aux parents comportent le même genre de préparation, mais on y trouve en plus, à l'intention des parents, de l'information écrite (Wolfer et Visintainer, 1979), des sessions de groupe (McGrath, 1979) ou des techniques d'ajustement (coping) (Peterson et Shigetomi, 1981; Robinson et Kobayashi, 1991). Les parents ayant bénéficié de ces interventions se disent moins anxieux et plus compétents au moment de la chirurgie que les autres parents. Toutefois, les auteures se contentent de demander aux parents s'ils sont satisfaits de leur performance à l'hôpital, sans mesurer de façon rigoureuse leurs compétences en matière d'aide à l'enfant. Dans l'étude de Ellerton et Merriam (1994), les infirmières rapportent que les parents ayant reçu des instructions écrites et des suggestions concernant la poursuite de la préparation à la maison étaient plus aptes à aider leur enfant à maîtriser son anxiété et retenaient plus d'information que les parents sans instructions écrites.

Meng et Zastowny (1982) ont utilisé une approche cognitive-behaviorale comprenant trois phases (enseignement, modèle de con-



duite, mise en pratique des techniques apprises) pour préparer des parents, à la maison, à l'hospitalisation de leur enfant d'âge préscolaire. Les parents ayant utilisé cette approche ont démontré plus d'habileté à aider leur enfant dans les moments de stress que les parents du groupe contrôle. En outre, les auteures soulignent l'importance des parents dans l'individualisation de la préparation de l'enfant.

Mazurek-Melnyk (1994) a évalué les effets de la transmission d'une information choisie sur le fonctionnement de 108 mères d'enfants de deux à cinq ans lors d'une hospitalisation non planifiée. Les mères ayant bénéficié de sessions d'information sur les réactions possibles de l'enfant et sur les moyens de l'aider à s'adapter ont rapporté avoir plus de connaissances sur l'enfant et être moins anxieuses pendant l'hospitalisation que les mères du groupe contrôle. Elles ont effectivement apporté plus de soutien à l'enfant à l'occasion d'une intervention nécessitant un procédé effractif que les mères de ce groupe.

Il semble donc que la préparation axée sur les parents facilite leur adaptation en réduisant leur degré d'anxiété et augmente leurs connaissances ainsi que leur capacité d'aider leur jeune enfant au moment de son hospitalisation. Les chercheuses citées plus haut font également état des effets de ce type de préparation sur la réduction de l'anxiété chez l'enfant.

Plusieurs centres universitaires pédiatriques canadiens et américains ont mis sur pied un programme systématique de préparation préopératoire. Ces centres utilisent des moyens comme l'information verbale et écrite (brochures, livres à colorier), les visites guidées de la salle d'opération, les films ou les bandes vidéo sur le déroulement de la journée à l'hôpital et la manipulation de l'équipement médical. Cependant, ces centres ne constituent que 40 % de tous les hôpitaux pédiatriques (Peterson, Ridley-Johnson, Tracy et Mullins, 1984). Bien que les effets de ces divers programmes n'aient pas été mesurés de façon systématique, ce type d'intervention serait bénéfique tant pour les parents que pour l'enfant.

### *Les stratégies éducatives*

Diverses stratégies éducatives ont été utilisées pour aider les parents à jouer leur rôle, dont le feedback (Meyer, 1987), qui constitue une forme d'apprentissage par observation et renforcement des conduites appropriées (Reinhart-Rahn, 1988). Brandt et Magyary (1993) ont également utilisé le feedback et l'apprentissage par observation avec des mères d'enfants diabétiques. Ils ont constaté que la quantité d'information

retenue et les compétences en matière de résolution de problèmes avaient augmenté de façon significative à la suite des sessions éducatives, tandis que les capacités psychomotrices avaient augmenté seulement chez les mères plus scolarisées. Ces résultats doivent cependant être considérés avec réserve, compte tenu de la taille de l'échantillon ( $n = 17$ ).

### *Les compétences parentales*

Les compétences des parents à l'hôpital ont été évaluées généralement en termes de participation aux soins. Deux moyens ont été utilisés : l'auto-rapport des parents (Caty et al., 1989; LaMontagne, Hepworth, Pawlak et Chiafery, 1992; Romaniuk et Kristjanson, 1995) et l'observation de leur conduite. Roskies, Mongeon et Gagnon-Lefèbvre (1978) parlent de la participation parentale aux soins physiques, psychologiques et médicaux. Elles ne précisent pas les actions spécifiques ni comment celles-ci ont été mesurées.

D'autres chercheuses ont observé la conduite de parents lors de divers actes médicaux et rapportent les types d'actions suivants : information, distraction, réconfort et affection (Dahlquist, Power, Cox et Fernbach, 1994; Mazurek-Melnyk, 1994). Fielding et Tam (1990), après avoir observé des mères à l'occasion d'une chirurgie électorale sur leur enfant de deux à dix ans, classent les interactions parents-enfants en trois catégories : les actions liées aux soins, au réconfort et au jeu. L'instrument utilisé n'étant pas décrit, sa validité n'a pas pu être établie.

L'analyse de la documentation montre que les interventions éducatives dirigées principalement vers les parents sont peu nombreuses, qu'elles n'ont pas de base théorique éducative clairement définie et qu'elles ont été peu évaluées en ce qui a trait aux compétences acquises et montrées par les parents. Dans le cas de la chirurgie d'un jour, les compétences dont font preuve les parents auprès d'un jeune enfant hospitalisé, à la suite d'une intervention éducative préopératoire, n'ont jamais été mesurées. Une stratégie ayant pour but de fournir aux parents de l'information sur la chirurgie de l'enfant et sur les moyens de l'aider à l'hôpital sera-t-elle efficace dans le contexte d'une chirurgie d'un jour? La recherche, qui avait pour but de répondre à cette question, posait l'hypothèse suivante : *Les parents ayant reçu une brochure éducative à la maison, quinze jours avant la chirurgie, montreront plus de compétences à l'hôpital que les parents ayant reçu une feuille d'information sur la chirurgie d'un jour.*

Vu l'importance du facteur anxiété parentale lié à une chirurgie de l'enfant (Schepp, 1991 ; Tourigny, 1992) et de sa relation avec la préparation des parents à la chirurgie (Mazurek-Melnyk, 1994 ; McGrath, 1979 ; Robinson et Kobayashi, 1991), une deuxième hypothèse a été formulée : *Les parents ayant reçu une brochure éducative à la maison, quinze jours avant la chirurgie, se diront moins anxieux que les parents ayant reçu une feuille d'information sur la chirurgie d'un jour.*

### Cadre théorique

Les compétences parentales ont été définies comme étant la démonstration des capacités d'apprentissage acquises par les parents à la suite d'une intervention éducative de type socio-cognitif.

La théorie de l'apprentissage-enseignement de Gagné (1985) a guidé le choix des capacités d'apprentissage désirées chez les parents. Celles-ci portent sur les aspects suivants : *l'information verbale*, c'est-à-dire la capacité d'énoncer une idée ou un fait sous la forme d'une proposition contenant des concepts significatifs pour l'apprenant, *les aptitudes intellectuelles*, soit la capacité d'identifier les concepts qui composent une règle et d'en montrer les interrelations, *les stratégies cognitives*, c'est-à-dire la capacité de résoudre des problèmes nouveaux en associant des principes de niveau inférieur, et enfin *les attitudes*, soit la tendance à réagir d'une certaine manière à certaines situations. L'intégration de ces capacités est favorisée par l'établissement de conditions internes et externes comme la répétition, le rappel des concepts et la communication verbale de la stratégie à utiliser. Gagné postule également que le fait de connaître d'avance les éléments pertinents à une situation nouvelle permet d'en réduire l'effet anxiogène.

Bandura (1986), à l'instar de Gagné (1985), souligne l'importance et l'utilité des modèles dans l'apprentissage de concepts, règles et attitudes. En effet, l'apprentissage par observation serait un moyen efficace d'intégrer des concepts et des règles en apprenant le vocabulaire adéquat et en combinant des idées ; cette méthode aiderait aussi à adopter de nouvelles attitudes en démontrant l'utilité de certaines conduites et en informant l'apprenant des bénéfices liés à l'adoption de la conduite modelée. La technique de modelage verbal, c'est-à-dire la transmission d'une variété de conduites au moyen de mots, a été utilisée dans cette étude.

Les programmes éducatifs s'adressant aux parents d'enfants hospitalisés et utilisant des méthodes d'apprentissage socio-cognitif ou par observation se sont avérés efficaces pour faire acquérir aux parents des

connaissances et des compétences (Brandt et Magyary, 1993; Meyer, 1987; Reinhart-Rahn, 1988). La réunion de ces deux modèles éducatifs à l'intérieur de la même intervention ne peut donc que favoriser l'acquisition des capacités désirées chez les parents, et c'est pourquoi ils forment le cadre théorique de l'étude.

### La méthodologie

Un devis de recherche quasi expérimental et post-test avec groupe contrôle a été utilisé pour évaluer les effets de la remise d'une brochure à deux groupes expérimentaux versus la préparation habituelle reçue par un groupe contrôle.

#### *L'échantillon*

À un seuil de signification de 5 % ( $p < 0,05$ ) pour un test unilatéral et un pouvoir de 90 %, le nombre total de l'échantillon a été fixé à 150, soit 50 parents (mères ou pères ou les deux) et 50 enfants par groupe (Kraemer et Thieman, 1987).

Une technique d'échantillonnage non probabiliste a été utilisée pour déterminer l'échantillon de convenance (Fortin, Taggart, Kérourac et Normand, 1988). Sur 245 familles jointes par téléphone, 172 ont accepté de participer à l'étude. Les parents qui refusaient invoquaient les raisons suivantes : la mère est très nerveuse ou l'enfant est impressionnable ; l'enfant n'en est pas à sa première chirurgie ; le parent n'est pas intéressé ou dit ne pas avoir ce type de besoin ; le parent refuse la vidéo ; le conjoint ou la conjointe refuse de participer. Sur les 172 familles ayant accepté de participer à l'étude, six ont changé d'avis avant la chirurgie, quatre n'ont pas été observées et douze chirurgies ont été annulées.

L'échantillon final était composé de 150 dyades parents (mères et pères)-enfants, répartis de façon aléatoire dans un des trois groupes suivants : le groupe expérimental I (50), dont les membres recevaient à la maison la brochure informative complète, le groupe expérimental II (52), dont les membres recevaient une brochure abrégée, et le groupe contrôle (48), dont les membres recevaient la préparation habituelle, soit une feuille d'information sur la chirurgie d'un jour. Les critères d'admissibilité pour les parents étaient d'accompagner un enfant de trois à six ans devant subir une chirurgie d'un jour, savoir lire et écrire en français, et signer le consentement de participation à l'étude.

La description de l'échantillon figure au tableau 1. Des analyses de khi carré ont démontré que les trois groupes étaient équivalents en ce qui a trait aux aspects suivants : l'âge ( $\chi^2 = 3,926$ ;  $dl = 4$ ;  $p = 0,416$ ), le niveau de scolarité de la mère ( $\chi^2 = 1,386$ ;  $dl = 4$ ;  $p = 0,847$ ), le nombre d'enfants dans la famille ( $\chi^2 = 1,646$ ;  $dl = 2$ ;  $p = 0,439$ ), le travail des parents à l'extérieur ( $\chi^2 = 1,372$ ,  $dl = 2$ ;  $p = 0,504$ ) et une expérience antérieure relative à la chirurgie d'un enfant ( $\chi^2 = 0,699$ ;  $dl = 2$ ;  $p = 0,705$ ).

### *La variable indépendante*

La variable indépendante dans cette étude était le programme éducatif pré-opératoire à l'intention des parents, offert sous la forme d'une brochure. Cette brochure de 28 pages a été conçue de façon à respecter les modèles théoriques adoptés et à fournir aux parents des données leur permettant de développer des compétences de type information verbale, aptitudes intellectuelles (concepts et règles), stratégies cognitives et attitudes. De plus, les conditions internes et externes propres à favoriser l'apprentissage ont été rigoureusement appliquées (Gagné, 1985). La brochure, intitulée « Votre enfant et sa chirurgie » comprend trois parties : la première porte sur le développement et les réactions d'enfants de trois à six ans lors d'une chirurgie (information verbale, concepts), la deuxième sur le déroulement de la journée à l'hôpital (concepts, information verbale) et la troisième sur les façons de préparer l'enfant à sa chirurgie et de l'aider au cours de la journée (concepts, règles, stratégies cognitives, attitudes). Chaque partie commence avec les objectifs d'apprentissage et se termine avec un résumé encadré. En outre, des exemples concrets de réflexions enfantines et de réponses parentales appropriées (modelage verbal, Bandura, 1986) figurent tout au long du texte, et un exercice à la fin de chaque partie permettait aux parents d'appliquer de façon théorique les notions apprises. On y trouve également un lexique de termes employés couramment à l'hôpital ainsi qu'une image à colorier représentant un enfant dans une salle d'opération. Enfin, les parents pouvaient mettre en pratique leurs compétences en matière de résolution de problèmes en résolvant une histoire de cas.

La brochure a été révisée par cinq expertes en soins pédiatriques (infirmières et professeures), qui ont vérifié la pertinence du contenu et la clarté du texte, et des corrections ont par la suite été apportées à la lumière de leurs commentaires. La brochure a ensuite été envoyée, dans le cadre de l'étude-pilote, à dix parents d'enfants de trois à six ans opérés en chirurgie d'un jour; ces parents ont à leur tour remis la



**Tableau 1** *Distribution des parents et des enfants dans les trois groupes selon les variables socio-démographiques*

Variable	Groupe I		Groupe II		Groupe III	
	<i>f</i>	%	<i>f</i>	%	<i>f</i>	%
<b>Sexe enfant</b>						
Garçons	35	23,3	36	24,0	30	20,0
Filles	15	10,0	16	10,7	18	12,0
<b>Âge Enfant</b>						
3-4 ans	27	18,0	26	17,3	28	18,7
5-6 ans	23	15,3	26	17,3	20	13,4
<b>Type chirurgie</b>						
ORL	40	26,6	43	28,6	39	26,1
Abdominale et urologique	6	4,0	6	4,0	6	4,0
Ophtalmo	4	2,7	2	1,3	2	1,3
Plastie	0	0	1	0,7	1	0,7
<b>Âge mère</b>						
20-29 ans	13	8,7	12	8,0	14	9,3
30-39 ans	35	23,3	36	24,0	28	18,7
40-49 ans	2	1,3	0	0	3	2,0
<b>Scolarité mère</b>						
Primaire	1	0,7	0	0	2	1,3
Secondaire	20	13,3	17	11,3	20	13,3
Coll. prof.	20	13,3	19	12,7	14	9,3
Univers.	9	6,0	11	7,3	9	6,0
<b>Autres enfants</b>						
Oui	39	26,0	41	27,3	41	27,3
Non	11	7,3	11	7,3	6	4,0
<b>Travail parents</b>						
Mère seul.	0	0	2	1,3	1	0,7
Père seul.	23	15,3	18	12,0	22	14,7
Mère et père	26	17,3	29	19,3	22	14,7
Aucun	1	0,7	1	0,7	1	0,7
<b>Expérience de chirurgie antérieure</b>						
Oui	31	20,7	28	18,7	28	18,7
Non	19	12,7	24	16,0	20	13,3



brochure avec des commentaires écrits dans la marge concernant la clarté du texte et l'utilité de chaque partie. Le pourcentage d'accord entre les parents a été de 85 % et plus. Une version abrégée de la brochure originale, comprenant les deux premières parties seulement, a servi à vérifier si le fait de fournir aux parents de l'information sur le développement et les réactions de l'enfant ainsi que sur les procédures hospitalières (concepts et règles) leur permettait de préparer et d'aider leur enfant le jour de la chirurgie (résolution de problèmes) aussi efficacement que les parents recevant la brochure complète.

### *Les variables dépendantes et les instruments de mesure*

Les variables se rapportant aux parents sont le niveau de compétences parentales\* et le niveau d'anxiété situationnelle†.

Le *Questionnaire sur les connaissances* servait à mesurer les aptitudes intellectuelles (concepts et règles) et comprenait des questions d'ordre socio-démographique ainsi que sur la préparation faite par les parents, sur les termes médicaux et sur le développement d'un enfant, de même qu'une courte histoire de cas à résoudre.

Des experts en soins infirmiers pédiatriques et en éducation ont aidé à établir la validité du questionnaire sur le plan de la forme et du contenu. Ce processus de validation s'est poursuivi pendant l'étude-pilote. Les parents ayant reçu la brochure informative à la maison ont obtenu un score moyen de connaissances de 88 %, tandis que les parents ne l'ayant pas reçue ont eu un score moyen de 71 %. De plus, des tests de concordance catégorie-total ont été effectués pendant l'étude et les coefficients de corrélation ont été respectivement de 0,68

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\* Les compétences parentales sont les conduites démontrant que les parents ont acquis les capacités d'apprentissage relatives aux aspects suivants : les aptitudes intellectuelles (concepts et règles), mesurées par le *Questionnaire sur les connaissances*, ainsi que l'information verbale, les stratégies cognitives et les attitudes, mesurées par la grille d'évaluation *Inventaire des conduites parentales*.

† L'anxiété situationnelle est le degré d'inconfort psychologique ressenti par le parent accompagnateur (mère ou père) à cinq (5) moments au cours de la journée, soit à l'admission, au départ de l'enfant pour la salle d'opération, pendant la période d'attente, au retour de l'enfant de la salle de réveil et durant l'heure qui suivait. Cette donnée a été mesurée selon une échelle numérique d'auto-rapport de 10 centimètres allant de 0 (le moins possible) à 10 (le plus possible). Le point d'intersection de la ligne verticale et de la ligne horizontale constitue le score obtenu. Ce type d'instrument a été fréquemment utilisé pour mesurer la douleur et l'anxiété (Ellerton et Merriam, 1994; Maxwell, 1978; Scott et Huskisson, 1979) et s'est avéré un instrument fidèle et valide. Vogelsang (1988) a établi une forte corrélation ( $r = 0,84$ ) entre l'échelle visuelle et le STAI (State-Trait Anxiety Inventory) de Spielberger, Gorsuch et Lushene (1970).

pour la connaissance des termes médicaux, de 0,79 pour la connaissance des réactions de l'enfant et de 0,64 pour la résolution de problème, tous trois avec un niveau d'erreur alpha de 0,01.

L'*Inventaire des conduites parentales* a été bâti par la chercheuse à partir des actions considérées par les parents eux-mêmes comme étant bienfaisantes pour l'enfant (Coty et al., 1989) et de plusieurs autres conduites mentionnées par Fielding et Tam (1990). L'instrument, composé au départ de 19 points, a été réduit à 16 lors de l'étude-pilote. On y trouve des conduites faisant partie des trois catégories mentionnées plus haut : l'information verbale (ex. : donner des renseignements, répondre aux questions), les stratégies cognitives (ex. : appliquer du renforcement, distraire) et les attitudes (ex. : regarder, sourire, serrer, rassurer). (Voir Figure 1.)

Le score total a été obtenu en additionnant les conduites dont ont fait montre les parents (mères et pères) à cinq (5) moments au cours de la journée : à l'admission, au départ pour la salle d'opération, à l'arrivée dans la salle d'attente du bloc opératoire, au retour de la salle de réveil et durant l'heure suivant le retour. Chaque conduite, présentée par la mère ou le père, n'était cochée qu'une fois. La difficulté d'obtenir des images vidéo de qualité et de durée identique a rendu impossible l'évaluation des conduites en terme de fréquence.

Des tests de fidélité inter-observateurs réalisés en cours d'étude sur au moins 15 % des bandes ont donné un pourcentage d'accord de 94,3 %. De plus, une analyse factorielle effectuée à la suite de l'étude a montré que les 16 indices avaient des coefficients de corrélations corrigées (factor loadings) de 0,43 à 0,78 et se regroupaient en six facteurs comptant pour 59,1 % de la variance expliquée.

### *Les variables étrangères et socio-démographiques*

Les variables étrangères sont l'âge de l'enfant et l'expérience antérieure des parents avec une chirurgie de l'enfant. D'après la documentation, d'autres variables socio-démographiques peuvent influencer sur les réactions des enfants et des parents, soit l'âge et le niveau de scolarité de la mère, le nombre d'enfants dans la famille et le nombre de parents travaillant à l'extérieur.

### *Le déroulement*

À la suite de l'approbation du comité de déontologie de l'hôpital, une étude-pilote de deux mois a été réalisée, afin de tester la brochure et les

**Figure 1** *Inventaire des conduites parentales : grille d'évaluation*

Périodes						
Indices	1	2	3	4	5	Total
<i>Information verbale</i>						
(1) Donner de l'information						
(2) Répondre aux questions						
(3) Faire montre de compréhension						
(4) Donner des instructions						
<i>Stratégies cognitives</i>						
(5) Appliquer du renforcement						
(6) Distraire						
(7) Aider à relaxer						
(8) Autre méthode						
<i>Attitudes</i>						
(9) Regarder l'enfant						
(10) Sourire à l'enfant						
(11) Se tenir à proximité						
(12) Manifester de l'affection						
(13) Rassurer						
(14) Renforcer						
(15) Participer						
(16) Défendre les intérêts de l'enfant (advocate)						
<b>Total</b>						

instruments de mesure ainsi que d'entraîner les assistantes de recherche à la manipulation de la caméra vidéo. Tous les parents répondant aux critères d'admissibilité ont été joints par téléphone et la recherche leur a été expliquée. Ensuite, les parents qui désiraient participer à l'étude ont été répartis au hasard dans l'un des deux groupes expérimentaux et dans le groupe contrôle, et ils ont reçu au moins 15 jours avant la chirurgie une enveloppe contenant une des deux brochures (longue ou abrégée) ou une feuille sur la chirurgie d'un jour. Le matin de l'opération, l'assistante de recherche a recueilli le formulaire de consentement et expliqué aux parents comment remplir le questionnaire et l'échelle d'anxiété. L'assentiment verbal de l'enfant a également été obtenu. De plus, on a de nouveau indiqué aux parents les moments où ils seraient enregistrés sur bande vidéo. Ceux-ci ont également été informés qu'ils pouvaient se retirer de l'étude à n'importe quel moment au cours de la journée.

## Les résultats

### *Les compétences parentales*

Les résultats de type descriptif se rapportant aux connaissances figurent au tableau 2. La moyenne totale du score de connaissances a été de 15,23 (80,2 %) pour le groupe I, de 14,46 (76,1 %) pour le groupe II et de 12,56 (66,1 %) pour le groupe III. Les parents des deux groupes expérimentaux ont donc obtenu un score plus élevé que les parents du groupe contrôle, et ce, pour les trois types de connaissances.

**Tableau 2** *Moyenne et écart-type des scores de connaissances des parents selon le groupe et le type de connaissances (n = 149)*

Type	Groupe I Brochure longue		Groupe II Brochure abrégée		Groupe III Contrôle	
	M	ÉT	M	ÉT	M	ÉT
Termes médicaux (5 points)	3,78	0,99	3,83	1,00	3,24	1,20
Développement de l'enfant (9 points)	7,25	1,47	7,00	1,47	5,80	1,51
Histoire de cas (5 points)	4,20	1,20	3,63	1,01	3,52	1,07
<b>Total : 19 points (100 %)</b>	<b>15,23 (80,2 %)</b>		<b>14,46 (76,1 %)</b>		<b>12,56 (66,1 %)</b>	

La moyenne et l'écart-type des scores au chapitre des conduites parentales figurent au tableau 3. Ce sont les conduites de type attitudes, comme le fait de manifester de l'affection, de se tenir à proximité et de rassurer, qui ont été les plus fréquentes chez les parents, suivies par les conduites de type information verbale, comme donner de l'information et répondre aux questions, et enfin par les conduites de type stratégies cognitives, comme distraire ou faire du renforcement.

**Tableau 3** *Moyenne et écart-type des scores de conduites parentales selon le groupe et le type de conduite (n = 142)*

Type	Groupe I Brochure longue		Groupe II Brochure abrégée		Groupe III Contrôle	
	M	ÉT	M	ÉT	M	ÉT
Information verbale	2,73	1,85	2,63	2,03	2,66	1,67
Stratégies cognitives	1,55	1,39	1,33	1,13	1,43	1,09
Attitudes	17,96	4,79	17,92	4,45	18,84	3,87

Les moments où les parents ont montré le plus grand nombre de conduites différentes ont été à l'admission ( $M = 5,98$ ;  $é.t. = 2,30$ ) et durant l'heure suivant le retour de l'enfant de la salle de réveil ( $M = 5,35$ ;  $é.t. = 1,99$ ). Une analyse de variance multivariée (MANOVA) ayant comme variables dépendantes les connaissances et les conduites a montré qu'il y avait une différence significative entre les groupes (test Hotellings,  $F = 7,91$ ;  $p = 0,000$ ), et les analyses univariées ont établi la différence relativement aux connaissances des parents. Les résultats de ces analyses figurent au tableau 4. De plus, des analyses comparatives à posteriori (contrast) ont montré que les deux groupes expérimentaux différaient grandement du groupe contrôle en ce qui a trait aux compétences (connaissances et conduites) (test Hotellings,  $F = 14,737$ ;  $p = 0,000$ ), mais qu'ils ne différaient pas entre eux de manière significative (test Hotellings,  $F = 1,215$ ;  $p = 0,300$ ) à ce chapitre.

L'hypothèse de recherche sur les compétences parentales est donc acceptée; les parents ayant reçu une brochure éducative (longue ou abrégée) à la maison ont fait montre de considérablement plus de types de compétences que les parents du groupe contrôle.

**Tableau 4** *Scores des connaissances et des conduites parentales selon le groupe*  
*Résultats des analyses de MANOVA (n = 142)*

Groupe					
Variable	Brochure longue	Brochure abrégée	Contrôle	F	P
Connaissances					
M	15,24	14,48	12,59	14,586	.0001
ÉT	(2,62)	(2,30)	(2,58)		
Comportements					
M	23,76	23,45	24,75	0.645	0,526
ÉT	(6,50)	(5,67)	(4,83)		

Les variables étrangères, soit une expérience antérieure des parents avec une chirurgie d'un enfant et l'âge de l'enfant n'ont pas eu d'effet significatif sur les connaissances et les conduites des parents. Par contre, le niveau de scolarité de la mère a eu un effet significatif sur l'acquisition des connaissances ( $F = 4,158$ ,  $p < 0,01$ ). En effet, les mères plus scolarisées ont obtenu un score plus élevé dans le questionnaire sur les connaissances.

De plus, les mères plus jeunes, celles entre 21 et 29 ans, ( $F = 4,139$ ;  $p < 0,05$ ) et les parents sans autre enfant ( $F = 4,028$ ;  $p < 0,05$ ) ont montré considérablement plus de types de conduites que les mères plus âgées et les parents ayant d'autres enfants.

### *L'anxiété parentale*

Les scores au chapitre de l'anxiété situationnelle du parent accompagnateur, obtenus à l'aide de l'échelle numérique, figurent au tableau 5. Les parents du groupe contrôle ont obtenu des scores plus élevés dans l'auto-rapport, et ce, pour tous les moments observés. Les deux moments pour lesquels les scores ont été les plus élevés sont au départ de l'enfant pour la salle d'opération et à son retour de la salle de réveil.

L'analyse de variance à mesures répétées (MANOVA) a montré qu'il y avait une différence significative entre les groupes (test Hotellings,  $F = 2,542$ ;  $p = 0,006$ ) et les analyses univariées ont révélé que le départ pour la salle d'opération et la période d'attente étaient les



**Tableau 5** Scores d'anxiété parentale selon le groupe et la période d'auto-rapport  
Résultats des analyses de MANOVA (n = 148)

Variable	Groupe			F	P
	Brochure longue	Brochure abrégée	Contrôle		
Admission					
M	1,49	1,88	2,04	0,743	0,390
ÉT	(1,85)	(2,57)	(2,53)		
Départ salle d'opération					
M	3,43	3,35	5,57	15,92	0,000
ÉT	(2,84)	(2,99)	(3,38)		
Attente					
M	2,90	3,65	4,54	6,39	0,013
ÉT	(2,48)	(2,63)	(3,35)		
Retour salle de réveil					
M	3,80	3,59	4,83	3,59	0,060
ÉT	(3,37)	(3,13)	(3,59)		
1 heure post retour					
M	1,47	1,61	2,09	1,85	0,176
ÉT	(1,96)	(2,40)	(2,42)		

moments particulièrement producteurs d'anxiété chez les parents ( $p < 0,05$ ).

Les analyses comparatives à posteriori (contrast) ont établi que les deux groupes expérimentaux différaient de façon significative du groupe contrôle (test Hotellings,  $F = 4,034$ ;  $p = 0,002$ ), mais qu'il n'y avait pas de différence importante entre ces deux premiers groupes (test Hotellings,  $F = 1,205$ ;  $p = 0,310$ ). L'hypothèse de recherche est donc acceptée; les parents ayant reçu une brochure éducative (longue ou abrégée) à la maison ont rapporté sur l'échelle une anxiété moindre le jour de la chirurgie que les parents du groupe contrôle.

Les variables étrangères et socio-démographiques n'ont pas influencé de façon significative le degré d'anxiété des parents.

## Discussion des résultats

### *Les compétences parentales*

Les analyses multivariées ont établi que les parents des deux groupes expérimentaux ont fait montre de considérablement plus de compétences, de connaissances et de conduites bienfaisantes combinées que les parents du groupe contrôle. L'approche éducative choisie a donc permis aux parents des groupes expérimentaux d'acquérir des connaissances et des compétences s'appliquant à une situation comme une chirurgie d'un jour. En outre, l'absence de différence significative entre les deux groupes expérimentaux en ce qui a trait aux compétences parentales semble démontrer que tous les parents possédant des concepts touchant l'enfant et la situation d'apprentissage, tels que présentés dans les deux brochures, font preuve d'un même degré d'habileté à résoudre des problèmes relatifs à la préparation et à l'aide à l'enfant le jour de la chirurgie. Le fait d'avoir ajouté une partie visant l'acquisition de certaines stratégies cognitives n'a pas entraîné de différence significative entre les deux groupes expérimentaux lors d'une expérience unique et de courte durée comme une chirurgie d'un jour. Reinhart-Rahn (1988) constate par contre dans son étude que tous les parents, quelles que soient les modalités de la formation reçue, ont montré avec le temps une augmentation de leurs compétences.

Dans la présente étude, les analyses univariées ont révélé que c'est au chapitre des connaissances qu'il existe une différence significative entre les groupes. En effet, les parents ayant reçu une brochure éducative à la maison avant la chirurgie possèdent plus d'aptitudes intellectuelles et ont intégré plus de concepts et de règles que les parents sans brochure. Mazurek-Melnyk (1994) mentionne que des parents d'enfants hospitalisés ayant reçu de l'information sur les réactions de l'enfant et sur les moyens de l'aider pendant l'hospitalisation possédaient plus de connaissances théoriques et montraient davantage d'habileté en résolution de problèmes que les parents sans information. Par ailleurs, Brandt et Magyary (1993) ont établi qu'un programme éducatif destiné à des mères et à leur enfant diabétique avait amélioré de façon significative les connaissances des mères ainsi que leur habileté en résolution de problèmes, mais pas leurs compétences psychomotrices. Ces auteures avaient utilisé des stratégies éducatives de même type comme le modelage, la répétition et le feedback.

Dans cette étude, les conditions internes et externes propres à faire acquérir, selon Gagné (1985), des compétences de type information verbale, aptitudes intellectuelles, stratégies cognitives et attitudes ont

été mises en place et réalisées au moyen d'une brochure éducative. Le concept de modelage verbal de Bandura (1986) a également été employé dans la brochure. L'utilisation de ces deux modèles semble efficace pour l'acquisition de concepts et de règles, mais pas pour l'intégration d'autres compétences comme les stratégies cognitives et les attitudes. Certains éléments des modèles manquaient lors de la recherche, comme le feedback donné aux parents, élément important selon Gagné et Bandura, la présence d'un modelage d'actions réelles et non uniquement verbal, et la possibilité pour les parents de mettre en pratique les nouvelles techniques apprises. Ce sont des considérations d'ordre pratique entourant l'expérimentation et le contexte de la chirurgie d'un jour qui ont empêché la mise en place de ces éléments.

De plus, comme l'affirme Coyne (1995), le stress entourant l'hospitalisation et la chirurgie de leur enfant et le fait d'être dans un environnement nouveau peuvent avoir inhibé chez les parents certaines capacités de réponse aux besoins de l'enfant, surtout lors des moments de stress. Gagné (1985) mentionne que des parents possédant déjà des compétences de type stratégies cognitives ne sont pas nécessairement capables de les transférer à une situation nouvelle. Il ajoute que le fait de communiquer la stratégie à l'apprenant ne garantit pas son utilisation réelle et qu'il faut tenir compte de sa volonté de résoudre le problème. Une prochaine étude qui appliquerait tous les éléments des deux modèles éducatifs, incluant le feedback et le modelage d'actions réelles, et qui mesurerait les capacités d'apprentissage avant et après l'utilisation du programme éducatif serait plus à même d'établir la valeur dudit programme.

En ce qui concerne l'aspect qualitatif des conduites des parents le jour de la chirurgie, on remarque que tous les parents, et plus particulièrement ceux du groupe contrôle, ont surtout manifesté des compétences de type attitudes, comme serrer, embrasser, caresser, rassurer. Des compétences de ce type ont été mentionnées dans d'autres études visant à mesurer les conduites d'aide des parents (Caty et al., 1989; Jones, 1994; LaMontagne, Hepworth, Johnson et Deshpande, 1994). Meyer (1987) et Roskies et al. (1978) ont observé que des parents ayant reçu une préparation de type cognitif sur le développement normal de l'enfant et sur l'importance de leur participation aux soins ont démontré plus d'empathie envers l'enfant et ont participé plus activement aux soins, particulièrement ceux de nature psychologique (affection, réconfort, distraction) que les parents des groupes contrôle.

Un autre facteur pouvant avoir influencé les résultats est le degré de détresse montré par l'enfant le jour de la chirurgie. Les enfants des

groupes expérimentaux ayant reçu une préparation sur mesure donnée par les parents à la maison ont montré moins de conduites de détresse que les enfants du groupe contrôle (Tourigny, 1996). Par contre, les parents des groupes expérimentaux, bien qu'ayant montré un peu plus de compétences de type information verbale et stratégies cognitives, ont fait preuve de moins de compétences de type attitudes que les parents du groupe contrôle. Ces derniers, n'ayant pas accès à la brochure, ont probablement tenté de suppléer au manque de préparation par l'usage plus fréquent de conduites d'aide, surtout celles de type attitudes comme serrer, embrasser, caresser. Il pourrait aussi s'agir de conduites de soutien plus fréquentes ou plus acceptables dans certaines familles.

L'utilisation de l'instrument de mesure des conduites parentales est un autre facteur pouvant avoir influencé les résultats. Bien que l'analyse factorielle ait établi une certaine validité hypothético-déductive de l'instrument, celui-ci a besoin d'une validation plus poussée. Ainsi, le fait d'avoir utilisé l'instrument pour mesurer la présence et non la fréquence des conduites a pu influencer les résultats. Les parents des groupes expérimentaux ont peut-être montré des compétences à une plus grande fréquence que ceux du groupe contrôle, mais ceci n'a pas été vérifié dans l'étude.

### *L'anxiété parentale*

Les parents accompagnateurs des deux groupes expérimentaux se sont dits moins anxieux que les parents du groupe contrôle ; cependant, les deux groupes expérimentaux ne différaient pas entre eux à cet égard. La remise d'une brochure abrégée, c'est-à-dire comprenant seulement de l'information sur le développement et les réactions de l'enfant et sur le déroulement de la journée à l'hôpital, a donc permis de réduire l'anxiété situationnelle relative à l'hospitalisation d'un enfant pour une chirurgie d'un jour. Le fait de fournir aux parents des concepts et des règles sur l'enfant et les procédures à l'hôpital a probablement contribué à la formation de schémas cognitifs propres à anticiper les événements et à en abaisser le côté anxiogène (Gagné, 1985). Ellerton et Merriam (1994), Mazurek-Melnyk (1994), Peterson et Shigetomi (1981), Robinson et Kobayashi (1991) et Vulcan et Nikulich-Barrett (1988) ont tous obtenu des résultats semblables en ce qui a trait à l'efficacité d'une préparation cognitive dans la réduction de l'anxiété situationnelle des parents. L'élément important de la présente étude est l'établissement de l'efficacité d'une préparation centrée sur les parents et effectuée dans le milieu familial pour les enfants de trois à six ans opérés dans le cadre d'une chirurgie d'un jour.

## Conclusion

Cette étude comportait certaines limites comme l'absence de contrôle sur l'utilisation de la brochure à la maison et la difficulté de recueillir des images vidéo de qualité comparable. De plus, il n'y a pas eu de mesure pré-opératoire des compétences parentales à cause de l'impossibilité d'observer les parents avant la chirurgie d'un jour. D'autres facteurs comme le degré d'intelligence des parents, leur perception de la gravité de la chirurgie, la dynamique familiale et l'attitude des soignants peuvent avoir influé sur les résultats. Enfin, le recours à un échantillon de convenance ne permet pas de généraliser les résultats à l'ensemble des parents qui font opérer leur enfant dans le cadre d'une chirurgie d'un jour.

Même si ce n'était pas le but de cette recherche, on constate cependant qu'elle a permis de déterminer, d'observer et de mesurer les conduites d'aide adoptées par des parents lorsque leur enfant subit une chirurgie. La connaissance de ces conduites devrait guider les intervenants en soins de santé dans la promotion et le soutien des actions d'aide à l'enfant. Les résultats obtenus montrent également que des parents ayant reçu une brochure éducative à la maison avant la chirurgie ont montré plus de compétences et se sont dits moins anxieux pendant la journée de la chirurgie que des parents n'ayant pas bénéficié de cette approche. Le fait d'avoir utilisé un moyen unique, la brochure, a permis de mieux vérifier les effets d'une approche spécifique sur les parents. Ainsi, cette auto-préparation à la maison semble permettre aux parents d'acquérir et de faire montre des capacités d'apprentissage nécessaires lors d'une chirurgie de l'enfant. Il serait cependant intéressant d'améliorer cette approche en y introduisant un volet visuel comme une bande vidéo ; il serait alors possible d'en vérifier les effets sur l'acquisition de stratégies d'aide à l'enfant.

Des recherches futures sont nécessaires pour vérifier de nouveau l'efficacité d'une approche combinée, comportant brochure et vidéo, auprès de parents dont l'enfant doit subir une chirurgie d'un jour ou des interventions douloureuses à répétition comme des ponctions lombaires ou de la moelle osseuse. Ces tests étant effectués fréquemment chez les enfants atteints de cancer, les parents peuvent en prédire le déroulement, en plus d'intégrer et de mettre en pratique des stratégies d'aide à l'enfant. En outre, la validation de l'instrument *Inventaire des conduites parentales* doit se poursuivre en observant à nouveau des parents lorsque leur enfant subit une chirurgie ou dans une situation plus contrôlée comme une ponction lombaire. Il serait également intéressant de comparer les compétences des mères à celles des pères



dans le contexte d'une chirurgie d'un jour. L'auteure a d'ailleurs constaté au cours de l'étude que les pères étaient très présents et attentifs aux besoins de leur enfant opéré.

La présente recherche ouvre la voie à l'exploration de nouvelles approches s'appliquant aux soins de type ambulatoire prodigués à l'enfant et à sa famille. L'aide aux parents en ce qui concerne la prise en charge des soins à l'enfant, à l'hôpital et à la maison, fait partie intégrante des responsabilités professionnelles de l'infirmière, dans un système de soins de santé qui change de plus en plus vite. La participation des parents aux soins de l'enfant s'inscrit bien dans une approche d'humanisation des soins et d'*empowerment*, qui s'avère nécessaire dans l'optique du virage ambulatoire.

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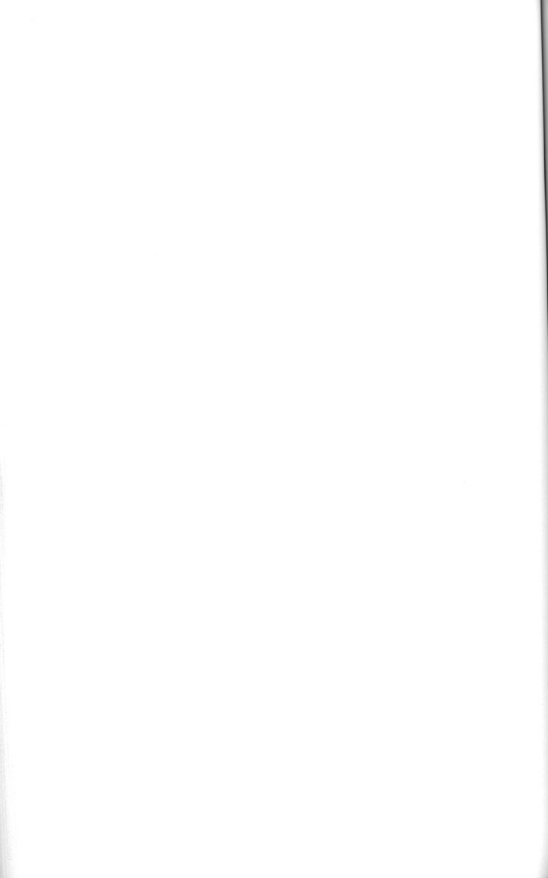
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## **Nurses' Knowledge, Experiences, and Attitudes Concerning Living Wills**

**Barbara Downe-Wamboldt, Lorna Butler,  
and Stephen Coughlan**

Une enquête a été menée auprès de 974 infirmières accréditées de la Nouvelle-Écosse, choisies selon un échantillonnage aléatoire, au cours de l'année d'accréditation 1995-96, afin de cerner les éléments suivants relativement aux testaments biologiques : le degré de compréhension manifesté par les infirmières concernant la législation à ce sujet; les expériences qu'elles ont eues, les rôles qu'elles ont joués et les attitudes qu'elles ont exprimées à cet égard; enfin, les obstacles qui, à leurs yeux, les empêchent d'avoir recours aux testaments biologiques dans l'exercice de leurs fonctions, de même que les ressources qui les y encouragent. Les réponses faites par 157 infirmières indiquent qu'elles connaissaient mal la loi sur le consentement médical, la loi sur les hôpitaux et la loi sur les procurations. Bien qu'elles révèlent une attitude positive à l'égard des testaments biologiques et désignent les infirmières comme étant les professionnelles de la santé aptes à aborder cette question avec les patients, peu d'entre elles ont effectivement joué ce rôle. Les répondantes ont évalué leur compréhension des testaments biologiques comme étant faible, et plusieurs ont indiqué qu'elles se sentaient mal à l'aise d'en discuter avec leurs clients. L'infirmière et le milieu de travail sont considérés par les répondantes comme des obstacles à l'utilisation des testaments biologiques; les commentaires révèlent de manière claire que des stratégies pédagogiques et interdisciplinaires devront être employées afin que les infirmières aient plus aisément recours aux testaments biologiques dans l'exercice de leur profession.

A random sample of 974 registered nurses in Nova Scotia were surveyed during the 1995-96 registration year to determine their understanding of living wills legislation; their experiences, roles, and attitudes related to living wills; and their perceptions of the barriers to and resources for using living wills in their practice. Responses from 157 nurses indicated that they were unfamiliar with the Medical Consent Act, the Hospitals Act, and the Powers of Attorney Act. Although they revealed that they had a positive attitude towards living wills, and they identified nurses as the appropriate health professional to initiate discussions about living wills with patients, very few had any actual experience in this role. Respondents rated their understanding of living wills as low, and many indicated that they were uncomfortable discussing the topic with clients. Respondents saw both the individual nurse and the practice environment as barriers to the use of living wills, and they clearly indicated the need for interdisciplinary educational strategies to facilitate the use of living wills in their nursing practice.

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The role of patients as responsible, autonomous decision-makers in determining their own health care has been the subject of much attention in the literature, specifically the literature on life-sustaining treatment and do-not-resuscitate orders (Fried, Stein, O'Sullivan, Brock, & Novack, 1993; Genuis, Genuis, & Chang, 1994; Law Reform Commission of Canada, 1983; Rasooly et al., 1994; Sabatino, 1993; Zimbelman, 1994). In the United States, the Patient Self Determination Act (PSDA) has shifted the burden to ensure that the public is informed of its rights, particularly in determining future health care, to the health-care agency (Haisfield et al., 1994; Rein et al., 1996). The Canadian Medical Association and the Canadian Nurses Association support the right of individuals to accept or refuse life-saving or life-sustaining treatment, which may be acknowledged by an advanced directive, or living will; however, living wills have not always been honoured (Canadian Medical Association, 1992; Canadian Nurses Association, 1994).

Nurses and other health-care professionals need to be cognizant of current legislation regarding living wills, as well as policies concerning their use within agencies, to ensure that the client's right to choose is upheld. Although living wills have been publicly endorsed and advocated by consumer groups, very little is known about their actual use and many people still are not aware of their rights regarding health-care decision-making (Canadian Pensioners Concerned, 1995). The purpose of this study was to identify and describe registered nurses' awareness and understanding of legislation on substitute decision-makers and living wills; their experiences, roles, and attitudes concerning these issues; and their perspectives on the barriers to and resources for using living wills.

### Literature Review

To make decisions about their future health care, people need to understand the meaning of *living will* and *designated proxy*. Previous studies have found a high degree of uncertainty about the concept of a living will and a lack of understanding, even when information has been provided, especially at a time of crisis (Gamble, McDonald, & Lichstein, 1991; Rein et al., 1996; Singer & Lowy, 1991). Patients' decisions to accept or reject a living will are reportedly influenced by their level of understanding, the need to maintain control over treatment decision-making, type of illness, family relationships that might result in burdening or conflict, and perceived authority of health professionals in making treatment decisions (Rein et al.).



The Nova Scotia Hospitals Act (1989) permits the next of kin of an incompetent person to consent to medical treatment on behalf of that person. This Act applies only when the person is being treated in a hospital.

In 1988, Nova Scotia became the first Canadian province to grant individuals some control over their medical care once they have become incompetent. The Medical Consent Act (1989) allows a competent adult to appoint another person to make health-care decisions when he or she is no longer competent: the decision need not automatically fall to the next of kin. This type of living will, usually referred to as a *proxy directive*, does not allow the person to indicate in advance that they would accept or refuse particular types of treatment, or to express other wishes with regard to medical care.

Since that time, some court decisions in Ontario have held that the clearly expressed wishes of a competent person must be respected, even if the person is no longer in a position to make decisions (Fleming v. Reid & Gallagher, 1991; Malette v. Shulman, 1990). As of January 1998, Manitoba, Newfoundland, Ontario, Quebec, and the Yukon have introduced legislation concerning living wills or a substitute decision-maker, while Alberta, British Columbia, and Prince Edward Island have passed new laws but have not yet proclaimed them in force. Each of these Acts goes beyond the proxy directives allowed in Nova Scotia, and in addition permits a person to express binding wishes with regard to treatment. This latter type of living will is usually referred to as an *instructional directive*.

Although instructional directives are not legally binding in Nova Scotia, this does not mean that health-care professionals cannot choose to follow them. Some groups have therefore tried to promote their use. The Law Reform Commission of Nova Scotia (1995) has conducted public consultations on living wills and has recommended that the legislation be amended to provide for instructional directives.

Nurses have been described as playing various roles in relation to living wills (such as educator, advocate, and facilitator for patients and families), yet no research has been carried out to describe these roles (Haisfield et al., 1994). Health professionals are responsible for ensuring that treatment choices are consistent with a patient's social, political, and spiritual values, even if these values conflict with those of the care provider (Higgins, 1993). Although both physicians and nurses support the use of living wills, in practice many ignore the instructions they provide (Molloy, Harrison, Farrugia, & Cunje, 1993).

There is a paucity of literature exploring nurses' knowledge, experience, and attitudes concerning living wills. The specific needs of nurses in various health-care settings to initiate and implement living wills requires further investigation.

## Method

### *Design*

This exploratory, descriptive study used a 12-page survey questionnaire consisting of true-false, yes-no, and Likert-scale items as well as open-ended questions. The questionnaire was developed by the researchers based on the current literature, and included 9 items from the Medical Consent Act Survey (Elgie, MacIntosh, & Rideout, 1992). It was designed to determine nurses' awareness of current provincial legislation; knowledge, experiences, roles, and attitudes concerning living wills; perceptions of barriers to the use of living wills; and resources to facilitate use of living wills in nursing practice. The instrument was assessed for content validity and clarity by a multidisciplinary panel of experts (lawyer, nurse, social worker) external to the research team.

### *Sample*

Subsequent to obtaining approval from the appropriate institutional ethical review boards, a random sample of 974 nurses was identified using the registration list of the Registered Nurses Association of Nova Scotia (RNANS). Sample size was determined on the basis of a 95% confidence interval, a 5% ( $\pm 0.05$ ) margin of error, and an expected response rate of 50%. The questionnaire, a letter describing the purpose of the study, and a stamped return envelope were mailed to the sample. A total of 157 nurses returned the completed questionnaire, yielding a response rate of 16%. The nurses who participated in the study were representative of the RNANS membership with respect to gender, age, and number of years elapsed since completion of initial nursing education (RNANS, 1996) (Table 1). Most were female ( $n = 144$ , 92%), the mean age was 41 years, and they had completed their initial nursing education an average of 19 years previously. The majority of respondents reported a higher level of nursing education than that for the RNANS general membership; 49% were prepared at the diploma level, differing significantly from the general membership ( $\chi^2 = 84.1$ ,  $p = 0.001$ ,  $df = 1$ ) (Table 1).

The most frequently identified practice settings were tertiary hospital (24%), regional hospital (18%), and community hospital (17%).

**Table 1** *Characteristics of Registered Nurses in Nova Scotia and of Sample*

Risk Status	Nova Scotia N = 9,260	Sample N = 157
	<i>P</i>	<i>P</i>
Gender		
Female	98	92
Male	2	8
Nursing education		
Diploma	80	49
Baccalaureate	20	51
Continuing education		
Nursing	22	22
Other	11	8
	<i>M</i>	<i>M</i>
Average age	41	41
Average number of years since graduation	18	19

Most respondents worked in rural Nova Scotia ( $n = 104$ , 66%) and were on staff as casual employees ( $n = 92$ , 58%). Within the practice setting, the nurses reported that they had little experience in the previous 5 years in attending educational sessions on living wills ( $n = 131$ , 83%) or participating on committees to address the use of living wills ( $n = 143$ , 91%).

### Data Analysis

Descriptive statistics were used to identify the mean, standard deviations and percentage of scores for responses to the close-ended items. The chi-square statistic was used to compare the characteristics of the sample and the population. Content analysis was used to categorize the narrative data from the open-ended questions. Categories were created by comparative analyses and synthesis of the responses with the relevant literature. Inter-rater reliability of the final category system was assessed through independent coding of a random selection of 56 units of analysis, resulting in a 95% agreement level. Because the sample was more highly educated than the population, Fisher's exact test and Student's  $t$  test were used to determine whether there were group differences, based on education, in knowledge, experience, and attitudes.

## Findings

### *Knowledge*

Nurses were asked if they were aware of options for people in Nova Scotia to use living wills. Using a Likert scale (1 = very aware, 10 = not at all aware), respondents rated themselves ( $M = 7.4$ ,  $SD = 2.62$ ) as not aware of the options. When questioned about specific Nova Scotia legislation affecting some aspects of living wills, the majority of respondents indicated that they were not familiar with the Medical Consent Act (1989) ( $n = 103$ ), the Hospitals Act (1989) ( $n = 118$ ), or the Powers of Attorney Act (1989) ( $n = 95$ ). However, 133 of the nurses knew the meaning of *durable power of attorney* (DPA) for health care and knew that an instructional directive provides instruction for the kinds of treatment a person wishes to receive ( $n = 69$ ).

Forty respondents identified (correctly) that a designated proxy is legally recognized in Nova Scotia. Many respondents ( $n = 69$ ) knew that under the Medical Consent Act (1989) a person could designate an individual to make decisions about their medical care. Sixty-four respondents knew that under the Medical Consent Act any competent person could write a living will and that under the Hospitals Act (1989) a patient's spouse was legally designated next-of-kin for the purpose of consent to treatment ( $n = 50$ ).

Fifty-two respondents believed (incorrectly) that it was the Hospitals Act (1989) that allowed a person to designate an individual to make decisions about their medical care. Fifty-six respondents thought that under the Hospitals Act any competent person could write a living will. Many ( $n = 50$ ) believed (incorrectly) that the Medical Consent Act (1989) rendered a patient's spouse a legally designated next-of-kin for the purpose of consent to treatment. Several respondents believed (incorrectly) that people could indicate the forms of treatment to be accepted or refused if they became incompetent under the Medical Consent Act ( $n = 66$ ) and under the Hospitals Act ( $n = 55$ ). The majority of respondents ( $n = 128$ ) believed (incorrectly) that the living will should be followed in a situation in which a designated proxy for an incompetent patient disagreed with the living will.

To identify a profile of the most knowledgeable respondents, Student's  $t$  tests and Fisher's exact test were used to compare nurses prepared at the diploma level to those who had received higher nursing education. No statistically significant differences were found between the two groups for awareness of legislation. Diploma-prepared nurses

were more knowledgeable about the extent to which a designated proxy could express an individual's preference for care ( $t = -2.51$ ,  $p = 0.013$ ). When respondents were asked if living wills provided instruction only for the kinds of treatment a person wished to receive, Fisher's exact test indicated that a diploma education was more strongly associated with the correct response for both instructional directive ( $p = 0.028$ ) and designated proxy ( $p = 0.021$ ).

### *Experience*

The majority of nurses indicated that they had no experience with using either instructional directives ( $n = 113$ ) or designated proxies ( $n = 120$ ). No statistically significant differences in experience based on education were found. The 37 respondents who reported experience with living wills indicated that the majority of their patients were 65 years of age or over. Using a checklist, these nurses identified their role in discussions related to living wills as advocate ( $n = 28$ ), combination of roles ( $n = 11$ ), facilitator ( $n = 5$ ), and educator ( $n = 2$ ). Narrative descriptions of experiences with living wills from 9 participants reflected the roles of educator ( $n = 6$ ), advocate ( $n = 3$ ), caregiver who follows the patient's wishes ( $n = 2$ ), and provider of support ( $n = 1$ ). These roles were reflected in the following comment: "I helped to get information to family and listened to clients express their desires on how they wished to be treated if and when hospitalization was needed." Five respondents indicated that they did not believe they had a role in relation to living wills: "Not my place, private matter." One respondent stated, "We were not permitted to follow the terms of her living will as her doctor would not honour it."

### *Attitudes*

Nurses reported that living wills were very helpful (1 = very helpful, 10 = not at all helpful) in their nursing care, identifying an instructional directive ( $M = 2.7$ ,  $SD = 2.5$ ) as slightly more helpful than a designated proxy ( $M = 3.02$ ,  $SD = 2.7$ ). Responses on a 10-point Likert scale indicated that both instructional directives and designated proxies helped nurses to plan care, helped patients to express their preferences for care, promoted effective communication between patients and health-care providers, and benefited family members by relieving them of difficult decision-making (Table 2). Respondents strongly disagreed (1 = agree strongly, 10 = disagree strongly) that living wills restricted their nursing practice (instructional directive,  $M = 9.2$ ,  $SD = 1.9$ ; designated proxy,  $M$



= 9.1,  $D = 1.9$ ) or altered the quality of the nursing care they provided to a patient (instructional directive,  $M = 9.1$ ,  $SD = 2.4$ ; designated proxy,  $M = 9.1$ ,  $SD = 2.3$ ). Respondents agreed (1 = totally agree, 10 = totally disagree) with the statement that nurses should promote the use of instructional directives ( $M = 3.3$ ,  $SD = 2.8$ ) and designated proxies ( $M = 3.3$ ,  $SD = 2.9$ ) with all of their patients.

**Table 2** *Nurses' Attitudes Towards Living Wills*

Attitude	Instructional Directive		Designated Proxy	
	$M^*$	$SD$	$M^*$	$SD$
Help nurses plan care	2.5	2.3	2.7	2.4
Help patients express wishes	1.7	1.5	1.8	1.5
Promote communication between patients and health professionals	2.5	2.1	2.5	2.0
Benefit family members	2.2	2.0	2.5	2.3
* 1 = very helpful, 10 = not at all helpful				

Few differences in attitudes were found between diploma and more highly educated nurses. The belief that a designated proxy was helpful in planning patient care was greater among diploma-educated nurses ( $t = -2.01$ ,  $p = 0.05$ ). Using Fisher's exact test, the belief that information on living wills should be offered to persons newly diagnosed with a life-threatening illness ( $p = 0.02$ ) or persons with a terminal illness ( $p = 0.05$ ) was found to be more closely associated with a diploma education.

Although most ( $n = 53$ ) of the respondents' narrative comments indicated that they had no experience with living wills, comments from those who did have experience ( $n = 19$ ) reflected a positive attitude towards their use. Benefits ( $n = 7$ ) were described for family, patients, and nurses: "I found a living will very beneficial to the care of my patients"; "Easier to deal with the family, patient more at ease"; "being aware of patient's and family's wishes makes nursing that person much easier." Two responses indicated that living wills had no effect on patient care: "Care remains the same for all patients"; "The living will did not alter the care given to the patient." Only one response reflected a negative experience with living wills: "It is not easy, especially if you don't agree with the decision."



A total of 29 respondents identified potential benefits of living wills for family and patients, as well as for nursing care. The following comments provide vivid examples of the perceived benefits for families and patients: "Opens communication"; "Family members can benefit because when a family member is very ill he may not express his desire to die because his family is doing everything to keep him alive, many families avoid the issue of death"; "Patients can be dealt with honestly and time allowed to share and express concerns, problems etc. in preparation for death." The following comments indicate that living wills provide direction for nursing care: "It would stand to reason that for us and for family to know a patient's wishes would be helpful"; "I believe living wills would be most helpful in care planning, decision making, and would not lower level of care"; "In our setting, nursing home, it would help us to know how aggressively the clients are to be treated or not." One response indicated a negative effect on family: "Opportunity for conflict exists if family members oppose the choices of the patient and proxy, for example if the proxy is not liked by the family."

### Barriers

Using a 10-point Likert scale, the nurses clearly identified lack of knowledge, legal concerns, lack of agency support, and ethical concerns as perceived barriers to the use of living wills in their practice (Table 3). They identified that they were not effective (1 = not effective, 10 = most effective) in implementing either instructional directives ( $M = 3.6$ ,  $SD = 3.0$ ) or designated proxies ( $M = 3.5$ ,  $SD = 2.9$ ). Many nurses ( $n = 55$ ) indicated that they were uncomfortable raising or discussing the topic of living wills, and 57 believed that patients and families were also uncomfortable with the topic. Interestingly, only 7 nurses thought it was the responsibility of the physician or some other health professional ( $n = 5$ ) to discuss living wills with patients or families.

**Table 3** *Barriers to Use of Living Wills in Practice*

Attitude	Instructional Directive		Designated Proxy	
	<i>M*</i>	<i>SD</i>	<i>M*</i>	<i>SD</i>
Lack of knowledge	1.9	2.0	2.0	2.0
Legal concerns	3.1	2.0	3.2	2.9
Lack of agency support	3.2	2.7	3.2	2.9
Ethical concerns	4.8	3.4	4.5	3.4

\* 1 = very helpful, 10 = not at all helpful

### Resources

Respondents' written comments ( $n = 157$ ) identified resources that would help their practice regarding living wills. The resources identified most frequently were lawyers (29.95%), continuing education on living wills (12.83%), development of agency policies (11.76%), relevant literature such as found in professional journals (10.16%), social workers (8.02%), clergy (7.49%), and hospice and/or palliative-care staff (7.49%). Other resources (12.30%) identified included family members, patients, physicians, and an interdisciplinary-team approach to practice.

**Table 4** *Perceived Helpfulness Ratings of Educational Topics*

Strategy	<i>n</i>	<i>M</i>	<i>SD</i>
Discussions of types of living will	142	9.4	1.54
Discussions of legal issues			
Instructional directive	144	9.3	1.60
Designated proxy	142	9.3	1.60
How to implement a living will			
Instructional directive	143	9.2	1.60
Designated proxy	140	9.3	1.50
How to facilitate the use of living wills			
Instructional directive	144	9.3	1.60
Designated proxy	142	9.3	1.60
Discussions of ethical issues			
Instructional directive	143	9.1	1.80
Designated proxy	140	9.1	1.80
How to write a living will			
Instructional directive	141	8.8	2.20
Designated proxy	138	8.8	2.10
Communication strategies with patients			
Instructional directive	144	8.7	4.70
Designated proxy	142	8.3	2.60
Communication strategies with families			
Instructional directive	143	8.5	2.50
Designated proxy	141	8.5	2.50

Nurses were asked to rate on a Likert scale (1 = not helpful, 10 = extremely helpful) each of 8 educational topics that could address issues related to living wills (Table 4). The mean scores, which ranged from 8.3 to 9.4, suggested that all of the topics were perceived as relevant. When asked to identify the ideal instructor for specific educational sessions, from a list of 9 options, respondents most frequently chose nurses, lawyers, physicians, clergy, social workers, and hospice staff (Table 5).



## **Discussion**

Of the 974 questionnaires mailed out, only 157 (16%) were returned. This unusually low response rate is itself significant. It may be that many nurses were unwilling to participate because of lack of familiarity with the issues. The respondents, who had a higher level of nursing education than the typical registered nurse in Nova Scotia, rated themselves as unaware of the options in Nova Scotia for using living wills, and the majority described themselves as unfamiliar with the Medical Consent Act (1989), the Hospitals Act (1989), and the Powers of Attorney Act (1989). Very few differences were found in participants' responses based on education, which means that a relatively small percentage of nurses are familiar with these Acts. These results are similar to those of an earlier, unpublished study with physicians (Elgie et al., 1992). The low response rate of the present study, and the sample profile in terms of education, limits the generalizability of the results.

It is possible that nurses under-reported their familiarity with issues surrounding living wills. Although only 54 respondents indicated that they were familiar with the Medical Consent Act (1989), 133 indicated that they knew the meaning of DPA for health care. Similarly, over half the respondents answered many of the specific questions about instructional directives and designated proxies. This could be interpreted to mean that many nurses were aware of the issues but were unfamiliar with the specific legislation and were uncomfortable with the language. Supporting this interpretation are the answers found in the knowledge section of the questionnaire. Generally, respondents' answers regarding the options available to patients were correct: 89% knew that any competent person could write a living will, 96% knew that under the Medical Consent Act one person could designate another to make decisions for them, and 71% knew that under the Hospitals Act (1989) a spouse was legally designated next-of-kin for the purpose of consent to treatment.

The respondents were generally mistaken in their understanding of instructional directives: 63% believed that this form of living will was recognized under Nova Scotia law. In similar findings, Elgie et al. (1992) reported that 95.2% of physicians in Nova Scotia believed, incorrectly, that a living will could be written under the authority of the Medical Consent Act (1989). The present study found that 85% of nurses thought the instructions in a directive should be followed even if the designated proxy disagreed with them. However, designated proxies were in fact recognized under Nova Scotia law and instructional directives were not.

The likely explanation is that respondents relied on their experience with or knowledge of do-not-resuscitate orders, commonly called DNRs, or no-codes. Although not actually legally recognized, DNRs are a type of instructional directive in one particular situation, and are in common use in hospitals across the country. Many comments from nurses indicated that their experience had been with DNRs. Further supporting this interpretation are some agency policies reported by respondents; for example, 99 nurses indicated that a special form was required for a designated proxy and an instructional directive ( $n = 104$ ). Although no special form is legally required for a designated proxy, hospitals do typically have rules for how DNRs are to be entered in a patient's chart.

The results reveal interesting contrasts between reported attitudes and reported practice. The respondents consistently indicated that the nurse was the most appropriate person to deal with living wills, whether this involved communicating with patients, communicating with families, or facilitating the use of and implementing living wills. Yet very few reported fulfilling any of these functions. Similarly, respondents reported a very positive attitude towards the principle of living wills. They thought living wills were helpful in planning patient care, promoted effective communication, and benefited family members. Virtually all comments on living wills were positive, indicating that nurses should promote their use and support policies in that direction. Yet respondents acknowledged that they were not acting on these beliefs.

The nurses rated their understanding of living wills as low. More significantly, many reported that they either were uncomfortable raising the topic or felt that patients and families would be uncomfortable with it. They believed that promoting living wills was an important part of their function, yet they were reluctant to play this role. This reluctance might be justified by the fact that it would be hard for nurses to assume this role without a greater understanding of the legal and ethical issues it entails.

### **Conclusion**

A very high percentage of respondents had a positive opinion of living wills, whether or not they had experience using them. Nurses perceived living wills as valuable for them, the patient, and the family. Nonetheless, a high percentage expressed a lack of knowledge about and some discomfort with the issue of living wills. The nurses acknowl-



edged that they were not promoting the use of living wills. This has been a consistent finding in Canada (Molloy et al., 1993).

Strategies to facilitate the use of living wills must focus on the individual nurse, the context of practice, and public awareness. To the extent that lack of information plays a role, steps can be taken. Table 4 describes the educational topics that nurses identified as potentially helpful in facilitating their practice. The central point to emerge from this table is that all of the listed strategies were identified as potentially helpful by a large majority of respondents. Further, Table 5 clearly indicates that an interdisciplinary model of education would address the issues that nurses perceive as relevant to their work. In addition, as recommended by Elgie et al. (1992), hospitals and other health-care agencies should be encouraged to develop policies concerning living wills, with a view to educating both health professionals and the general public.

Future research should examine the effectiveness of various interdisciplinary educational strategies in facilitating nursing practice in the area of living wills. The present study found that many nurses are uncomfortable discussing living wills with patients, families, and other health professionals. Further research could explore the effectiveness of collaborative models of communication among agencies and disciplines on the use of living wills.

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## Maternal Infant-Feeding Decisions: Reasons and Influences

Kay Matthews, Karen Webber,  
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and Maureen Laryea

L'objectif de cette étude longitudinale prospective est de déterminer quelles sont les raisons qui poussent les mères à prendre telle ou telle décision en matière d'allaitement pendant les six mois qui suivent la naissance de leur enfant et ce qui les influence à ce chapitre. En six mois, le nombre de mères qui allaitent au sein passe de 41,7 % à 11,4 %. Les principales raisons qui poussent les mères à ne pas allaiter sont la gêne et un certain inconfort à l'idée d'allaiter. Les mères plus jeunes et moins instruites, dont les revenus sont inférieurs, sont moins susceptibles d'allaiter, plus enclines à interrompre prématurément l'allaitement maternel et plus susceptibles de donner à leur enfant des laits évaporés bon marché. Les mères cessent d'allaiter tôt, soit parce que c'est trop difficile, soit parce qu'elles doivent reprendre le travail. Les mères qui allaitent et celles qui allaitent au biberon changent de lait, soit parce que le bébé n'était « pas satisfait », soit parce qu'il « digérait mal » le lait en question. En règle générale, c'est le réseau social, plus que les professionnels de la santé, qui exerce l'influence la plus marquée sur les décisions des mères.

The purpose of this prospective longitudinal study was to determine the reasons for and influences on mothers' infant-feeding decisions over the 6 months post-birth. The breastfeeding initiation rate of 41.7% had declined to 11.4% at 6 months. The major reasons for not choosing breastfeeding were embarrassment and discomfort with the idea. Younger, less-educated mothers with lower incomes were less likely to start breastfeeding, more likely to discontinue breastfeeding early, and more likely to feed their babies cheaper evaporated milks. Mothers gave up breastfeeding early because it was too difficult or because they were returning to work. Reasons given by both breastfeeding and bottle-feeding mothers for switching milks were that the baby was "not satisfied" on the milk or that it was "not agreeing with" the baby. Generally, the social network, rather than health professionals, had greater influence on mothers' decisions.

An integral part of a mother's caretaking role is infant feeding. Method of feeding is an important determinant of an infant's health and its growth and development (Chandra, 1990). National and provincial programs have been introduced to promote breastfeeding as the

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optimal type of feeding, and national infant-nutrition guidelines have been established (Health and Welfare Canada & Canadian Paediatric Society, 1986; Nutrition Committee, Canadian Paediatric Society, 1979). However, in spite of these initiatives many mothers choose not to breastfeed or to give up breastfeeding within the first few months. Of the mothers who choose bottlefeeding, many switch from the formula recommended in the guidelines and started in hospital to milks not considered suitable for very young infants.

The degree to which both breastfeeding and bottlefeeding mothers follow established guidelines was examined in one Canadian province (Matthews, Webber, McKim, Banoub-Baddour, & Laryea, 1995), with the following results: the breastfeeding initiation rate was 41.7%; by 6 months after the birth the majority of breastfeeding mothers had given up; among bottlefeeding mothers, 33% switched from a commercially prepared infant formula (CPIF) to evaporated milk; solid foods were introduced earlier than the recommended 4 to 6 months; and, for some babies, iron and vitamin supplementation was either lacking or inappropriate. The study collected data on mothers' reasons for their infant-feeding decisions. The purpose of this paper is to present these data and discuss the reasons for maternal infant-feeding decisions and the factors that influenced the mothers' choices. The results of this analysis have implications for educational programs that target pregnant and postpartum women and their families.

### **Literature Review**

Most studies examined demographic variables to determine which mothers are likely to breastfeed and found that feeding method is largely determined by socio-economic factors: women from higher-income and more highly educated groups are more likely to breastfeed (Aberman & Kirchhoff, 1985; Grossman, Fitzsimmons, Larsen-Alexander, Sachs, & Harter, 1990; Jones, West, & Newcombe, 1986; Michaelsen, Larsen, Thomsen, & Samuelson, 1994). For North America, however, income and education factors are true for white populations only; black and Hispanic women are likely to follow accepted cultural practices and choose breastfeeding (Ford & Labbock, 1990). Psychosocial factors also play a part in infant-feeding decisions. For example, spousal support and having a mother who breastfed her children were found to be positively associated with a mother's decision to begin breastfeeding (Jones et al.; Littman, Mendendorp, & Goldfarb, 1994).

The most common reason for mothers to choose to breastfeed was found to be that it is better for the baby (Aberman & Kirchhoff, 1985). Giugliani, Caiaffa, Vogelhut, Witter, and Perman (1994) note that reasons for breastfeeding tend to be more infant-centred, while reasons for bottlefeeding tend to be more mother-centred. A study with low-income breastfeeding mothers (Libbus, Bush, & Hockman, 1997) also found that the women perceived the advantages of breastfeeding to be infant-related and the disadvantages to be mother-related. A study with young, single, multiparous mothers found that embarrassment, limitations on freedom, and inconvenience were the reasons for choosing not to breastfeed (Dix, 1991). The fact that breastfeeding is better for the baby may not be sufficient motivation for a woman to choose it, Dix comments, if breastfeeding does not meet her personal needs. The major reasons offered by bottlefeeding mothers for choosing this method were negative attitudes towards breastfeeding and convenience. Few studies have asked specifically why mothers chose not to breastfeed. Morse and Bottorff (1989) found that complicated decision-making was required when returning to work was the reason for giving up breastfeeding. Indecision and temporizing marked these mothers' approach to their infant-feeding decisions.

Duration of breastfeeding has been positively correlated with social support (Giugliani, Caiaffa, et al., 1994; Richardson & Chapman, 1992). In a study of the importance of the social network for choosing and persevering with breastfeeding for mothers of pre-term infants, Kaufman and Hall (1989) found that breastfeeding mothers reported significantly more social support than bottlefeeding mothers and were more motivated to comply with the wishes of the baby's father, the doctor, and the nurses. This group is likely to be more influenced by health professionals because of the dangers of prematurity and the close follow-up it requires. These investigators concluded that the social network significantly influenced the duration of lactation. If the social network is more influential than professional support systems in maternal infant-feeding decisions, the question arises: How much knowledgeable support is available to mothers? Giugliani, Bronner, et al. (1994) studied fathers as a source of support and reported that older, more-educated fathers who had attended prenatal classes were more knowledgeable about infant feeding and more supportive than younger, less-educated fathers. However, they found that many fathers felt helpless and unprepared to support their breastfeeding partners. Although breastfeeding mothers have been found more likely than bottlefeeding mothers to have sought and received professional advice when making their initial feeding

decision, the mothers' choice was influenced less by health-care professionals than by the informal network. Grossman et al. (1990) found that professional health-care providers had little influence on whether a mother chose to breastfeed. Dix (1991), in a study with low-income black women, found that the women were influenced more by nurse-midwives than by physicians.

In summary, a review of the literature suggests that maternal age, education, and income influence infant-feeding decisions. Women in higher socio-economic groups are more likely to breastfeed and to breastfeed longer than women in lower socio-economic groups. Major reasons for choosing breastfeeding are infant-related, although recognition of the superior quality of breastmilk may not influence some mothers if breastfeeding does not meet their own needs. Cultural and psychosocial factors also play a part. Mothers' support networks play a key role in their decisions, with family and friends being more influential than health professionals.

### **Rationale for the Study**

Although breastfeeding rates for Newfoundland increased from 17% in 1978 (Alton-Mackey & Orr, 1978) to 33% in 1983 (Banoub et al., 1985), the rates remained the lowest in Canada. The rates for persevering with breastfeeding were even lower. Despite provincial and local initiatives to promote breastfeeding, such as publicity campaigns and the establishment of support groups for nursing mothers, anecdotal reports from hospital and community-health nurses suggested that breastfeeding initiation and continuance rates were still low and that bottlefeeding mothers were using milks not recommended for infants.

While infant-feeding patterns require investigation, knowledge of such patterns in a population is incomplete if the influences on a woman's decision are not also studied. In a large, random survey of Newfoundland mothers, Matthews et al. (1995) found that 41.7% started breastfeeding, 11.6% were still breastfeeding exclusively at 6 months, and a significant number of both breastfeeding and bottlefeeding mothers were not following the Health and Welfare Canada & Canadian Paediatric Society (1986) infant-feeding guidelines. Knowing who or what influences women in their infant-feeding decisions will guide the development of effective institutional and community-health programs for prepartum and postpartum families.



### *Objectives*

1. To establish the reasons for initial maternal infant-feeding decisions.
2. To establish the reasons for changing the initial feeding decision over the first 6 months.
3. To determine which members of support networks, both informal and professional, most influence a mother's feeding decisions.

### *Research Questions*

1. What reasons are given by mothers for choosing not to breastfeed?
2. What reasons are given by mothers for changing their initial infant-feeding decision?
3. Who are the major influences in maternal infant-feeding decisions?
4. What role do health professionals play in infant-feeding decisions?

### **Method**

The data for this paper were collected during a prospective longitudinal study of infant-feeding practices conducted in Newfoundland and Labrador from January 1992 through June 1993.

### *Sample*

The inhabitants of the island of Newfoundland are primarily Caucasian, many descending from people who came from Devon, Cornwall, and Dorset in England or from the south of Ireland. A small number of Micmac Indians live in the Conne River area; while distinct as an ethnic group, these generally have been assimilated into rural Newfoundland culture. The inhabitants of coastal Labrador can be classified as native (both Innu and Inuit), Caucasian, and mixed origin (or "settlers" — the products of intermarriage between European settlers and Inuit). Europeans settled in the towns of Happy Valley/Goose Bay, at the head of Lake Melville, and Cartwright and Black Tickle in southern Labrador. The Innu reside mainly in Sheshashit and Davis Inlet, the Inuit in the communities of Nain, Postville, Rigolet, Hopedale, and Makkovik. Many of the inhabitants of Makkovik are "settlers." In western Labrador, near the Quebec border, the population of the mining-company towns of Labrador City and Wabush is similar to that of the island of Newfoundland. While most people on the island of

Newfoundland live in areas that are easily accessible, most of the native populations, as well as the inhabitants of Cartwright and Black Tickle, are located along coastal Labrador in areas reached only by boat or small aircraft. Almost all the mothers of coastal Labrador give birth at the regional hospital in Goose Bay.

A sample size of 400 was needed to establish a 95% confidence interval. This number would allow for an estimate of the prevalence of various characteristics of infant feeding, analysis of the patterns of starting solid foods, and the reasons for changing feeding methods. However, in order to ensure a minimum number of 400 throughout the 6 months of follow-up, a total sample of 900 (approximately 1 mother in 6) was required. Of the 909 breastfeeding and bottlefeeding mothers recruited (73%) — including 69 (6%) from coastal Labrador — 778 (85%) were retained for 6 months; this was 14% of the total population of mothers who gave birth in Newfoundland and Labrador in 1992. Anonymous demographic data were collected for mothers who declined to participate, for the purpose of identifying differences between participants and non-participants; no significant differences between the groups were found for age, ethnic background, living status, education, or spousal employment.

### *Sample Selection*

Mothers who spoke English, or, in Labrador, the aboriginal languages of Innu or Innuktitut, and whose healthy, full-term babies were being discharged with them, were eligible for enrolment. For practical reasons, given the geography of the province and the low number of births in some of its maternity units, the mothers of Newfoundland and western Labrador were randomly selected according to the week they gave birth. The 54 weeks of data collection were divided into nine periods of 6 weeks each. Within each period 1 week was identified by the throw of a die. All eligible mothers who gave birth during these randomly selected weeks were asked to participate. This method allowed for possible seasonal differences over the data-collection period. The exception to the sampling method was coastal Labrador, where a survey for the year prior to the start of data collection showed that recruitment of 1 mother in 6 would yield only 8 or 9 mothers for each of the Innu and Inuit groups. For this reason and because of lack of telephone access for some families, *every* mother who delivered in coastal Labrador was invited to participate.

### *Procedure*

Ethical approval was obtained from the Human Investigation Committees of sponsoring and participating institutions. All institutions providing maternity care in Newfoundland and Labrador were approached and gave permission for data collection at their institutions.

All eligible mothers were recruited in maternity units through an intermediary within the first few days postpartum. After the study was explained to the mother and signed consent was obtained, the local data collector administered questionnaire 1. At 1, 4, and 6 months postpartum the data collector telephoned the recruited mothers and administered questionnaire 2.

As with sampling, data were collected differently in coastal Labrador. Aboriginal leaders were approached for permission to conduct the study with their peoples. Permission was granted on condition that data collection among Innu and Inuit mothers would be carried out by aboriginal community health representatives (CHRs). Although this method would not be consistent with data collection for the rest of the study population, the investigators agreed because it would allow for mothers to be interviewed in the language of their choice, because they felt the involvement of the CHR would encourage participation, and because telephone follow-up was not feasible for coastal communities. Therefore, coastal Labrador mothers were recruited as soon as they returned home from the hospital and were followed up by interview at each data-collection week. To give mothers an opportunity to respond in their own language, the questionnaires were translated into the Innu and Innuktitut languages.

Throughout the data-collection period the research team communicated with all data collectors by telephone and newsletter to ensure that any misinterpretations or questions could be clarified.

### *Preparation for Data Collection*

The province of Newfoundland and Labrador is divided into five public health regions. One team member was assigned responsibility for data collection in each region. Preparatory work included selection of 21 data collectors throughout the province, development of an instruction manual for data collection, and a teleconference training session. With the exception of the CHRs in the aboriginal communities, all data collectors were registered nurses residing near the data-collection sites.

### *Instruments*

Two questionnaires were developed for the study. Questionnaire 1, administered at the initial interview in the hospital following the birth, was used to gather data on maternal demographic variables, infant birth weight, the mother's initial feeding choice, reasons for not choosing breastfeeding, and the persons most influential in her infant-feeding decisions. Questionnaire 2, administered by telephone at 1, 4, and 6 months after the birth, focused on ongoing feeding practices, changes in practice, and maternal infant-feeding decisions. The questionnaires comprised both closed-ended and open-ended questions. Close-ended questions dealt with specific feeding methods (e.g., "What milk are you feeding your baby now?"). Open-ended questions dealt with the reasons for feeding decisions made both before and after the birth (e.g., "If you are bottlefeeding, why did you choose not to breastfeed?"). The mothers were asked to give their reasons for choosing not to breastfeed and their reasons for switching from the original feeding method. They were also asked with whom, if anyone, they discussed infant feeding prior to making their decisions and by whom, if anyone, they were influenced in making their decisions.

The questions were developed by the research team — all of whom were mother-child health specialists — based on a review of the literature, information on infant feeding obtained from both mothers and hospital and community-health nurses, and consultations with experts in both perinatal care and questionnaire development. The questionnaires were reviewed by a bio-statistician and a nutritionist for face and content validity. A pilot study was conducted to test the questionnaires and the interview procedure. Minor modifications were made.

### *Data Analysis*

Data were analyzed both quantitatively and qualitatively: The numerical data on methods of feeding, demographic data, and persons influencing the mother were analyzed using descriptive statistics to calculate frequencies and means. Cross-tabulations and chi-square were used to test for relationships between method of feeding and demographic variables such as age, education, parity, living status, ethnic group, and monthly income. Cross-tabulations and chi-square were also used to determine whether a relationship existed between feeding method and spousal, family, and/or professional influences. The demographic categories were collapsed into two or three major categories — for example, completed high school or did not complete high school; income less than \$1,500/month or greater than \$1,500/month; and

living with spouse/partner, with family or friends, or alone. Age was divided into under 21 years, 21–30 years, and over 30 years. The significance level was set at 0.05.

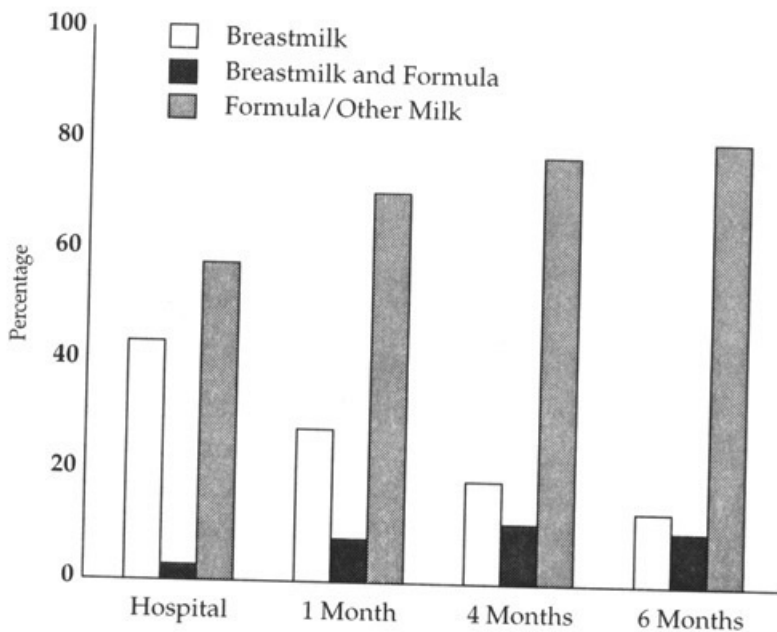
The qualitative data were obtained from the open-ended questions related to mothers' reasons for choosing not to breastfeed and for changing feeding method. The mothers' comments were typed. Each idea, belief, or feeling was the unit of data analysis. The research team sorted each unit into a major category or theme expressing the particular belief or feeling until agreement was reached that each unit was correctly identified with a particular theme. The categories were then coded and ranked in order of frequency to determine the most common reasons for maternal decisions.

## Results

### *Breastfeeding and Bottlefeeding Initiation and Continuance Rates*

In the hospital after birth, 379 mothers (41.7%) started breastfeeding, 11 (1.2%) started both breastfeeding and bottlefeeding, and 519 (57.1%) started bottlefeeding. However, over time the breastfeeding rate declined sharply and the bottlefeeding rate increased. By 6 months only 11.6% of the mothers were breastfeeding without a formula supplement.

**Figure 1** *Breastfeeding and Bottlefeeding Rates at Birth and at 1, 4, and 6 Months*



**Table 1** *Effect of Demographic Variables on Choice of Feeding Method*

Variable	N	Breast		Bottle		$\chi^2$	P
		N	%	N	%		
<b>Monthly Income</b>							
< \$1,500	649	99	15.2	228	35.1	44.69	0.00
> \$1,500		181	27.2	142	21.9		
<b>Educational Level</b>							
Grade 12 or less	902	127	14.1	361	40.0	125.82	0.00
> Grade 12		260	28.8	154	17.1		
<b>Maternal Age</b>							
< 20 years	909	30	3.3	104	11.4	33.86	0.00
21-30		269	29.6	333	36.6		
31-41		91	10.0	82	9.0		
<b>Parity</b>							
Primipara	909	186	20.5	229	25.2	1.16	.558
Multipara		204	22.4	290	31.9		
<b>Attend Prenatal Class</b>							
All classes	909	111	12.2	67	7.4	39.93	0.00
Some classes		56	6.2	66	7.3		
No classes		223	24.5	386	42.5		
<b>Living Status</b>							
Alone	909	10	1.1	24	2.6	16.90	0.02
With husband/partner		332	36.5	386	42.5		
With family/friends		48	5.3	109	12.0		
<b>Ethnic Group</b>							
Caucasian	847	362	42.7	487	57.5	22.57	0.004
Innu	24	17	66.6	8	33.3		
Inuit	23	4	17.4	16	82.6		
Micmac	10	3	30.0	7	70.0		
Other (Asian,	5	4	80.0	1	20.0		
African, etc.)							
p = < 0.05							

### Demographics

The mean age of the mothers at the time of enrolment in the study was 26.0 years (SD 4.96, median 26.0, mode 23.0); 5 mothers were under 16. The majority were Caucasian (93.1%); there was a small group of Micmac mothers (1.1%); 5.2% were aboriginal from coastal Labrador; further breakdown of the coastal Labrador data indicated that there were 24 Innu (34.3%), 23 Inuit (32.6%), 20 Caucasian (29.9%), and 2 mothers of mixed origin (3%). Most (77.2%) of the Newfoundland and



## Maternal Infant-Feeding Decisions

Labrador mothers lived with a husband or partner, 17.3% lived with friends or relatives other than husband or partner, and 3.7% lived alone. The majority of mothers (77.4%) had completed high school. Eighteen percent of fathers were unemployed. Primiparous mothers made up 45.7% of the sample, multiparous mothers 54.3%; 16 mothers had 5 or more children.

### *Effect of Demographic Variables on Infant-Feeding Practices*

**Breastfeeding.** The findings from the chi-square test for relationships between type of feeding and demographic variables revealed that mothers who breastfed were more likely to be older ( $p = 0.00$ ), better educated ( $p = 0.00$ ), and belong to higher-income groups ( $p = 0.00$ ).

**Bottlefeeding.** Younger, single, and less-educated mothers were more likely to choose bottlefeeding ( $p = 0.00$ ). Mothers who were young ( $p = 0.00$ ), single ( $p = 0.02$ ), and from low-income groups ( $p = 0.00$ ) were more likely to switch to evaporated milks from commercially prepared infant formulas (CPIFs) ( $p = 0.00$ ).

**Table 2** *Effect of Demographic Variables on Choice of Bottlefeeding at 1 Month*

Table 2 <i>Effect of Demographic Variables on Choice of Bottlefeeding at 1 Month</i>							
Characteristics	N	Formula		Evaporated Milk		$\chi^2$	P
		N	%	N	%		
<i>Maternal Age</i>							
≤ 26 years		215	37.2	95	16.4		
26–30		147	25.4	32	5.5		
31–41		81	14.0	8	1.4		
Total	578					22.47	0.000
<i>Educational Level</i>							
≤ Grade 12		259	44.7	116	20.0		
> Grade 12		181	31.3	18	3.1		
Total	579					34.81	0.000
<i>Living Status</i>							
With spouse/partner		338	58.6	89	15.4		
Single		105	18.2	45	7.8		
Total	577					5.22	0.022
<i>Monthly Income</i>							
< \$1,500		174	40.2	83	19.2		
> \$1,500		160	36.9	16	3.7		
Total	433					31.89	0.000
Note: Some mothers may have chosen not to answer all questions.							

### *Reasons for Choosing Not to Breastfeed*

The reasons for not breastfeeding were ranked in order of their frequency in the mothers' responses. At the time of the first interview, 33.7% of the 519 bottlefeeding mothers in the sample reported embarrassment, distaste, or discomfort as the major reasons for not breastfeeding. Another 23% either "preferred not to" breastfeed, believed it was inconvenient, or considered it too demanding or time-consuming. Other reasons included medical factors, early infant-health problems, return to work, and a previous bad breastfeeding experience. Twenty-three mothers preferred not to breastfeed because they smoked.

**Table 3** *Reasons for Choosing Not to Breastfeed*

Reason	Frequency	%	Valid %
Not comfortable, embarrassing, distasteful, not emotionally prepared	176	19.4	33.7
Did not want to/preferred not to (mother's decision)	52	5.7	10.0
Returning to work	43	4.7	8.2
Do not know/no particular reason	42	4.6	8.0
Inconvenient	39	4.3	7.5
Medical reasons (maternal-related, physician advised)	34	3.7	6.5
Early post-partum reasons (mainly infant-related)	30	3.3	5.7
Too demanding or time/energy-consuming	28	3.1	5.4
Bad previous experience	26	2.9	5.0
Because I smoke	23	2.5	4.4
Other	17	1.9	3.3
Not encouraged to/advised against by family, friends, or spouse	7	0.8	1.3
Wanted father more involved	5	0.6	1.0
Missing or N/A	387	42.6	—

## Maternal Infant-Feeding Decisions

### *Reasons for Switching to Bottlefeeding*

By 1 and 4 months, respectively, 132 (35%) and 224 (59%) of the 390 mothers who had started breastfeeding had switched to bottlefeeding. The small group of mothers who both breastfed and bottlefed in hospital had given up breastfeeding by 1 month. The most common reasons for quitting at 1 and 4 months were perceiving that the baby was not being satisfied on breastmilk (24% at 1 month, 21% at 4 months); finding breastfeeding too difficult (16% at 1 month, 9.7% at 4 months); and baby not doing well (7.5% at 1 month, 9.3% at 4 months). By 6 months, 256 (67.5%) of the 379 mothers in the initial breastfeeding group had switched to bottlefeeding. The most common reason for weaning at this time was return to work.

### *Reasons for Feeding Changes*

In hospital, 519 bottlefeeding mothers had started their babies on CPIF with iron. By 1 month, 184 mothers had switched to CPIF without iron and 117 had switched to evaporated milks. The main reason for switching from the iron-fortified formula was the perception that the iron was causing infant side effects. Like breastfeeding mothers, the bottlefeeding mothers switched because they perceived that the baby was not satisfied with the milk, was "allergic" to the milk, or "did not like" the milk. Expense was a major reason for switching to evaporated milk. At 1 month, only three mothers had changed feeding method on the advice of a health professional.

**Table 4** *Health Professionals with Whom Mothers Discussed Feeding Methods*

Member	Frequency	%	Valid %
Doctor	245	27.0	46.8
Public health nurse	198	21.8	37.9
Prenatal instructor	170	18.7	32.5
Midwife	28	3.1	5.4
Hospital nurse	173	19.0	33.1
La Leche League	16	1.8	3.1
Other	14	1.5	2.7
Missing or N/A	386	42.5	—

*Influence of Others on Infant-Feeding Decisions*

Prior to making their decision on feeding method, a small majority of respondents (57.7%) reported that they had discussed feeding methods with health professionals, family/friends, or both. However, only 27% of the total had discussed it with the physician (all mothers saw a physician during their pregnancy). Other sources of advice were the public-health nurse (21.8%), the prenatal instructor (18.7%), and a hospital nurse or midwife (22%). Several mothers had discussed feeding methods with more than one health professional (see Table 4); 3% had consulted the La Leche League, a self-help group of breastfeeding mothers. As for non-professionals, 70.4% of mothers ranked their husband/partner as the person with whom they discussed infant feeding; friends (54%), mother (47.2%), and sisters (34%) were also consulted (see Table 5).

**Table 5** *Members of Social Network with Whom Mothers Discussed Feeding Methods*

Member	Frequency	%	Valid %
Husband/partner	368	40.5	70.4
Mother	247	27.2	47.2
Mother-in-law	114	12.5	21.8
Sisters	179	19.7	34.2
Friends	283	31.1	54.1
Other	34	3.7	6.5
Missing or N/A	386	42.5	—

Mothers were not necessarily influenced by their discussions about infant feeding. When asked who was the most influential person in their decision, 30% of the mothers said they had made their own choice and had not been influenced by anyone and 20.5% said they had been most influenced by their husband or partner; friends and mothers accounted for approximately 19%. Health professionals appeared to have little influence with this group. A small group of mothers (7.8%) reported that the public-health nurse was the most influential health professional in their feeding decisions, followed by the physician (4.6%), the prenatal instructor (3.6%), and the hospital nurse or midwife (3%). When tested for relationships among method of feeding, mater-

nal demographic variables, and those mothers most likely to be influenced, breastfeeding mothers were found more likely to be influenced by health professionals and family and friends. Bottlefeeding mothers were more likely to say they had made their own decision or to have been influenced by their partner ( $p = 0.002$ ). As expected, primiparous mothers were significantly more likely to be influenced by health professionals and family and friends than multiparous mothers ( $p = 0.000$ ), as were mothers not living with a spouse or partner ( $p = 0.000$ ). Education or age of the mothers were not significant factors in the influence of health professionals.

**Table 6** *Most Influential Person in Maternal Feeding Decision*

Member	Frequency	%	Valid %
No one/own decision	156	17.2	29.8
Husband/partner	107	11.8	20.5
Friends	49	5.4	9.4
Mother	49	5.4	9.4
Public health nurse	41	4.5	7.8
Sisters	34	3.7	6.5
Doctor	24	2.6	4.6
Prenatal instructor	19	2.1	3.6
Other	16	1.7	3.1
Hospital nurse	10	1.1	1.9
Midwife	5	0.6	1.0
La Leche League	3	0.3	0.6
Missing or N/A	386	42.5	—

### Summary and Discussion

This study, like others, found demographic variables to be significant factors in maternal infant-feeding choices. Younger, less-educated, unsupported mothers with low incomes were found to be less likely to breastfeed, although breastmilk is much more economical than artificial milks. The mothers who chose bottlefeeding were more likely than breastfeeding mothers to switch to cheaper evaporated milks within the first few months. There were significant differences among ethnic

groups. Innu mothers showed a significantly higher rate of breastfeeding than Inuit, Micmac, or rural Caucasian mothers. In this sample, ethnicity was associated with less education and lower income. Embarrassment and "preferred not to" were the most common reasons given by mothers in the total sample for choosing not to breastfeed. Over time, many mothers changed their feeding method. Breastfeeding mothers switched to bottlefeeding because they found breastfeeding too difficult or time-consuming or because they perceived that the baby was not being satisfied on the breastmilk. Bottlefeeding mothers gave similar infant-related reasons for switching from the CPIX started in the hospital. The formula either did not satisfy or did not agree with the baby. Younger, less-educated mothers with lower incomes were more likely to switch from formula to the cheaper evaporated milks. A small majority of mothers had discussed infant feeding with a health professional during pregnancy but were more likely to be influenced by their social network, especially their husband or partner.

From this study it appears that there are two major decision-making periods for mothers: prior to the birth, when they make their infant-feeding choice, and the first few weeks following the birth, when they decide whether to continue breastfeeding or, if bottlefeeding, whether to continue with the milk recommended in the hospital.

Several studies, including the present one, support the contention that choice of feeding method is determined by socio-economic factors and that more-educated women from higher-income groups are more likely to breastfeed (Aberman & Kirchhoff, 1985; Grossman et al., 1990; Michaelson et al., 1994). The identification of specific groups with lower breastfeeding rates and higher rates of using milks not recommended for infants suggests that breastfeeding-promotion programs and infant-feeding information strategies should target these groups. One such initiative has been taken by Healthy Baby Clubs (Rabinowitz & McKim, 1996), whose aims are to meet the prenatal and postpartum needs of socially disadvantaged mothers and to encourage breastfeeding.

Ethnicity was found to be an important demographic variable in choice of feeding method, independent of socio-economic status. In coastal Labrador, significantly more Innu mothers than Inuit mothers chose to breastfeed (McKim, Laryea, Matthews, Webber, & Banoub-Baddour, 1997). On the island of Newfoundland, the breastfeeding rate of 30% among Micmac mothers reflects the rates of their rural neighbours. Some possible explanations for the differences among the groups may relate to the Innu having a strong commitment to their traditional ways. Caution is needed when analyzing aboriginal or native popula-



tions, as relatively little is known about native feeding practices in general. Most studies have involved small groups, and, as these data show, groups can vary greatly.

It must be recognized that provision of information is not enough. Other factors, particularly maternal attitudes, have been shown to be important variables in maternal infant-feeding decisions. In the present study, the major reasons given for not breastfeeding were psychological, relating to embarrassment, distaste, or simply "preferred not to." Healthier attitudes about what is an important nutritional and nurturing function of parenting must be developed. Mothers who find breastfeeding embarrassing and distasteful are not going to breastfeed, and they are likely to pass their attitudes on to their peers and their own children. In some environments breastfeeding is the norm. The 17% breastfeeding rates for Newfoundland in 1978 (Alton-Mackey & Orr, 1978) indicate that this generation of young mothers had few breastfeeding role models. If breastfeeding rates continue to rise, societal attitudes will change and it will become the preferred method. Strategies to change societal attitudes towards breastfeeding are prerequisites for promotion and educational programs. Ellis (1981) makes several suggestions for cultivating conducive attitudes towards breastfeeding, such as promotion in schools, homes, and clinics; provision of role models; public-awareness campaigns; and political action. Friel, Hudson, Banoub, and Ross (1989) found that attitudes among female adolescents are positively affected by media campaigns. Current initiatives such as Health Canada's "Breastfeeding Anywhere, Anytime" campaign and a video targeting low-income Newfoundland families (Breastfeeding Coalition of Newfoundland and Labrador, 1997) are examples of strategies to normalize breastfeeding. Health professionals, especially those who see mothers regularly during their pregnancy, can take an active role by initiating one-to-one discussions with them about the advantages of breastfeeding and good infant-feeding practices.

Bottlefeeding mothers ranked inconvenience high on their list of reasons for not breastfeeding. Women who terminated breastfeeding early said they found it too difficult; they also reported fatigue and stress with breastfeeding, and cited the convenience of being able to have someone else do the bottlefeeding for them. The notion that breastfeeding is inconvenient contradicts a major argument *for* breastfeeding — that it is easy and convenient. Therefore, mothers' perceptions of which method is more convenient requires further exploration.

In both breastfeeding and bottlefeeding groups, a significant number of women switched feeding method or type of milk over the

first few months, some of them frequently, because they perceived that their babies were not being satisfied. The perception that the iron in the CPIF had infant side effects was the major reason for switching to a non-iron-fortified formula. Expense was a major reason for bottlefeeding mothers to switch to evaporated milk. Clearly, there was overlapping of reasons, as the breastfeeding mothers who found their babies to be not satisfied with the milk were likely to also find breastfeeding difficult and time-consuming.

Social support was the other major factor in maternal feeding decisions. Prior to making their initial decision, 58% of the sample reported having discussed it with a health professional. The data did not cast light on the quality of these discussions. The content and tone of the discussion are likely to vary with the knowledge level and philosophy of the health professional. Generally, as can be seen in Table 6, health professionals had little influence on the mothers' decisions. The exceptions were primigravidas and breastfeeding mothers, who reported being more influenced by health professionals.

The social network, particularly the spouse or partner, was found to have the most significant influence on the mother. The male partner and the mother's mother were found to be the main sources of support in Newfoundland families. Several other studies (Bevan, Mosley, Lobach, & Solimano, 1984; Black, Blair, & Jones, 1990; Littman et al., 1994) also found the baby's father and the social network to have a significant influence on the mother's choice of feeding method. However, a study of the comparative influence of the social network on Anglo-Americans (Giugliani, Bronner, et al., 1994), which reported similar findings, found that several fathers reported feeling helpless and unprepared to support their breastfeeding partners. The authors suggest that paternal lack of preparedness tempers the effect of fathers' support and that the influence of the partner may be positive or negative. An interesting finding of the Newfoundland study was that 30% of the mothers stated they made their own decisions, uninfluenced by any one person. The majority of these women were in the bottlefeeding groups. This suggests that the decision whether to breastfeed is ultimately, given the psychological reasons cited for not breastfeeding, a very personal one.

Most studies have found the influence of health professionals on mothers' feeding choices to be minimal. The present investigation found that only 27% of the mothers discussed the topic with their physician, 40.8 % with a nurse, which raises questions about the nature of professional support. An earlier study by Starbird (1991), which examined influences through 2 decades, found that women were 3.5

times more likely to start breastfeeding if they had received information from a medical professional. Almost all studies, however, found family and friends to be more influential than health professionals. Possibly the day-to-day social presence has more effect on maternal decision-making than the more remote professional presence. Readily available services for mothers to resort to in times of feeding difficulties, such as a 24-hour hotline, are useful resources for mothers and families.

This study found the first month to be the period in which the largest numbers of mothers made a switch, although some mothers continued to change milks throughout the first 6 months in an attempt to "satisfy" the baby. Both bottlefeeding and breastfeeding mothers switched because they perceived that the baby was "not satisfied." The issue of mothers' perception of infant satisfaction with milk has been observed in other studies (Hillervik-Lindquist, Hofvander, & Sjolin, 1991; Tully & Dewey, 1985) and needs further exploration. What are a mother's expectations of her infant's response to feeding? Are they realistic? Are her interpretations of infant hunger accurate? These are some of the questions raised in studies. These observations about mothers' perceived infant cues on their feeding decisions have profound implications for breastfeeding satisfaction and continuance rates, and they pose challenges to clinical practice. Pridham and Schutz (1981) found that information given to parents on how to evaluate infant-hunger cues was inadequate, as was, indeed, how to tell when the infant has had enough to eat. Judging from the comments of some of the women in the present study, mothers still have difficulty responding appropriately to infant-feeding cues. The resources developed by Barnard, Blackburn, Kang, and Spitz (1978) to facilitate parent-infant interaction and help parents read infant cues may be useful for nurse educators and clinicians who work with families.

### **Conclusion**

The results of this study suggest that infant-feeding education and promotion requires a family-centred and/or a social-network approach. Since health professionals apparently have a relatively minor influence on mothers, compared to members of their social network, the nature of individual professional advice, knowledge, and support needs to be examined, to find out why the influence is low and determine the quality of advice given.

Strategies for changing societal attitudes might include not only mothers, but partners, mothers, mothers-in-law, and friends. Husbands/partners especially need more information and help in

supporting breastfeeding mothers. Infant-feeding education must go beyond "what and how to feed" to include the broader issues of parental expectations of infant behaviour, especially infant-feeding behaviour. Public-health agencies must seek ways to reach a greater number of expectant parents and families, especially those in groups with low breastfeeding rates and groups that require extra advice and support, whether breastfeeding or bottlefeeding. Changing attitudes towards breastfeeding and infant-feeding behaviour requires innovative strategies by informed, skilled health professionals to support mothers, fathers, and their families during pregnancy and childbearing.

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## Book Review

### *Nursing Wounds: Nurse Practitioners, Doctors, Women Patients, and the Negotiation of Meaning*

Sue Fisher

New Brunswick, NJ: Rutgers University Press, 1995. 251 pp., index  
ISBN 0-8135-2180-7 cloth; 0-8135-2181-5 pbk.

Reviewed by Donna L. Wells

As nurse practitioners assume their legitimate place in the health-care system, it is critical that they be able to articulate the distinctiveness and potential effectiveness of their practices, in order to cogently argue their value. Furthermore, although the work they do may sometimes overlap with that in the domain of medicine, the new nurse practitioners perceive their role as independent, not as secondary to that of the physician. Sue Fisher's book *Nursing Wounds: Nurse Practitioners, Doctors, Women Patients, and the Negotiation of Meaning* offers nurse practitioners the opportunity to read about how their unique approach to the health care of women patients differs from the approach of physicians.

Fisher is a medical sociologist interested in the health care of women. Her disillusionment with the care women receive from physicians inspired her to study the approach of nurse practitioners. Her contention is that, because of their social/psychological skills, nurses accomplish more: "They nursed wounds better, they cured the physical body and cared for more socioemotional concerns as well" (p. 6). *Nursing Wounds* thus focuses on comparisons of how physicians and nurse practitioners provide care to women.

In Chapters 1 and 2 the author outlines the study rationale and its multiple theoretical underpinnings, and outlines the perspectives of other medical sociologists (such as Mishler, Silverman, and Waitzkin) who have analyzed the physician-patient relationship, as well as ideas from feminist and critical theory. Yet Fisher is unclear about how these various viewpoints guided her analyses. Moreover, nurses unfamiliar with these points of view will find her discussion obscure and her use of jargon bothersome.

In Chapters 3 to 6 she offers verbatim accounts of four consultations that she observed in clinic examining rooms, two with family-

practice doctors and two with nurse practitioners. In her ongoing analysis, Fisher compares the two ways of communicating. One of her major conclusions is that the consultations with nurse practitioners are "more complex and more fluid than those with doctors.... The social/biographical context of patients' lives is rendered as connected to, rather than separated from, the medical process of making a diagnosis and a treatment recommendation" (p. 180). As such, nurse practitioners render patients competent and "in charge of their lives and their health care" (p. 180). Nurse practitioners thus care for social wounds differently — they merge care with cure, the medical with the social/psychological. Nevertheless, her analysis is not convincing. The patterns guiding the interpretations, which Fisher claims to have identified in her analyses of the transcripts (p. 19), are never clearly delineated. Furthermore, in drawing out the different ways that physicians and nurse practitioners assign meaning to women's symptoms, she stresses the notion of dominant cultural assumptions about women and their complaints over other theoretical concepts, despite having stated earlier that multiple perspectives would be used in the analyses. Additionally, she fails to address how her own biases (noted on p. 15) could influence her portrayal of the negotiation of meaning in physician-patient and nurse practitioner-patient interactions. Consequently, her interpretations are questionable.

In Chapters 7 and 8 Fisher sets out to examine how the institutions of medicine and nursing, as well as historical and cultural contexts, affect the contrasting communication practices of physicians and nurse practitioners. However, her treatment is superficial. Mostly she restates prior interpretations instead of enlightening the reader about the interface between institutional structures and the different behaviours of physicians and nurse practitioners. The language she uses in these analyses, as in prior ones, is obscure, and the terms are often ill-defined (e.g., "social/ideological work," p. 66; "oppositional discourse," p. 166).

Fisher's intent in the Epilogue is to link her findings to health-care policy, yet her general denunciation of the health system, in her letter to the Clinton administration, fails to contribute to her argument that the approach of nurse practitioners offers an alternative to that of physicians.

Despite the shortcomings of Fisher's methods, and despite the book's outdated bibliography, *Nursing Wounds* contributes to the literature on nurse practitioners, by capturing the style of health care they provide. "By initiating topics, asking open-ended questions, probing for additional information and legitimating feelings," Fisher states, the

nurse practitioner "provides the space for the patient to display her competence and even to diagnose herself" (p. 84). Women can thereby be directly involved in determining or negotiating the meaning of their symptoms, which, Fisher argues, could lead to a better medical/health outcome.

Nurse practitioners seem to be going further than physicians in their interactions with patients. However, the precise styles, and their outcomes, vis-à-vis the actual health care of women patients must be evaluated before the true value of nurse practitioners can be known and reasonable adjustments made to the health-care system.

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## Video Review

### *Not My Home*

Produced and directed by Suzanne Babin,  
Tynette Deveau, and Bert Deveau  
Toronto: Deveau-Babin Productions, 1994. 46 min.

### Reviewed by Rhonda Seidman-Carlson

This video, recorded at a long-term-care facility (LTCF) in eastern Canada, chronicles the lives of various residents, their families, and the staff of the LTCF. The impact of entering and living in an institution is demonstrated in a poignant and realistic fashion.

The residents talk about the dichotomy of their lives: living in a *home* but having no home; being alive but having no life; and receiving everything tangible the staff can provide (physical care, security) but losing themselves as people.

These residents never accept their situation; rather, they become resigned to it. This parallels the experience of the staff. The team members interviewed describe settling for doing the best they can, given their limited time and resources. However, like the residents, they mourn the lack of connectedness, the lack of sharing personhood with others in their daily lives at the nursing home.

The most striking element of *Not My Home* is the lack of normal, everyday conversation in the institution. The silence of daily life is interrupted only occasionally, by the ringing of the fire alarm for drills, the voices on the overhead announcements, and the rolling of the wheels as the trolleys move down the corridors. There is talking *to*, talking *over*, but no talking *with* the residents. The comments of one resident best capture the essence of this video: "It is the small things that make a life."

Finding out what makes life meaningful to another is at the core of nursing. Nurses in all sectors — hospital, community, and long-term care — would benefit from viewing *Not My Home* and discussing: (a) how decisions are reached in recommending LTCF placement; (b) whether issues and concerns that might be alleviated by the move are replaced with other risks, such as loss of personhood; and (c) whether nurses can make life for nursing-home residents more natural, made up of more of those "small things."

Nurses may also wish to review the video with new LTCF residents or with families considering placement for a loved one. The words of those who have gone through the experience can assist the nurse in helping the individual and family to discuss their fears and hopes around LTCF placement.

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# Call for Papers

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## *Research Utilization*

Spring 1999 (vol. 31, no. 1)

Research utilization and its precursor, research dissemination, are subjects that have not received the attention of nursing research until relatively recently. The aim of this issue is to advance our knowledge in both these areas. Topics to be examined include evidence-based strategies for dissemination and innovation adoption strategies, research utilization frameworks, evaluations of clinical research-utilization projects, and models for overcoming threats and barriers to research utilization. Papers that advance the science of research utilization are of particular interest and may include theoretical, research, or evaluation perspectives.

**Guest Editor: Dr. Heather F. Clarke**

**Submission Deadline: October 15, 1998**

## *Mental Health*

Summer 1999 (vol. 31, no. 2)

The continuing growth in mental-health problems and the ongoing transformation in services for the people affected pose a major challenge for nursing. With this issue focusing on mental health, we hope to publish the latest research results as well as theoretical and critical articles likely to influence nursing interventions and thus contribute to improved care. Of particular interest are studies from a nursing-science perspective focusing on those factors that influence recovery among persons with transitory or persistent problems. Priority will be given to articles dealing with the evolving role of nurses in the mental-health sector and with the development and application of new interventions geared for individuals, their families, and their communities.

**Guest Editor: Dr. Nicole Ricard**

**Submission Deadline: January 15, 1999**

*Please send manuscripts to:*

The Editor  
*Canadian Journal of Nursing Research*  
McGill University School of Nursing  
3506 University Street  
Montreal, QC H3A 2A7 Canada

# Appel de soumission d'articles

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## *Utilisation des résultats de recherches*

Printemps 1999 (vol. 31, no 1)

L'utilisation des résultats de recherche et leur diffusion, qui en est la condition préalable, commencent à peine à retenir l'attention des chercheurs en sciences infirmières. Ce numéro a pour but d'élargir nos connaissances dans ces deux domaines. On y traite donc de stratégies de diffusion et d'adoption d'innovations fondées sur des données probantes, de cadres d'utilisation des résultats de recherche, d'évaluations de projets d'utilisation des résultats de recherches cliniques et de modèles permettant de surmonter les différents facteurs qui entravent ou risquent de compromettre l'utilisation des résultats de recherches. Les articles qui contribuent au progrès de la science dans ce domaine revêtent un intérêt particulier, notamment ceux qui traitent de ces questions sous l'angle de la théorie, de la recherche ou de l'évaluation.

**Collaboration spéciale : Heather F. Clarke, Ph.D.**

**Date limite pour les soumissions : le 15 octobre 1998**

## *Santé mentale*

Été 1999 (vol. 31, no 2)

L'augmentation progressive des problèmes de santé mentale au sein de la population et la transformation actuelle des services posent des défis importants sur le plan de l'efficacité et de l'efficience des interventions infirmières en regard de ce problème de santé publique. Ce numéro consacré à la santé mentale vise la publication de résultats de travaux de recherche et d'articles théoriques ou critiques à la fine pointe des connaissances, susceptibles d'influencer les modes de prestation des soins et le renouvellement des interventions infirmières. Les manuscrits soumis doivent, partant d'une perspective en sciences infirmières, permettre une meilleure compréhension des facteurs influençant le processus de rétablissement des personnes présentant des problèmes transitoires ou persistants. Également, seront privilégiés les écrits portant sur l'évolution du rôle de l'infirmière en santé mentale, ainsi que la mise en oeuvre et l'évaluation de nouveaux modes d'intervention auprès de la personne, de la famille ou de la communauté.

**Collaboration spéciale : Nicole Ricard, inf., Ph.D.**

**Date limite pour les soumissions : le 15 janvier 1999**

*Prière d'envoyer les manuscrits à :*

La rédactrice en chef

Revue canadienne de recherche en sciences infirmières  
École des sciences infirmières de l'Université McGill  
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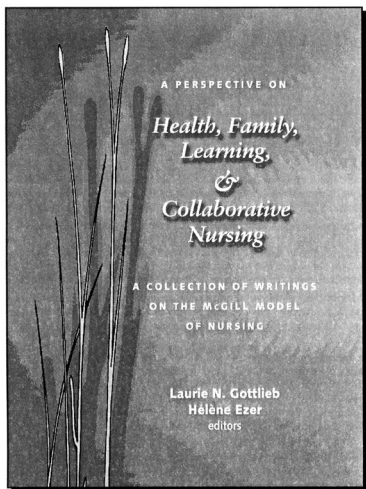
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