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GUEST EDITORIAL

Advancing the Contribution of Gerontological Nursing Research

Carol McWilliam

Rising to the challenges of an aging population, in recent years nurse researchers have made tremendous inroads in advancing the body of knowledge for evidence-based practice in the field of gerontological research. The papers in this issue reflect the breadth and scope of investigation since the last time *CJNR* focused on this topic (1998, 30[2]). A cross-section of national and international work, collectively these papers provide an overview of nursing's multifaceted attention to enhancing the health and life of older people.

The topics addressed in this issue clearly emphasize priority areas of gerontological nursing. The majority of the studies reported (Heinrich, Neufeld, & Harrison; Kaasalainen & Crook; Peacock & Forbes; Voyer, McCubbin, Préville, & Boyer; Ward-Griffin, Bol, Hay, & Dashnay) address questions related to gerontological nursing practice and policy. Several papers focus directly on practice, providing quantitative evidence to inform approaches in the important areas of pain assessment (Kaasalainen & Crook) and medication management (Voyer et al.). However, attention to the needs and involvement of caregivers of frail older people is particularly apparent. Qualitative investigations illuminate, in depth, important understandings related to relationships (Ward-Griffin et al.) and interactions (Heinrich et al.) between caregivers and health personnel. A systematic literature review and synthesis (Peacock & Forbes) provides a comprehensive overview of tests of interventions to educate and support caregivers. This cluster of caregiver studies does much to inform nurses confronted with the challenge of ensuring that their caring efforts are appropriately extended to all who informally contribute to both the quality and the quantity of health care available to frail seniors.

The subject of several other papers (Forbes et al.; McGilton) is more broadly one of health-services delivery. Forbes et al. identify the determinants of home-care nursing and home-support services, while McGilton makes a significant scholarly contribution through the rigorous development and evaluation of scales to measure supportive leadership in long-term-care settings. Given the major policy, planning, and administrative roles that gerontological nurses play in these two health-care sectors, each of these studies provides important evidence for refining health services for older people.

The third focus of work in this issue (Phinney & Wallhagen) advances evidence-based gerontological nursing specifically related to optimizing the health and life of seniors. Over 80% of people 65 years of age and over have chronic medical conditions requiring daily self-care and management (Statistics Canada, 1999). As frontline workers in primary health care, gerontological nurses face increasing challenges in the field of health promotion for an aging population. The insights gained from Phinney and Wallhagen's investigation of older persons' experiences of the symptoms of type 2 diabetes inform one of many challenges in this area of practice.

Beyond their content foci, the research papers in this issue also provide gerontological nurse researchers with many fine examples of both research methods and the art of publishing research studies. Readers can learn a great deal by comparing and contrasting qualitative approaches (Heinrich et al.; Phinney & Wallhagen; Ward-Griffin et al.), by studying the quantitative analysis strategies (Forbes et al.; Kaasalainen & Crook; McGilton; Voyer et al.), and by examining the construction of a systematic literature review and synthesis (Peacock & Forbes) and the application of critical reflection in the discussion of research results (Voyer et al.).

Several key messages are apparent in this issue of the Journal. First, if one looks at the content emphasis, and considers it in light of funding agency priorities, one will see that gerontological nurse researchers have an opportunity to expand their efforts in the arena of healthy aging. The papers by Peacock and Forbes, Phinney and Wallhagen, Heinrich et al., and Voyer et al. invite gerontological nurse researchers to address the theory and practice of health promotion and health education for older people, in particular through intervention studies. The level of general health of people in their sixties has been improving. Older people are living longer, as medical treatment has meant that chronic diseases are less likely now than in the past to lead to early death. The number of older people reporting significant activity limitation has declined substantially (Pransky, 2001), and many caregivers of the frail elderly are also older people. Researchers have demonstrated that aging is not a state of progressive decline, but rather one that reflects a multitude of interrelated and constantly changing life patterns, including that of healthy aging, with or without chronic disease, with or without the need for medical treatment, and with or without the need for ongoing care. Health promotion and health education therefore merit increasing attention as part of the gerontological nursing research agenda.

Secondly, the importance of human relationships throughout all aspects of gerontological nursing is very apparent in the research featured in this issue, especially in Pringle's passionate and poignant plea for "Making Moments Matter." Human nature being what it is, relationships between professionals and older people (Forbes et al.), between professionals and the caregivers of older people (Ward-Griffin et al.), between supervisory and frontline professionals (McGilton), and between both professional and informal caregivers and those who are cognitively impaired (Pringle) present challenges to practitioners, educators, and researchers alike. Nor can gerontological nursing research overly attend to the quintessential relationship element, human understanding, an element that is perhaps particularly important when those of us working with either cognitively intact or cognitively impaired older people stop to consider that we do not have the advantage of a firsthand perspective, the vast majority of us having not yet "been there, done that." The importance of continuing to work with this orientation is underscored by the papers in this volume (Kaasalainen & Crook; Phinney & Wallhagen; Pringle).

In truly solid academic fashion, the papers in this issue of *CJNR* raise as many questions as they answer. For me, one particular question that we might ponder as we continue our scholarly work in the field of gerontology stands out: Are the notions of aging that we convey not only consistent with the most recent advances in the field of gerontology, but also exemplary in promoting healthy societal attitudes towards aging? Herein lies both the opportunity and the invitation to rise beyond the successes of this issue to create an even more varied, multi-pronged gerontological research agenda, one that recognizes the heterogeneity of people of all ages.

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CJNR 2003, Vol. 35 Nº 4, 7–13

Discourse

Making Moments Matter

Dorothy Pringle

I am going to argue in this Discourse that two of the greatest challenges facing gerontological nursing research are understanding the quality of the lives lived by severely cognitively impaired people, particularly those in residential facilities, and finding effective ways of ensuring that these people have the opportunity to live as rich, interesting, and pleasurable lives as they are capable of. By asserting this agenda, I mean not to diminish other research foci in the area of aging but rather to nudge — no, that is not strong enough — to *compel* more nurse researchers to attend to these topics. I acknowledge that we still have much to learn about the prevention of disability and illness in later life, the management of disorders that are common in the senior years — incontinence, limited mobility, diminished vision, depression, and a host of others — but we are aware of the need to continue to work on these. Nurse researchers have already made important contributions to understanding them and to developing effective interventions for dealing with them.

Family caregivers, particularly of people who are cognitively impaired, have been the subject of much research attention over the last 25 years. We have learned a great deal about caregivers' lives, their personal characteristics, their health status, and their sources of stress and the interventions that reduce this stress. Faran (2001) provides a useful summary of the types of caregiver intervention studies that have been carried out since the 1980s, the research issues that have surfaced and how they have been managed, and what has been learned from these studies. She goes on to identify the kinds of studies that are still needed: those with caregivers of many different cultures, those with caregivers in different types of caregiver-care recipient relationships, and those that focus on different sets of health outcomes. Caregiving research has been on the nursing research agenda since its inception and should remain on the agenda, but, in keeping with the proposed research agenda, I would add to Faran's list the need for studies that examine how family caregivers know if the care recipient is content, happy, or experiencing pleasure at some level. What are the indicators that family caregivers use? How universal are these indicators? What do caregivers do that generates positive responses from dependent family members, and how much of this is carried forward from their earlier life experiences? How do these sources of pleasure change over the course of the deterioration in cognitive function, and how do the caregivers adapt to and compensate for these changes? The information generated from this type of research would be invaluable to the nursing staff of long-term-care facilities in assuming their day-to-day responsibilities with persons who are cognitively impaired.

It is important to acknowledge the critical advances in the care of cognitively impaired residents in long-term care that have resulted from research in the last decade. Nursing research has made significant contributions to these advances. For example, Wells and Dawson have been developing knowledge about reducing "excess disabilities" and reinforcing "retained abilities" in cognitively impaired individuals (Wells & Dawson, 2000, 2002), gone on to develop the reliability and validity of their assessment tools (Wells, Dawson, Sidani, Craig, & Pringle, 2000), and then demonstrated the effectiveness of teaching nursing staff how to use these skills in morning care to reduce distress and disturbed behaviour (Wells et al.). The concepts of excess disability and retained ability have taken hold in long-term care; in many facilities it has become part of the philosophy and practice to support retained abilities and eliminate excess disability.

Over this same period, the management of disturbed behaviour has received much attention. The incidence and types of disturbed or disruptive behaviours, such as yelling and striking out, exhibited by some cognitively impaired people, and the triggers for these behaviours, have been described (Beck et al., 1997, 1998), and effective ways of intervening have been developed and tested (Beck et al., 2002; Forbes, 1998). Unfortunately, it seems that a reduction in disturbed behaviour has become the preferred outcome for quality of care and health services research in long-term care. Is this good enough? Is it not possible to move beyond reducing negative behaviour, to increasing positive aspects of the behaviour of cognitively impaired persons as indicators of the quality of care provided and the quality of their daily lives? I believe this is not only possible but essential if we are to create the kinds of environments these people need in order to thrive.

A recent editorial in the *British Medical Journal* states: "Only relatively recently have we understood that people with dementia need to be more than clean, warm, and comfortable. Many staff may still believe that people with dementia are unaware of the world and unable to benefit from interaction" (Marshall, 2001, p. 410). I would restate this somewhat. I think most staff — make that nursing staff — do know that those with even advanced cognitive impairment are aware of at least some elements of their world and benefit from particular kinds of approaches and relationships. I believe what is missing is an acknowledgement that it is their responsibility to ensure that the persons for whom they are responsible have the best possible day they can have, in addition to ensuring that they are clean, warm, and comfortable. This speaks to nursing's responsibility for residents' quality of daily life.

Nurse researchers have long been interested in patients' quality of life as an outcome of treatment for specific diseases and disorders (Harrison, Juniper, & Mitchell-DiCenso, 1996), but I believe that nursing has not yet wholly embraced the notion that it is the nursing staff's responsibility to ensure that cognitively impaired older people have the best quality of daily life possible, and that includes taking care of their "being" as well as their bodies. It is nursing's responsibility because of the nature of cognitive impairment. When you cannot remember, you cannot anticipate; you do not derive pleasure from remembering what a lovely time you had at the concert, nor from looking forward to a visit with your grandchild. What matters in the moment-to-moment life in long-term-care residences is the responsibility of nursing staff. It is our domain. Others — social workers, recreational and occupational therapists — come and go, and it is their responsibility to attend to enhancing the quality of the residents' lives while they are with them. But it is nurses or their surrogates, health-care aides or personal-support workers, who stay and do. It is the nursing staff who are there when residents awake, have baths, eat meals, go for walks, have naps, get ready for bed, and enjoy pleasurable activities. The activities of daily living are the tapestry on which nurses sew the individual stitches of the day. They can be all one colour and have single strands, or they can be multicoloured and have single, double, or multiple strands. I believe it was Powell Lawton (Lawton, Van Haitsma, & Perkinson, 2000) who first spoke of the quality of *daily* life, a concept that is different from quality of life. David Streiner (personal communication, July 25, 2003) takes it one step further and suggests that, with this population of cognitively impaired people, we should be interested in "improving the quality of the moment." But what constitutes a high-quality moment, and how many high-quality moments does it take to make a high-quality day? If people who are cognitively impaired are to have good days that vastly outnumber not-so-good days, it will be because nursing staff give the creation of quality moments the priority they now give to bathing, feeding, and skin care.

What does this mean in terms of a research agenda? Clearly, we need to understand what individuals who are cognitively impaired experience, particularly what they experience as pleasurable or as distressing. The slate is not blank on this matter. Mitchell and Kolodny (1996) were among the first to interview cognitively impaired residents of an institution about their daily lives. Perhaps their most interesting finding is that the residents' lives, as viewed by the residents themselves, were not as bleak as they looked. Investigators in Sweden (Zingmark, Norberg, & Sandman, 1993; Zingmark, Sandman, & Norberg, 2002) used a combination of participant and non-participant observation of residents and interviews with their care providers to determine what everyday life was like for severely impaired women living in a small special-care unit and how to make them feel at home in this environment. The care providers reported that play and joy were important, and this objective was achieved by including fun as part of daily activities (Zingmark et al., 2002). But there are many other questions to be answered. Is assessing affect the best way, or the only way, to determine whether a particular approach is effective? What about those individuals who no longer demonstrate affect? Can affect be "resuscitated" through the use of particular interventions? Are there some effective ways of working with this population generally, or must a quality-intervention map be developed for each person? Are some people more effective than others in creating high-quality moments — for example, are family members more effective than staff? Are staff who are consistently assigned to a person more effective than skilled staff who work with the person only periodically?

It is not possible to deal with quality-of-life topics without at least some philosophic basis, and, fortunately, we have been well served in this area by the work of Kitwood (Kitwood, 1997, 1998; Kitwood & Bredin, 1992) and Sabat (1998). Kitwood, while challenging some of the assumptions about the biological basis of Alzheimer disease, was a pioneer in trying to determine what people with dementia experience, and he used this background to assert the central role that personhood plays in quality of life. He argues passionately that an individual's personhood does not change when he or she becomes cognitively impaired. For Kitwood, personhood is "the standing or status that is bestowed upon one human being, by others, in the context of relationship and social being" (1997, p. 8). Sabat supports this view, arguing that the "treatment" of those who are cognitively impaired must be based on the idea of personhood. Sabat extends this thinking and introduces the concept of selfhood, the ascribing of which does not depend on others. If "caregiving and quality of life are about preserving, conserving, sustaining, nurturing, and eliciting… personhood" (Jennings, 2000, p. 175), what does this mean for nursing staff in relation to the cognitively impaired residents in their care?

Other researchers have used quantitative methods to assess a cognitively impaired individual's quality of life. Lawton and his colleagues (Lawton, Van Haitsma, & Klapper, 1996; Lawton, Van Haitsma, Perkinson, & Ruckdeschel, 1999) developed an observational scale (Apparent Affect Rating Scale, AARS) that allows for the quantification of five affective states (pleasure, anxiety/fear, anger, sadness, interest) in those with advanced impairment, which, they argue, provides some evidence on quality of life. They also advocate for assessment using a set of objective indicators, including a home-like environment and reasonable staff-patient ratios, to complement the observed indicators. Brod and his colleagues (Brod, Stewart, & Sands, 2000), building on Lawton's work, developed the Dementia Specific Quality of Life Model, or D-QoL (Brod, Stewart, Sands, & Walton, 1999), an assessment tool for use with those who are still capable of participating in an interview. The scale operationalizes their view that quality of life in this population includes both positive and negative affect, feelings of self-esteem and belonging, and the ability to appreciate the beauty in nature and in one's surroundings. Perhaps some of these attributes could be assessed through observation as well. Another useful assessment approach that can be applied at individual and group levels is Dementia Care Mapping, based on Kitwood and Bredin's (1994) work. Trained staff observe, on a predetermined schedule, the indicators of personhood — for example, interacting with others, being socially engaged, or doing work or pseudo work — which are then converted to a quantitative score that indicates whether care is satisfactory or needs improvement. These tools are relatively new and need much more use before it can be determined whether they are sufficient to assess the effectiveness of interventions to improve quality of daily life, including the moments that matter, if additional tools and methods are required. Despite these and other initiatives, this area is still in an early phase of development. Much more attention needs to be focused on conceptualizing the quality of daily life and quality of the moment in the cognitively impaired elderly population. The range of qualitative and quantitative methods that have so far been used to study various issues illuminates the need for creative research strategies to investigate this population when interviewing has limited potential.

This research agenda involves two particular issues: moving the agenda forward, and getting nursing staff to assume primary responsibility for ensuring that people who are cognitively impaired have the best possible quality of daily life. Several factors may serve to propel this research forward. Because of the aging of our population and the resulting increase in the number of people who are cognitively impaired, more people will have parents and grandparents with cognitive impairments and will insist that their lives be lived as fully as possible. Even without this reality, however, I think the opportunity to be creative and to bring innovative approaches to understanding behaviour and to testing different ways of being with and engaging these people will become irresistible to some of our best researchers. Perhaps a competition funded by the

CIHR Institute of Aging for research on ways of contributing to the quality of daily life of those with advanced impairment would be an appropriate incentive. But how do we get nurses to agree that we must incorporate making moments matter into our daily work with these people? To use an earlier analogy, how do we get them to sew the tapestry using multiple colours and strands? First we have to learn how to sew, and that is what research will bring us. Then we have to teach students and nursing staff how to sew, and that will require more research. Only then will we be in a position to hope that the rewards of bringing highly textured, interesting, and enjoyable days to the hundreds of thousands of cognitively impaired older people living out their days in long-term-care facilities will be so compelling and so reinforcing that nurses would not think of caring for them in any other way.

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Résumé

Déterminants individuels en matière de soins infirmiers à domicile et d'aide aux travaux domestiques

Dorothy A. Forbes, Norma Stewart, Debra Morgan, Malcolm Anderson, Karen Parent et Bonnie L. Janzen

Cette étude a pour but d'examiner les déterminants individuels qui conditionnent le recours aux soins infirmiers à domicile et à l'aide aux travaux domestiques financés par les fonds publics, chez des Canadiennes et des Canadiens de 18 ans et plus, de 1994 à 1999. La sélection de variables, les analyses et l'interprétation des résultats ont été réalisées selon le modèle behavioriste de l'utilisation des services de santé [Behavioural Model of Health Services Use] d'Andersen et de Newman. Des analyses descriptives et corrélatives ainsi que des analyses de régression logistique ont été effectuées dans les trois premiers cycles transversaux des Enquêtes nationales sur la santé de la population, de Statistique Canada. Selon l'étude, les conditions suivantes ont été identifiées comme des déterminants conditionnant le recours à l'aide aux travaux ménagers : être d'un âge avancé; être de sexe féminin; vivre seule; avoir un faible revenu; être limitée dans ses capacités d'activités; avoir besoin d'aide pour les travaux ménagers; ne pas avoir été hospitalisée dans les années antérieures; être atteinte d'au moins une maladie chronique. Toutefois, les déterminants liés au recours de soins infirmiers à domicile avaient tendance à être contraires à ceux liés aux demandes d'aide pour les travaux ménagers. Entre 1994 et 1999, le recours à l'aide aux travaux ménagers a semblé diminuer et la demande de services infirmiers à domicile semble être demeurée relativement stable.

Les résultats soulignent le besoin de cibler ces deux sous-groupes discrets d'utilisateurs de services de soins à domicile, ainsi que le besoin d'assurer des fonds pour les services de soutien et les services infirmiers.

Mots clés : enquêtes nationales sur la santé de la population, soins infirmiers à domicile, modèle behavioriste de l'utilisation des services de santé d'Andersen et de Newman

CJNR 2003, Vol. 35 Nº 4, 14–36

Individual Determinants of Home-Care Nursing and Housework Assistance

Dorothy A. Forbes, Norma Stewart, Debra Morgan, Malcolm Anderson, Karen Parent, and Bonnie L. Janzen

The purpose of this study was to examine individual determinants of use of publicly funded home-care nursing and housework assistance by Canadians 18 years and older from 1994 to 1999. Andersen and Newman's Behavioural Model of Health Services Use guided the selection of variables, analyses, and interpretation of the findings. Descriptive, correlation, and multiple logistic regression analyses were completed in each of the first 3 cross-sectional cycles of Statistics Canada's National Population Health Surveys. The determinants of use of housework assistance were older age, female, living alone, lower income, activity restriction, needing help with housework, not hospitalized in the previous year, and having at least 1 chronic condition. The determinants for home nursing tended to be the opposite of those for housework assistance. Between 1994 and 1999, use of housework assistance appeared to decrease and use of nursing services appeared to remain relatively stable. The findings underscore the need to target these 2 discrete subgroups of home-care users and ensure that funding is directed at support services as well as nursing services.

Keywords: National Population Health Surveys, home nursing, home support services, Andersen and Newman Behavioural Model of Health Services Use

Home care is an essential and growing component of Canada's health-care system. The pressure to continue to expand and enhance home-care services is a result of an increase in the population over the age of 75, a decrease in hospital beds, an increase in outpatient care and day surgery, changing consumer expectations with respect to service and care options, and technological, scientific, and pharmaceutical advancements that have enabled more care to be delivered in the home (e.g., dialysis, chemotherapy, epidurals) (Canadian Institute for Health Information [CIHI], 2002; Roos et al., 2001).

During the last decade, home-care programs have been growing at an annual rate of 9.0%, compared to an annual increase of only 2.2% in average health-care spending (Coyte & McKeever, 2001). Yet, the reallocation of funding to home care has not kept pace with the increased demand on home-care programs (Commission on the Future of Health Care in Canada, 2002; Parent & Anderson, 2001). In 1998/99, home-care expenditures made up only 4.7% of all publicly funded health-care spending in Canada (CIHI, 2002). Home-care programs have responded to the increased demand for their services by attempting to meet the more pressing needs of short-term, post-acute clients, resulting in less capacity to serve long-term clients (i.e., those who require home care beyond 3 months). Support home-care services (e.g., housework assistance) have been reduced or eliminated. The result of these changes has been a shifting of the responsibility and cost to clients, family members, and other unpaid informal caregivers and an increase in the number of private firms that provide these support services, known as "passive privatization" or "privatization by attrition" (Deber, 2000).

This shift to the provision of care to post-acute clients at the expense of long-term clients reflects two philosophies currently competing in the Canadian health-care system — the curative or biomedical model of care, and the supportive or psychosocial model of care that focuses on care, support, and "enablement" (Hollander & Prince, 2002). The dichotomy of these models is especially obvious within home-care programs. Professional services (e.g., nursing) that fall under the biomedical model receive universal coverage (no fees for service) while the support services (e.g., housework assistance) are income tested and/or means tested in most provinces (Hollander, 1999). With the reduction or elimination of support services, those with "independent" means pay for the services privately and/or have family members and friends take on the care responsibilities previously funded by the state. Frail and disabled elderly who do not have family, friends, or financial resources do without (Hollander & Tessaro, 2001). This trend appears to be contrary to one of the fundamental values that Canadians consider to be important in guiding and shaping the development of home care, that "there should be equity and fairness in the provision of home care, regardless of whether people require short- or long-term care" (Health Canada, 1999, p. 9).

The 2003 First Ministers' Accord on Health Care Renewal identified home care as one of three priorities for reform (primary health care and catastrophic drug coverage are the other two). The federal government will create a 5-year, $16-billion Health Reform Fund that will transfer resources to the provinces and territories to address these priority areas (Health Canada, 2003). There is, however, a need to better define the purpose and goals of home care, assist in the development of home-care funding models, and assist provincial health ministers and program planners in determining the minimum services that will be accessible to those who stand to benefit most from home care over the short and long terms. The purpose of this paper is to address these issues by developing a better understanding of the individual predictors of use of specific home-care services such as home nursing and housework assistance at different points in time.

Conceptual Framework

Over the past 25 years the Andersen and Newman Behavioural Model of Health Services Use has been used almost exclusively to conceptually organize health services utilization research (Andersen, 1995; Andersen & Newman, 1973). The model organizes the independent variables into societal determinants, health-care-system determinants, and individual characteristics, and operationalizes the dependent variables as the use or non-use of services and perceived health practices (Andersen). The individual variables consist of predisposing (e.g., demographic and social structural), enabling (e.g., education, income, social relationships), and need variables (e.g., self-rated and objective measures of health). Empirical applications of the model have primarily examined the individual variables (Crets, 1996). The Andersen and Newman Model was used as a framework for the present study to provide a structure for the literature review, the selection of study variables, and the analyses.

Critical Review of the Literature

Use of Home Care

There is some evidence from Canadian research suggesting that home care enhances clients' quality of life and is a cost-effective alternative to recovery in hospital (Health Services Utilization & Research Commission [HSURC], 1998) and to residential long-term care (Hollander, 1999). Thus, the value and effectiveness of the substitution function of home care in place of acute-care and long-term-care facilities have been demonstrated. However, the evidence regarding the effectiveness of the maintenance function of home care is conflicting (Clatney, 2001/02). The maintenance component of home care consists primarily of supervision, psychosocial support, and assistance with activities of daily living (e.g., dressing, bathing) and instrumental activities of daily living (e.g., laundry, vacuuming) (CIHI, 2001). The Health Services Utilization and Research Commission's (2000) study, based on analyses of Saskatchewan Health administrative data, revealed that Saskatchewan seniors receiving maintenance home care were 50% more likely to lose their independence (defined as not living in a nursing home) or die than those not receiving any service. Parent, Anderson, and Keretzes (1999) examined the impact of reducing home support services to home-care clients in Ontario and found little effect on clients' health, use of other health-care services, and mortality rates. Hollander and Tessaro (2001) compared individuals in British Columbia who received housekeeping home support services with those who had their services cut. The results revealed that clients who no longer received this service not only cost the health system significantly more, but also had higher mortality rates. The results of caregiving research show that (a) unpaid caregivers provide up to 90% of home-care services (Commission on the Future of Health Care in Canada, 2002); (b) the estimated value of unpaid caregivers' work was up to $5.7 billion per year in 1996; and (c) unpaid caregivers report negative physical, psychological, social, and economic consequences of caregiving (Fast, Forbes, & Keating, 1999). Unpaid caregivers cannot continue to take on ever increasing responsibility for providing care.

Predisposing Variables

There appears to be a shift in the age of home-care clients. Historically, 85% of home-care clients were 65 years of age and older (National Advisory Council on Aging, 1994). In 1998/99, only 67.2% of home-care clients were older adults (Statistics Canada, 2001). Women are more likely than men to seek help (Millar & Beaudet, 1996). However, in their analysis of the National Population Health Surveys (NPHS) data, Wilkins and Park (1998) found that although two thirds of home-care recipients were women, the odds of receiving home care were no higher for women than for men after adjusting for age, having chronic conditions, and needing help with activities of daily living. Additionally, Wilkins and Park found that those living alone were more likely to use home care.

Enabling Variables

Research examining the relationship between enabling factors and home-care use has produced conflicting results. Solomon and colleagues (1993) found that an education level of less than 12 years predicted increased use of home care, whereas the National Alliance for Caregiving study (1997) revealed that caregivers with higher levels of education were more likely to arrange home-care services for their loved ones. Similarly, while one study reports income adequacy as having a clear inverse relationship with receiving home-care services (Wilkins & Park, 1998), another study reports a positive association (HSURC, 1998).

Although some research has found the availability of informal support to be inversely related to the utilization of home-care services (Solomon et al., 1993), other research suggests that social support has a positive influence on the use of formal services (Chappell, 1987). A possible explanation for these conflicting results is suggested by Logan and Spitze (1994). They propose that the informal support systems of older adults provide two functions: a compensatory process, in which family support substitutes for formal support; and a bridging function, whereby the informal network helps link the older adult to services. Informal caregivers' level of personal burden has been found to affect use of formal services (Miller & McFall, 1991).

Antonovsky's (1987) Salutogenic Model postulates that individuals with a strong sense of coherence (SOC) are more likely to (a) define life events as less stressful (comprehensibility); (b) mobilize resources to deal with encountered stressors (manageability); and (c) possess the motivation, desire, and commitment to cope (meaningfulness). Individuals with a strong SOC are more likely to redefine the meaning of a stressful situation, select realistic coping strategies, and avoid potentially maladaptive or unhealthy behaviours (Baro, Haepers, Wagenfeld, & Gallagher, 1996). Previous analysis of the NPHS revealed SOC to be strongly and positively associated with health status among older Canadians and negatively associated with use of home-care services (Forbes, 2001). To the knowledge of the authors, previous research conducted by other researchers has not examined the influence of SOC in predicting use of home care.

Need Variables

The strongest single determinant of utilization of home care is functional disability (Diwan, Berger, & Manns, 1997; Hall & Coyte, 2001; Wilkins, & Park, 1998). Other important indicators of the need for home care are the number and type of chronic conditions, self-reported perceived health, and time spent in hospital (Wilkins & Park).

In summary, previous research shows that age, gender, and living arrangement may be predisposing factors in the use of home-care services. The influence of the enabling factors, namely education, income, and availability of informal support, are contradictory in the literature, and the influence of SOC has not been previously studied to the knowledge of the authors. Clearly, restriction of activities, perceived health, number of overnight hospitalizations, and number and type of chronic conditions are all need factors that influence the use of home care. However, there is a paucity of research that specifically examines the determinants of home nursing and housework assistance and whether these patterns of determinants have shifted at different points in time.

Purpose and Research Questions

The purpose of the research was to inform policy-making on home care in Canada through an examination of the determinants of the use of home nursing and housework services by Canadians 18 years of age and over from 1994 to 1999. The specific research questions were (a) *Among home-care users, what are the similarities in and differences between those who received home nursing and those who received housework assistance in 1994/95,* *in 1996/97, and in 1998/99?* (b) *Which individual variables best predict use of home nursing and use of housework assistance in 1994/95, in 1996/97, and in 1998/99?*

Method

Design

The National Population Health Surveys (Statistics Canada, 1996, 1999, 2000) provide an opportunity to examine home-care use from the perspective of Canadian users. The NPHSs were designed to collect information related to the health of the Canadian population. The questionnaires had components on health status, use of health services, risk factors, and demographic and socio-economic characteristics. This research focuses on deriving estimates from the first three cycles of cross-sectional data collected in 1994/95, 1996/97, and 1998/99.

Sample

The target population of the NPHS included household residents in all provinces excluding populations on Indian Reserves, Canadian Forces Bases, and some remote areas in Quebec and Ontario. The data set used in this study also excluded those living in institutions. The sample sizes for the cross-sectional components were 11,969 in 1994/95, 13,070[1] in 1996/97, and 14,148 in 1998/99. The number of respondents who received home-care services was 283 in 1994/95, 438 in 1996/97, and 499 in 1998/99. Of these respondents, 111 in 1994/95, 187 in 1996/97, and 199 in 1998/99 received nursing services and 138 in 1994/95, 253 in 1996/97, and 252 in 1998/99 received housework assistance. A power analysis, based on the Andersen and Newman Model, calculated using alpha set at .05, a small effect size with 80% power, and 13 independent variables revealed that 78 subjects were needed (Cohen, 1988). This number is well below the number of respondents in each subgroup. The selected person response rates were 96.1% in 1994/95, 98.7% in 1996/97, and 98.5% in 1998/99 (Statistics Canada, 1996, 1999, 2000).

Indicators

The dependent variables were use of home nursing and use of housework assistance. Respondents were read the following definition: "Home-care services are health-care or homemaker services received at home, with the cost being entirely or partially covered by government."

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[1] The 1996/97 sample was originally 81,804 due to the buy-ins from Ontario, Manitoba, and Alberta (i.e., specific questions requested by these provinces). The core sample (n = 13,070) that excluded the buy-ins was obtained through remote access to the survey master file at Statistics Canada.

Respondents were then asked: "Have you received any home-care services in the past 12 months? What type of services have you received: nursing care (e.g., dressing changes, VON[2]), housework (e.g., cleaning, laundry)?" Respondents may have selected more than one service. Use of other health-care providers (i.e., physical and occupational therapists, social workers), personal care, meal preparation, shopping, and respite were not included in the analyses because the sample sizes were often less than 30 per cell and the results cannot be released. Similarly, the numbers of those who received nursing and housework services at the same time were too small to include in the analyses (Statistics Canada, 1996).

Thirteen independent variables were examined based on Andersen and Newman's Model. The predisposing variables included: age (< 65 and ≥ 65), gender, and living arrangement (alone and with at least one other person). The enabling variables included education (< secondary education and ≥ secondary education); income adequacy based on household income and size (lowest, lower middle, middle, upper middle, and highest); sense of coherence (13 items on a scale developed by Antonovsky [1987] measure the extent to which respondents perceive events as comprehensible, manageable, and meaningful); and social support. The variables used to measure social support varied somewhat in the data sets. In 1994/95 and 1996/97, four items measured perceived social support: someone to confide in, someone you can count on, someone who can give you advice, and someone who makes you feel loved. In 1998/99, social support was measured using the Tangible Social Support–Medical Outcomes Study (MOS) subscale (availability of someone to help if confined to bed, to take to the doctor, to prepare meals, and to help with daily chores when sick). Both measures of social support were used in the present study.

The need variables included: restriction of activities (because of a long-term [≥ 6 months] physical or mental condition or a health problem, respondents were limited in the kind or amount of activity they could do at home, school, work, and other); need for help with normal everyday housework or with personal care such as washing, dressing, or eating; presence and type of chronic conditions (e.g., arthritis/rheumatism, chronic bronchitis, cancer, cataracts, diabetes, heart disease, effects of stroke, urinary incontinence) that have lasted or were expected to last 6 months or more and have been diagnosed by a health professional; perceived health (self-report measure of general health: excellent-good and fair-poor); and overnight hospitalizations in the past 12 months. In addition, the frequency of not receiving needed health care or advice during

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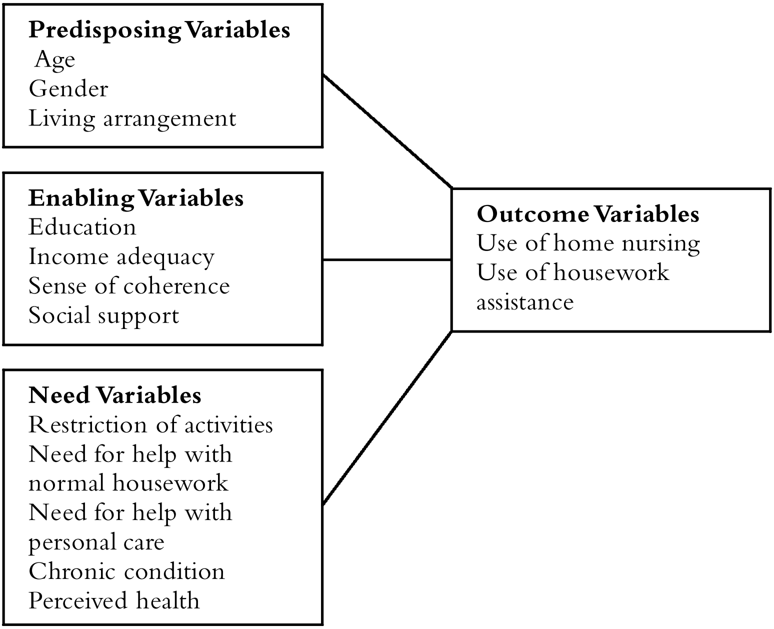
[2] Victorian Order of Nurses.

the past 12 months and the reported reasons were examined (e.g., waiting time too long, not available when needed, cost, felt care would be inadequate, and not available in the area).

Data Analyses

The planned data analyses entailed a multi-stage process consisting of data description and bivariate and multivariate analyses using SPSS® 11.0 for Windows.™ Tabulations of the predisposing, enabling, and need variables were used to describe users of home nursing and housework assistance in 1994/95, 1996/97, and 1998/99. Differences between the cohorts were tested using the chi-square analysis of contingency tables, Mann-Whitney U test, or one-way ANOVA (Munro, 2001). Pearson product-moment correlations were used to determine the strength and association between the independent variables and the dependent variables. Potential confounders were revealed by these analyses. Variables that were marginally significant (i.e., $\leq$ 0.25 [Hosmer & Lemeshow, 1989]) and theoretically appropriate were retained for inclusion in multivariate analyses.

Figure 1 *Variables Included Based on the Andersen and Newman Model*



For each NPHS cycle, multiple logistic regression analyses were performed to examine the associations of the independent variables with home nursing and housework assistance. Based on Andersen and Newman's Model, independent variables were entered into the regression in three blocks: predisposing factors, enabling factors, and need factors. Only the final models are presented in Table 3. To account for design effects, odds ratios were considered statistically significant if the values of the lower and upper bounds of their 95% confidence intervals were not in the range 0.945 to 1.055. To permit greater generalizability to the Canadian population, sampling weights were calculated for each respondent. An average sampling weight was used in the multivariate analyses (Statistics Canada, 1996).

Results

A brief overview of home-care use and satisfaction with the amount of care received are provided. The most significant findings are then described in relation to the two research questions.

Only 2.4%, 2.3%, and 2.7% of Canadians received home-care services in 1994/95, 1996/97, and 1998/99, respectively. Compared to non-users of home care (6.5%), users of home care were significantly more likely to report that they were not receiving the health care they needed (10.4%) (1998/99: $\chi^2 = 8.21, p = .00$) The most frequent reasons cited for not receiving care, when perceived as needed, were: (1) a long wait list, (2) not being available when needed, (3) not getting around to it, (4) believing that care would be inadequate, (5) the cost of care, and (6) not being available in the area.

Question 1: *Among home-care users, what are the similarities in and differences between those who received home nursing and those who received housework assistance in 1994/95, in 1996/97, and in 1998/99?*

The use of specific types of home-care services appeared to differ for the three periods (Table 1). Nursing services increased in 1996/97, but in 1998/99 returned to a proportion similar to that in 1994/95.

Table 1 ***Frequencies and Percentages of Home-Care Users Who Received Home-Care Nursing and Housework***

Estimated population	**1994/95** ***N*=505,061**		**1996/97** ***N*=544,687**		**1998/99** ***N*=612,868**	
Type of service	***f***	**%**	***f***	**%**	***f***	**%**
Nursing	198,500	39,300	250,900	46,100	252,400	41,200
Housework	246,100	48,700	229,300	42,100	255,800	41,700

Housework assistance appeared to decrease over the three periods. It is interesting to note that of those who received home care, an increasing proportion reported needing assistance with housework but not receiving it (1994/95: 38.3%; 1996/97: 41.2%; 1998/99: 48.5%).

Predisposing Variables

Table 2 reports the proportion of home-care users who received nursing and/or housework assistance in each of the three periods in relation to the predisposing, enabling, and need variables. The relationship between age and use varied with the type of service: in all three periods, home-care users under the age of 65 were more likely to receive nursing services, while users over the age of 65 were more likely to receive housework assistance. A higher percentage of women than men received housework services in all three periods, while in 1996/97 a greater percentage of men than women received nursing services. Similar results were found for living arrangement: home-care users living alone were more likely to receive housework assistance in all three periods compared to those living with others, while in 1994/95 and 1996/97 those living with others were significantly more likely to receive nursing services than those living alone.

Enabling Variables

There were no significant differences in education level between home-care users who received home nursing and those who received housework assistance. However, significant differences were found for income level. A larger percentage of lower-income than higher-income home-care users received housework assistance in all three periods. However, the reverse was true for nursing services; in 1994/95 and 1996/97, a significantly larger percentage of home-care users with higher income than with lower income received nursing services. In contrast, users of home nursing and housework assistance did not differ on levels of SOC and perceived/tangible social support.

Need Variables

Home-care users who received housework assistance were more likely to report restrictions in activities of daily living and needing help with housework in all three periods. In contrast, those who received nursing services were more likely to report no restrictions in their daily activities in 1994/95 and 1998/99 and less likely to report needing help with housework in the three periods. These findings may indicate that those who receive nursing services are short-term recipients of home care and their housework can be managed by others or left undone for a brief period. Nearly one third of those who reported not needing help with housework received housework assistance. This finding is difficult to explain. Perhaps, because these respondents were receiving assistance, they believed further housework assistance was not needed. No significant differences were found between those who reported needing assistance with personal care and those who received nursing and housework assistance.

Regarding chronic conditions, home-care users who received housework assistance were more likely than those who did not receive such services to report having a chronic condition in all three periods. The most common chronic conditions reported were arthritis or rheumatism, high blood pressure, back problems, heart disease, cataracts, and diabetes. Conversely, home-care users who received nursing services were more likely to report no chronic condition in 1994/95 and 1996/97. There were no significant differences in levels of perceived health among those who received nursing care and those who received housework assistance. However, a larger percentage of those receiving nursing services were hospitalized overnight in the previous 12 months in all three periods, while those who received housework assistance in 1996/97 and 1998/99 were less likely to have been hospitalized overnight in the previous 12 months.

Question 2: *Which variables best predict use of home nursing and use of housework assistance in 1994/95, in 1996/97, and in 1998/99?*

Predictors of Home Nursing

Table 3 reports the significant findings of the logistic regressions. In 1996/97, gender was the only predisposing variable associated with use of home nursing, with men being twice as likely as women to receive home nursing. In 1994/95, individuals who received home nursing services were 2.5 times as likely as those who did not receive such services to have a high income. In addition, having less than secondary education was strongly associated with receiving home nursing in 1996/97. Regarding the need variables, those who received home nursing were nearly four times as likely to report no chronic condition in 1994/95 and two to three times as likely to perceive their health as poor (likely due to an acute episode) in 1994/95 and 1998/99. Not surprisingly, those who received nursing services were two to three times as likely to be hospitalized in the previous year in all three periods, and nearly three to four times as likely not to need housework assistance in 1994/95 and 1996/97.

Predictors of Housework Assistance

The variables associated with use of housework assistance were different from those associated with use of home nursing. Home-care users who

Table 2 *Use of Home Nursing and Housework Assistance by Predisposing, Enabling, and Need Variables*

Independent Variables		% of Home-Care Users Who Received Home Nursing			% of Home-Care Users Who Received Housework Assistance		
		1994/95	**1996/97**	**1998/99**	**1994/95**	**1996/97**	**1998/99**
Estimated Population Size		***N*=198,500**	***N*=250,900**	***N*=252,400**	***N*= 246,100**	***N*=229,300**	***N*=255,800**
Predisposing Variables							
Age	≥ 65 years	31.3	36.7	36.4	61.2	54.2	48.8
	< 65 years	56.8★★★	52.7★★	51.1★★	28.3★★★	32.4★★★	27.3★★★
Gender	Male	46.3	54.3	42.5	40.1	36.6	28.0
	Female	37.3	36.9★★	40.5	54.4★	51.1★	49.3★★★
Living arrangement	Alone	28.0	26.1	42.6	65.0	72.9	61.8
	With Others	48.4★★	52.3★★★	40.4	39.6★★★	30.4★★★	30.2★★★
Enabling Variables							
Education	Higher (> secondary)	53.3	32.7	50.7	42.2	40.2	37.5
	Lower (< secondary)	37.6	44.3	38.9	51.2	48.1	43.2
Income	Higher (4,5)	59.6	53.4	39.1	37.2	31.2	28.5
	Lower (1,2,3)	33.4★★★	36.8★	41.2	54.3★	52.2★★	46.4★★
Perceived social support	Higher (3,4)	39.3	41.2	43.8†	50.2	49.8	44.6†
	Lower (0–2)	39.1	42.1	33.3†	52.2	46.1	52.9†
Sense of coherence	Higher (41–80)	38.7	—	43.4	51.9	—	44.7
	Lower (1–40)	48.7	—	33.8	48.0	—	47.9

Need Variables							
Restriction of activity	Yes	36.3	41.0	37.3	53.5	51.2	46.8
	No	52.6★	45.9	53.7★★	37.9★	33.5★★	25.7★★
Need for housework	Yes	27.5	31.5	32.5	61.7	58.8	51.5
	No	52.9★★★	53.3★★★	51.8★★★	37.8★★★	34.2★★★	29.8★★★
Need for personal care	Yes	34.4	40.2	34.4	59.6	39.4	39.3
	No	41.7	43.0	44.2	47.4	49.4	42.8
Chronic condition	Yes	36.4	38.8	41.6	53.9	51.1	44.0
	No	69.8★★★	69.5★★	37.0	18.3★★★	12.0★★★	19.3★★
Perceived health	Excellent-Good	37.1	39.8	37.1	47.9	47.1	39.9
	Poor-Fair	43.6	44.8	45.1	51.9	46.3	43.5
Overnight hospitalization	Yes	50.5	54.9	51.9	45.6	35.3	33.0
	No	29.4★★★	30.0★★★	32.8★★★	54.2	57.6★★★	49.3★★

Notes: ★$p < 0.05$ ★★$p < 0.01$ ★★★$p < 0.001$; † Tangible Social Support: Higher (9–16), Lower (0–8).

Table 3 *Significant Odds Ratios of Use of Home Nursing and Housework Assistance*

Independent Variables	**Odds Ratios of Use of Home Nursing**						**Odds Ratios of Use of Housework Assistance**					
	1994/95		**1996/97**		**1998/99**		**1994/95**		**1996/97**		**1998/99**	
Sample Size	*N* = 379		*N* = 368		*N* = 381		*N* = 379		*N* = 368		*N* =381	
	Odds ratio	**95% CI**	**Odds ratio**	**95% CI**	**Odds ratio**	**95% CI**	**Odds ratio**	**95% CI**	**Odds ratio**	**95% CI**	**Odds ratio**	**95% CI**
Predisposing Variables												
Older adults	—	—	—	—	—	—	3.83***	1.96–7.48	—	—	—	—
Female (Male)	—	—	(2.00*)	(1.05–3.79)	—	—	2.04*	1.11–3.78	—	—	—	—
Lives alone	—	—	—	—	—	—	—	—	4.94***	2.46–9.93	2.08*	1.00–4.36
Enabling Variables												
Lower education	—	—	3.41**	1.47–7.93	—	—	—	—	—	—	—	—
Higher (Lower) income	2.54*	1.19–5.41	—	—	—	—	—	—	—	—	—	—
Need Variables												
Restricted activities	—	—	—	—	—	—	—	—	—	—	3.62**	1.54–8.54
Needs housework assistance (Does not)	(2.79**)	(1.35–5.78)	(3.76**)	(1.75–8.06)	—	—	2.10*	1.06–4.14	4.83***	2.13–10.94	6.36***	2.85–14.17
Does not need personal care	—	—	—	—	—	—	—	—	6.71***	2.81–16.13	2.66*	1.13–6.26
No chronic condition	3.81*	1.31–11.09	—	—	—	—	—	—	—	—	—	—
Poor perceived health	3.41***	1.65–7.04	—	—	2.01*	1.05–3.83			—	—	—	—
Hospitalizations (No)	2.92***	1.56–5.48	3.15***	1.78–5.76	2.28**	1.31–3.98			—	—	(2.56**)	(1.35–4.87)

Note: *$p < 0.05$ **$p < 0.01$ ***$p < 0.001$

received housework services, compared with those who did not, were nearly four times as likely to be over the age of 65 in 1994/95, twice as likely to be female in 1994/95, and two to nearly five times as likely to be living alone in 1996/97 and 1998/99. No enabling variables were associated with housework assistance. Home-care users who identified a need for assistance with housework were two to six times as likely to receive housework assistance in the three periods. Those who received housework assistance were nearly four times as likely to be restricted in their activities of daily living in 1998/99, two and a half times as likely not to be hospitalized in the previous year in 1998/99, and approximately three to seven times as likely not to require assistance with personal care in 1996/97 and 1998/99. This finding may reflect the eligibility criterion in some jurisdictions that requires home-care recipients to receive personal care assistance in order to receive housework assistance; because respondents were receiving help with their personal care, they reported that no further assistance was required.

Discussion

The percentage of Canadians who receive home care (2.3 to 2.7%) appears to have changed little from 1994 to 1999. This finding is difficult to explain, as the funding to home care increased significantly over this period (Coyte & McKeever, 2001). A possible explanation is that greater amounts of home-care services (i.e., units of service or service hours) are provided to clients with more complex and acute-care needs for shorter periods of time but the percentage of clients who receive home care at each point in time remains the same. Another possible explanation is that funding has been targeted to enhancing new information systems, medical technology, and/or improving the wages of home-care workers, rather than to admitting increasing numbers of clients.

The use of housework assistance appears to have decreased and the use of nursing care appears to have remained relatively stable from 1994 to 1999. Fiscal, demographic, and political pressures have made it necessary for home-care programs in Canada to ration, prioritize, and target home-care services. The result of restricting eligibility to support services, limiting hours of available support services, eliminating access to services such as housekeeping, and limiting services to those who are more acutely ill has been an increase in the proportion of clinical services and a decrease in the proportion of support services such as housework assistance (Parent, Anderson, Keefe, & MacLellan, 2002). When housework services are not available through publicly funded home care, those who require these services in order to remain in their own home and not be institutionalized have the following options: ask unpaid caregivers to take on this responsibility; purchase the service from a private firm; or, if they do not have family, friends, or financial resources, do without. None of these options are sustainable, as unpaid caregivers may already be providing up to 90% of the care and those who cannot afford to hire private housework assistance will do without. These options increase the burden on seniors and their unpaid caregivers and may result in greater costs to the health-care system (Deber, 2000).

This study extends the work of others who have used the Andersen and Newman Model (e.g., Hall & Coyte, 2001) by examining specific types of home-care use (i.e., nursing and housework assistance) and generalizing the results to all Canadians over the age of 18. The findings reveal that the predisposing variables (e.g., older adult, female, and living alone) have a stronger association, at some points in time, with use of housework assistance than with home nursing. Living alone continues to be a significant predictor of housework assistance, while advanced age and being female appear to be less significant over time (perhaps because increasing proportions of younger individuals are being admitted to home care and because the gender gap in life expectancy is narrowing). These findings underscore the importance of targeting specific resources to specific subgroups. None of the enabling variables were significant in predicting use of housework assistance, and lower education and higher income were significant only in predicting use of home nursing at one period.

The need variables were found to have the strongest association with use of home nursing and housework assistance; those who have the greatest need (or do not need) housework assistance and personal care assistance tend to receive/not receive home nursing and housework assistance. However, fewer home-care users who perceived a need for housework assistance received this service over time. In 1998/99, nearly half of the home-care users who reported needing this service did not receive housework assistance through home care. In addition, the need variables that predict use of nursing and housework assistance differ. Prior hospitalizations (at each period) and poor perceived health (in 1994/95 and 1998/99) were associated with home nursing, while restriction in activities of daily living (in 1998/99) and needing help with housework (at each period) predicted use of housework assistance. Indeed, the need for housework assistance appears to be increasing in significance in predicting use of housework assistance over time.

The study revealed two distinct subgroups of home-care users. Those who received nursing services were more likely to be under 65 years of age (at each period), male (in 1996/97), living with others (in 1994/95 and 1996/97), higher income (in 1994/95 and 1996/97), not restricted in their activities (in 1994/95 and 1998/99), not in need of assistance with housework (at each period), hospitalized in the previous year (at each time period), and to report no chronic condition (in 1994/95 and 1996/97). These individuals required the expertise of health professionals following an acute episode. Because of their younger age, supportive living arrangement, higher income, and absence of chronic conditions, they did not require support services such as housework assistance.

In contrast, those who received housework assistance were more likely to be older (at each period), female (at each period), living alone (at each period), lower income (at each period), restricted in their activities (at each period), in need of assistance with housework (at each period), not hospitalized in the previous year (in 1996/97 and 1998/99), and to report at least one chronic condition (at each period). This subgroup required support services because of their more advanced age, unsupportive living arrangement, low income, and chronic condition(s). Females were also more likely than their male counterparts to require housework assistance, probably due to the fact that women are more likely to be widowed and also tend to experience the onset of activity limitations earlier and at a higher rate then men, especially among old-old individuals (Martel & Belanger, 2000). All these factors contribute to poor health and should be considered when assessing those who request housework assistance.

The findings underscore the need to carefully target these two discrete subgroups and ensure that funding is directed not only at clinical services such as nursing, but also at support services such as housework assistance. The implication is that adequate funding levels are required to sustain both types of care, which has not been the case to date. Coyte (2002) estimates that an increase of $1.46 billion in public home-care expenditures is required to ensure that all Canadians have access to at least the benchmark level of publicly funded home care. However, no matter how much home-care funding is made available to provincial home-care programs, priority-setting with scarce public resources will always be a reality. Resource allocation should reflect the differences in the determinants of use of home nursing and housework assistance. For example, nursing services should be targeted to those who require the expertise of a health professional in managing their symptoms or treatments. Housework assistance should be targeted to the oldest-old who live alone, whose social support network may be unable/unwilling to assist, and who are unable to manage with their housework because of restrictions in their activities of daily living due to physical or cognitive impairments. Without housework assistance these individuals would require institution-based care. In addition, because there is often a fee for housework assistance, policies must recognize that income barriers and eligibility requirements may prevent access to these services, and thus negatively affect the physical and mental health of both clients and their family caregivers. Some jurisdictions have an eligibility criterion: clients must need hands-on care, such as personal care, in order to access support services. However, some clients may simply not need personal care in order to function independently in their home setting. While support services for such people — aside from the compelling case regarding quality of life — represent a cost to the system in the short run, the investment may well reduce long-term costs by delaying placement in an institution.

The Romanow Report (2002) recommends that a publicly funded National Post-Acute Home Care Program, National Palliative Home Care program, and Home Mental Health case management and intervention services be included within the Canada Health Act. While this recommendation is commendable and important for some subgroups of home-care users, the Royal Commission has not adequately addressed the needs of other subgroups such as those with chronic conditions, those with physical disabilities, and frail older adults. A philosophical shift by policy-makers, from the current biomedical model of curing disease and treating medical conditions to a supportive model of care that reduces the rate at which individuals deteriorate and promotes optimal quality of life through health and support services, is required if a national home-care program is to realize its full potential.

Limitations and Areas for Further Research

Although use of the NPHS has many advantages (accessible, large samples, collected every 2 years over 20 years, reliable and valid data sets), its limitations should also be acknowledged. Although sample sizes were adequate to conduct analyses at a national level, they were not large enough to conduct home-care utilization comparisons between provinces or regions. Provincial and regional jurisdictions differ greatly in terms of the structure, access, and content of home-care services. The effect of these differences was beyond the scope of this study. As well, individuals who receive both nursing and housework assistance (an eligibility requirement for accessing housework in some jurisdictions) could not be examined in this study due to the small sample size.

Analyses of population-based survey data such as the NPHS data reveal only part of the story. There is other critical information not collected in the NPHSs that would enhance the decision-making ability of policy-makers at different organizational and jurisdictional levels.

This includes the following: rural/urban location, levels of cognitive impairment, the *amount* of home-care services received, satisfaction with the care received, and the types of services and amount of care received from unpaid caregivers and private organizations (both for-profit and not-for-profit). In addition, as all the NPHS data were self-reported their degree of validity is unknown. Despite these limitations, however, the utility of the current study is that population-based data have been examined to identify the individual determinants of home-care nursing and home support services.

This sector still requires much research. Different research methods, including a range of qualitative approaches, can examine, for example, the experiences of unpaid caregivers or the perceptions of clients who have had changes to their services imposed due to fiscal constraints. Comparative analyses can be conducted to examine the experiences of care recipients and formal providers in their respective jurisdictions. Linking data sets such as the Canadian Community Health Survey with provincial administrative data could compare the use of the specific types of home-care services by regions and provinces, and examine the health and cost effect of "passive privatization" on frail elderly, their unpaid caregivers, and the health-care system. Indeed, little work has been done to examine the characteristics and effects of different models of home care in place across the country. Finally, and more closely tied to this present paper, structural equation modelling could be used to determine whether and to what extent the Andersen and Newman Model explains the use of home-care services among different subgroups of users.

Conclusion

This study has revealed that housework assistance through home care is especially needed by old-old individuals who live alone, whose social support network is unable/unwilling to assist, and who are unable to manage their housework because of restrictions in their activities of daily living. As this paper goes to press, the provincial health ministers are determining a core set of portable home-care services to be provided in their provinces through the new platform for a national strategy for home care in Canada. This basket of services should include not only short-term, acute home care but also the supportive services that will allow frail elderly Canadians to remain in their homes. Otherwise, housework assistance through publicly funded home-care programs will continue to gradually decrease and may over time cost the health-care system significantly more. Can we afford not to adequately fund all current functions of home care?

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Résumé

À la recherche d'un soutien : stratégies d'interaction utilisées par les aidantes naturelles auprès des professionnels de la santé

Myrna Heinrich, Anne Neufeld et Margaret J. Harrison

Un soutien de la part des professionnels de la santé peut aider les aidantes naturelles à accomplir leurs tâches et produire un effet positif sur leur santé. Cette étude a pour but d'explorer les perceptions que détiennent les femmes concernant le soutien qu'elles peuvent obtenir des ressources communautaires en situation où elles prennent soin d'un membre de la famille atteint de démence. Les questions énoncées dans le cadre de cette recherche sont les suivantes : quels sont les facteurs influençant les interactions des aidantes naturelles avec les professionnels de la santé lorsque celles-ci demande de l'aide? Quelles stratégies les femmes emploient-elles dans leurs interactions avec le personnel de la santé pour s'assurer un soutien? L'interaction symbolique a servi de fondation théorique dans le cadre de cette étude, qui incluait une analyse secondaire de 62 entrevues réalisées auprès de 20 femmes portant sur leur vécu en tant que dispensatrices de soins. De plus, de nouvelles données ont été recueillies auprès de deux groupes de discussion avec l'aide de huit volontaires recrutées au sein des 20 participantes originelles. Selon les données, les attentes des femmes concernant leur rôle de pourvoyeuses de soins et leur évaluation de l'état de la personne recevant les soins ont influencé leurs interactions avec le personnel soignant lorsqu'elles ont demandé de l'aide. Elles avaient recours à quatre stratégies élargies : la collaboration, l'entente raisonnable, la réticence et la bataille / la lutte. Le recours à ces stratégies variait selon le degré de partage décisionnel dont elles bénéficiaient avec le personnel soignant et était accompagné d'expériences positives et négatives. Ces résultats confirment l'importance de la réciprocité dans les relations avec le personnel soignant et appuie l'utilisation de modèles de pratiques professionnelles axés sur le partenariat et l'autonomisation.

Mots clés : démence, femmes

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Seeking Support: Caregiver Strategies for Interacting with Health Personnel

Myrna Heinrich, Anne Neufeld, and Margaret J. Harrison

Support from health professionals can assist family caregivers and have a positive impact on their health. The purpose of this study was to explore women's perceptions of support from community resources while caring for a family member with dementia. The research questions were: What factors influence female caregivers' interactions with health personnel when seeking support? What strategies do women employ in interactions with health personnel to secure support? Symbolic interaction was the theoretical foundation for the study, which included secondary analysis of 62 interviews with 20 women concerning their caregiving experience. In addition, new data were collected from 2 focus groups with 8 volunteers recruited from among the original 20 participants. The data indicated that the women's expectations of their caregiving role and their appraisal of the care recipient influenced their interactions with health personnel when seeking support. They employed 4 broad strategies: collaborating, getting along, twigging, and fighting/struggling. A woman's use of strategies varied according to the degree of mutuality in decision-making with staff and was accompanied by both positive and negative experiences. These findings confirm the importance of mutuality in relationships with health personnel and support the use of partnership and empowerment models of professional practice.

Keywords: family caregiving, social support, qualitative, dementia, women

Family members, particularly women, continue to be the primary source of assistance to older people with Alzheimer disease and other forms of dementia (Chappell, 1992; Martin-Matthews, 1999). As the demands of caring for a relative with dementia accelerate, women experience a negative impact on their personal health (Lee & Porteous, 2002) and require community and institutional assistance to sustain their caregiving role (Liken, 2001; Stevenson, 1990). The use of community resources concurrent with support from family and friends may assist family members caring for elders (Chappell).

The purpose of this research was to explore women's perceptions of support from community resources while caring for a family member with dementia. The specific research questions were: (a) *What factors influence female caregivers' interactions with health personnel when seeking support?*

and (b) *What strategies do women employ in interactions with health personnel to secure support?* The women's sources of support included the staff and resources of continuing-care institutions and community health-care services such as respite services, home care, or adult daycare.

Background

Care of a family member with dementia generates physical and emotional demands that may result in exhaustion, social isolation, and negative health effects such as depression (Grasel, 2002; Stevenson, 1990; Tennstedt, Cafferata, & Sullivan, 1992) or reduced immune response (Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991). Social support can have a positive impact on the health of caregivers (Redinbaugh, MacCallum, & Kiecolt-Glaser, 1995; Robinson-Whelan, Tada, MacCallum, McGuire, & Kiecolt-Glaser, 2001), either by meeting social needs for information, esteem, aid, and reliable alliance directly or by influencing the effect of stressful experiences (Stewart, 1993). Sources of social support include family members and friends (informal support) as well as professional or community services (formal support). Formal sources of support are frequently sought to supplement the care of family and friends when caregivers are unable to provide the amount of assistance needed (Edelman & Hughes, 1990) or lack the necessary technical expertise (Chappell & Blandford, 1991; Litwak, Messeri, & Silverstein, 1990).

Social support from both formal and informal sources is best understood in the context of the relationships through which support is experienced (Badr, Acitelli, Duck, & Carl, 2001). Caregivers, like other individuals, hold expectations and beliefs about preferred means of support in specific relationships.

Previous research has addressed interactions with staff and expectations of family caregivers about participation in decisions concerning the care of persons living in the community or in various types of supportive-care facilities. In a study with caregivers of family members living in the community, Adams (2000) used discourse analysis to examine conversations during home visits between a family caregiver of a person with Alzheimer disease and psychiatric nurses. The caregiver used creativity by employing language and a caregiver identity of "worrier" to influence decisions about care. Duncan and Morgan (1994) explored the expectations of caregivers concerning their relationships with staff caring for a relative with Alzheimer disease in community agencies and residential institutions. Their qualitative study comprised 29 focus groups with 179 caregivers and 10 individual interviews. Caregivers sought to influence care by building ongoing relationships with staff and facilitating positive and emotionally connected interactions between staff and their relative. They expected staff to recognize their expertise in caring for their family member.

Several researchers have examined family caregivers' involvement in decisions about care in institutional settings. Walker and Jane Dewar (2001) used participant observation of multidisciplinary team meetings (in which family caregivers were included) and interviews to study caregivers' involvement in decision-making concerning relatives in respite care or in assessment units of a psychiatric hospital in the United Kingdom. The findings confirm those of previous research indicating that caregivers want to be involved in decision-making but feel they are inadequately informed about how decisions are made and lack influence when they do participate. Bowers (1987, 1988) found that family caregivers of persons institutionalized with a chronic health condition expected staff to provide care in ways that nurtured their relative's individuality and personhood, thus helping caregivers to preserve his or her identity. Health-care personnel, however, often did not recognize or meet these expectations. Hertzberg and Ekman (2000) examined interaction between relatives of persons with dementia and staff in nursing homes in Sweden. Their study involved three weekly focus group discussions with staff and relatives over a period of 9 weeks. Caregivers emphasized the importance of influencing the care of their relative. They took the initiative by establishing ongoing relationships with staff and actively seeking information about their relative. When the caregivers' contributions and suggestions were not taken into account, they felt neglected, distrustful, and frustrated. Hurley, Volicer, Rempusheski, and Fry (1995) conducted a grounded theory study of the nursing role in advance planning for end-of-life decisions. The study included nurses and family caregivers of persons with late-stage Alzheimer disease in an institutional setting. They generated a model of consensus decision-making that included participation of family caregivers and contextual influences such as staff development, unit philosophy, patient status, and family coping.

In summary, the literature indicates that as caregivers seek support they want to participate in decisions about the care of their relative, whether he or she resides in a community or institutional setting. Several studies have found that caregivers rely on strong, ongoing relationships with staff to achieve this influence. In one study, a caregiver used creative communication to influence care. There is a need for further research to identify how caregivers perceive formal support from health professionals and the strategies they employ in their relationships with health personnel in community and continuing-care settings.

Method

Symbolic interaction (Blumer, 1969; Prus, 1996) was the theoretical foundation for this study. Individuals engage in social interaction on the basis of the meaning they bring to the situation and modify their understanding of a situation by reflecting on the experience. Consequently, information about family caregivers' perceptions of support from health professionals is an important basis for understanding their interactions with health professionals.

Caregivers' perceptions of support from health personnel were explored through secondary analysis of interview data obtained in a previous study and two focus group interviews with participants recruited from the original study. The original study addressed the perceptions of social support and relationships of caregivers of cognitively impaired older adults. The findings on informal support from family and friends are reported elsewhere (Neufeld & Harrison, 1995). In the original study, 20 women participated over 18 months in three or four in-depth interviews about their caregiving experience, for a total of 62 interviews. The interviews lasted approximately 90 minutes and were audiotaped and transcribed verbatim. The interviewers were nurses experienced in working with families in similar situations and trained by the investigators in qualitative interviewing methods. The participating women were recruited through health-care agencies and advertisements in community newspapers. Women were included in the study if they defined themselves as the primary caregiver of a relative 60 years of age or older with dementia (the time of life when dementia is most common) and if they spoke English. Most interviews were conducted in the home of the caregiver.

The present study included secondary analysis of data from these interviews in relation to formal support. In addition, new data were collected from two focus group discussions with eight volunteers recruited from among the 20 original participants (all of whom had been invited to participate). The first author led the focus group discussions, which were held at a university location. The purpose of these discussions was to confirm and elaborate on the themes identified during secondary analysis of the interview data. In the focus group discussions, preliminary findings on women's strategies to secure formal support were shared. The women were asked to indicate whether these were similar to or different from their own strategies, to describe variations in their own experience, and to indicate whether they used other strategies. The discussions were audiotaped and transcribed verbatim.

The transcripts were reviewed in detail and categories generated (using the participants' own words where possible) to group data portraying similar dimensions and properties. Similarities and differences in caregivers' experiences were noted and possible relationships among categories were explored to identify linkages. Data from all interviews with each woman were compared, as well as data from different women. Coding and memoing, including diagrams, were used throughout the analysis to record the researchers' thoughts and questions (Morse & Field, 1995). The Ethnograph computer program was used to assist with the coding and analysis of data.

The original study and the present study were cleared separately by the university ethics review committee. All participants gave their written consent.

Findings

Sample

Of the 20 caregivers interviewed, nine were daughters of the care recipient, eight were wives, two were daughters-in-law, and one was a granddaughter. The women were between the ages of 37 and 71 and had been caregiving from 1 to 20 years. Their education levels were: post-secondary (13), high-school completion (2), and less than Grade 12 (5). Annual household incomes (in Canadian $) were: under $20,000 (3), $20,000 to $40,000 (7), and over $40,000 (10). The characteristics of the subgroup of women who chose to participate in the focus group were similar to those of the group as a whole.

Of the 20 care recipients, 12 were male and 8 were female. Nine were reported as having Alzheimer disease, five had vascular dementia, three were described as having senile dementia, and three had cognitive impairment of unknown cause. When the interviewing commenced, 12 care recipients were in nursing homes, seven were residing with the caregiver, and one lived alone in her own home. At the completion of the interviews, 18 months later, 12 were in nursing homes, including three who had moved from their home during the study, five remained at home with the caregiver, and three were deceased.

Influences on Caregivers' Interactions with Health Personnel

The women's descriptions of caregiving support included both assistance with their caregiving role and assistance given to their relative that indirectly relieved their perceived demands as a caregiver. In seeking support, the women interacted with health personnel in the context of their role of preservative caregiving.[1] In this role they acted as ombudswomen for

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[1] As our description of caregiving is similar to that of Bowers (1987, 1988), we use Bowers's term, preservative caregiving, to represent caregivers' overall goal of preserving their relative's identity and personhood.

their relatives, managing care and preserving their personhood, making decisions on their behalf if they were no longer competent to make decisions independently, and seeking to sustain their unique personhood. These decisions required the women to maintain a constant vigil, checking the care recipient and seeking information from all available sources.

The women's expectations of themselves as family caregivers and their appraisal of the cognitive status of their relative influenced their work as preservative caregivers and their strategies in interacting with health personnel. For example, they described a keen sense of personal responsibility and a belief that they were the best person to take care of their relative:

> *I'm the only one around who is really close to my mom, that knows her… What if I was in that same position and I didn't have anyone around that really…cared about me…knew the way I used to be?*

The daughters, daughters-in-law, and granddaughter considered caregiving an opportunity to reciprocate for all the elder's past contributions. The wives spoke of a strong marriage commitment, believing their husband would do the same for them. When the marital relationship was conflicted, they described their caregiving role as an obligation. Family expectations also supported the women's belief in filial responsibility:

> *My mom kept saying, "We never put our people in a nursing home"… That was a very powerful message to me.*

One woman feared she would be disowned by her family if she did not continue to care for her husband on her own:

> *I think I'll go over and say to them, "Are you going to disown me if I put him in long-term care?"*

Because of personal and family beliefs that women are responsible for caregiving and are the "best" caregivers, the participants were vulnerable to a sense of failure when they sought assistance and continued to view themselves as responsible for care of their relative. The perceived expectations of health personnel and health-care policies also influenced their interactions with personnel and their requests for help. For example, one woman described a need to establish a good track record; she felt she had to demonstrate that she had done everything she could before the professionals would consider her request for help. Others thought that nursing-home staff expected them to do more for their relative, and the wives believed that physicians expected them to "be there" for their husbands. Nearly all of the women believed that health-care resources are scarce and accepted the societal expectation that public resources be available only to those who need them most. This made them hesitant to seek help. In some cases, the women waited until a crisis occurred before requesting aid.

Appraisal of the person's cognitive status influenced the caregivers' ability to secure assistance. However, the unpredictability of the course of dementia made it difficult for the caregivers to anticipate when they would need help. The women did not want to place their relative in a nursing home before it was necessary, but found it difficult to know when to make the decision, particularly since facilities had waiting lists with uncertain wait times. As a result of the variation in and unpredictability of the care recipient's cognitive status, it was difficult for the women to get timely and appropriate assistance.

When the care recipient was in the early stages of dementia, the women could access help from formal sources only when it was acceptable to their relative. One woman described talking the care recipient into accepting certain kinds of help, but the mother of another woman refused to sign the necessary forms because she did not want to have people in her home:

> *In order to really get my mother [into] the system, she would have to sign the forms, which of course she would refuse to do because she doesn't need any help in her mind — "Thank you very much but get out of here."*

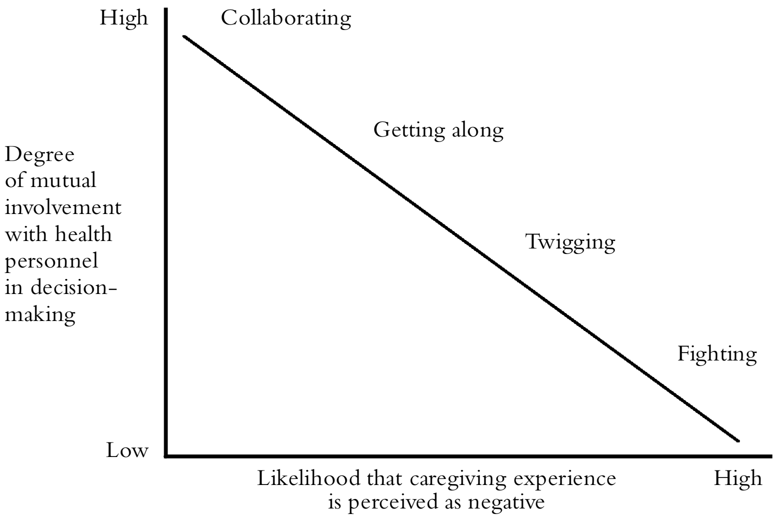
This caregiver did not want to go against her mother's wishes and seek guardianship through the courts. In the later stages of caregiving it became easier to access help; when the care recipients were unaware of what was happening, the women felt they were able to make decisions on their behalf.

Interaction Strategies

In their role as preservative caregiver the women employed several strategies in their interactions with health personnel as they sought support. A woman's strategies varied according to the degree of mutuality with staff in decision-making. Although the strategies are described individually, they are not mutually exclusive; each caregiver may have used several in her interactions with personnel. The women's perception of the caregiving experience varied according to the strategies used. For example, when they were able to collaborate, something that entailed a high degree of mutuality, they perceived the caregiving experience as positive. When they fought with staff, however, mutuality was absent and they perceived the experience as negative. These strategies and the caregivers' experiences are illustrated in Figure 1.

Collaborating. A state of collaboration resulted when the caregivers' relationships with staff were characterized by the sharing of information and goals. In these complementary relationships, the caregivers con-

Figure 1 ***Interactional Strategies in Relation to Mutual, Consensual Involvement with Health Personnel and Negative Caregiving Experience***



tributed their knowledge to the decision-making process and the staff valued their contribution:

> *We get our heads together with [the] charge nurse… Any time we have a problem, we all get our heads together and deal with it.*

One woman described the staff's sharing of information at a conference soon after her family member had been placed in a nursing home:

> *I think one of the things that I really found helpful was…a caregivers' conference… I learned more from that and felt more at home, more able to relate to those people, better understood what they did and why they did it.*

The opportunity for collaboration was facilitated by certain characteristics of the relationship with health personnel. For example, some professionals affirmed the women's caregiving work, expressed emotional support, and demonstrated an understanding of family caregiving that was based in experience as well as professional knowledge. Sometimes a physician would affirm the woman's preservative caregiving role:

> *He said, "You look after your mother but you don't let her sit around and vegetate." …He knew how I always kept her going…there were always some little chores for her to do.*

Staff members expressed their emotional support by taking an interest in both the caregiver and the care recipient, being friendly, having a positive attitude, and showing compassion:

> *When I see them [the home-care nurse and the physician] they always ask… People don't realize how much that helps…just asking, "Is there anything I can [do]?" or "How are things going?" …Then you know they care…they wouldn't ask otherwise.*

Collaboration was facilitated when staff members had experiential as well as professional knowledge of caregiving. The women valued interactions in which a staff member who had personal caregiving experience shared this experience with them. They believed that only those personnel who understood the caregiver and the cognitively impaired person could provide the affirmation and emotional support necessary to facilitate collaboration. Such understanding required both formal education and practical experience caring for an elderly person with cognitive impairment.

Collaboration was inhibited, however, when caregivers were excluded from decision-making. They often attributed their exclusion to inadequate knowledge and lack of understanding on the part of staff. Some said that the care needs of their relative were not being met because staff had inadequate knowledge. One woman was frustrated and angry when she learned incidentally that her mother had long been receiving an anti-anxiety agent without her knowledge:

> *She was like a zombie… It was bothering me terribly… I called the doctor… The nurse…said, "Oh…I think your mother should be cut back on the tranquillizers," and I said, "the what?" And I found out at this time that they had her on…Ativan three times a day… This is what her problem [was]… Then I was really angry.*

Stereotyping by health personnel was another barrier to collaboration:

> *They're inclined maybe to stereotype people…especially a younger person [staff member]. I mean, a hundred [years old] — you're supposed to be out for the count…[but] we knew different.*

The women felt that stereotyping encouraged a standardized rather than an individualized approach to care. Some women also thought that illness in elderly people was treated less seriously than in young people:

> *It was really scary how weak she was, and…listless… They were saying they were feeding her… Nobody saw it… She was just weaker and weaker, and they were accommodating her weakness by keeping her in bed and feeding her and doing nothing about it.*

This woman felt that staff overlooked her mother's symptoms because they attributed the changes to the aging process rather than to a specific health issue.

When caregivers were able to collaborate with staff they expressed satisfaction with their relationships with health-care providers. Collaboration served to affirm their contribution to the care of their relative and increase their understanding of the role and contribution of health-care providers. Collaboration caused the women to perceive the caregiving experience as positive.

Getting along. Sometimes the women used a strategy of getting along to establish and maintain a good working relationship with personnel in institutional and home-care settings. In adopting this strategy, the women were not engaged in a reciprocal relationship with staff, but had assumed personal responsibility for maintaining a positive connection despite indifference or intimidation on the part of staff. They viewed staff members as busy and tired and were reluctant to be a "pest." One woman said it was not easy to talk to staff members "standing there in a uniform… in a hurry and [with] things on their minds." They reported that personnel responded abruptly to their requests for information, were threatened by their questions, or viewed the caregiver as snooping or checking up on them. The women felt that staff members were less available to them as a source of support if they were very young or, because of frequent staff turnover, were strangers.

Getting along had two components: initiating action diplomatically and negotiating among multiple providers. One woman described how she initiated action diplomatically when she found something amiss with the care recipient:

> *I get things going… I don't go [to the nursing home]…half-cocked, either, because I'm annoyed… [I say,] "Let's just see what the problem is."*

A woman caring for her husband at home had to negotiate among multiple health professionals and secure their ongoing commitment. This was demanding and stressful work:

> *A lot of your time is spent just acting as a little go-between…and hoping everybody will get along…to buoy everybody up…to keep going for [the care recipient] and be cheerful and keep Home Care going, and always negotiating, always having to…play the end against the middle and hope somebody won't get angry or quit or [that] this won't fall apart.*

The primary conditions influencing the use of the strategy of getting along were perceived discomfort, intimidation, or indifference in relationships with agency staff. Getting along enabled the women to maintain a satisfactory relationship with professionals but inhibited the free exchange of information. For example, one woman expressed overall satisfaction with her interactions with formal providers but said that caregivers sometimes withheld information from staff because they were afraid of the response:

> *We don't always tell [health personnel] everything we'd like to tell them. They're just not another shoulder to cry on… they're paid to do their job… Lots of times we're afraid to tell them some of the things we'd like to.*

The women also found getting along to be fatiguing: "You're just giving like that all the time, and that's very tiring."

The women who employed this strategy often found their caregiving role to be a negative one. Getting along made them feel alone and as if they were doing all of the relationship work. Their relationship with health personnel could be characterized as draining.

Twigging. Some women described "twigging" the staff to unmet needs or showing them how to meet the needs of the care recipient. The caregivers also shared information about changes in health status. Although some felt this was part of their role because it was they who best knew the care recipient, other caregivers were disappointed by the staff's inattention. One woman tried daily to have nursing-home personnel insert her mother's dentures and hearing aid, which, she said, were important for her mother's quality of life even though she could not ask for them herself. The daughter was frustrated that these "basics" were being neglected even though she had posted signs to remind staff. Another woman was concerned about her mother's declining appetite. She was disappointed that she had to ask nursing-home staff to give her a dietary supplement. Another daughter observed symptoms of a urinary infection that the staff had not recognized:

> *It just dawned on me that somebody should be checking something… I phoned the nursing supervisor at the nursing home the next day…and said, "I think we should do the basic [urine] test anyway" …Within a day they had given her the preliminary test and reported to the doctor and they had her on [medication]… It was just amazing to see how she perked up… Mother would have been close to…death…if this [had not] been done.*

One woman had to speak up to ensure that her husband was included in social activities at the nursing home.

Twigging included teaching others, including health personnel, how to be helpful. One woman spent a great deal of time teaching the care attendants who came to her home how to meet the complex care needs of her husband. Women initiated twigging or sharing of information when their vigilance revealed inadequacies in care or a change in their relative's health status that put them at risk. Use of this strategy implied that the women expected staff to act on their feedback. The women found that twigging could be stressful:

> *It kind of concerned me that any time I made a big fuss about something or other they would retaliate on my mom… When her glasses disappeared at one time, I [wondered] did they take them away from her…because I had complained about something?*

As this quotation illustrates, some women feared retaliation against the care recipient if they consistently urged health personnel to change their relative's care.

Fighting/struggling. Several women described their interactions with health personnel in institutional or home settings using words such as fighting or struggling. Unlike twigging, which was intended to elicit a positive response from staff, this strategy was employed when staff did not readily respond to caregivers' information about their relative and they believed the person was at risk. Their stories indicated that they were prepared to act until they secured the help needed.

One woman planned to persevere until she obtained information about the medications administered to her mother, who resided in a nursing home. In the past, this woman had received a monthly itemized list of her mother's medications and dosages. When her mother was reassessed at a higher level of care, she no longer received this information because the government paid for the medications:

> *I'm not getting an itemized list from them… They will give the normal printout of the drugs the doctor orders…but not the specific amount in a month that is actually administered to her, which is what I want… I will not let it rest. There will be some way…maybe I'll have to go as far as being declared a legal guardian…which I will do.*

One caregiver was frustrated when she had to wait for necessary equipment for her home before her husband could be discharged from hospital:

> *It went back and forth… I had to change the whole back entry…because he couldn't [climb] stairs… We put a lift in… They told me there's a grant for people like that. So I applied for the grant and I was pushed on time because [the hospital] had to discharge him… I was on the phone every day… I said, "I need this and I need this." So I was between the [hospital] who would like to send him home and Home Care who had the red tape from here to Rome.*

Another woman had to battle to secure adequate personal care for her family member:

> *I have battled it out with Home Care… I have worked very hard on that… I do qualify for the time and I did get it…[but] with the Home Care situation you have to remember that it is re-evaluated very frequently and at any moment you may be cut back or you might have to go to bat for what you've got in the first place.*

She went on to describe the advice she would give to other caregivers:

> *You have to be prepared for a long, long wait with the services…applications for pensions, you're looking at a year to a year and a half…it goes on forever; you just have to keep on going… If you want something, just don't back off. I mean, if you keep at it long enough…they're going to say yes to get rid of you.*

The women used the fighting/struggling strategy when their attempts to obtain support were met by a long wait, when their initial requests for help were rejected, or when they had to appeal a decision about the amount of support allocated. These experiences were highly stressful.

Women employing this strategy lacked affirmation in their caregiving role and were frustrated by their inability to secure the assistance needed by their relative. Although they found it stressful, they considered this strategy a necessary part of preservative caregiving if the health of their relative was threatened and it was the only way they could ensure a satisfactory level of care.

Discussion

The finding that participation in the decision-making process is important for family caregivers when seeking support confirms the findings of other studies on the care of individuals with dementia. Walker and Jane Dewar (2001) found that caregivers were satisfied with their participation in decision-making when information was shared, caregivers were included in decision-making, there was a person available to contact, and the service agency was responsive to their needs. Hertzberg and Ekman (2000) also report that family caregivers of persons with dementia expect to participate actively in decisions about care and to have their expertise valued.

The importance of mutuality is also evident in research and theoretical models of the relationship between health personnel and family caregivers of persons who do not have a diagnosis of dementia (Eales, Keating, & Damsma, 2001; Gladstone & Wexler, 2002; Guberman & Maheu, 2002; Ward-Griffin & McKeever, 2000) and receive either home care (Guberman & Maheu; Ward-Griffin & McKeever) or long-term care (Gladstone & Wexler). The themes implicit in those models of the caregiver/professional relationship include a desire for mutuality with staff concerning decisions about care and negative outcomes when mutuality is not achieved.

In the present study, the caregivers' strategies for interacting with health professionals were influenced by their expectations of the professionals. Negative expectations hindered mutuality and the ability of family caregivers to seek assistance. Other research has found that the expectations or beliefs of staff and the psychological environment of the care unit can influence the ability of family caregivers and staff to reach consensus (Hurley et al., 1995). For example, in a respite and assessment unit of a psychiatric hospital in the United Kingdom (Walker & Jane Dewar, 2001), family caregivers were dissatisfied because meetings with staff were dominated by the professionals' agenda, there was no follow-up, they felt excluded, and they lacked information about how decisions were made. Health personnel were not proactive in approaching caregivers and caregivers were reluctant to disturb them. In a Swedish study, Hertzberg and Ekman (2000) report that staff thought family caregivers had unrealistic expectations and that family caregivers were frustrated by a lack of staff follow-up on their inquiries and were uncertain about and distrustful of staff members despite viewing them as "nice." Staff and family caregivers did not let each other know what they were thinking. The authors comment that it was as if each group avoided learning whether their view of the other was accurate.

In a study employing participant observation and interviewing in two long-term-care units, Gladstone and Wexler (2002) generated a model of five types of family-staff relationship: collegial, professional, friendship, distant, and tense. Their findings are consistent with those of the present study. The family caregivers viewed collegial, professional, and friendship relationships as positive. These involved interactions with staff that were focused around a specific purpose, shared experiences, and a sense of trust accompanied by positive feelings. Distant or tense relationships emerged when family caregivers were critical or distrustful of staff, angry, or frustrated. This type of relationship is consistent with the strategy of fighting/struggling described by the family caregivers in the present study. In a study of nurse and family caregiver dyads in a home-care setting, Ward-Griffin and McKeever (2000) found that tension can arise between family caregivers and nurses in the absence of mutual decision-making. They identified four relationship types: nurse-helper, worker-worker, manager-worker, and nurse-patient. In the nurse-helper relationship, tension arose when caregivers were uncomfortable assuming responsibility for the complex tasks delegated to them. In the manager-worker relationship, caregivers were upset when nurses withdrew emotionally and assumed the role of resource person. Tension also arose when nurses were caught between contradictory requirements — to meet the needs of the care recipient as well as those of the caregiver — and when the nurse and the family caregiver had contradictory expectations of each other. None of these relationship types represented the partnership of mutual involvement in decision-making sought by the women in the present study. Usually the family caregiver assumed the greatest responsibility for care while the nurse was the primary decision-maker and the arbiter regarding available resources.

An implication of the present findings is the need for models that support the mutual involvement of health personnel and family caregivers in decision-making. Guberman and Maheu (2002) propose a partnership model for working with families of individuals with chronic conditions in home-care settings. This model, which is based on earlier research, reflects the value on mutuality as expressed by the women in the present study. In Guberman and Maheu's model, the caregiver and care recipient are co-clients and the family caregiver assumes primary responsibility for care while health professionals facilitate access to resources.

Given the importance of mutuality in the caregiver-professional relationship, partnerships between health professionals and caregivers of persons with dementia in home-care and long-term-care settings can be informed by perspectives on partnerships and empowerment from other settings and populations (Courtnay, 1995; Courtnay, Ballard, Fauver, Gariota, & Holland, 1996; Hulme, 1999). In Courtnay's community partnership model, the professional negotiates a sharing of power with individual, family, or community partners. The emphasis is on mutual interaction and facilitation of client empowerment. This contrasts with the traditional model of professional practice in which professional expertise and decision-making dominate. Hulme's model of family empowerment was designed for interventions for families with a child with a chronic health condition. Empowerment is conceived as a four-phase interactive process that moves from domination by professionals to participatory interaction. The balance of power shifts from professionals to the family until, finally, collaboration is achieved and the family is a full partner in the care of their child. A prominent characteristic of partnership models is the mutual valuing of professional knowledge and the experiential knowledge of clients or family caregivers. The findings of the present study support the application of these models to the relationship between professionals and the family caregivers of individuals with dementia, in order to establish mutuality and share in decision-making power.

This study was limited to the perspective of family caregivers concerning their relationships with health personnel as they seek to engage in preservative caregiving of a person with dementia. It nevertheless contributes new information on the strategies that caregivers use in order to influence care and confirms previous findings on family caregivers' experience of formal support. Future research might include the perspectives of health personnel as well as family caregivers and address the structural characteristics of health-care agencies and systems.

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Résumé

Une comparaison des outils d'évaluation de la douleur utilisés auprès des personnes âgées

Sharon Kaasalainen et Joan Crook

Le but de cette recherche consistait à étudier les propriétés psychométriques (fiabilité de test-retest, coefficient d'objectivité, critère de validité concourante) de trois outils d'évaluation verbale de la douleur (échelle des visages douloureux, échelle d'évaluation numérique, *Present Pain Intensity Scale*) et d'une échelle d'évaluation comportementale de la douleur utilisée auprès des personnes âgées. On a fait appel à un modèle de mesures répétées pour vérifier la fiabilité et la validité de ces outils chez quatre groupes de participants atteints de déficience intellectuelle à des degrés divers, constituant un échantillon stratifié non aléatoire de 130 résidents en soins de longue durée. Les résultats confirment la fiabilité de test-retest et le coefficient d'objectivité de l'échelle d'évaluation comportementale pour tous les degrés de déficience intellectuelle, tout en révélant que la fiabilité des outils d'évaluation verbale diminuait en fonction du degré de déficience intellectuelle; cependant, la majorité des personnes âgées montrant une déficience légère à modérée avaient été en mesure de compléter au moins l'une de ces évaluations. Ces conclusions sont analysées à la lumière de leurs implications pour la pratique clinique et la recherche.

Mots clés : personnes âgées, déficience intellectuelle, évaluation de la douleur, soins de longue durée

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A Comparison of Pain-Assessment Tools for Use with Elderly Long-Term-Care Residents

Sharon Kaasalainen and Joan Crook

The purpose of this study was to examine the psychometric properties (test-retest and interrater reliability, criterion concurrent validity) of 3 verbal pain-assessment tools (Faces Pain Scale, Numerical Rating Scale, Present Pain Intensity Scale) and a behavioural pain-assessment scale for use with an elderly population. The study used a repeated-measures design to examine the reliability and validity of the tools across 4 groups of participants with varying levels of cognitive impairment using a non-random stratified sample of 130 elderly long-term-care residents. The findings support the test-retest and interrater reliability of the behavioural pain-assessment tool across all levels of cognitive impairment, whereas the same measures of reliability for the verbal-report tools decreased with increasing cognitive impairment; however, the majority of elderly with mild to moderate cognitive impairment were able to complete at least 1 of these tools. The findings are discussed in relation to their clinical and research implications.

Keywords: elderly, cognitive impairment, pain assessment, long-term care

Background

Research findings indicate that pain is a serious problem in the elderly population (Desbiens, Mueller-Rizner, Connors, Hammel, & Wenger, 1997; Kaasalainen et al., 1998; Ross & Crook, 1998). However, limited research has been done on the psychometric properties of pain-assessment methods for the elderly, especially those with cognitive impairment. For the elderly with cognitive impairment, pain assessment is further complicated by their limited communication abilities. Inaccurate assessment of pain intensity in this group can lead to unnecessary pain and suffering, which may compromise their remaining limited abilities. Reliable and clinically feasible methods of assessing pain are desperately needed so that pain can be managed appropriately.

According to Marzinski (1991), the tragedy of dementia includes the possibility that the non-verbal elderly will be unable to communicate their pain, which may lead to unnecessary suffering. For those elderly with dementia or cognitive impairment, the task of pain measurement can be quite complex. The pain-assessment methods described in the literature are varied and often exclude the elderly with dementia. Some methods focus on verbal or self-reports of pain while others involve the use of non-verbal assessment. Elderly persons who are capable of verbally reporting their pain in a reliable and valid fashion should have their voice heard. For those who are not capable of doing so, behavioural-observation methods should be employed to ensure that their pain is recognized.

Studies have found that patients with mild to moderate cognitive impairment can report their pain verbally (Chibnall & Tait, 2001; Ferrell, Ferrell, & Rivera, 1995; Parmelee, Smith, & Katz, 1993). The Present Pain Intensity (PPI) scale, the Numerical Rating Scale (NRS), and the Faces Pain Scale (FPS) may be the preferred tools for use with the elderly (Chibnall & Tait; Ferrell et al.; Herr & Mobily, 1993; Herr, Mobily, Kohout, & Wagenaar; 1998; Parmelee et al.). Jensen, Bradley, and Linton (1989) suggest that the elderly have particular difficulty using the visual analogue scale because it requires abstract thinking.

Non-verbal or behavioural-observation methods of pain assessment are particularly helpful for use with individuals who are unable to communicate their pain, such as those with severe dementia. Feldt (2000) developed the Checklist of Nonverbal Pain Indicators (CNPI) to assess pain in the elderly with and without cognitive impairment in an acute-care setting following a recent hip fracture. Initial testing supports the reliability and validity of the CNPI for use in this particular setting but further testing is needed to support its use in long-term care. Residents in long-term care are plagued with chronic pain on a daily basis, and chronic pain can be more difficult to assess than acute-pain episodes in hospital settings.

The Pain Assessment in the Communicatively Impaired (PACI) tool has recently been developed (Middleton et al., 2003) for use in long-term care. It incorporates three of the four facial movements used to depict pain as identified by Prkachin (1992) as well as specific body movements (e.g., guarding, rubbing/touching) and sounds (e.g., moan, yell, grunt, cry) that have been associated with pain. There is evidence of strong reliability (Kappa = 0.74 - 0.85) and validity (Middleton et al.). This tool is a promising means of assessing pain in the elderly with cognitive impairment.

In summary, the elderly with dementia represent a unique group of individuals with whom little pain research has been conducted. However, pain-assessment approaches are beginning to be explored with this population in an attempt to produce feasible and accurate measurements. Once reliable and valid methods of pain assessment are established, unnecessary suffering among the elderly with cognitive impairment can be avoided and their quality of life improved.

The purpose of this study was to examine, within the elderly population, the psychometric properties of three self-report pain-assessment tools that have been developed for use with other populations (e.g., children, adults) as well as a behavioural-observation tool. The rationale for this approach is to provide: (1) support for the use of pain-assessment tools with acceptable psychometric properties that are feasible for use in clinical settings, and (2) direction for the future education of direct-care staff about pain assessment in the elderly.

Method

This study utilized a repeated-measures design involving four groups of elderly participants: (1) cognitively intact, (2) mildly cognitively impaired, (3) moderately cognitively impaired, and (4) extremely cognitively impaired. It examined the reliability (i.e., test-retest, interrater) and validity (i.e., criterion concurrent) of four different pain-assessment scales across all four groups of elderly participants.

Sample

Data were collected at a 240-bed long-term-care facility in urban southwestern Ontario, Canada. Inclusion criteria were: at least 65 years of age and a resident of a long-term-care facility for more than 3 months. Residents were excluded if they had significant hearing or visual impairment or were non-English-speaking. A non-random stratified sample of 130 participants was used: 20 in the cognitively intact group, 30 in the mild cognitively impaired group, and 40 each in the moderate and extremely impaired groups.

Instrumentation

The Global Deterioration Scale (GDS) was used to group residents according to their stage of dementia. Specifically, residents were screened and classified according to their clinical phase of cognitive decline (Reisberg, Ferris, deLeon, & Crook, 1982). The GDS covers seven stages, ranging from no cognitive decline to very severe cognitive decline. These seven stages were collapsed into four clinical phases of cognitive decline (i.e., none, mild, moderate, extreme). The four groups were analyzed separately.

Three different verbal pain-assessment scales and a behavioural-observation measure were used to assess pain. The PACI (Middleton et al., 2003), which is a behavioural-observation tool, was developed to assess pain in the non-verbal elderly or those with cognitive impairment. It has seven items; three measure specific facial movements or expressions (i.e., brow lower, eyelid tighter, cheek raise), two measure body movements (i.e., guarding, rubbing/touching), and two measure sounds and words that have been associated with pain. Each item has a dichotomous response (yes/no) with a possible range of scores from 0 (no pain) to 7 (high pain). The PACI tool appears to be a reliable and valid measure of pain in the elderly (Middleton et al.).

The FPS, which is a set of seven schematic faces, was originally developed for use with children (Bieri, Reeve, Champion, Addicoat, & Ziegler, 1990) but later modified slightly for use with the elderly (Herr et al., 1998). Participants in this study were asked to choose the one face in the FPS that best depicted their level of pain at that moment. Herr et al. found evidence of strong construct validity and strong test-retest reliability ($r = 0.94, p = 0.01$) of the FPS within an elderly population.

The PPI, which is a subscale of the McGill Pain Questionnaire (Melzack, 1987), is a self-report six-point word-number scale used to measure pain intensity at the moment and ranges from 0 (no pain) to 5 (excruciating pain). This scale was also enlarged and bolded for use with an elderly population. Ferrell et al. (1995) found that, out of five different pain-assessment scales, the PPI had the highest completion rate (65%) among the elderly and also provided evidence of concurrent validity with the other scales ($r = 0.54$–0.72).

The NRS measures pain ranging from 0 (no pain) to 10 (worst possible pain). This scale was enlarged and bolded for use with an elderly population. The NRS has been shown to produce reliable responses for different stimulus-response functions for pain-sensation intensity and to provide consistent measures of both experimental and clinical pain intensity (Price, Bush, Long, & Harkins, 1994).

Procedure

The study was approved by a university ethical review board in southwestern Ontario. The investigator and research assistant were trained to use the PACI in a correct and consistent manner. The training involved watching a 5-minute video that described in detail each of the pain behaviours included in the PACI. Initial interrater reliability using the PACI was acceptable (ICC = 0.80–0.92).

Residents were screened before being asked to participate in the study to ensure that they met the inclusion criteria. If the resident was unable to provide verbal/written consent as determined by the investigator and/or expert clinical nurse, proxy consent was obtained.

Consenting residents were then approached for data collection. The investigator and the research assistant conducted the pain-measurement procedure twice — at Time 1 and at Time 2 — during the same event but 48 hours apart. These interviews took place in the morning since pain is generally worse when residents awaken in the morning (Ferrell & Osterweil, 1990).

First, the investigator and the research assistant measured the resident's pain independently during a naturally occurring, movement-exacerbated painful event (e.g., transfer from bed to chair, performing ADLs). This event was chosen to elicit a pain response because it is representative of the normal, day-to-day kind of pain that is most frequently experienced by long-term-care residents. It seems prudent to use the most common pain events in instrument testing so that future intervention studies (e.g., use of analgesics, staff development, non-pharmacological strategies) can be designed to address the pain events or experiences that are unique and typical in this population and setting. Moreover, movement-exacerbated pain events have been recommended for use in pain-measurement studies with the elderly, especially those who live in long-term-care facilities, as other pain events that often take place in these settings (e.g., flu shots, venipuncture) have been shown to elicit a poor pain response (Hadjistavropoulos, LaChapelle, MacLeod, Snider, & Craig, 2000; Middleton et al., 2003). Previous testing of the PACI has shown that it is a valid measure of movement-exacerbated pain in long-term-care; therefore, the PACI was deemed an appropriate measure for use in this study (Middleton et al.).

The PACI was completed over a 2-minute interval before the verbal reports of pain, to blind the investigator and the research assistant to the verbal-report scores for pain. Immediately following the behavioural assessment, residents were asked to rate their pain using the FPS, the PPI, and the NRS. They were given at least 30 seconds to respond to each scale before the next scale was presented. If, at the end of the 30 seconds, the resident did not respond, he or she was considered unable to respond to that particular scale. The scales were administered in random order to each resident to control for the effect of order.

Results

The mean age varied slightly across groups, ranging from 81.75 in Group 1 (cognitively intact) to 86.20 in Group 2 (mild cognitive impairment). The majority (60–67%) of the participants were women. The majority of the participants had been previously employed in the labour market, and in Group 3 (moderate cognitive impairment) almost one half (43%) had been homemakers. All of the participants were Caucasian.

The most common diagnoses in all four groups were dementia, arthritis, and history of fracture. In Group 3 and Group 4 (extreme cognitive impairment), all had a diagnosis of dementia. In Group 1, over two thirds (69%) had a diagnosis of arthritis. In all four groups, over 10% had

Table 1 ***Maximum, Minimum, Mean, and Standard Deviation of Pain Scores and Percentage of Residents "In Pain" Using Four Pain Scales***

	PACI-1[a] 0–7	PACI-2[b] 0–7	FPS 0–6	PPI 0–5	NRS Range 0–10
All Groups					
Mean	1.89	1.46	2.18	1.69	3.74
SD	1.88	1.69	1.90	1.47	3.05
"In pain"	67%	56%	73%	69%	77%
Group 1: Intact					
Maximum	4.00	4.00	6.00	5.00	10.00
Minimum	0.00	0.00	0.00	0.00	0.00
Mean	1.20	1.00	1.90	1.50	4.00
SD	1.20	1.17	1.89	1.28	3.25
"In pain"	65%	55%	70%	75%	80%
Group 2: Mild					
Maximum	6.00	5.00	6.00	4.00	10.00
Minimum	0.00	0.00	0.00	0.00	0.00
Mean	2.00	1.53	2.50	1.70	3.60
SD	1.94	1.80	1.74	1.37	2.87
"In pain"	67%	53%	83%	70%	77%
Group 3: Moderate					
Maximum	7.00	7.00	6.00	5.00	10.00
Minimum	0.00	0.00	0.00	0.00	0.00
Mean	1.78	1.43	2.10	1.80	3.75
SD	1.99	1.85	2.13	1.73	3.18
"In pain"	62%	47%	57%	62%	70%
Group 4: Extreme					
Maximum	7.00	6.00	⋆	⋆	⋆
Minimum	0.00	0.00	⋆	⋆	⋆
Mean	2.25	1.68	⋆	⋆	⋆
SD	1.94	1.67	⋆	⋆	⋆
"In pain"	72%	67%	⋆	⋆	⋆

[a] First rater, [b] Second rater
⋆Participants unable to complete measure

a history of fracture. The percentage of those with a history of depression ranged from 15% (*n* = 3) in Group 1 to 28% (*n* = 11) in Group 2.

For all of the participants (*N* = 130), the pain reports on average were low (Table 1). The percentage of participants "in pain" (i.e., scores > 0) according to their verbal reports (i.e., FPS, PPI, NRS) ranged from 69% to 77%. However, the behavioural reports of residents "in pain" that were scored by two raters were lower (i.e., PACI-1: 67%; PACI-2: 56%).

For those participants with no cognitive impairment or with mild or moderate impairment, the behavioural reports of pain did not reach the maximum possible score, whereas their verbal reports of pain did reach the maximum possible score. Finally, both of the raters' behavioural reports of residents "in pain" were highest for Group 4 (extreme cognitive impairment).

The intraclass correlations (ICCs) for the PACI were moderate to strong for all groups (0.62 to 0.78) and the error variance (s^2_{error}) remained relatively constant across all groups (Table 2). The ICCs for the three verbal-report scales were moderate to strong for the cognitively

Table 2 ***Test-Retest Reliability: Source of Variance and Intraclass Correlation Coefficient for the Four Pain-Assessment Tools***

	Group (Level of Cognitive Impairment)			
Pain Scale	**1 (Intact)**	**2 (Mild)**	**3 (Moderate)**	**4 (Extreme)**
PACI				
$\sigma^2_{subject}$	1.39	2.75	2.22	1.71
σ^2_{error}	0.38	0.48	0.28	0.33
ICC	0.78	0.70	0.73	0.62
FPS				
$\sigma^2_{subject}$	2.91	1.36	1.68	*
σ^2_{error}	0.53	1.46	3.49	*
ICC	0.84	0.39	0.32	*
PPI				
$\sigma^2_{subject}$	0.87	0.81	1.29	*
σ^2_{error}	0.71	1.22	1.21	*
ICC	0.55	0.40	0.51	*
NRS				
$\sigma^2_{subject}$	9.31	3.67	5.23	*
σ^2_{error}	1.45	5.89	5.92	*
ICC	0.87	0.38	0.45	*

*Participants unable to complete measure intact group (FPS: ICC = 0.84; PPI: ICC = 0.55; NRS: ICC = 0.87) but decreased for the other groups. In addition, the error variances were low for the cognitively intact group (FPS: $s^2_{error} = 0.53$; PPI: $s^2_{error} = 0.71$; NRS: $s^2_{error} = 1.45$) but increased with increasing cognitive impairment. The error variances for the PPI were lower than for the FPS and NRS for Group 2 ($s^2_{error} = 1.22$) and Group 3 ($s^2_{error} = 1.21$).

Interrater reliability for the PACI was high for all groups (ICC = 0.82–0.88). The group with mild cognitive impairment had the highest subject variance ($s^2_{subject} = 2.75$). The error variance for the PACI was low across all groups ($s^2_{error} = 0.28\text{-}0.48$).

The Pearson *r* correlations of the PACI with the three verbal-report scales (FPS, PPI, NRS) were low to moderate (Table 3). For the cognitively intact group, all of these correlations were moderate and significant (FPS: $r = 0.66$, $p < 0.001$; PPI: $r = 0.62$, $p < 0.01$; NRS: $r = 0.65$, $p < 0.01$). For the mildly impaired group, none were significant at the $p < 0.05$ level. For the moderately impaired group, the PACI correlated moderately and significantly with the FPS ($r = 0.63$, $p < 0.001$) and PPI ($r = 0.64$, $p < 0.001$). However, the correlation between the PACI and NRS for those with moderate impairment was low and nonsignificant ($r = 0.30$, $p < 0.12$).

Table 3 ***Criterion Concurrent Validity: Pearson r Correlations and Level of Significance Between the PACI and Each of the Three Verbal Pain Scales***

	Group (Level of Cognitive Impairment)			
Pain Scale	**1 (Intact)**	**2 (Mild)**	**3 (Moderate)**	**4 (Extreme)**
PACI				
$r =$	0.66	0.30	0.63	*
$p <$	0.001	0.10	0.001	*
PPI				
$r =$	0.62	0.32	0.64	*
$p <$	0.01	0.10	0.001	*
NRS				
$r =$	0.65	0.23	0.30	*
$p <$	0.01	0.22	0.12	*

*Participants unable to complete measure

Discussion

The rates of residents "in pain" ranged from 56% to 77% depending on the tool used. These rates of pain in the elderly are high and are similar to those found in other studies (Desbiens et al., 1997; Ferrell & Osterweil, 1990; Simons & Malabar, 1995). These findings indicate that pain is prevalent and a serious problem for residents of long-term-care facilities.

For most groups, the behavioural reports of pain using the PACI did not reach the maximum possible score, whereas the verbal reports of pain did reach the maximum possible score. It appears that the PACI may not be a good measure of pain intensity. One explanation for this may be that some elderly persons are incapable of expressing their pain using certain behaviours due to physical limitations such as paralysis, contractures, or even the immobilizing effects of the pain itself. As well, LeResche (1984) postulates that facial expressions of pain may be blunted due to the physical face changes that occur with age.

Although the PACI may not be a good measure of pain intensity for all elderly persons, it appears capable of detecting the majority of those who are in pain. Among elderly persons with extreme cognitive impairment, the PACI can detect pain in those who are incapable of reporting their pain verbally. Without the measurement of pain using behavioural indices, the majority of pain in this vulnerable population would go unnoticed. In addition, the ICCs for the test-retest reliability of the PACI were moderate to strong for all groups and the error variances remained relatively constant across all groups. These degrees of reliability of the PACI across all levels of cognitive impairment are acceptable for clinical settings. Thus, it seems prudent to use the PACI, despite its limitations, to measure pain in those elderly with extreme cognitive impairment so that attempts can be made to manage their pain therapeutically.

As expected, test-retest reliability for the three verbal-report scales was moderate to strong for elderly persons with no cognitive impairment but decreased for the other groups. Similarly, error variances were low for those with no cognitive impairment but increased with increasing cognitive impairment. These findings indicate that the level of cognitive impairment decreases the reliability of verbal reports of pain.

Test-retest reliability for both the NRS and the FPS was strong for residents without cognitive impairment but declined considerably for those with mild and moderate impairment, suggesting that these tools may not be good choices for use with these two groups. However, the test-retest reliability of the PPI appears to be slightly better for those residents with mild to moderate levels of cognitive impairment. This finding indicates that the PPI may be a better choice of tool for use with these residents, as it is also easier to apply. This finding is congruent with the findings of previous studies that have compared a verbal descriptor scale with other types of tools used with an elderly population (Feldt, Ryden, & Miles, 1998; Ferrell et al., 1995; Herr & Mobily, 1993; Parmelee et al., 1993).

It may be that the PPI is a more reliable measurement of pain for those with mild to moderate cognitive impairment, because these people retain their ability to use words to describe their pain longer than their ability to use numbers or abstract tools such as the FPS. Perhaps scales such as the PPI, which has different terms for qualifying pain, is particularly helpful for older persons since it allows them to use more words to describe their pain and to reserve the word "pain" for severe discomfort (Heye, 1997). Although language skills diminish with the onset of dementia, a simple tool that uses few words, such as the PPI, may afford the elderly a way to express their pain accurately and in a personal and meaningful way.

The high interrater reliability for the behavioural observation tool (i.e., PACI) and low error variances across all groups of elderly residents support the use of the PACI to assess for pain in clinical settings. Interestingly, however, the correlations of the behavioural-observation tool (i.e., PACI) with the three verbal-report scales (FPS, PPI, NRS) were low to moderate. These correlations were lower than expected and suggest that the PACI was measuring a slightly different dimension of pain compared to the verbal-report scales. Hadjistavropoulos et al. (2000) also found that self-reports of pain using a coloured visual analogue scale did not correlate with a behavioural-observation measure (i.e., FACS). They suggest that each measure taps very different parameters of the pain experience when used with the elderly, implying that a comprehensive assessment of pain should include both self-report and behavioural indices.

It is worth noting the nonsignificant correlations between the PACI and all three verbal-report scales for the residents with mild cognitive impairment. These may be due to the low subject variance. This group of participants appeared to be more homogeneous in their pain ratings; they had the lowest amount of subject variance, which could account for the poor and nonsignificant correlations between the PACI and each of the verbal-report scales. According to Mitchell (1979), an instrument will have a lower reliability when used with a homogeneous group. Therefore, future research is needed to address the reliability and validity of these pain-assessment tools on a more heterogeneous group of residents with mild cognitive impairment.

There are limitations to the present study. First, all of the participants were Caucasian, so the findings cannot be generalized to elderly residents from different racial backgrounds. Also, the type of activities that were performed (i.e., ROM, walking) appear to have induced low amounts of pain in general, which resulted in relatively low subject variances. The reliability of the tools used could be improved by increasing the magnitude of the variance between subjects (Streiner & Norman, 1995). Thus, future research is needed to test the reliability of these pain-assessment scales, especially the PACI, using situations that elicit more variation in pain responses in the elderly, such as hip fractures and surgical procedures, along with ROM and walking activities.

In summary, the findings of this study support the use of a behavioural-observation tool (i.e., PACI) for use in clinical settings. This tool is particularly useful for detecting pain in elderly persons with extreme cognitive impairment. For those with no cognitive impairment or with mild impairment, the use of verbal reports of pain appear reliable and accurate. However, it is recommended that elderly persons with moderate cognitive impairment be assessed using both behavioural and verbal-report methods, since the reliability of verbal reports of pain decreases for this group. For those with moderate cognitive impairment, the PPI seems to be a more appropriate and reliable tool than the FPS or the NRS to assess for pain using verbal-report scales. If more research attention is devoted to this vulnerable population, pain management will be improved and unnecessary suffering avoided.

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Résumé

Évaluation des échelles de leadership sous l'angle de leur élaboration et de la psychométrie

Katherine S. McGilton

Cette étude vise à élaborer deux échelles de leadership soutenant et à en évaluer les propriétés psychométriques. Il s'agit d'une échelle de soutien dispensé par les infirmières responsables [*Charge Nurse Support Scale*] et d'une échelle de soutien dispensé par les chefs d'unités [*Unit Manager Support Scale*], conçues pour des environnements de soins à long terme. Ces échelles d'auto-vérification contenant six points ont été appliquées auprès de 70 membres du personnel infirmier et la fiabilité de consistance interne, la fiabilité de test-retest, la validité de contenu, la structure factorielle et la validité conceptuelle ont été évaluées. La validité de contenu a été établie avec l'aide d'experts. Les résultats ont démontré que les deux échelles étaient fiables. Conformément à l'hypothèse, l'étude a révélé une relation significative entre le mesurage de l'interaction du personnel infirmier avec les bénéficiaires et le mesurage des comportements soutenant des infirmières responsables (r = 0,42), p = 0,05). Des méthodes de mesurage fiables et valides du leadership soutenant pourraient être élaborées afin d'évaluer la qualité du soutien offert au personnel œuvrant dans des environnements de soins à long terme.

Mots clés : échelles de leadership soutenant, soins à long terme

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Development and Psychometric Evaluation of Supportive Leadership Scales

Katherine S. McGilton

The purpose of this study was to develop and evaluate the psychometric properties of 2 supportive leadership scales, the Charge Nurse Support Scale and the Unit Manager Support Scale, designed for long-term-care environments. These 6-item self-report scales were administered to 70 nursing staff and their internal consistency reliability, test-retest reliability, content validity, factor structure, and construct validity investigated. Content validity was established with the assistance of experts. Both scales were deemed reliable. As hypothesized, a significant relationship was found between the measure of how nursing staff related to residents and measures of charge nurses' supportive behaviours ($r = .42, p = .05$). Reliable and valid measures of supportive leadership could be developed for use in identifying the quality of support provided to staff in long-term-care environments.

Keywords: supportive leadership scales, instrument development, supervisors and long-term care

Lack of knowledge about effective management strategies for improving the quality of nursing homes has been identified as a priority concern in long-term care (Binstock & Spector, 1997). Thomas (1994) summarizes the current reality eloquently: "Nursing homes often try to promote warm, nurturing bonds between staff and residents while maintaining a paramilitary command structure" (p. 15). Increasingly, non-registered professionals are being used to provide care and registered staff are being placed in supervisory roles without any training. Despite these demands on the system, there remains a paucity of research on conceptualizing and operationalizing supportive nursing roles in long-term-care environments. The purpose of this research was to develop two instruments to evaluate the supportive behaviours of charge nurses and unit managers, respectively, in these environments. Supportive leadership behaviours were defined as behaviours in which the leader demonstrates empathy and reliability towards staff. This article focuses on the development and testing of the two scales.

Literature Review

Effective support for nursing staff has been subject to little analytical investigation despite the presence of several descriptive reports in the literature. Before this study was developed, only two studies on the supportive qualities of nurse leaders were found, one conducted in a psychiatric setting and the other in health-care centres in Finland. Firth, McIntee, McKewon, and Britton (1986) attempted to clarify the nature of effective support from a superior as perceived by qualified nursing staff in psychiatric settings. Personal respect, empathy, absence of interpersonal defensiveness, absence of impatience, and concern for feelings were the concepts they used to define support. Firth and colleagues found that empathy and respect on the part of supervisors contributed to reduced burnout amongst nursing staff. Sihvonen and Kekki (1991) identified supportive leaders by their ability to encourage, counsel, and guide their subordinates, communicate information about the subordinates' work, and offer rewards. They found that supportive leaders made staff feel that they were doing a worthwhile job. The scales used in these studies had not been psychometrically tested and were lengthy, atheoretical, and designed for different populations. Previous to the development of the supportive leadership scales by McGilton (2001), Buelow, Winburn, and Hutcherson (1999) developed a supportive scale for supervisors of home-care assistants in a community setting, with the attributes of supportive supervisors being an ability to communicate effectively with staff, show personal concern or caring, and maintain high professional standards. Buelow and colleagues found that supportive leadership practices explained 39% of the variance in intrinsic job satisfaction for the home-care assistants.

The development and testing of the supportive leadership scales in the present study was part of a larger study, The Effects of a Relationship Enhancing Program of Care on Residents and Nursing Staff, in which the principal investigator designed a program of care to enhance both the relational care provided by nursing staff and the supportive behaviours of supervisors (McGilton et al., 2003). To enhance the way nursing staff related to residents, Winnicott's (1970) relationship theory was selected, as it not only characterizes the abilities that nursing staff need in order to relate effectively to their residents, but also includes the conditions necessary to enhance their relational abilities. Winnicott advises that continuity in terms of approach and a supportive work environment will enhance the relational abilities of the nursing staff. A supportive work environment is conceptualized as one that includes a supportive leader or supervisor. Many long-term-care environments have two types of leader, the unit manager and the charge nurse. Evidence is beginning to accumulate that, from the perspective of nursing staff, effective long-term-care environments feature supervisors who demonstrate effective relational behaviours (Buelow et al., 1999; Chou, Boldy, & Lee, 2002; Kovach & Krejci, 1998; McAiney, 1998; Sheridan, White, & Fairchild, 1992; Tellis-Nayak & Tellis-

Nayak, 1989). Based on the theoretical model for this intervention study, it was proposed that the supervisor–nursing staff relationship would mirror the relationship between nursing staff and residents. Since a tenet of Winnicott's relationship theory is that nursing staff relate with empathy and reliability towards elders, leaders (unit managers and charge nurses) are expected to show empathy and reliability towards their staff. Supportive leadership is therefore measured by the extent to which the leader demonstrates empathy and reliability towards staff. In the present study, the development of supportive measures was guided by Winnicott's theory to interpret specific empathic and reliable behaviours that serve to support nursing staff. Rafferty (2000) also uses Winnicott's theory to conceptualize the attributes of clinical supervisors in nursing and health visiting. She believes that the application of Winnicott's orientation to clinical supervision involves an empathic concern for the health and welfare of one's colleagues, which leads to a relationship of mutual trust. The supervisors' supportive behaviours were two of the outcome measures for the intervention study (McGilton, 2001).

The purposes of this paper are to (a) describe the development of two supportive leadership scales, one for charge nurses and one for unit managers, specifically designed for long-term-care environments; (b) present the findings regarding the psychometric properties of the measures; and (c) suggest uses for the scales.

Method

The Unit Manager and Charge Nurse Support Scales

The first stage in developing the support scales consisted of delineating the theoretical domains of Winnicott's (1970) theory, generating concepts related to the specific behaviours for each domain, and constructing items to reflect these concepts (Lynn, 1986). The main relational skills were the supervisors' empathy and reliability. Supervisor empathy was conceptualized as the ability to recognize the standards of care among the nursing staff, to recognize and accommodate the nursing staff's expressed needs, such as providing for shift changes, and to understand the nursing staff's point of view when they came forward with concerns. Supervisor reliability was conceptualized as the ability to be available to nursing staff if things were not going well with residents or families, to protect the nursing staff from the unpredictable by keeping them informed of changes in the work environment, and to tolerate feelings of frustration on the part of nursing staff. Thus the six-item Unit Manager Support Scale (UMS scale) and the six-item Charge Nurse Support Scale (CNS scale) were designed to capture the supervisors' characteristics with regard to empathy and reliability.

A five-point adjectival scale was used to measure supervisors' empathy and reliability. The response options were "always," "often," "occasionally," "seldom," and "never." A five-point response scale was selected to allow for a reasonable distribution of responses. To facilitate the interpretation of the measure, the responses to the six items in each scale were summed to obtain a total score. The instruments could yield an overall score ranging from 6 to 30. Nursing staff were asked to complete the six-item supervisory scales with respect to their main charge nurse and their unit manager.

Establishing content validity of the UMS scale. To establish content validity, five local administrative experts were asked to evaluate the UMS scale (Grant & Davis, 1997). All five had master's degrees in nursing, obtained between 1978 and 1993. Two also held doctorates, while the other three were pursuing a doctorate in nursing. On average, they had 20 years of administrative experience. Three had particular knowledge of long-term-care supervisor-staff relationships, and two had expertise related to Winnicott's (1970) theory. Two held faculty positions and had published in the area of administration and leadership, and three held administrative positions at teaching hospitals.

Each reviewer received a detailed package that included a description of the purpose of the UMS scale, a theoretical overview of Winnicott's (1970) work, and instructions for assessing content validity. The panel was asked to indicate on a four-point rating scale whether each item reflected the reliable and empathic concepts and whether it was relevant (i.e., reflective of the underlying theory). The content validity assessment scale was adapted from Lynn's (1986) work. The content validity index is the percentage of total items receiving a score of 3 or 4 and thus deemed content valid. A new instrument should have a minimum content validity index of 80% (Davis, 1992). The content validity index at this phase was 83.5%. The panel was also asked to comment on the comprehensiveness of the total instrument and on the clarity of the items. The main criticism of the initial scale was its failure to contextualize the items. For example, in the case of an item that stated "is dependable," the experts felt it was important to describe the particular situations in which this attribution applied.

The scale was revised based on the panel's recommendations. The panel was then asked to rate the revised scale. At that time, the content validity index was 100%. The experts agreed that the items represented a realistic expectation of a unit manager in a long-term-care facility. All felt that the items covered appropriate context and specificity and therefore that the final scale operationalized three empathy items and three reliability items. The scale was pilot tested for clarity, clinical utility, and reading level with 30 members of the nursing staff, and no changes were required (see Figure 1).

Establishing content validity of the CNS scale. The CNS scale was developed following pilot testing of the UMS scale. When the investigator was on the unit testing the UMS scale, it became evident that the role of the charge nurse in supporting staff was also important in long-term care. The UMS items were revised to reflect the charge nurses' scope of practice and their responsibilities. Hence, the creation of the CNS scale. Since the UMS had undergone rigorous content validation with the five experts, and since the constructs of the CNS were identical to those of the UMS scale, only two of the experts, both of whom had worked as

Figure 1 ***Unit Manager Support Scale***

Below are 6 statements that relate to how you feel about your unit manager. Please circle the number that reflects your relationship with your unit manager. Please be as honest as you can. Your answers are confidential and will not be shared with others you work with or with your unit manager.

	Never	**Seldom**	**Occasionally**	**Often**	**Always**
My unit manager recognizes the standards of care I try to deliver.	1	2	3	4	5
My unit manager tries to meet my needs in such ways as making shift changes that allow me opportunities to meet family responsibilities or training opportunities.	1	2	3	4	5
My unit manager knows me well enough to know when I have concerns about patient care and tries to understand my point of view.	1	2	3	4	5
I can rely on my unit manager to be there for me when I ask for help, for example, if things are not going well between myself and my co-workers or between myself and residents and/or their families.	1	2	3	4	5
My unit manager keeps me informed of any major changes in the work environment or organization.	1	2	3	4	5
My unit manager tolerates me feeling frustrated or overwhelmed without responding negatively in return.	1	2	3	4	5

administrators in a long-term-care facility, were asked to review the CNS scale. The two experts felt that the items represented what was expected of a charge nurse in a long-term-care facility and that the items covered appropriate context and specificity. Following this process, five charge nurses reviewed the scale for face validity; their comments indicated that they believed the items reflected what was expected of them at work (see Figure 2).

Figure 2 ***Charge Nurse Support Scale***

Below are 6 statements that relate to how you feel about your charge nurse. Please circle the number that reflects your relationship with your charge nurse. Please be as honest as your can. Your answers are confidential and will not be shared with others you work with or with your charge nurse. If you work with more than one charge nurse, please answer these questions in relation to the charge nurse that you work with most often.

	Never	**Seldom**	**Occasionally**	**Often**	**Always**
My charge nurse recognizes the standards of care I try to deliver.	1	2	3	4	5
My charge nurse tries to meet my needs in such ways as informing me of what is expected of me when working with my residents and providing feedback and recognition when I meet these expectations.	1	2	3	4	5
My charge nurse knows me well enough to know when I have concerns about patient care and tries to understand my point of view.	1	2	3	4	5
I can rely on my charge nurse to be there for me when I ask for help. That is, she/he is approachable, for example, if I need assistance with a resident, or if I need someone to talk to if things are not going well between myself and residents and/or their families.	1	2	3	4	5
My charge nurse keeps me informed of any decisions that were made in regards to my residents, for example, information obtained from family meetings or multidisciplinary rounds.	1	2	3	4	5
My charge nurse tolerates me feeling frustrated or overwhelmed without responding negatively in return.	1	2	3	4	5

Setting and Sample

Nursing staff from two mid-sized long-term-care facilities in a large Canadian city participated in the scale development and testing. The data reported in this paper were collected from a correlational study in which the measures were further tested for construct validity (McGilton & Streiner, 2002). Eligibility criteria for participants in the studies were (a) worked longer than 3 months on the unit; and (b) full-time, part-time, or casual status. Ninety members of the nursing staff were approached and 70 (77%) agreed to participate. The majority of the participants were female (84%), ranging in age from 22 to 62 with a mean age of 45 years (*SD* = 9.2); they had worked on the unit for an average of 10.3 years (*SD* = 9.9) and most (70%) were full-time; 25 were health-care aides, 23 were registered practical nurses, and 22 were registered nurses.

Instruments

In addition to the UMS and CNS scales, one other instrument was used to evaluate the construct validity of the scales during the correlational study. The relational care that nursing staff provided to clients was measured using the Relational Behavior Scale (RB scale), a three-item scale that measures the ability of nursing staff to relate to their clients with empathy and reliability. The three items selected for the present study were based on Brown's (1995) and Winnicott's (1970) work and measure effective relational behaviours. The first item was the ability to stay with the resident during the care episode; examples of such behaviours include maintaining close proximity, using various forms of touch that are comforting for the resident, and sitting beside the person. The second item was the ability to alter the pace of care by recognizing the resident's rhythm and adapting to it; examples include hesitating when necessary, being flexible, and pausing, stopping, and trying another approach. The third item was the ability to focus care beyond the task; examples include acknowledging the person's subjective experiences and offering verbal reassurances. Specific nursing-staff actions that demonstrate these behaviours were developed in the pilot phase of the intervention study (McGilton, 2001), and the items and specific behaviours were verified by Maryanne Brown, a clinical nurse specialist, and Francine Wynn, an expert in Winnicott's work. The RB scale is able to capture the unpredictable nature of the interaction between nursing staff and persons with dementia because the constructs focus on adapting care based on the persons' responses. The RB scale is an observational seven-point semantic differential scale with a range of scores from 1 to 7 for each item. The scores for each of the three items were summed. The scores ranged from

6 to 19 (out of a possible range of 3–21). Higher scores indicate more positive behaviours on the part of nursing staff.

Interrater reliability of the RB scale, assessed using Kappa, was .80, .83, and .83 for each domain, and the internal consistency estimate was .89. Construct validity of the RB scale was initially assessed by testing its relationship to negative affect states using the Pittsburgh Agitation Scale, or PAS (Rosen, et al., 1994), and the Philadelphia Center Affect Rating Scale, or ARS (Lawton, 1994). Based on Winnicott's theory and empirical evidence (Brown, 1995; Caris-Verhallen, Kerkstra, & Bensing, 1999; Caris-Verhallen, Kerkstra, Van Der Heijden, & Bensing, 1998; Hallberg, Holst, Nordmark, & Edber, 1995), it was proposed that if residents were relating effectively with the nursing staff they would experience less anxiety, sadness, and agitation during the episodes of care. This hypothesis was supported; the RB scale was negatively correlated with anxiety ($r = -.59, p < .005$), sadness ($r = -.59, p < .005$), and agitation ($r = -.39$, $p < .05$).

For construct validation of the UMS and CNS scales, it was hypothesized that the RB scale composite score would moderately correlate with those of the UMS and CNS scales. Based on Winnicott's (1970) theory and empirical evidence (Glass, 1992; Kovach & Krejci, 1998; Tellis-Nayak & Tellis-Nayak, 1989), it was proposed that if nursing staff felt supported by their supervisors, they would relate more effectively to their residents.

Analysis

A multiple analytic approach was employed. First, Cronbach's alphas were calculated to evaluate the internal reliability and item homogeneity of the scales. In addition, item analyses were conducted. Construct validity was examined by exploring the relationship between supportive supervisors and related constructs. Finally, dimensionality was assessed using exploratory principal components factor analysis. An orthogonal rotation (varimax) was used to obtain as distinct and maximally interpretable a solution as possible. Items with loadings greater than .50 were used to interpret the content of the factor.

Procedure

The studies were described to the participants following approval by the Ethical Review Board. Care providers were approached to participate and informed consent was obtained. All consenting nursing staff were observed while delivering care and their behaviours were assessed using the RB scale. The residents were informed of the study and consent was obtained from the participants prior to the observation day. A research assistant observed the relational care provided to residents during morning or evening care. The nursing staff were asked to complete the UMS and CNS scales on the same shift during which they were observed, at a time most convenient for them.

Results

Reliability

Table 1 summarizes the means, standard deviations, and Cronbach's alpha reliability coefficients for the three scales used in this study. Further item analysis revealed that item-total correlations for the CNS and UMS scales were positive and were in the .41 to .70 range. This result is acceptable as the criterion is between .2 and .8 (Nunnally, 1978). For the test-retest correlation, 30 members of the nursing staff were asked to complete the UMS and CNS scales 2 weeks apart. This time frame was chosen so that recall would not be a concern (Waltz, Strickland, & Lenz, 1991). The correlation was .87 for the UMS scale and .85 for the CNS scale, which represented acceptable ranges for stability (Nunnally & Bernstein, 1994). A ceiling effect was noted for 10% of the participants' scores on the UMS scale and 8% of the participants' scores on the CNS scale.

Table 1 ***Summary of Means, Standard Deviations, Range, and Internal Reliability of Coefficients of the Instruments (N = 70)***

	Mean *(SD)*	**Range**	**α**
Charge Nurse Support Scale	24.2 (9.1)	16–30	0.81
Unit Manager Support Scale	22.6 (7.8)	12–30	0.80
Relational Behavior Scale	5.1 (2.2)	3–21	0.90

Validity

Two methods were used to assess the construct validity of the UMS and CNS scales: factor analysis and correlations based on the theoretical predictions. Data from the correlational study were used because there were enough cases to meet the criterion of more than 10 subjects per variable (Streiner & Norman, 1991). Based on Winnicott's (1970) conceptualization of effective supportive/relational care, a 1-factor solution was predicted. The first factor of the UMS scale explained 51% of the variance. The eigenvalue was 3.0, with factor loadings between .6 and .82 for all six items. The first factor of the CNS scale explained 53% of the variance, with factor loadings between .7 and .8.

The second method used to evaluate construct validity was the extent to which the supportive supervisory scales correlated with predictions based on our theory. It was hypothesized that the UMS and CNS scales would be moderately positively correlated with the RB scale. However, only the hypothesized relationship between the CNS and the RB scales was supported ($r = .42, p = .05$); the hypothesized relationship between the UMS and the RB scales was not supported ($r = .27, p = .23$).

Discussion

The items selected for the UMS and CNS scales were derived from Winnicott's (1970) theory, with contributions from the empirical literature on attributes of supportive supervisors (Buelow et al., 1999; Firth et al., 1986; Rafferty, 2000; Sihvonen & Kekki, 1991). Development of these six-item instruments was guided by content validity assessment and pilot testing. Although the scales are brief, there was no tradeoff in the internal consistency of the measures and the content experts felt that the items reflected the characteristics of a supportive supervisor. Both scales demonstrated good stability. Further, the content experts agreed that they represented adequate sampling of a collection of situations in which supervisors demonstrate reliability and empathy. Ceiling effects were noted for both scales and the means for the scales were skewed. To counteract this bias, the centre will be shifted in future testing so that evaluators have five intervals above average to rate their leader instead of just three (Streiner & Norman, 1991).

Preliminary construct validity of both scales was supported by factor analysis. Because the items had been written to reflect two conceptual domains, reliability and empathy, the 1-factor dimension underlying the scale initially appeared to contradict the conceptual premise of the instrument. However, as Winnicott (1970) states, empathy and reliability are not mutually exclusive attributes. The 1-factor solution was consistent with the Cronbach's alphas of .80 and .81, which provided further evidence that the scales were tapping one domain.

Construct validity of the CNS scale was further supported when relationships predicted on the basis of theory and empirical evidence were tested. As predicted, there was a positive correlation between the CNS and RB scales. This finding provides empirical support for the research hypothesis that when staff members perceive they are valued, they will manifest that perception in the work they do (Gilster, 2002; Kovach & Krejci, 1998). However, no significant relationship emerged between the UMS and RB scales. This finding is not surprising given that supportive behaviours by charge nurses may have a greater impact on nursing staff and the subsequent care of residents because these supervisors interact more frequently with staff. Furthermore, with the downsizing of nurse-manager positions in all facilities, unit managers have increasing responsibilities that preclude them from being on the unit to support staff. Nonetheless, the significant positive correlation that was found should be viewed with caution, as both the CNS and RB scales were newly developed with limited testing.

Another question worth discussing is whether the behavioural attributions of reliability and empathy should be expected of supervisors. One content expert challenged this expectation as unrealistic in the case of unit managers and suggested that such behaviour falls beyond their scope of practice. Another content expert, in her feedback on the scales, validated this concern. She suggested that implementing empathic and reliable behaviours would require a change in mindset. Although agreeing that reliability is an important aspect of the role of nursing staff, she said she had never thought about its relevance from the perspective of a frontline worker, even after holding management positions for the past 15 years. Having said this, she said she realized that being empathic and reliable was pertinent to the supportive supervisory relationship. Investigators whose findings are consistent with the opinion of this content expert have proposed that the characteristics of an effective long-term-care workplace include a unit manager who makes staff feel they are doing worthwhile work, attempts to meet their personal needs, and makes them feel supported and valued (Firth et al., 1986; Glass, 1992; Gilster, 2002: Kovach & Krejci, 1998; Tellis-Nayak & Tellis-Nayak, 1989).

These supportive leadership scales have potential utility for nursing administration and practice. Clinically, the supportive leadership indicators could be used as outcome measures to identify the quality of supportive care provided to staff in long-term-care environments. The scales also could be used to help supervisors determine the needs of their staff. If supervisors associate low scores with the perception that nursing staff are not being supported, they may be motivated to learn how to provide more support. In contrast, if they take high scores as indicating effective supervisory support, they may recognize and reinforce that support. The scales could thus be used as assessment tools to identify areas of supervisory practice that require more focus or as standards for the hiring of supervisors in long-term-care environments. The utility of adopting these instruments as part of a performance evaluation tool requires further testing.

The UMS and CNS scales could also be used to determine the efficacy of various interventions designed to enhance supportive behaviours among supervisors in long-term-care environments, and therefore used indirectly to guide nursing interventions. Recently the scales were used to measure the effectiveness of a relationship-enhancing program of care.

This was a multidimensional program that included an intervention for supervisors, focusing on their supportive role. In this case, the measures were sensitive to change (McGilton, 2001).

Links have yet to be established between supportive leadership behaviours and improved resident outcomes and nursing-staff outcomes. Ineffective management practices have been found to have a negative impact on employees, such as job dissatisfaction and high turnover (Chou et al., 2002; Clarke et al., 2001). Vance and Larson (2002) note that few studies have demonstrated a link between leadership and client outcomes, but anecdotal evidence suggests that interpersonal relationships with managers may influence the care delivered by nursing staff (McAiney, 1998; Sheridan et al., 1992; Tellis-Nayak & Tellis-Nayak, 1989; Thomas, 1994). Such relationships require empirical validation in long-term-care settings.

Although the present findings support the reliability and validity of the UMS and CNS scales, the instruments must be tested with larger samples and within long-term-care facilities that are not affiliated with a teaching institution. Given the variation in responses found for both scales, further research is needed to determine individual nurse characteristics that may influence nursing-staff perceptions about supervisory support. Use of larger samples may also allow for the testing of differences among staff subgroups. Additional prospective studies using the scales may provide further evidence concerning their validity. In their recent review of leadership research in business and health care, Vance and Larson (2002) conclude that the ability to measure meaningful outcomes is often limited by the lack of precise definitions and sensitive and specific measurement tools. The availability of evaluative instruments that measure supportive leadership would therefore be most helpful.

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Résumé

Interventions auprès des aidantes naturelles dispensant des soins aux personnes atteintes de démence : une évaluation systématique

Shelley C. Peacock et Dorothy A. Forbes

Le taux de démence chez les personnes âgées est à la hausse. En raison d'une diminution du financement attribué aux institutions de soutien formel, de nombreuses familles se voient obligées de prendre en charge un être cher atteint de démence. Cette évaluation systématique a relevé et synthétisé de l'information sur les interventions conçues pour améliorer le bien-être des aidantes naturelles qui prennent soin de personnes souffrant de démence. Une recherche documentaire a identifié 36 études pertinentes, dont 11 études de valeur sûre, 11 de valeur moyenne, 13 de valeur faible et 1 de valeur médiocre. Cet article se penche sur les études de valeur sûre. Aucune des interventions évaluées n'avait un impact global important sur le bien-être des aidantes naturelles. L'évaluation a démontré que plusieurs interventions étaient bénéfiques aux aidantes naturelles mais que les interventions produisant peu d'impact étaient plus nombreuses. Il est important de pousser davantage les recherches dans le domaine. La réalisation d'évaluations systématiques constitue un important outil qui peut aider les consommateurs et les praticiens à prendre des décisions fondées sur des résultats.

Mots clés : révision systématique, intervention, bien-être, aidantes naturelles

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Interventions for Caregivers of Persons with Dementia: A Systematic Review

Shelley C. Peacock and Dorothy A. Forbes

The prevalence of dementia in older adults is increasing. Due to cuts in funding for formal support, many families are having to provide care for a loved one with dementia at home. This systematic review gathered and synthesized information on interventions designed to enhance the well-being of caregivers of people with dementia. A search of the literature resulted in 36 relevant studies. Of these, 11 were rated as strong, 11 as moderate, 13 as weak, and 1 as poor. This paper focuses on the strong studies. No one intervention had an overall significant impact on the well-being of caregivers. Although several interventions have been shown to be of benefit to caregivers, non-significant findings were more common. Further investigation is greatly needed. Systematic reviews are an important means of guiding consumers and practitioners in making evidence-based decisions.

Keywords: systematic review, informal caregiver, intervention, Alzheimer disease, well-being

With people living longer, the increasing prevalence of dementia in the older population is cause for concern (Hill, Forbes, Berthelot, Lindsay, & McDowell, 1996). In Canada, 8% of those 65 years and older and 35% of those 85 years and older are diagnosed with dementia, and half of all cases live in the community with a spouse, other family members, or friends (Canadian Study of Health and Aging Working Group [CSHAWG], 1994). Alzheimer disease (AD) is the most common form of dementia, affecting 5% of persons 65 and older and up to 26% of those 85 and older (CSHAWG). The Canadian Study of Health and Aging Working Group estimates, from data collected in 1991, that the number of cases of dementia in Canada will nearly triple by the year 2031, affecting approximately 778,000 individuals.

Persons with AD and related dementias suffer a number of consequences, as do their carers. As dementia progresses, caregivers must take on more and more responsibilities to sustain their loved one at home (Kuhn, 2001). Caregiving results in both negative and positive responses. The literature includes an abundance of interventions to assist unpaid caregivers, particularly in coping with the negative consequences of caregiving.

Caregivers experience negative consequences in relation to their physical health, mental heath, social network, and finances (George &

Gwyther, 1986). Their physical health may be compromised by disruptions in sleep. Their mental health can be affected in a number of ways, including depression and strain. Caregivers may have to limit their contacts in social networks even though these play a vital role in sustaining caregivers (Hibbard, Neufeld, & Harrison, 1996). Often caregivers must sacrifice financially in order to fill their caregiving role, such as by limiting career or employment choices and paying out of pocket for formal caregiving services.

Caregivers are primarily adult children or spouses and are predominantly female (Hibbard et al., 1996). The literature indicates that women and men take on different types of caregiving responsibilities. Women tend to engage in more hands-on activities such as personal care, meal preparation, and housekeeping, although when the primary caregiver is a husband he takes on these tasks (Keating, Fast, Frederick, Cranswick, & Perrier, 1999). Men are more likely to provide household maintenance and financial planning assistance (Keating et al.). Most of the assistance given to persons with dementia in their homes is provided with little or no formal support. In recent years there has been a decrease in the funding of formal home-care support services (Armstrong & Kits, 2001), while placement in long-term care has become more and more difficult because of the shortage of beds (Dyck, 2001). The effectiveness of interventions for caregivers varies, however (e.g., Acton & Kang, 2001; Knight, Lutzky, & Macofsky-Urban, 1993), which may be due to the type of and exposure to the intervention, the characteristics of the caregiver, and the stage of the dementia. Practitioners need assistance in assessing the abundance of information about caregiver interventions and deciding which interventions are most effective for particular types of caregivers and care recipients.

There are no recent reviews of the overall well-being of caregivers of persons with dementia. The goal of this review was to determine the effectiveness of a range of interventions to enhance the well-being of caregivers of elderly persons with dementia living in the community.

Method

To assess the effectiveness of interventions for caregivers of persons with dementia, a systematic review was conducted using a framework based on the work of Forbes (1998) and Forbes and Strang (1997). Forbes and Strang conducted a review of the effectiveness of interventions for individuals with AD. Their tool was nursing-based, user-friendly, and relevant to the content of the present review. The relevance, validity, and data-extraction tools developed for their review were modified to reflect the caregiver population in the present review.

In light of the enormous amount of literature available and the barriers to accessing journals (e.g., lack of time, resources, and appraisal skills), systematic reviews can serve to demonstrate to practitioners and consumers the effectiveness of health-care interventions (Forbes, 2003). Conclusions about the evidence are reached using defined assessment steps. Forbes (2003) identifies the steps of a systematic review as: (a) developing a research question, (b) developing relevance and validity tools, (c) conducting a thorough literature search (including both published and unpublished studies), (d) assessing the studies using relevance and validity tools, (e) extracting the data, (f) synthesizing the findings, and (g) writing the report. Steps (a) through (f) apply to the present review.

Developing the Research Question

The question to be addressed in this study is a result of personal clinical experience. It is *What interventions are effective in supporting the well-being of unpaid caregivers of elderly persons with dementia residing in the community?* Such interventions could include any means that support carers and contribute to their well-being. The question is broad in order to allow for the inclusion of a significant number of studies, all of which must meet the relevance and validity criteria.

Developing Relevance and Validity Tools

Relevance tool. To screen for studies that might be included in the review, we developed a relevance tool. In order to be included in the review, a study had to have: (a) been conducted or published in 1992 or later; (b) evaluated an intervention directed at caregivers of an elderly individual with dementia living in the community; (c) measured one of the following caregiver outcomes: well-being (physical, mental, social, or financial), depression, strain, and/or other (e.g., institutionalization, health-care expenditures); and (d) incorporated a control group or a pretest-posttest design with a sample size greater than one. When all four criteria were met, the study was included in the validity appraisal. The relevance tool was pre-tested by both authors using studies that appeared appropriate to the review and then revised accordingly.

Validity tool. To assess the quality of the studies, limit bias in the systematic review, and guide interpretation of findings (Clarke & Oxman, 2000), we developed a validity tool. The criteria for the validity tool, validity tool dictionary, and rating scale were modified versions of those used for the tools developed by Forbes and Strang (1997). The five validity criteria for this review were: design and allocation to intervention: random (pass), before/after or matched cohort (moderate), or other (fail); attrition: < 10% (pass), 11–20% (moderate), > 20%, not applicable, or not reported (fail); confounders controlled (e.g., age or sex of caregiver, cognitive impairment of care recipient: at least four controlled (pass), at least two to four controlled (moderate), one or less of confounders controlled (fail); measures/data collection: methods well-described, piloting or pretesting data-collection instruments, and blinding of data collectors (at least two of the three categories rated yes, [pass]), one of the categories rated yes (moderate), none of the categories rated yes (fail); types of statistical analysis: multivariate (pass), bivariate (moderate), descriptive or not reported (fail). A study was rated as *strong* if it had no fail ratings and no more than one moderate rating; *moderate* if it had no fail ratings and more than one moderate rating; *weak* if it had one or two fail ratings; and *poor* if it had more than two fail ratings. The strong studies are identified with an asterisk in the reference list.

Literature Search Strategies

We conducted online searches of CINAHL, PubMed, and PsychINFO for the period 1992 to April 2002 in consultation with an experienced librarian. The keywords were caregiver, carer, dementia, Alzheimer, burden, depression, strain, stress, support, respite, education, intervention, effective, assess, evaluate, and measure. In order to access as many studies as possible, we also used the thesaurus for each of the keywords in the individual databases. All inter-library loan requests were received. We used the online CISTI Source to aid in hand searching the table of contents of the *The Gerontologist, Journal of Gerontological Nursing,* and *Journal of the American Geriatrics Society.* The reference lists of retrieved studies were also searched for relevant studies, which were then retrieved and reviewed. The primary authors of some articles were contacted for clarification and additional information.

Assessment of Studies Utilizing Relevance and Validity Tools

Of the 92 studies retrieved, 36 met all four relevance criteria. The first 19 of these were reviewed by both authors. A high level of agreement (kappa = 0.8) was reached by the authors. Therefore, the remaining studies were assessed independently by one author, with any subsequent concerns discussed and consensus reached.

In the next phase of the review, the 36 relevant studies were rated for validity. The first 12 of these were rated independently by both authors and 100% agreement was reached. The remaining studies were rated by one author, with any concerns discussed and consensus reached. Of the 36 studies reviewed, 11 were rated as strong, 11 as moderate, 13 as weak, and 1 as poor. Descriptive analyses were completed for the 11 strong studies in the areas of methodological weaknesses, country in which the study was conducted, interventions, outcomes, and study design.

Data Extraction

Consistent, uniform data extraction is required to obtain essential information from studies (Forbes, 2003). To minimize bias in extracting information from studies, a data-extraction tool was developed, to include general information and specific study characteristics as reported by the primary researcher. The data-extraction tool was pre-tested and revised accordingly to reflect the criteria for the validity tool. This process was undertaken independently by the primary author, with any concerns discussed with the second author.

Data Synthesis

Based on the information in the data-extraction tool, descriptive synthesis was used to summarize the characteristics of the participants, interventions, outcomes, and quality of the studies. Descriptive synthesis enables readers to survey the pattern of characteristics found in the studies and helps them to make decisions about applying the findings to their population of caregivers (Moher, Jadad, & Klassen, 1998). The findings of the strong studies are discussed according to type of intervention. Due to the diversity of interventions, statistical analysis (i.e., meta-analysis) was not possible. If the level of significance was found to be equal to or less than $p = 0.05$, the findings were considered statistically significant.

Findings

A brief summary of the strong studies is followed by a summary of their findings, by type of intervention. Please see Appendix 1 for individual summaries. A more detailed description of the strong studies and moderate studies can be found elsewhere (Peacock, 2003).

The most common methodological weakness of the strong studies related to data collection. For 7 of the 11 strong studies, data-collection strategies did not include piloting of tools and blinding of data collectors. Although these studies utilized well-known tools, the authors did not test the tool on a population similar to that used in the study, nor did they blind the data collectors. The majority of studies were conducted in the United States ($n = 8$), with one each conducted in Australia, Finland, and the United Kingdom. No studies conducted in Canada received a strong rating. All studies employed randomization of participants to an intervention or control group. The studies were categorized according to type of intervention: education ($n = 4$), case management ($n = 4$), psychotherapy ($n = 2$), and computer networking ($n = 1$). The most commonly measured outcome was institutionalization of the care recipient ($n = 6$), followed by death of the care recipient ($n = 3$), perceived behaviour disturbances in the care recipient ($n = 3$), caregiver depression ($n = 3$), caregiver strain ($n = 2$), caregiver stress ($n = 2$), and use of formal services ($n = 2$).

Case-Management Interventions

Four studies rated as strong examined the effect of intensive case management on caregivers. Three of the four utilized data obtained from the Medicare Alzheimer's Disease Demonstration and Evaluation (MADDE), with each study focusing on different caregiver outcomes. The MADDE was developed to address the ongoing needs of both care recipients with dementia and their caregivers, with the goal of improving the well-being of participants. The MADDE intervention consisted of two program models with four sites in each. The two program models differed in the amount of reimbursement and in the case manager–client ratio.

The fourth case-management study (Eloniemi-Sulkava et al., 2001) examined whether seniors with dementia could remain in the community longer with the assistance of a nurse case manager. The case manager provided coordinated care, including services and support for caregivers. The control-group caregivers received the usual services provided in the area.

The findings of these studies conflict with respect to the effectiveness of case management in decreasing the rate of institutionalization. Eloneimi-Sulkava et al. (2001) found a decrease in the rate of institutionalization in the first year of their study, while the MADDE study (Miller, Newcomer, & Fox, 1999) found that case management did not reduce the rate of institutionalization. Case management did double the likelihood of the intervention group's using community services, while the control group's use of community services increased by 50%, in the MADDE study (Newcomer, Spitalny, Fox, & Yordi, 1999). However, case management on the whole did not impact levels of strain or depression for caregivers despite support from the case manager and access to community services (Newcomer, Yordi, DuNah, Fox, & Wilkinson, 1999).

Education Interventions

Four studies utilizing an education intervention were rated as strong. For this review, education as an intervention was defined as researchers/clinicians providing education about a subject and/or teaching the participants a new skill, either in a group setting or individually. The first study (Brodaty, Gresham, & Luscombe, 1997) provided caregivers in the intervention groups with training and education in a variety of topics (e.g., distress, guilt, assertiveness training) while care recipients participated in a memory clinic. The control-group caregivers were provided with respite while care recipients participated in the memory clinic. The second study examined the effects of a stress-adaptation model on improving interaction between care recipients with dementia and their caregivers (Corbeil, Quayhagen, & Quayhagen, 1999). The third education intervention study (Marriott, Donaldson, Tarrier, & Burns, 2000) aimed at reducing the strain experienced by caregivers of individuals with AD. The intervention group received a modified family intervention initially developed in the treatment of schizophrenia while control groups received no training. Finally, the fourth study (Wright, Litaker, Laraia, & DeAndrade, 2001) evaluated an education program for individual caregivers that included counselling by a nurse. The control group received no education or counselling.

The results indicate that education interventions are insufficient to improve overall caregiver psychological well-being, such as decreasing strain and depression or reducing disruptive behaviours by the care recipient (Corbeil et al., 1999; Wright et al., 2001); Marriott et al.'s (2000) education intervention is an exception in that it resulted in decreased depression for caregivers through to follow-up. There are, however, a few significant findings. Brodaty et al. (1997) were able to demonstrate that institutionalization and death of the care recipient were delayed with a caregiver training program. As well, interventions that provided the caregivers with coping methods were shown to enhance positive reappraisal (Corbeil et al.), thus improving interactions between caregivers and care recipients.

Psychotherapy Interventions

Two studies utilizing psychotherapy were rated as strong. They used the same data but reported different outcomes. An intervention at the New York University-Aging and Dementia Research Center (NYU-ADRC) consisted of six sessions of individual and family counselling that focused on communication and problem-solving in relation to caring for someone with AD. Intervention caregivers were required to join a support group and had access to further counselling at any time, while control-group caregivers received the standard assistance provided by the NYU-ADRC. The intervention benefited caregivers most by delaying institutionalization of the care recipient (Mittelman et al., 1993; Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996). Predictors of institutionalization after 12 months in the program included: not being involved in a support group and care recipients with greater levels of dementia (Mittelman et al., 1993). After 3½ years of follow-up, the level of dementia remained significant in predicting institutionalization (Mittelman et al., 1996). Contradictions were found between the studies with regard to gender and age as predictors of institutionalization.

A strength of these studies was the inclusion of spouse caregivers only; however, this limits the generalizability of the findings to other types of caregivers.

Computer-Networking Intervention

Brennan, Moore, and Smyth (1995) examined the effects of a special computer network on caregivers of people with AD. Participants were randomly assigned to have a computer installed in their home or to the comparison group. Through the computer network, caregivers could receive information, decision-making support, communication, and an opportunity for questions and answers. Analysis revealed that the intervention group experienced a significant increase in decision-making confidence; however, no significant differences between the groups were found in relation to decision-making skills, social isolation, or use of health services.

Discussion

This systematic review reveals few significant effects for caregiver interventions. Positive findings include: (a) case management increased the likelihood of using formal support services (Newcomer, Spitalny, et al., 1999) (but the results are conflicting with regard to delaying institutionalization [Eloniemi-Sulkava et al., 2001; Miller et al., 1999]); (b) an education intervention was able to decrease depression among caregivers at 3 months follow-up (Marriott et al., 2000); (c) psychotherapy for caregivers delayed institutionalization of the care recipients (Mittelman et al., 1993, 1996); and (d) the use of computer networking improved decision-making confidence (Brennan et al., 1995).

Non-significant findings were more common. Case management had no significant effect on strain or caregiver depression (Newcomer, Yordi, et al., 1999). On the whole, education interventions had no effect on overall psychological well-being, including depression and strain (Corbeil et al., 1999; Wright et al., 2001), with the exception of Marriott et al.'s (2000) study. Lastly, the networking intervention using a home computer did not decrease social isolation, improve decision-making skills, or increase use of formal supports (Brennan et al., 1995).

Limitations

Overall, the most common weakness is in the area of data collection. Seven of the 11 studies rated as strong did not report pre-testing the tools they used and blinding the data collectors regarding participants' membership in either control or intervention groups. Although many used well-known tools (e.g., Mini-Mental State Examination [Folstein,

Folstein, & McHugh, 1975]) and may have described the tool well, the fact remains that the tool was not pre-tested by the current researcher on a sample similar to the one included in the study.

Although all the strong studies employed randomization, the authors do not always describe how this was achieved for the benefit of the reader. Often a sentence or two is all that is needed to adequately describe the steps taken by a researcher, yet, for whatever reason (e.g., space limitations), reports often lack the detail necessary for the reader to have a full understanding of the process. Furthermore, all the strong studies used convenience sampling with caregivers who had already accessed the formal system. This limits the generalizability of the findings.

This review is limited by the articles retrieved. Research may have been completed in this area but not published, resulting in limited access to the findings; none of the researchers who were contacted shared information on other work in progress. Publication bias (i.e., not publishing studies that revealed only non-significant results) could also skew the results of this review. The findings of the review must be considered in light of the methodological limitations found in the included studies and in the conduct of the review.

Implications for Practice

Although the variances explained by the interventions were not reported by the authors of the included studies, several of the interventions appear to have clinical significance as well as statistical significance in supporting caregivers. The use of computers for networking would particularly benefit caregivers living in rural communities. The MADDE case-management intervention was successful in helping caregivers to access formal support services. When there are resources available to assist with the strain of caregiving, case managers would be invaluable in referring caregivers to those reliable resources. Education interventions that included training in coping skills, in addition to information on dementia, had more success than those that offered education alone (e.g., Marriott et al., 2000). The content of education interventions should be relevant to participants. The relationship of the caregiver to the care recipient, as well as their living arrangement, and the gender of the caregiver are some of the factors that can affect the caregiving experience. Education programs may have to take these into consideration.

Clinicians wishing to advise caregivers should pay particular attention to the type of strain (i.e., objective or subjective) that the caregiver may be experiencing. In turn, caregivers should be as explicit as possible about what they need from the formal system. Six of the studies examined ways of delaying institutionalization, as if this were always a positive outcome. There may come a time for any caregiver when keeping a loved one at home means delaying relief from various types of strain. Providing the right intervention, at the right time in the caregiving journey, to the right caregiver, represents a huge challenge. Further research is required to determine which intervention is most effective for which type of caregiver, and when.

Implications for Research

All studies rated as strong employed randomization of participants. However, considering the population under study, randomizing individuals to an intervention or control group may not always be possible. An alternative is the use of waitlist control groups to ensure that all participants will eventually receive the intervention. Potential participants may then be more willing to participate in the study, since most individuals volunteer with the expectation that they will receive help in managing their caregiving.

Not surprisingly, most of the studies in this review recruited individuals who had already accessed help from the formal system. It may be useful to aggressively recruit less available participants in order to increase the generalizability of findings. How do caregivers who do not ask for assistance and manage their loved one independently differ from those who receive formal assistance? In addition, researchers frequently include different types of caregivers in an intervention instead of focusing on a single type of caregiver — for example, female spouses.

An outcome not often measured is quality of life. Some caregivers are able to enjoy a positive quality of life regardless of their caregiving situation. Perhaps the focus should be less on strain, depression, and rate of institutionalization and more on the quality of caregiving as experienced subjectively.

The majority of research in the area of interventions for caregivers of individuals with dementia is conducted in the United States. In light of Canada's different health-care system, there is a need for research that reflects the services delivered in Canada. In addition, a large proportion of Canada is rural and remote, which may have an impact on the caregiving experience.

Finally, both researchers and journal editors have an obligation to publish readable and complete reports of studies. Clinicians and caregivers would benefit from studies that are appropriate to their level of understanding. The systematic review is a valuable form of research that combines studies and disseminates information in an unbiased, rigorous manner.

Conclusion

We located an abundance of research examining the effectiveness of interventions for caregivers of people with AD. Of the 92 articles retrieved, 36 met the relevance criteria and the 11 studies rated as strong were described. Several of the interventions were shown to be of benefit to caregivers. Individualized approaches may address the uniqueness of caregivers or care recipients more readily than a single intervention delivered to a group of caregivers. Use of computers in a networking intervention is especially interesting for rural caregivers and may increase in relevance as technology becomes more advanced. Case management was effective in increasing the use of formal services. Generally, non-significant findings were more common. Clearly, further research, particularly in Canada, is essential to determine which intervention(s) best fit the needs of particular types of caregivers and best apply at particular stages in the course of dementia.

Appendix 1 *Summaries of Strong Studies*

Study	Participants	Intervention and Provider	Outcomes
CASE MANAGEMENT			
Eloniemi-Sulkava et al. (2001) Finland RCT	*Caregiver participants:* *Intervention:* $n = 53$ Male 25%/female 75% Age: mean 64.8 (range 34–83) Spouse 60%/child 27% *Control:* $n = 47$ Male 38%/female 62% Age: mean 63.3 (range 40–86) Spouse 51%/child 43%	Intervention group provided with systematic comprehensive support for 2 years by a family coordinator. The coordinator provided: support for clients; advocacy; counselling; annual training courses for clients; follow-up calls; in-home visits; assistance to arrange for additional services and physician referrals; 24-hour/day availability by mobile phone. Control group received the usual services provided by the health-care system. Participants were followed for 2 years; date of institutionalization or death was recorded.	*Significant:* In the first months, significantly fewer intervention participants were institutionalized compared to the control group ($p = .04$). The participants with severe dementia benefited the most from the intervention, by remaining in the community longer compared to the control group. *Nonsignificant:* By the end of the first and second year there were no differences in the number of deaths between groups. By the end of the second year there was no difference between groups in rate of institutionalization.
Miller et al. (1999) USA RCT	*Caregiver participants:* *Intervention:* $n = 4,151$ Male 31.7%/female 67.3% Age: 58% < 70 Spouse 46.9%/child 40.5% *Control:* $n = 3,944$ Male 30.9%/female 69.1% Age: 59% < 70 Spouse 46.4%/child 39.9%	Intervention group received intensive case management in addition to a set amount of reimbursement per month towards community services. Four Model A sites had case manager to client ratio of 1:100 and community service reimbursement cap of \$290–\$489 per client. Four Model B sites had manager to client ratio of 1:30 and an amount of \$430–\$699 per client. Control group received usual care. All participants received baseline and semi-annual assessments for up to 3 years.	*Significant:* No significant findings found. *Nonsignificant:* Institutionalization rates did not differ between intervention and control groups, either for individual sites or all combined. The aim of this intervention was to reduce strain among caregivers and no constraints were imposed to decrease the likelihood of institutionalization (unlike with other case management models).

Newcomer, Spitalny, et al. (1999) USA RCT	*Caregiver participants:* *Intervention:* *n* = 2,682 Male 28.3%/female 71.7% Age: mean 63.8 (*SD* 14.3) Spouse 51.2%/child 40.2% *Control:* *n* = 2,527 Male 27.1%/female 72.9% Age: mean 63.6 (*SD* 14.5) Spouse: 51.3%/child: 39.1%	As above.	*Significant:* The intervention group was more than twice as likely to use home-care services ($p < .01$) and adult daycare ($p < .05$) than the control group caregivers. *Nonsignificant:* No nonsignificant findings were reported.
Newcomer, Yordi, et al. (1999) USA RCT	*Caregiver participants:* *Intervention:* *n* = 2,731 Male 41%/female 59% Age: mean 63.0 (*SD* 14.2) Spouse 49%/child 43% *Control:* *n* = 2,576 Male 26%/female 74% Age: mean 63.0 (*SD* 14.4) Spouse 50%/child 41%	As above.	*Significant:* The intervention group had small reductions in strain (four of eight sites) and depression (three of eight sites) that were significant for some individual sites over the 36 months. *Nonsignificant:* Depression and strain were not found to be significantly different at any time period between the groups.

Appendix 1 (cont'd)

Study	Participants	Intervention and Provider	Outcomes
EDUCATION			
Brodaty et al. (1997) Australia RCT	*Caregiver participants:* n = 96 at baseline n = 93 at completion Immediate Intervention (group I): n = 33 Waitlist (group II): n = 31 Memory retraining only (group II): n = 30 (Demographics reported combined) Male 46.2%/female 53.8% Age: mean 67.5 (*SD* 8.0) Spouses 93% (child not reported)	Caregiver training consisted of 10-day program with a variety of sessions. Care recipients participated in a program concurrently consisting of memory training, reminiscence therapy, relaxation techniques, and outings. Group II waitlist received program 6 months later. Group III caregivers received 10 days' respite, during which time care recipients completed the memory training. All received 12-month booster sessions, and interviews were the same for all groups. Groups were followed for between 6.5 and 8 years (at the end of which period the care recipient was institutionalized or died).	*Significant:* Length of follow-up differed significantly ($p < .01$) between groups; groups I and III were followed for 7.8 years, while group II was followed for 7.4 years. When groups I and II (caregivers received training) were combined (they did not differ significantly), there was a significant ($p < .05$) impact on delaying institutionalization compared to group III (control). Eight-year survival analysis revealed that caregivers who received training (groups I and II) kept care recipients at home longer ($p = .04$). *Nonsignificant:* Care recipients who were institutionalized or died did not differ between groups.
Corbeil et al. (1999) USA RCT	*Caregiver participants:* *Intervention:* n = 28 Male 25%/female 75% Age: mean 69.0 (*SD* 9.8) Spouse/child not reported Placebo: n = 28 Male 11%/female 89% Age: mean 63.9 (*SD* 12.3) *Control:* n = 31 Male 32%/female 68% Age: mean 68.2 (*SD* 10.6)	Caregivers in *active cognitive-stimulation* group attended 1-hour sessions six days/week for 12 weeks. Caregivers were trained in activities to stimulate the mind of the care recipient. The *passive* (placebo) cognitive-stimulation group were presented with passive activities (watching television). Caregivers in the control group were contacted only for assessments. Assessments occurred pre-intervention and at 9 months and 3 months follow-up.	*Significant:* Positive interaction between caregivers and care recipients remained positive in the intervention group but became negative for the control group ($p < .05$). *Nonsignificant:* Intervention had no impact on the level of stress for the caregivers when interacting with the care recipient.

Marriott et al. (2000) United Kingdom RCT	*Caregiver participants:* *Intervention:* $n = 14$ Male 36%/female 64% Age: mean 69.6 (*SD* 15.2) Spouse 64%/child 21% *Control 1:* $n = 14$ Male 21%/female 79% Age: mean 58.1 (*SD* 16.7) Spouse 36%/child 57% *Control 2:* $n = 14$ Male 36%/female 64% Age: 63.0 (*SD* 14.0) Spouse 57%/child 43%	Intervention group received the Camberwell Family Interview (CFI) and a modified cognitive-behavioural intervention. Intervention consisted of education, stress management, and coping skills training delivered by a clinical psychologist in 14 sessions with 2 weeks between each session. The group also received written material. Control Group 1 received no intervention. Control Group 2 received the CFI interview only. Assessments completed at pre-treatment, post-treatment, and 3 months follow-up.	*Significant:* At 3-month follow-up there was a decrease ($p < .001$) in depression for the intervention caregivers compared to the control groups. A decrease ($p = .024$) in behavioural disturbances of the care recipients in the intervention group at post-treatment only. Intervention group had fewer psychiatric cases than the control groups at post-treatment ($p = .014$) and follow-up ($p = .001$). *Nonsignificant:* There were no significant differences between the control groups, thus the CFI alone had no impact on control 2 caregivers.
Wright et al. (2001) USA RCT	*Caregiver participants:* *Intervention:* $n = 68$ Male 24%/female 76% (average of both groups) Age: mean 60.4 (*SD* 14.6) Spouse 50%/daughter 35% *Control:* $n = 25$ Male 24%/female 76% Age: mean 57.2 (*SD* 9.8) Spouse 32%/daughter 44% (groups differed by ethnicity)	Intervention group contacted by clinical nurse specialist (CNS) after initial assessment made on the hospital unit. CNS made three home visits to caregiver 2, 6, and 12 weeks post-discharge, then phoned 6 and 12 months post-discharge. The CNS provided strategies for troubling behaviour by the care recipient, monitored the care recipient's medication, and offered supportive counselling. Control group contacted by phone for data-collection purposes only. Data collected at baseline while in hospital, and subsequently 2, 6, and 12 weeks and 6 and 12 months post-discharge.	*Significant:* The percentage of care recipients at home at 12 months post-discharge was higher for the intervention group than the control group ($p < .03$). *Nonsignificant:* None of the expected outcomes had any lasting effects or reached significance — e.g., reducing care recipient agitation, caregiver depression or stress; no positive impact on health.

Appendix 1 (cont'd)

Study	Participants	Intervention and Provider	Outcomes
PSYCHOTHERAPY			
Mittelman et al. (1993) USA RCT	*Caregiver participants:* *Intervention:* n = 103 Male 49.5%/female 50.5% Age: 45% are 70–75 Spouse 100% *Control:* n = 103 Male 34%/female 66% Age: 43% are 70–79 (groups had to be controlled for gender)	Intervention group caregivers provided with six individual and family counselling sessions by family counsellors; caregivers were required to attend a weekly support group indefinitely and had further access to counsellor. Control group participants had access to services normally provided in their area. They were not required to participate in support groups but were not denied if they wished to attend. All caregivers were interviewed and completed questionnaires every 4 months in the first year, then every 6 months for up to 8 years of follow-up. The present study covers data from baseline to 12 months' follow-up.	*Significant:* At 12 months the intervention group had less than half as many care recipients institutionalized as the control ($p < .05$). Increased rate of institutionalization was impacted by lower care-recipient income ($p < .05$), severity of dementia ($p < .05$), and increased dependence in activities of daily living ($p < .01$). The older the care recipient ($p < .05$) and the younger the caregiver ($p < .05$), the greater the likelihood of the care recipient being institutionalized. *Nonsignificant:* Caregiver gender did not affect rate of institutionalization. Nonsignificant predictors of institutionalization: number of caregiving years, depression, informal and formal support, number of services, and physical health of caregivers/care recipients.

Mittelman et al. (1996) USA RCT	As above.	As above. The present study considers data from baseline to 3½ years' follow-up.	*Significant:* Intervention care recipients remained at home significantly ($p = .02$) longer than those in control group. Intervention caregivers were not as likely to institutionalize the care recipient as control caregivers ($p = .02$). Female caregivers were more likely than male caregivers to institutionalize their spouse ($p = .04$). Severity of dementia in care recipient was a major predictor of institutionalization; the greater the deterioration the greater the likelihood of placement in long-term care ($p = .001$). *Nonsignificant:* Caregiver age was not significant in explaining institutionalization.
COMPUTER NETWORKING			
Brennan et al., 1995 USA RCT	*Caregiver participants:* n = 102 at baseline n = 96 at completion *Intervention:* n = 51 *Control:* n = 51 (demographics reported combined) Male 33%/female 67% Age: median 64 Spouse 68%/child 28%	Intervention group received a computer installed in their home, thus having access to computer link 24h/d, at no charge. Participants received 90 minutes of training. Access to information, decision support, communication, and a question and answer segment provided by a nurse. Time logged on the computer was tracked. Control group received no computer and were given placebo training session.	*Significant:* Intervention group caregivers had significant increase in decision-making confidence ($p < .01$). *Nonsignificant:* Intervention caregivers experienced no change in decision-making skills or social isolation compared to control group. Results of intervention not changed when intervening variables (e.g., strain) controlled. No difference between groups in the number of services used by caregivers.

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* Strong study included in the review.

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Résumé

L'identification et la compréhension des symptômes du diabète de type 2

Alison Phinney et Margaret Wallhagen

Bien que l'éducation sur le diabète encourage les gens à surveiller les symptômes de déséquilibre glycémique, il existe peu de recherches portant sur la façon de reconnaître et de comprendre les symptômes de cette maladie chez les minorités ethniques. Afin d'explorer cette question, des entrevues semi-structurées ont été menées auprès de 23 Afro-américains âgés de plus de 60 ans et atteints du diabète. Une analyse thématique a révélé trois types d'expérience quant aux symptômes. Les personnes éprouvant des symptômes importants comprenaient que leur corps communiquait de l'information claire sur les manifestations du diabète et sur leurs efforts pour gérer la maladie. Les personnes qui n'éprouvaient pas de symptôme concluaient que la maladie était bien maîtrisée. Les personnes qui éprouvaient des symptômes peu clairs ne pouvaient pas interpréter les messages qu'ils recevaient de leur corps. Elles étaient donc découragées de ce fait et avaient souvent l'impression qu'elles ne pouvaient pas faire confiance à leur corps. Les résultats indiquent la nécessité de mettre au point des stratégies novatrices amenant les gens à être davantage à l'écoute de leur corps et à mieux reconnaître et comprendre les symptômes qu'ils éprouvent.

Mots clés : diabète, symptômes, ethnique

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Recognizing and Understanding the Symptoms of Type 2 Diabetes

Alison Phinney and Margaret Wallhagen

Although diabetes education encourages people to monitor symptoms of glycemic imbalance, there has been little research on how people from ethnic minorities recognize and understand their symptoms. To explore this question, semi-structured interviews were conducted with 23 African Americans over age 60 living with diabetes. Thematic analysis revealed 3 patterns of symptom experience. Those with prominent symptoms understood their body to be providing meaningful feedback on the diabetes and their efforts to manage the disease. Those with absent symptoms perceived no physical response to their diabetes, which they took to mean that the disease was well controlled. Those with perplexing symptoms could not interpret the messages they received from their body and were discouraged by this, often feeling they could not trust their body. The findings suggest that innovative strategies are needed to help people become more attuned to their body so they might better recognize and understand their symptoms.

Keywords: elderly, diabetes, symptoms, ethnic, qualitative, African-American

The everyday practice of diabetes management is complex and taxing. People are asked to adhere to demanding dietary restrictions and medication regimens and, moreover, to be continuously vigilant, watching for symptoms that might indicate altered blood glucose levels. Such symptoms usually demand immediate response if glycemic control is to be maintained and future complications prevented.

However, using symptoms to guide self-care practices is effective only if these body signals are accurately perceived and understood. Yet research has shown that when people with type 1 diabetes rely on how they feel, they often have trouble identifying when their blood glucose is too high or too low. They may be completely unaware of the accompanying symptoms (Clarke et al., 1995; Weinger, Jacobson, Draelos, Finkelstein, & Simonson, 1995) or may misinterpret their meaning (Pohl, Frohnau, Kerner, & Fehm-Wolfsdorf, 1997).

It has been shown that body knowledge is a requisite for expert self-care in type 1 diabetes (Paterson & Thorne, 2000). However, very little is known about this phenomenon in type 2 illness. Research has shown that symptoms experienced by persons with type 2 diabetes may not be consistent with physiological markers or commonly used symptom checklists (O'Connell, Hamera, Schorfheide, & Guthrie, 1990) and that people are often unable to estimate their blood glucose levels with any degree of accuracy (Diamond, Massey, & Covey, 1989). However, this research is very limited. While it indicates that people's judgement may be lacking, it reveals little about body knowledge — that is, how individuals actually recognize and understand their symptoms in the context of everyday life.

In fact, symptom recognition and understanding may be a particular challenge for those with type 2 diabetes. This disease is most often diagnosed in older adults, who are likely experiencing symptoms of other chronic illnesses as well as age-related changes. Also, type 2 diabetes symptoms are often insidious, passing unnoticed for many years. For many individuals, the ability to identify diabetes symptoms may not come naturally or easily, which suggests that interventions to teach these important skills could be beneficial. However, the evidence in this area of clinical practice is sparse. Virtually no research has been conducted to determine how people with type 2 diabetes recognize and understand symptoms in the context of their everyday lives.

Symptom recognition will become an increasingly important clinical issue as the population ages, especially in light of the rising prevalence of diabetes. Approximately 150 million people are affected worldwide, a figure that has increased five-fold in the last 15 years and is expected to double again by 2025 (International Diabetes Federation, 2000). Also of concern is the fact that minority populations are disproportionately affected. While between 13 and 20% of North Americans over the age of 60 have diabetes (Center for Chronic Disease Prevention and Control, 2002; Harris et al., 1995), the figure is significantly higher in certain ethnic groups. For example, the prevalence of diabetes among African and Asian Americans is twice as high as among Caucasians (Harris et al., 1995). In Canada, prevalence rates are three to five times as high among First Nations people as in the general population (Center for Chronic Disease Prevention and Control).

Specific complications are also much more common in certain ethnic groups than in the general population (Konen, Summerson, Bell, & Curtis, 1999). For example, Mexican Americans have significantly increased rates of diabetic retinopathy, and African Americans and Native Canadians are three times as likely as members of the general population to suffer end-stage renal disease (Center for Chronic Disease Prevention and Control, 2002; Harris et al., 1995; Harris, Klein, Cowie, Rowland, & Byrd-Holt, 1998). Clearly, there is a critical need to improve disease-management strategies for minority populations, and to not assume that what works for one group will work for all (Agency for Health Research and Quality, 2001). It is important therefore that nurses learn to better understand how elderly people from different ethnic backgrounds experience their diabetes symptoms, so that educational resources might be designed to meet the needs of diverse populations.

Methods

To address this gap in our knowledge, a qualitative study was conducted to address the following research question: *How do elderly African Americans with type 2 diabetes perceive and interpret the meaning of their symptoms?*

Institutional Review Board approval was obtained to conduct semi-structured interviews with a convenience sample of 23 African Americans over the age of 60. The participants lived in a variety of urban and suburban communities in a western US state and were recruited through hospital and community clinics, diabetes education programs, and home-care associations. They came from varying socio-economic backgrounds and had a broad range of experiences living with type 2 diabetes.

The interviews lasted approximately 45–60 minutes and were usually conducted in participants' homes. Participants were asked open-ended questions about how they viewed and managed their diabetes and its influence on their lives. The interviews were audiotaped and transcribed verbatim.

A thematic analysis was conducted in three stages (Benner, 1994; van Manen, 1990). First, notes were written in the margins of each transcript describing and interpreting all statements that related to the individual's experience of diabetes symptoms. Each case was then discussed with the research team, each team member having previously read through the transcript several times. The purpose of this discussion was to encourage team members to challenge the initial interpretations, thus opening the analysis to new insights and guarding against interpretive bias. Next, the 23 cases were compared to identify similarities and differences across individuals. Based on these comparisons, a richly detailed text was written to describe as completely as possible people's perception and interpretation of their symptoms. Members of the research team reviewed this text for coherence and plausibility (Packer & Addison, 1989). The final stage of the analysis involved an in-depth reading back and forth between the text and the raw data in order to identify themes that best captured the full range of variation in the data by articulating the distinct ways in which symptoms were recognized and understood by the study participants.

Results

The sample comprised 12 men and 11 women with an average age of 69.9 years. Eleven of the participants were married and all but four were retired. The duration of the illness ranged from a few months to more than 25 years. All participants reported having some form of health insurance, and all were receiving medical care for their illness. Fourteen participants were taking insulin and seven were taking oral hypoglycemic medications. The average hemoglobin A1c level across the sample was 8.5% (sd = 1.8). Most of the participants (n = 18) reported having received some diabetic education and more than half (n = 13) said they followed a special diet for their diabetes. The sample had significant comorbidity, with participants reporting an average of two additional chronic health conditions, most commonly hypertension (n = 11) and cardiovascular disease (n = 8).

Thematic analysis illustrates that diabetes symptoms were experienced in one of three distinct ways: (1) prominent, (2) absent, or (3) perplexing. The following discussion will explore each of these patterns using examples from the interview data to illustrate the meaning of each in terms of how people lived with their illness.

Prominent Symptoms: "Your body talks back to you"

Symptoms of diabetes were very prominent in the interviews of 11 participants. This group had been living with diabetes for an average of 10 years (range 0.5–26 years). Eight were taking insulin and one was taking an oral hypoglycemic medication. The average hemoglobin A1c in the group was 7.9%.

This group seemed to take their physical experiences as meaningful indicators of their diabetes. For example, Mr. J described his symptoms as follows:

> *Your body talks back to you.... It reminds me. A lot of time I feel the diabetes is when it's low. I get sweaty, hot, and hungry.*

Alternatively, when his sugar was high, he experienced considerable pain:

> *When my sugar is high, this hurts [pointing to side]. I mean, it hurts! This will really expose my diabetes. It'll tell me right on this side. All this side there's a terrible pain!*

For Mr. J the diabetes was hidden away, brought out into the open only through his symptoms. His body "reminded" him of the diabetes when the symptoms "exposed" the underlying disease. For Mr. J, the symptoms were a direct consequence of his diabetes and, as the main source of his suffering, required immediate attention.

Like many of the participants, Mr. J considered symptoms to be more or less reliable indicators of dietary transgression; he trusted his symptoms and took them to mean that he had failed to follow his diet: "Generally, it's because of what I eat." Others also noted that when they did not follow their medication regimen they "felt" the results. Mr. N. explained that he relied on

> *how I feel, because if I don't do what is taught to me — I don't do one thing or the other — [I'm] going to feel it later on in some kind of way. So I have to take my insulin.*

Mr. N's words suggest an underlying belief that symptoms are a kind of penalty for not following the rules. Almost all of the participants complained about the difficulty of adhering to their diet and managing their medications. Those who experienced prominent symptoms seemed to view their body as giving them feedback on how well they were adhering to a rigorous regimen.

For several participants, symptoms figured prominently in the historical recounting of their diagnosis. These were such powerful symptoms that they could not be ignored. Mr. A said:

> *Couldn't get enough to eat. Whatever I ate [tasted] like nothing. Whatever I drank… Couldn't get enough to drink. And I was going to the bathroom every half hour. …I never had these symptoms in my life before…. [Things began to appear hazy.] My teeth got loose.*

This experience was paradigmatic to the extent that it shaped Mr. A's subsequent efforts to manage his diabetes. Unmistakable symptoms such as these were uncomfortable and frightening, and he was intent on avoiding a recurrence: "I was just seeing that it would never happen again." Mr. A explained again and again throughout his interview that it was important for him to take care of his body by constantly watching for symptoms of diabetes:

> *I knew how I was feeling. I know my symptoms, and [regarding] what else is in my life, well, it takes second and third place. [The diabetes] is number one.*

Mr. A's management strategies appeared to be driven by his desire never to relive this initial experience. Several other participants described a similar approach to the management of their illness. As long as the most severe symptoms did not recur, they tended to believe they were well.

Prominent symptoms were not always dramatic, however. In fact, a few participants described their diabetes symptoms as typically quite subtle. When asked how he knew his sugar was high, Mr. G responded:

> *I get a little drowsy. I have a nasty taste in my mouth. I don't know, I can't describe [it]. But it's a lot of little ways — if you pay attention to yourself.*

Although Mr. G's symptoms were difficult to put into words and required a certain level of attention on his part, they were nevertheless clear messages, distinct and meaningful.

Often, symptoms stood out by virtue of how they impacted on everyday activities and family life. As one man explained, "My problem is just the physical stuff. It's doing just normal things that other people do." Several participants said that diabetes had its greatest impact on their daily schedules, as they had to carefully time their meals. One woman explained:

> *[Diabetes] has made quite a difference because…I have to get up at a certain hour to eat. And if I don't eat, I get low sugar and it seems to give me blindness…like something always in front of my eyes.*

Several participants spoke of symptoms as humiliating or embarrassing. One woman described incontinence as her most significant diabetes symptom, mainly because it limited her ability to go shopping:

> *You're always spilling urine, and that is too embarrassing. And you're never clean. That's why you can't go shopping.… You know how you try on clothes? You can't do that [any] more.*

Mrs. O was reluctant to acknowledge her symptoms because she did not want to be a burden to her family:

> *I let my sugar get too low last night. …I was just sweating and very weak. I get my husband up so much. I didn't want to get him up and pass me a banana to eat. So I just suffered on through.*

The symptom was a glaring indicator of Mrs. O's growing dependence on others. Its significance for her health was secondary.

While most participants emphasized the immediate distress of symptoms, some also spoke of symptoms as threatening or as a warning of possible complications. These individuals worried about eventually going blind or losing a limb. One woman said, "I'm always afraid that I'll go into a diabetic coma or something." This was particularly evident for people who had experienced complications such as retinopathy or skin breakdown or had witnessed complications in family members with diabetes. These people tended to be particularly attuned to their symptoms, and some made a special effort to monitor themselves and take immediate action when they noticed a change. This was a common pattern amongst those with neuropathy, who watched their feet for signs of skin breakdown. Mrs. R had discovered a sore on her ankle when she was travelling:

> *It scared me half to death because it was bleeding. I immediately washed it off and put Listerine on it because I didn't have anything with me at the hotel. And as soon as I got home I put some antibiotic cream and a band-aid on it. I kept watching it and it healed within a week, and that made me feel good.*

Absent Symptoms: "I didn't have any response to it"

In marked contrast to those who experienced prominent symptoms were seven individuals who did not perceive symptoms at all. This group had been living with diabetes for an average of 9.5 years (range 0.25–25 years). Three were taking insulin and four were taking oral hypoglycemic medication. The average hemoglobin A1c in this group was 9.1%.

In describing her absence of symptoms, one person said:

> *I don't feel bad. I don't tingle. I don't have dry mouth. My feet aren't hurting, and, so far, when I hurt my leg it healed.*

Another said that when she was diagnosed with diabetes she hadn't known that anything was wrong, because "I didn't have any response to it." For some individuals, the absence of symptoms meant that the diabetes was far in the background: "I don't ever think about it"; "The diabetes [doesn't] bother me."

People who claimed that they had no response to the diabetes may have been attributing their symptoms to a different source. For example, several of the participants downplayed the significance of their symptoms as a sign of disease, arguing that these experiences were normal for them. One man said, "I'm tired most of the time, but I've been tired most of my life." These participants may have been so accustomed to feeling tired or having poor vision that they no longer noticed it as unusual.

Other co-existing chronic illnesses were common in this sample, and some believed their symptoms were the result of a disease other than diabetes. One man insisted that his symptoms were due to his longstanding heart problems:

> *Every time I go [to the hospital] they say it's my diabetes, and I say it's got to be something else. …they…never tell me it [is] my heart.*

For this man, the diabetes was not problematic, despite the efforts of his clinicians to convince him otherwise.

Symptoms may have seemed non-existent because people had other, more pressing, concerns. Many of the participants described busy, hectic lives. Some had demanding jobs, while others were responsible for the care of a partner, children, or grandchildren, and in one case even several foster children. Moreover, many were in difficult socio-economic circumstances. Given the multiple demands on them, these people may have lacked the time or energy to be attuned to their body. Alternatively, failure to identify symptoms may have resulted from a value orientation in which one puts others before oneself. Mrs. C had been widowed for 23 years but maintained close contact with her children and lived in what she described as a "family building" where everyone knew and looked after one another. Mrs. C admitted that she often diagnosed herself incorrectly when she relied on how she was feeling:

> *That's why I'm not too good at [it]. I can always dose the medicine in everybody else but not in myself....I was taking care of them but I guess I didn't take care of myself.*

This woman felt that her deepest commitment was to others. "Even at my worst, I'm still of service to someone else. That makes me feel good." Mrs. C's obligation to family and friends came before her obligation to her own health. This may have led her to ignore her symptoms.

It is also possible that diabetes symptoms are so subtle or vague that they go unnoticed. The physical symptoms may be outside one's conscious awareness. One woman spoke of realizing she was hungry only when she found herself standing in front of the refrigerator, eating. The way she described it, it was as if her body had its own tacit awareness, acting in response to its low blood sugar without her consciously perceiving, interpreting, and responding to an explicit symptom. Yet another possibility is that the body's response to alterations in blood sugar becomes muted over time. One man commented that he was less aware of his symptoms since starting insulin:

> *When [the blood sugar] was up, I used to tell just by the way I [felt]... That was before I started to take the insulin.*

The absence of symptoms was almost always seen as positive. Even though people knew their sugar might be out of balance, as long as they had no symptoms they were more or less indifferent. Mr. T, who emphasized that he knew his body, said:

> *I'm not too concerned about low blood sugar. I think the other morning I was down around 68 and I had no glycemic reaction.*

People were even relieved by the absence of symptoms. Mr. J, who often suffered with pain, said:

> *When I first wake up, regardless of whether my sugar is up or down [my body] is at peace — no pain or aches. And I just [lie] there and enjoy it.*

Several participants believed that the absence of symptoms meant that they were following the rules of diabetic management and were taking good care of themselves. When asked what made him feel that he was managing his situation, Mr. L replied:

> *What helps me is my feelings. You can feel if your blood sugar gets too low… If I feel okay, things [will] be managed. If I make a mistake, my blood sugar gets low. But if I eat at the proper times, take the insulin at the proper time, everything [is just] great.*

Most people in this group believed they were well as long as they felt fine and had no obvious symptoms:

> *I look at my daily feelings. You know, if I don't have…anxiety attacks or anything, I don't get the sweats, then, to me, I'm feeling good. If I can go through my normal routine, that's what I look at. That's my measure.*

In other words, the absence of symptoms meant that everyday life was unaffected. The people in this group felt comfortable and were able to engage in their usual activities. "Everything's just like before I had it," said one man. "I do everything I want to do." Even when they admitted that their glucometer readings were consistently high, these participants felt that as long as they had no symptoms they had a good quality of life free from the intrusion of diabetes.

Perplexing Symptoms: "These were the symptoms, but I didn't know what they were for"

Five participants received messages from their body but had difficulty understanding their meaning. This group had been living with diabetes for an average of 13.4 years (range 1.6–25 years). Three were taking insulin and two were taking an oral hypoglycemic medication. The average hemoglobin A1c in this group was 9.0%.

In describing how he was perplexed by his symptoms, one man said, "These were the symptoms, but I didn't know what they were for." In part, this was a result of insufficient knowledge. As people gained more experience with the illness, they came to better understand their body's responses. However, several participants commented that they would have benefited from further education. Even though they understood the theoretical facts, they were not always able to make use of this knowledge in the context of their own experience. One woman who had recently taken a course at a university hospital clinic said:

> *I know the diabetes affects your eyes. Now, on occasion, my eyes are a little blurry, but I don't know if that's from my sugar being elevated.*

Symptoms were often experienced as ambiguous. Blurred vision might have been related to diabetes, but, as more than one person pointed out, it could also be caused by a cataract. Fatigue was common in this sample, and some people simply did not know what to make of it. The confusion was particularly evident in those who had multiple health problems. Mrs. R not only had experienced diabetic complications, but was living with rheumatoid arthritis and had been receiving chemotherapy and radiation therapy for breast cancer. All of this made it especially difficult for her to distinguish and make sense of her diabetes symptoms. She had been "tired a lot" when first diagnosed with diabetes but was not sure if this was related to the diabetes: "That's just the way of my life. I'm tired." This woman did not immediately assume that her fatigue was due to one of her other health conditions but, rather, was uncertain as to its meaning and significance.

The information offered by symptoms was sometimes found to be indeterminate and not very helpful. Mrs. D described her particular dilemma as follows:

> *In the morning my energy runs out because my sugar is too low; in the evening it runs out because it's too high.*

Even though the symptom was apparent, it was not particularly meaningful. Mrs. D could not use the information to help her decide how to respond.

Perhaps because symptoms could be so inscrutable, a full third of the participants used their glucometer to help them judge how their disease was being managed. "It will tell me the truth!," said one man. People often noticed that the readings bore little relation to how they felt, which further supported their belief that they could not rely on their own bodily perceptions. One woman explained that the previous night she had awoken "feeling" that her sugar was low but when she measured the levels in the morning she found it was 97.

> *That was better than I thought. I thought my sugar had dropped down to about 40, but it was up... So it was just a bad dream, a nightmare or something I was having.*

This woman did not assume that the machine had given her an inaccurate reading or that her blood sugar simply increased since the middle of the night, but instead concluded that she could not trust her own body and wondered if she had just dreamt the entire thing.

Often, people continued to experience significant symptoms despite their best efforts to control their diet. This may have been partly because they had inaccurate information in this area. It was a common belief, for example, that simply avoiding extra salt and sugar could keep blood glucose under control. When observance of these rules failed to change their symptoms, some participants became discouraged, feeling their body could not be trusted: "I'd just like to know why [the blood sugar] is up with me trying to control what I eat." These individuals concluded not that they had made a mistake with their diet but rather that their body was erratic and unreliable. Diabetes was a force of uncertainty in people's lives. "I don't trust the diabetes," said one man. "I just don't know what it's going to do next."

Discussion

One focus of diabetes education is helping people to monitor their blood glucose levels and develop effective strategies for maintaining glycemic control. Often, little attention is paid to how people recognize and understand their diabetic symptoms. The findings of this study demonstrate the variability of symptom experiences and the impact of these experiences on self-care practices and management strategies.

Prominent symptoms forced people to take note of their diabetes. The participants who experienced prominent symptoms believed their bodies were sending them messages that the diabetes was not being adequately controlled. These symptoms could not be ignored. They caused discomfort, interfered with daily activities, and served as a warning of future complications.

Given these negative meanings, it is not surprising that people tended to feel relieved when the symptoms subsided. But physiologic alterations caused by diabetes can be subtle and produce no easily discernible symptoms, and, as with hypertension, the pathophysiologic consequences are often hidden until organ damage becomes significant. Many participants in this study did not seem to grasp this, generally believing that if specific symptoms were mild, the disease was under control. As long as they felt well and could do their normal activities, they were unconcerned.

This phenomenon was particularly evident amongst people who spoke of being reassured when they did not "feel" their diabetes, when symptoms were notable only by their absence. It is possible that diabetic symptoms truly do not exist if one's body has become unresponsive to changes in blood glucose. Hypoglycemic unawareness is well documented in type 1 diabetes (Clarke et al., 1995; Weinger et al., 1995) and may also apply to some individuals with type 2 who require insulin (Samuel-Hodge et al., 2000). However, the findings of this study point to the possibility that many people with type 2 experience symptoms but do not associate these with their diabetes. Several participants said that a particular symptom had been with them most of their lives or was the natural result of growing older. Others identified their symptoms as belonging to a co-existing disease that they considered far more serious. In short, diabetes symptoms may not always manifest if people have concerns that direct their attention elsewhere. In the face of multiple demands, it may be difficult for people to attend to their bodies. They do what they can with regard to diet and medications, but symptoms simply do not stand out in the context of busy, stressful lives.

The participants with prominent or absent symptoms trusted their bodies to tell them the truth; the meaning of their symptoms was unambiguous. However, many of the participants were confused by their symptoms. The addition of other chronic health conditions seemed to make it difficult for them to distinguish and interpret symptoms. Moreover, even though most participants had received diabetes education, their beliefs and health-care practices were often at odds with the recommendations of their health-care providers. Thus when symptoms of glycemic imbalance appeared despite their best efforts to manage the disease, they became discouraged. They did not consider the possibility that their management strategies were ineffective or misguided, believing instead that their body had failed to provide accurate feedback.

Research conducted in the 1980s and 1990s found that "knowing the body" is a necessary skill for diabetes self-management (Paterson, Thorne, & Dewis, 1998). However, most of that research was based on interviews conducted with well-educated Caucasian married women with type 1 disease. The present findings show that the experience of elderly African Americans with type 2 diabetes may be quite different. Schoenberg, Amey, and Coward (1998) found that even though African-American women with diabetes used the same information sources as white women, they had less knowledge of their illness. The reason for this is not known, although sociocultural and environmental factors likely influence self-care practices (Samuel-Hodge et al., 2000; Whittemore, 2000) and almost certainly influence the reception and use of available health information (Brody, Jack, Murry, Landers-Potts, & Liburd, 2001). This issue should be a focus of future research.

The participants' descriptions of their self-care practices indicate a growing dependence on technology for monitoring the disease. Indeed, most participants who monitored their blood glucose levels believed that the numbers reflected "the truth" even if this did not agree with what their bodies were telling them. However, the incongruence between symptom experience and monitoring results also caused tension and confusion, contributing to some participants' lack of trust in their bodies.

This finding could have implications for diabetes self-management, especially in light of research showing that blood glucose monitoring may not result in tighter metabolic control (Koch, 1996). For example, a study with 98 African Americans with type 2 diabetes found that blood glucose levels were similar for the 61 individuals who regularly self-monitored and the 37 who did not (Oki, Flora, & Isley, 1997). It is possible that only through an embodied awareness of symptoms are people with diabetes prompted to take action. For many, a number on a glucose monitor may simply not be a sufficiently salient cue. Of course, this awareness must be an informed one; people need to know how to respond to their symptoms appropriately. The results of the present study suggest that this is not always the case, given that blood glucose was poorly controlled even in the group experiencing prominent symptoms.

Misinterpretation and misunderstanding of symptoms were common in this sample of elderly African Americans with type 2 diabetes. This suggests that people with diabetes require more complete information. But offering individuals a comprehensive list of possible symptoms along with a thorough explanation of their significance may be insufficient to help them identify their own symptoms. Benner and Wrubel (1989) argue the theoretical point that, as experiences of the lived body, "symptoms can seldom if ever be separated into pure sensation and pure emotional responses" (p. 212). Symptoms embody a depth of personal and cultural meaning that can be fully understood only in the context of a person's past and current life situations. Asking people to match their symptoms to those on a list may serve only to promote further distrust of one's body when it does not behave according to abstract, decontextualized definitions.

Ultimately, if nurses are to help people better manage their diabetes, we will need to develop strategies to bring them more in tune with their body so they will see how it responds to the illness even when symptoms are subtle and difficult to discern. An area that needs further research is precisely this — how to refine people's body awareness so they are able to more accurately interpret their own unique symptoms and respond appropriately (Hernandez, Bradish, Rodger, & Rybansky, 1999). It is especially critical that such research be conducted with socially and ethnically diverse populations.

Such research will inform nursing's theoretical understanding of symptom management. Current theory in this area proposes a model with three components: symptom experience, management strategies, and outcomes (Dodd et al., 2001). The findings of the present study deepen our knowledge about the first component by underscoring the idea that recognizing and understanding symptoms is a matter of not just grasping facts about one's illness but also coming to an embodied understanding of the illness over time (O'Flynn-McGee, 2002). By developing this kind of body expertise, those with type 2 diabetes might be able to achieve better glycemic control and have fewer long-term complications.

As a final note, the present findings are limited in that participants were asked to report retrospectively on experiences that may have been difficult for them to discern or recall. Indeed, participants often had trouble describing their symptoms, thus raising the possibility that symptoms were absent or perplexing less frequently than the interviews suggest. The symptom experiences may have been forgotten, or may have been taken for granted such that the participants found it difficult to reflect on them in an interview.

Future research in this area should include additional data-collection techniques such as direct observation or symptom diaries that would permit the collection of data as symptoms occur. Future research should also consider participants' medical details, including specific diagnoses and medications, as these factors can greatly influence symptom experience.

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Résumé

Facteurs associés à la durée de la consommation des anxiolytiques, des sédatifs et des hypnotiques chez les personnes âgées

Philippe Voyer, Michael McCubbin,
Michel Préville et Richard Boyer

Plus de deux décennies de recherche descriptive sur les facteurs associés à l'usage des psychotropes chez les personnes âgées n'ont pas permis d'aboutir à des résultats convergents. Les auteurs avancent que la durée de la consommation pourrait avoir brouillé les résultats des études antérieures, étant donné que les variables influant sur la consommation initiale pourraient être différentes de celles qui influent sur la consommation de longue durée. Ils ont procédé à une analyse secondaire des sujets interrogés lors de l'Enquête de santé menée au Québec en 1998 (n = 3,012). Les résultats démontrent clairement que les facteurs associés à la consommation variaient en fonction de la durée de celle-ci. Le cas de la dépression mis à part, les facteurs d'ordre médical et de santé mentale prépondérants associés à l'usage à court terme ne pouvaient être associés à la consommation à long terme. Les seuls facteurs susceptibles d'expliquer la consommation de longue durée mais non la consommation de courte durée étaient le sexe (féminin) et la perception de l'état de santé (moins que positive). Ces conclusions indiquent qu'il est peu probable que ce soit les bienfaits thérapeutiques pour la santé mentale qui expliquent un recours prolongé à ces médicaments. Les auteurs émettent l'hypothèse que l'accoutumance aux médicaments pourrait être en jeu. Ils encouragent par conséquent les infirmières en santé communautaire à mettre en œuvre des programmes de sevrage dans la perspective de réduire la nocivité de la consommation de longue durée.

Mots clés : psychotropes, personnes âgées, consommation de longue durée, consommation de courte durée, anxiolytiques, hypnotiques, sédatifs, accoutumance, sevrage

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Factors in Duration of Anxiolytic, Sedative, and Hypnotic Drug Use in the Elderly

Philippe Voyer, Michael McCubbin, Michel Préville, and Richard Boyer

At least 2 decades of descriptive research on factors associated with psychotropic drug use by the elderly in the community has failed to yield convergent results. The authors posited that duration of use may have been confounding results of previous studies, since variables influencing initial use may not be those influencing long-term use. They conducted a secondary analysis of the elderly respondents in the cross-sectional 1998 Quebec Health Survey (n = 3,012). Results clearly show that factors associated with ASH use vary with duration of use. Apart from depression, medical and mental health factors significant for short-term use are not associated with long-term use. The only factors found that explain long-term but not short-term use were gender (female) and health perception (less than positive). These findings suggest that over the long term it is unlikely that mental health therapeutic benefits explain ASH use. The authors hypothesize that drug dependency could play a role in long-term use. They therefore encourage community health nurses to implement withdrawal programs in order to reduce harmful long-term consumption.

Keywords: psychotropic, elderly, long-term use, short-term use, tranquillizer, anxiolytic, hypnotic, sedative, benzodiazepine, addiction, withdrawal

Introduction

The use among the elderly of psychotropic drugs, most of which are anxiolytics, sedatives, or hypnotics (ASH) in the tranquillizer class of psychotropics, has been attracting considerable research interest. This interest has developed in a context of increasing use of ASH over the past decades (Caces, Harford, & Aitken, 1998), while during this same period it has become clear that much ASH use does not respect standards in the medical literature. Most notably: (a) ASH are widely prescribed for mental health conditions like depression for which they are not indicated (Kelman & Mayer-Oakes, 1994); (b) they are usually administered for long periods, which is contraindicated; and (c) they are prescribed at much higher rates for elderly people, particularly the very old, than for younger people, despite the fact that the risks associated with ASH use increase with age (Glazer & Zawadski, 1981; Jenkins, 1976; Linden et al., 1999).

The prevalence of psychotropic use by the elderly living in the community is high, varying from 25% to 48% (Statistics Canada, 1994; Tamblyn et al., 1994; Wancata, Benda, Meise, & Müller, 1997). Although use of tranquillizers for more than 30 days is contraindicated due to a lack of evidence for efficacy of sustained use (Allen, 1986; Thomson & Smith, 1995) and the risks of dependence, more than half of elderly users are long-term consumers of those drugs (Blazer, Hybels, Simonsick, & Hanlon, 2000b; Tamblyn et al.). In Canada, 69% of elderly persons using tranquillizers have been taking them for at least 1 year (Statistics Canada).

The negative consequences of psychotropic use among the elderly are significant and varied. They can include cognitive loss, falls and other injuries, psychomotor slowing, delirium, and, consequent to these problems in addition to overdose, hospitalization (Berg & Dellasega, 1996; Dealberto, McAvay, Seeman, & Berkman, 1997; Ebly, Hogan, & Fung, 1997; Paterniti, Dufouil, & Alpérovitch, 2002; Ray, 1992; Tromp et al., 2001). Former use of benzodiazepines has also been associated with dementia (Lagnaoui et al., 2002) and modest functional declines among elderly people when also controlling for prior health conditions (Gray et al., 2002). Finally, it is estimated that 17% to 50% of psychotropic drug prescriptions for the elderly in Canada are inappropriate (Tamblyn et al., 1994; Thomson & Smith, 1995).

Factors Associated with Elderly Psychotropic Use

Inappropriate prescribing of or long-term use of psychotropic drugs in the elderly population unnecessarily increases the risks that the elderly are particularly vulnerable to. These risks can be offset by the therapeutic benefits for persons with mental health problems. However, epidemiological studies clearly demonstrate that the mental health of the elderly is not the only factor determining psychotropic use. Indeed, while most studies have found an association between mental health status and psychotropic use (Dealberto, Seeman, McAvay, & Berkman, 1997; Kirby et al., 1999), several have not (Blazer, Hybels, Simonsick, & Hanlon, 2000a; Lyndon & Russell, 1990; Newman & Hassan, 1999). The ambiguous or relatively weak relationship of mental health status and psychotropic use suggests that the risks posed by these drugs are not always counter-balanced by their therapeutic benefits. This reinforces the argument that psychotropics are being inappropriately prescribed for elderly persons (e.g., excessive renewals, inadequate examination of the patient, failure to fully consider risks for that patient, inadequate consideration of treatment alternatives) (see Mort & Aparasu, 2002; Talerico, 2002).

In order to reduce inappropriate use we need to know why it occurs. In other words, what factors, apart from mental health status, determine psychotropic use among the elderly? This question has been addressed by many researchers in recent decades (Linjakumpu et al., 2002), yet there have been no convergent results. For example, although some researchers have found significant results for age (Chen, Dewey, Avery, & the Analysis Group of the MRCCFA Study, 2001; Taylor, McCracken, Wilson, & Copeland, 1998), gender (Colvez, Carrière, Castex, & Favier, 2002; Gleason et al., 1998), marital status (Fourrier, Letenneur, Dartigues, Moore, & Bégaud, 2001; Jorm, Grayson, Creasey, Waite, & Broe, 2000), education (Allard, Allaire, Leclerc, & Langlois, 1995; Gleason et al.), and health perception (Blazer et al., 2000a; Gustafsson, Isacson, Thorslund, & Sörbom, 1996), these findings have not been supported by other studies addressing the same factors — for example, age (Allard et al.; Larose, 1996), gender (Mayer-Oakes et al., 1993; Pérodeau, King, & Ostoj, 1992), marital status (Koenig, Rüther, & Filipiak, 1987; Gleason et al.), education (Blazer et al., 2000b; Pérodeau & Galbaud du Fort, 2000), and health perception (Antonijoan, Barbanoj, Torrent, & Jane, 1990).

The above are some of the key studies assessing these factors; the pattern of conflicting results in other studies paints the same confusing picture. The absence of strong evidence on the phenomenon hinders nurses from intervening in an effective and meaningful way in order to reduce inappropriate use of psychotropic drugs by elderly persons living in the community.

The Duration-of-Use Hypothesis

Methodological aspects of these studies could explain some of the conflicting results, but issues that have been ignored could also be contributing factors. One possible explanation, tentatively supported by existing research and clinical experience, is that *duration* influences some factors associated with the use of psychotropics — or, conversely, that some factors influence the duration of use but not necessarily in the same way that they influence *initial* use. Our hypothesis in the present study was that several factors influencing initial use are less important or unimportant in influencing long-term use, and that some factors (not necessarily those posited in the literature) tend to structure duration (but not necessarily initial use). For instance, the chief determinant of long-term use is initial use. It is 15 times more likely that an initial elderly user will still be a user 3 years later than to be a non-user (by comparison, the odds ratio is only 4.7 for being depressed) (Dealberto, McAvay, et al., 1997). This raises the hypothesis that the likelihood of psychotropic long-term use by the elderly is related more to an "unknown factor" than to mental health status.

The "Unknown Factor" in Long-Term Use: Three Candidates

Dependency. It is possible that dependency and fear of withdrawal symptoms explain the long-term use of psychotropic drugs (Cohen & Collin, 1997). Surprisingly, although theoretical approaches to understanding this problem are emerging in the literature (e.g., Borg & Larsson, 2001), epidemiological research has not investigated the role of dependency in long-term use. This seems inexplicable given the ample evidence that psychotropics like ASH can be addictive and tend to be used for periods much longer than recommended in the literature, and despite evidence that mental health status is not the only determinant of such use. The proposition that dependence contributes to long-term use is partially supported by one study which demonstrated that 71% of middle-aged psychotropic users wanted to stop using them; half of these stated that they feared stopping because of withdrawal symptoms (Ettore, Klaukka, & Riska, 1994).

Lack of physician reassessments. Researchers have also demonstrated that doctors' prescription patterns differ according to duration of consumption (Damestoy, Collin, & Lalande, 1999). Seniors in one study (*n* = 48) stated that visits to their physician seldom included reassessment of the relevance of the drug (Voyer, 2001), which implies that even when the problem that initially led to the prescription finally diminishes or disappears, medication use frequently continues. While the first psychotropic drug prescription is likely a response to psychological distress, depression, or insomnia, these factors might be less associated with renewals some time later.

Differential cost-benefit analysis for elderly as opposed to younger people. For those considering whether to continue or end psychotropic use, the risk-benefit assessment is quite different for seniors and for young adults; the risks in taking these drugs generally accumulate over prolonged use, whereas the risks in terminating include withdrawal symptoms, which are immediate and can be painful. The lower life expectancy of elderly people can affect such cost-benefit assessment, placing greater weight on current benefits and less on future costs. The assessment of many seniors that the costs of quitting psychotropics exceed the net benefits of continuing them is supported by Voyer's (2001) study in which seniors were interviewed.

Pertinence of Duration Factors: Research for Nurses

The evidence cited above, while not exhaustive of the pertinent literature, seems adequate to support the argument that duration of use contributes to the confused picture in the literature regarding the factors and circumstances that influence the use or cessation of psychotropics. This critical public health issue has barely been addressed by Canadian nurses. There is almost no nursing research on the topic in the literature, nor are there nursing clinical guidelines on how to intervene with respect to psychotropic use among seniors (Voyer, 2001; Voyer, Lauzon, Collin, & McCubbin, 2003). More generally, research on the determinants of psychotropic use has made no distinction between short- and long-term consumers.

Nurses could play an important role in helping long-term users deal with dependency issues around benzodiazepines, the psychotropic most commonly used by seniors. While there is growing awareness of the risks of benzodiazepine use, including dependency, many seniors were first prescribed them during an earlier era when these drugs were frequently prescribed and physicians held them to be non-habit-forming. Hence today there is a sizeable cohort of persons with not short- or medium-term but very long-term dependency — which renders withdrawal all the more difficult (Isacson, 1997; Ohayon, Caulet, & Lemoine, 1996; Statistics Canada, 1994). Accordingly, the problem of unnecessary long-term use has drawn the attention of a sizeable body of researchers (Cohen & Collin, 1997; McLeod, Hung, Tamblyn, & Gayton, 1997; Tamblyn et al., 1994). This issue undoubtedly requires levers for action; it is impossible to find them without ascertaining the determinants of not only initial use, but also, and separately, *continued* use. Similarly, we need to know whether continued and long-term use alter the fundamental determinants of consumption.

Hypothesis of This Research

Our hypothesis was that various factors are associated with long-term as opposed to short-term use of psychotropic drugs by the elderly living in the community. This paper considers what these findings might imply for nursing practice with elderly people in the community.

Method: The Quebec Health Study

The 1998 cross-sectional Quebec Health Survey (Institut de la statistique du Québec) reached 30,386 individuals in 15,409 households (institutionalized persons were excluded). Households were randomly selected using a multi-stage sampling design in 16 regions (out of 18; Inuit or Cree territories were excluded); the sample represented 97.4% of Quebec's population. Methodological issues and details of the sampling procedure are discussed in Daveluy et al. (2001).

Each senior was interviewed face-to-face, in either French or English, regarding diseases, disabilities, activity limitations, health-care utilization, and medication use. Participants were then asked to complete a questionnaire on health habits, health perception, and mental health. The response rate was 82.1%. The interviewers were professional interviewers from the Institut de la statistique du Québec (ISQ). From this sample we drew all persons aged 65 years and older (n = 3,012) for completion of a secondary data analysis.

Ethics

Two Quebec laws regulate access to these data in order to protect the confidentiality of respondents *(Loi sur l'Institut de la statistique du Québec* and *Loi sur l'accès aux documents des organismes publiques et sur la protection des renseignements personnels).* Pursuant to those laws, the principal investigator signed a contract with the ISQ in which he agreed not to divulge, during or after the research, the identities of respondents. Further, as required by the ISQ, prior to our accessing the data (restricted to the offices of the ISQ), the data were masked (denominalized) to hinder identification of respondents.

Variables

Sociodemographics. These included age (65–74, 75–84, 85 and older); gender; education (0–9 years, 10–13 years, attended university); marital status (married, divorced/separated, widowed, single); and personal income (0–$19,999, $20,000–49,999, $50,000 or more, in Canadian dollars).

Social support. Low or high social support was assessed using seven questions on the nature and frequency of social activities, how leisure time was spent, satisfaction with social life, types of close family relationships, how many people the respondent could confide in, how many people would help in time of need, and how many people were close to or felt affection for the respondent (for details see Audet, Lemieux, & Cardin, 2001).

Physical health. Perceived health status was assessed using the question "In general, compared with other persons your age, would you say your health is (1) excellent, (2) very good, (3) good, (4) fair, or (5) poor?" Fourrier et al. (2001) found perceived poor health in the elderly to be related to ASH use, and it has long been established that perceived health status is strongly correlated with diagnosed health status and mortality (e.g., Golstein, Siegel, & Boyer, 1984; Mossey & Shapiro, 1982; Ware, 1986). For logistic regression, categories 4 and 5 were retained but categories 1 to 3 were collapsed into one: health status perceived as "positive."

Depression. Respondents were asked "Are you afflicted by a depression?"

Nervous problems. Respondents were presented with two questions "Have you felt preoccupied or nervous in the last week?" and "Have you been through either a period of high tenseness or irritability?" An affirmative answer to both questions was taken to indicate the presence of nervous problems.

Psychological distress. The 14-item short version (Préville, Boyer, Potvin, Perrault, & Légaré, 1992) of the 29-item Psychiatric Symptoms Index (PSI) (Ilfeld, 1976) was used to assess anxiety, depression, anger, and cognitive problems. Validity and reliability of the PSI are well established in English for the full Index (Ilfeld, 1976, 1978; Préville et al., 1992) and in French for the short version (Préville, Potvin, & Boyer, 1995). Respondents were asked about experience and frequency, from (1) never, to (5) almost always, of various symptoms over the previous month. For example: "… I had the feeling that I had wasted my life" or "… I lacked self-confidence." Scores of up to 70 were grouped into levels of psychological distress characterized as low (less than 15), intermediate (15–28), or high (at least 29).

Medical visits. Respondents were asked if they had consulted a physician during the previous 2 weeks.

Medications use. To minimize recall bias, respondents were asked about amounts taken in the previous 2 days of various categories of medications, including ASH. Then, the number of medications taken was calculated. Respondents were then asked how long they had been using each drug; answers were grouped into categories of 0–6 months, 7–11 months, and at least 12 months.

Data Analysis

Data were weighted to infer results to the target population as suggested by Quebec Health Survey investigators (Daveluy et al., 2001), on the basis of individual selection probability, variance of the sampling plan, refusal, age, sex, and geographical area. Frequencies and chi-square tests (on whether ASH were taken at all during the previous 2 days) were calculated using SAS 8.0.

Bivariate analyses were performed for each variable, for two purposes. The first was to assess the level of association between all independent variables with the use of ASH for the four different groups of consumers (all those who had used ASH; ASH use less than 6 months; ASH use 7–11 months; ASH use 12 months or more). The second purpose of the bivariate analyses was to assess for multicollinearity between independent variables according to the method described by Besley, Kuh, and Welsch (1980). Due to high multicollinearity between income and education, the former was excluded from further analysis. Then, statistically significant variables were tested again for their association with ASH use while

Table 1 ***Bivariate Analysis Between Factors and ASH Use***

Independent Variables	**Total Population (n = 3,012)**	**ASH Use**		
	%	**Yes (%)**	**No (%)**	**(Chi^2) $P<$**
ASH use	16.5	16.5	83.5	
Age				0.0155
65–74 years	64.6	14.7	85.3	
75–84 years	30.1	19.8	80.2	
85 years and over	5.3	22.1	77.9	
Sex				0.0001*
Female	57.5	19.8	80.3	
Male	42.5	12.4	87.6	
Education				0.0008*
0–9 years	62.7	19.0	81.0	
10–13 years	27.4	11.8	88.2	
Attended university	9.9	10.2	89.8	
Marital status				0.0001*
Married	54.8	13.9	86.1	
Separated or divorced	9.6	15.19	84.81	
Widowed	29.4	22.8	77.2	
Single	6.2	13.4	86.6	
Individual income				0.0063*
0–$19,999	66.3	18.3	81.7	
$20–49,999	30.9	11.2	88.8	
$50,000+	2.9	19.6	80.4	
Social support				0.4725
Low	15.7	18.1	81.9	
High	84.3	16.1	83.9	
Perceived health status				0.0001*
Excellent	11.2	8.2	91.8	
Very good	24.3	7.1	92.9	
Good	41.6	17.6	82.4	
Fair	18.5	27.7	72.3	
Poor	4.4	31.5	68.5	
Depression				0.0001*
Yes	2.7	50.9	49.2	
No	97.3	15.7	84.4	
Nervousness				0.0001*
Yes	28.6	25.5	74.6	
No	71.4	13.1	86.9	
Psychological distress				0.0001*
Low	30.4	8.9	91.1	
Intermediate	63.7	16.7	83.3	
High	5.9	33.6	66.5	
Medical visits				0.0026*
Yes	23.7	21.6	78.4	
No	76.3	15.1	84.9	

* significant at $\alpha \leq .05$

controlling for age, gender, and education. Subsequently, binary logistic regressions (all those who had used ASH; ASH use less than 6 months; ASH use 7–11 months; ASH use 12 months or more), incorporating all the statistically significant variables included in the bivariate analysis, were performed to assess the independent impact of each independent variable for each group.

Sample Characteristics

Demographic characteristics (Table 1). In our sample of elderly persons living in the community, respondents typically were women (58%), had 9 or fewer years of education (63%), were married (55%) or widowed (29%), and had an income of less than $20,000 (66%).

Social and health characteristics. Most respondents reported a high level of social support (84%) and a positive perception of their health (77%). Similarly, a minority reported mental health problems of depression (3%), nervousness (29%), or a high level of psychological distress (23%). Despite the overall favourable physical and emotional health picture, more than half of these seniors used at least three drugs (52%) and 17% were ASH users. A relatively high proportion (23%) had consulted a doctor in the previous 2 weeks.

Results

Factors in Use: Bivariate Analysis

Chi-square tests show that ASH use increases by *age* category and is more prevalent in women than men. Seniors with a lower level of *education* used more ASH, as did those who were widowed. There is an association between *income* and consumption of ASH. Middle-income persons used less ASH than low- or high-income persons. Social support was not found to be related to ASH use. Finally, all *health status variables* — emotional, psychological, and physical — suggested a strong association with prevalence of use.

Factors and Duration of Use: Logistic Regression

Table 2 presents only the variables that were significantly associated in the logistic regression with one of the four dependent variables. For having used ASH at all, the logistic regression provided a very different picture from the bivariate analysis, taking into account interdependencies of the independent variables. Logistic regression revealed no significant association between the fact of ASH use and the senior's age, level of education, marital status, or income. Use of ASH was nevertheless associated with fair or poor perceived health, nervousness, and depression.

Table 2 *Logistic Regression of Factors and Duration of ASH Use*

Categories of Reference	Independent Variables	ASH Use	ASH Use ≤ 6 Months	ASH Use 7–11 Months	ASH Use ≥ 12 Months
Male	**Female**	1.35[1] [0.98–1.86][2]	1.07 [0.48–2.39]	1.48★ [1.03–2.12]	1.47★ [1.02–2.13]
Positive perceived health	**Fair or poor**	1.89★ [1.36–2.63]	1.34 [0.60–3.01]	1.98★ [1.38–2.84]	1.88★ [1.30–2.73]
No depression	**Depression**	3.12★ [1.41–6.91]	5.71★ [1.54–21.08]	3.23★ [1.42–7.34]	2.96★ [1.29–6.80]
Low level of psychological distress	**Intermediate**	1.48 [0.95–2.31]	1.74 [0.44–6.81]	1.63★ [1.00–2.65]	1.59 [0.96–2.61]
	High	1.80 [0.88–3.66]	1.22 [0.19–7.80]	1.98 [0.90–4.32]	2.10 [0.96–4.64]
No nervousness	**Nervousness**	1.92★ [1.36–2.71]	3.63★ [1.54–8.55]	1.43 [0.98–2.09]	1.42 [0.96–2.09]
No medical visit	**Medical visits**	1.30 [0.94–1.81]	2.89★ [1.38–6.04]	1.04 [0.72–1.50]	1.00 [0.68–1.46]

1. Odds ratio
2. 95% confidence limits
★ Significant at ≤ .05

The picture further changed with multivariate analysis of *duration* of use. Whether factors were statistically significant for use largely depended on the duration of use. Gender and perceived health status variables were associated with ASH use only for 7 or more months. Psychological distress was not associated with short- or long-term use; for intermediate-term use (7–11 months) there was an association with intermediate, but not high, distress. Nervous problems and medical visits related only to short-term use. While depression remained significant at all duration levels, the odds ratio declined as use became long-term.

The factors associated with the use of ASH for 6 months or less were, in descending order by odds ratio, depression, nervousness, and medical visits. For use of ASH for 7 to 11 months, the associated factors were, in descending order, depression, fair or poor perceived health, intermediate level of psychological distress, and being female. For use of ASH for 12 months or more, the associated factors were, in descending order, depression, fair or poor perceived health, and being female.

Discussion

Our logistic regression revealed that depression was the only factor associated with short-term use that remains so for long-term use — although its explanatory power declined as duration increased. ASH use is frequently found among depressed elderly persons in the community; indeed one study found that benzodiazepines are prescribed as frequently as antidepressants for such persons (Wilson, Copeland, Taylor, Donoghue, & McCracken, 1999), yet ASH are not indicated for depression (Grossberg & Grossberg, 1998; Kelman & Mayer-Oakes, 1994). In any event, even if being depressed significantly raises the odds of an elderly person using ASH, it can only explain use by a very small proportion of elderly ASH users, since only 3% reported suffering from depression (while 29% reported nervousness). If medically indicated treatment for psychological problems does not explain long-term use, what does explain it? We can probably provide only a partial answer here, since we included only variables that had been studied for psychotropic use in general; much more research and theoretical development may be required in order to identify appropriate candidates for explaining duration of use. What we did find is that elderly persons who perceive their health as poor or only fair and who are female are associated with long-term but not short-term use.

The observation that long-term use is linked to factors other than mental health suggests that sociocultural factors (Préville, Hébert, Boyer, & Bravo, 2001) as well as other health problems (Jones, 1992; Kung, Gibson, & Helme, 1999) might help to explain our finding of health perception and gender as factors, but may also further explain long-term use independent of those factors. Very little is known about those factors not tested in our study. However, we see three insightful tendencies in our data regarding duration of ASH use by elderly people in the community: (a) the longer ASH is used, the less important mental health factors become; (b) medical visits vanish as a predictor of ASH use beyond 6 months; and (c) gender and health perception seem to play a role in long-term but not short-term use.

Long-Term Use Not Explained by Mental Health or Medical Visits

Apart from depression, mental health factors, particularly nervousness, become less significant with prolonged ASH use. Depression is significantly associated with long-term use, but is a weaker explanatory factor in long-term than in short-term use. In other words, medical and mental health factors do not differentiate long-term from short-term use, nor do they explain long-term use; seniors using ASH for long periods do so for reasons other than those that explain initial use. One very likely factor in continuous use is dependency on ASH; it is well documented that long-term ASH use can lead to addiction (Rickels, Schweizer, Case, & Greenblatt, 1990; Stewart, 1994; Taylor et al., 1998). Furthermore, elderly persons are at increased risk for dependence (Petrovic, Vandierendonck, Mariman, & Maele, 2002). All of our findings separately, and especially together, support the proposition that as use becomes long-term it is associated more with dependence and factors predisposed to dependence than with the emotional-psychological problems for which the psychotropics were originally prescribed.

However, the implications of this knowledge for clinical practice have rarely been addressed. While expert panels (Grossberg & Grossberg, 1998; McLeod et al., 1997) agree that use of ASH for longer than 30 days is not recommended, several epidemiological studies report that seniors who use ASH usually do so for more than 1 year (Berg & Dellasega, 1996; Dealberto et al., 1997; Statistics Canada, 1994). In fact, duration of use increases with age (Ohayon, Caulet, Priest, & Guilleminault, 1998; Pérodeau, Jomphe-Hill, Hay-Paquin, & Amyot, 1996; Voyer, 2001), which makes the issue of ASH dependency particularly worrisome for elderly persons.

What can nurses do about this in their community practice with elderly persons? ASH withdrawal programs are not widely implemented in community centres or day hospitals. Nevertheless, there is now consensus in the scientific literature on the importance of implementing such programs (Finlayson, 1995; Grymonpre, Badger, Tabisz, Jacyk, & Powell, 1996; Miller & Mahler, 1991; Voyer & Martin, 2003), and a Cochrane meta-analysis found withdrawal programs to be one of five types of interventions likely to be beneficial in preventing falls among the elderly (Gillespie et al., 2001). It has been argued that nurses should take a leadership role in putting these programs in place in such settings. Nursing research has already demonstrated the ability of nurses to take on this role (Haack, 1998; Tabloski, Cooke, & Thoman, 1998; Voyer, Richard, & Dupont, 2001).

Lockwood and Berbatis (1990) found a relationship between ASH use and medical visits. While we also found this for short-term use, in our study the relationship between medical visits and use disappeared over the long term. This suggests that medical practice has yet to find ways to withdraw patients from these drugs. Studies suggest that when their ASH prescriptions run out, seniors influence their physicians to renew them (Ankri, Collin, Pérodeau, & Beaufils, 2002; Collin, Damestoy, & Lalande, 1999; Sleath, Svarstad, & Roter, 1997). It is possible that seniors are promoting such prescription renewals because they hold positive perceptions about the drugs. It has been demonstrated that the longer the duration of ASH use, the more positive the senior's perception of the drug (Chambers & White, 1980; Clinthorne, Cisin, Balter, Mellinger, & Uhlenhuth, 1986), and, similarly, that seniors tend to minimize the potential harmful effects of these drugs (Chambers & White, 1980; Helman, 1981).

On the other hand, a large study by Straand and Rockstad (1997) demonstrated that 87% of psychotropic drugs used by seniors resulted from a prescription renewal, and that the continued need for these drugs was rarely assessed by their physicians. Indeed, studies have found that 60% to 70% of the renewals of these drugs are ordered outside of medical visits (Straand & Rockstad; Van der Waals, Mohrs, & Foets, 1993). The renewals are often ordered, without any evaluation, via a phone call to the physician. This has led some researchers to assert that once a senior begins using ASH, it is extremely unlikely that he or she will quit (Isacson, 1997; Stewart, 1994). In other words, the greatest determinant of long-term use is initial prescription. However, as clinicians, and as researchers working with clinicians, we have observed that often physicians would like to withdraw their patients from these drugs, but to be effective they need to work in collaboration with other health-care providers such as nurses and pharmacists. From our point of view, nurses are very well positioned in public home-care programs, community health centres, and day hospitals to collaborate with physicians in implementing withdrawal programs for the benefit of seniors.

Gender as a Contributing Factor in Long-Term ASH Use

According to the logistic regression, gender does not begin to play a role until long-term use (7 months and more), which also remains very difficult to explain. The literature offers many hypotheses regarding what leads more women than men to use these drugs. However, these hypotheses do not take duration of use into account. They focus mainly on the role of the elderly woman and on the responsibility of the physician. Researchers have suggested that women are more inclined to reveal their emotional problems to their physician (Cafferata, Kasper, & Bernstein, 1983), are more liable than men to self-treat "feminized nerves" with psychotropics (whereas men more frequently self-treat "masculinized stress" with alcohol) (Ettore & Riska, 2001), or tend to more explicitly ask their doctor to prescribe a psychotropic (Hohmann, 1989). Our results do not support these hypotheses, since one would think they would apply to short-term as well as long-term use and we found gender to be associated only with the latter.

Given the finding that physician characteristics and practice styles influence relative frequencies of prescribing for men and women (Tamblyn, Laprise, Schnarch, Monette, & McLeod, 1996), an alternative hypothesis might be that doctors are more inclined to prescribe a psychotropic for a woman than for a man (Hohmann, 1989; Mamdani, Herrmann, & Austin, 1999). For example, it has been argued that physicians tend to "medicalize" the social and psychological problems of women more than those of men (Pihl, Marinier, Lapp, & Drake, 1982).

It has frequently been observed that women's life problems — and "nerves" — are more likely to result in an ASH prescription than men's conditions, whereas men are more likely to self-medicate with alcohol (Cooperstock, 1971; Ettore & Riska, 2001; Hohmann). However, one would expect these tendencies to result in an association of gender with short-term as well as long-term use, yet they do not.

Some researchers suggest that since women live longer than men they are more vulnerable to the effects of aging, have more health problems, and are more exposed to the loss of persons close to them — including their social and economic roles. All of these factors can increase the probability of psychotropic drug use (Cooperstock & Parnell, 1982; Jorm et al., 2000). Yet, although such factors are associated with advanced age, entering age into the regression did not capture this effect. The gender effect in our data, which remains while also incorporating health problems, must be explained largely by some other factor. While many studies over the past 2 decades have found women more likely than men to be ASH users (even much more likely in the earlier studies), there may have been a tendency over the years for the gender gap to narrow due to changes in social representations and expectations regarding gender roles. Increasingly, physicians entering practice and elderly women seeking medical advice have been part of this new cultural era. As previous cohorts diminish, then, we might expect to see the gender effect disappear. One might postulate that the cohort effect helps to explain the long- but not short-term use, given that, according to the bivariate analysis, ASH use increases with age among the elderly and is higher among women than men, and as the age group increases so does the proportion of women in that group. However, this hypothesized cohort effect would require a sizeable proportion of users to have been using ASH for extremely long periods, even decades; our study does not indicate this. Furthermore, one would expect this explanation to suggest an impact for age in the logistic regression, yet it does not.

None of the above explanations seem to distinguish the role of gender in long-term but not short-term use. We are left, then, with one hypothesis that we cannot at this point dismiss: that women are more likely than men to become dependent on ASH. While there may well be some sociocultural reasons for this, translating into personality characteristics predisposing to dependence upon this class of drugs (see Marinier, Pihl, Wilford, & Lapp, 1985), researchers also need to consider physiological reasons. One such reason could be that if women and men are taking doses of similar strength, women may become addicted to ASH more quickly because of their relatively lower body weight. This bears investigation.

Health Perception as Dependent or Independent Factor in Long-Term ASH Use

The direction(s) of causality for health perception is not clear. Further investigation, including qualitative research (e.g., Collin, 2001), is needed to explore the relations between health perception and elderly use of ASH. Iatrogenic effects of long-term use may impact on health and hence health perception, as found by Arinen et al. (1998). It has been demonstrated that after controlling for competing factors, benzodiazepine use decreases the functional capacity of older people (Ried, Johnson, & Gettman, 1998). Since nurses are particularly concerned with physical autonomy and independence, the prolonged use of these drugs by elderly people warrants nursing attention. In the other causal direction, relatively poor health (and the perception of such) may affect the person's cost-benefit calculation, in that withdrawal effects may be considered too difficult to bear ("now is not the time to stop taking them") on top of not feeling well, and/or the pleasurable feelings the drugs provide may make the perception of poor health more bearable.

In one respect this issue is different for elderly persons: for such persons a chronic illness may be seen as a sign of limited life expectancy. As discussed earlier, the perception of lower life expectancy can make the long-term benefits of withdrawing not seem worth the short-term costs of withdrawing. Note that the positive association of age with ASH use found in the bivariate analysis fell out of the logistic regression; it would appear that health perception, which may become less positive with age, is the factor explaining the role of age in the bivariate analysis.

More generally, there is a strongly anchored belief in Western culture that the way to deal with health problems is through pills — perhaps through any pill (Cohen, McCubbin, Collin, & Pérodeau, 2001). The primary conclusion of a small (*n* = 28) study with elderly benzodiazapine users in France was that the pills were taken mainly for "chemical relief of a moral discomfort" (Fernandez & Cassagne-Pinel, 2001, p. 19 [translated]; see also Zarifian, 1998) ensuing from physical health problems and negative life events. Nurses should supplement their knowledge about appropriate use, iatrogenic effects, particularly in terms of differential impacts on the elderly, and issues of dependence and withdrawal with an in-depth understanding of seniors' needs, motives, and expectations when taking ASH for prolonged periods. They will then be well placed to conduct health education among elderly people around issues such as appropriate therapeutic use, polypharmacy, dependency, and toxicity. Such health education should be carried out in a manner that empowers seniors to act responsibly and to adopt positive health behaviours (Voyer, 1999).

Limits of the Study

There are limits to this study that should be acknowledged. First, its cross-sectional nature does not allow us to determine the precedence of the independent variables on psychotropic drug use (except in the case of gender). Second, the study relies on self-report data, which could have been influenced by social desirability or denial. For instance, it is likely that some seniors hid their depression or exaggerated their levels of social support. Also, it is possible that we have underestimated the true prevalence of ASH use; elderly persons in the community tend to underreport their drug use (Spagnoli et al., 1989). Finally, duration of use is vulnerable to forgetfulness; this could have influenced our results.

Conclusion

As noted at the beginning of this paper, there are ample indications of long-term ASH use by elderly persons for reasons not fully explained by medical necessity. This should be of concern to nurses working with elderly people in the community, given the documented negative effects of long-term ASH use. Effective intervention to reduce unnecessary long-term ASH use requires an understanding of not only dependence itself, but also the determinants of dependence among elderly people. While the factors associated with ASH use by elderly persons in the community have been extensively researched, no single factor has been unambiguously supported by the study investigating it; all that remained clear in each study was that psychological problems explain only a part of use. However, there has been no previous study of the factors associated with duration of use among seniors living in the community.

We posited that one explanation for the conflicting results of studies is the confounding effect of duration of use. Our results support this hypothesis. But while our findings support the idea that mental health problems lead seniors to *initially* use ASH, the role of such problems in long-term use is less evident. We proposed that dependency is a likely factor in long-term use. Our results are therefore consistent with the conclusions of the Addiction Science Network (2003):

> Many factors influence a person's initial drug use (personality characteristics, psychological stress...)... [However,] these factors are less important as drug use continues and the person repeatedly experiences the potent pharmacological effects of the drug. This chemical action, which stimulates certain brain systems, produces the addiction, while other psychological and social factors become less and less important in influencing the individual's behavior.

While further research and theory development are required to more fully explain the roles of gender, health perception, and other determinants, including dependence, in prolonged ASH use, the results of both previous research and the present study provide evidence to guide nurses in implementing ASH withdrawal strategies for seniors.

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Résumé

Analyse critique de la relation entre familles et infirmières autorisées dans les centres de soins de longue durée

**Catherine Ward-Griffin, Nancy Bol,
Kim Hay et Ian Dashnay**

Même si on a beaucoup écrit sur le lien unissant les familles et les infirmières, peu d'analyses systématiques ont porté sur cette relation dyadique dans le domaine des soins de longue durée. S'inspirant d'une approche ethnographique critique, les chercheurs ont mené des entrevues individuelles approfondies auprès de 17 dyades famille-infirmière s'occupant de résidents d'un centre de soins de longue durée atteints de la maladie d'Alzheimer ou d'un trouble connexe. L'analyse des transcriptions d'entrevue et des notes d'observation révèle l'existence de quatre types de relations famille-infirmière (traditionnelle, concurrentielle, coopérative et « empreinte de sollicitude » qui mettent en évidence le rôle de l'infirmière et de la famille, les stratégies de négociation et les conséquences. En outre, on s'est rendu compte que des facteurs intrinsèques et extrinsèques venaient influencer l'évolution de certains types de relations. Ces résultats entraînent des conséquences pour la pratique infirmière, l'élaboration de lignes directrices et la recherche au sein des centres de soins de longue durée.

Mots clés : soins de longue durée, relation famille-infirmière, soins de santé

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Relationships Between Families and Registered Nurses in Long-Term-Care Facilities: A Critical Analysis

Catherine Ward-Griffin, Nancy Bol, Kim Hay, and Ian Dashnay

Although much has been written about the relationship between families and nurses, little systematic analysis has been undertaken of this dyadic relationship in long-term care (LTC). Using a critical ethnographic approach, the researchers conducted separate in-depth interviews with 17 family-nurse dyads caring for residents with Alzheimer disease or a related disorder in one LTC setting. Analysis of interview transcripts and fieldnotes revealed 4 types of family-nurse relationships — conventional, competitive, collaborative, and "carative" — each reflecting the roles of nurse and family, negotiating strategies, and consequences. In addition, it became apparent that intrinsic and extrinsic factors influence the development of certain types of relationships. The findings have implications for nursing practice, policy development, and further research within LTC settings.

Keywords: long-term care, dementia, health-care relationships, family-centred care, caregiving

Introduction

Over the past decade the citizens of the province of Ontario have experienced an upheaval in health care. Years of restructuring and underfunding have created gaps in health care that have led to increased reliance on family members to provide care to elderly persons. There has been a significant movement towards the sharing of care between unpaid family caregivers and paid health-care professionals in hospitals, nursing homes, and the community (Duncan & Morgan, 1994; Harvath et al., 1994; McKeever, 1994). Although much has been written about the relationship between these two types of caregivers and about the benefits, to both family and staff, of "sharing the caring"(Duncan & Morgan; Gladstone & Wexler, 2000), this dyadic relationship has undergone little empirical analysis. We know very little about the relationship between families and staff in long-term-care (LTC) settings and how to improve this relationship to ensure quality care. Hence, while it may be desirable to forge partnerships between staff and family members in LTC settings, the move towards the sharing of care is occurring without a critical analysis of this relationship. Moreover, the limited empirical evidence that does exist on the successful application of the partnership ideal suggests that the relationship presents challenges (Hertzberg & Ekman, 1996, 2000; McWilliam, Ward-Griffin, Sweetland, Sutherland, & O'Halloran, 2001; Pillemer, Hegeman, Albright, & Hendershot, 1998).

Nurse-family relationships in LTC settings cannot be improved without a better understanding of how these relationships develop and how the practices and policies of each facility contribute to the development of positive relationships. The findings of this qualitative study, based within a program of research focused on health-care relationships, illustrate how family-nurse relationships are formed and negotiated at one particular LTC setting as well as the factors that shape the development of those relationships. The paper concludes with practice, policy, and research implications.

Literature Review

There is a dearth of literature on the relationship between families and health professionals in LTC settings. Most of the work that does exist suggests that conflicts may arise between informal and formal caregivers when professionals fail to recognize family caregivers' experience-based expertise (Duncan & Morgan, 1994; Hasselkus, 1989; Hertzberg & Ekman, 1996; Kellett, 1999), when staff are insensitive to family feelings or needs (Hertzberg & Ekman, 2000), when roles overlap (Cott, 1991; Kaye, 1985; Rosenthal, Marshall, MacPherson, & French, 1980; Schwartz & Vogel, 1990), when roles are rigidly defined (Bowers, 1988; Duncan & Morgan), when there is limited contact between staff and family (Sandberg, Lundh, & Nolan, 2001), or when professional expectations of family caregivers are contradictory (Hertzberg & Ekman, 2000; McKeever, 1992). It appears that family caregivers occupy an ambiguous position in relation to health professionals, who tend to view them as both the problem and the solution (Kaye, 1985; Nolan & Grant, 1989; Thorne & Robinson, 1988; Twigg & Atkin, 1994). This ambiguity can and often does lead to conflict.

Most of the literature on family caregiving is situated within the home (Pearlin, 1992; Ward-Griffin, 2001), with little attention being paid to families who provide informal care in LTC institutions. However, research shows that many families continue to assist in their relative's care following relocation to an LTC setting (Bitzan & Kruzich, 1990; Kellett, 1999; Ross, Rosenthal, & Dawson, 1997b; Sandberg, Nolan, & Lundh, 2001). Some studies indicate that LTC staff must work with families in the transitional period and beyond (Dellasega & Nolan, 1997; Ross, Rosenthal, & Dawson, 1997a, 1997b, 1997c; Sandberg, Nolan, & Lundh, 2001; Tickle & Hull, 1995). In Laitinen and Isola's (1996) study, nursing staff believed that family participation in care requires a family-nurse partnership of cooperation, equality, and trust, but families noted that nurses lacked the communication skills and expertise necessary to deal with their concerns.

Several studies cite the failure of professionals to value family caregiving expertise and affective work in formal care settings as a source of conflict in formal-informal caregiver relationships (Bowers, 1988; Duncan & Morgan, 1994; Keady & Nolan, 1995; Kellett, 1999; Powell-Hope, 1994; Robinson, 1985; Sandberg, Nolan, & Lundh, 2001). While both families and staff generally consider staff to be primarily responsible for technical care in nursing homes, there is much less agreement concerning the importance and responsibility of affective care. In a study with family caregivers of nursing-home residents, Bowers found that, in order to ensure quality care, family members actively monitored staff and sought to work collaboratively and cooperatively by learning technical skills and teaching individualized preservative (affective) care; however, they felt that both the importance of individualized affective care and the need for complex partnerships to ensure quality care went unrecognized or ignored by staff.

Similarly, Ross, Rosenthal, and Dawson (1997b) found that spouses of institutionalized elders provided preservative care and consistently perceived more tasks as falling within their domain rather than within the domain of staff or as a shared responsibility. These findings are similar to those of Rubin and Shuttlesworth (1983) and Schwartz and Vogel (1990). When asked about their caring work in relation to that of formal caregivers, family caregivers often claim to be experts and expect their expertise to be acknowledged (Ong, 1990), which indicates that their preferred role is that of full partner in care (Hasselkus, 1992; Keady & Nolan, 1995; Kellett, 1999; Nolan & Grant, 1989; Ong, 1990). These findings point to the invisibility of the work and experiential knowledge of family caregivers, particularly in the affective realm.

Few researchers have actively sought insights from both family caregivers and health professionals on how they work together in providing care (Fischer & Eustis, 1994; Frankfather, 1981; Hasselkus, 1992; Twigg & Atkin, 1994; Schwartz & Vogel, 1990; Ward-Griffin, 1998) or how the relationship changes over time (Clark, Corcoran, & Gitlin, 1994; Keady & Nolan, 1995). Some investigators report that negotiating a partnership between professionals and family caregivers is a complex, dynamic process (McKeever, 1992; Powell-Hope, 1994; Thorne & Robinson, 1989; Ward-Griffin & McKeever, 2000). Twigg and Atkin identify four service-agency responses to families as caregivers: as resources, as co-workers, as co-clients, and as superseded carers. Similarly, in their qualitative study of community nurses and family members providing care to elders living at home, Ward-Griffin and McKeever found four distinct yet interconnected relationships: nurse-helper, co-workers, manager-worker, and nurse-patient. Only the first prototype involved nurses taking the major responsibility for care, with the other three exhibiting various degrees of a "working relationship," characterized by gradual delegation and transfer of care from nurse to family caregiver. In contrast to the findings of Twigg and Atkin, that study captured the nurse-helper relationship and the surveillance role of the nurse. Social-care agencies, rather than health professionals, were the focus of Twigg and Atkin's work, which may help explain the difference.

Less clear and less documented, however, are the specific relationships between family members and staff in LTC settings, and the factors that influence the development of these relationships. Gladstone and Wexler (2002) report family perspectives of five types of family-staff relationships in two LTCs: collegial, professional, friendship, distant, and tense. They found the majority of the relationships to be positive, with the most common being professional and collegial. They also found participating in care decisions, sharing experiences, and establishing trust to be associated with positive relationships. Other studies report similar findings (Hertzberg & Ekman, 2000; Ward-Griffin & Bol, 2000). Shuttlesworth, Rubin, and Duffy (1982) remind us that efforts to forge a close partnership between families and nursing staff depend, in part, upon the degree to which institutions encourage and support family involvement. While these studies encourage us to think about factors associated with the development of such relationships, very few investigators have questioned the role of social power in relations between family caregivers and LTC staff. This information is vital if family caregivers and staff are to enter a genuine partnership.

In summary, although much has been written about how families and staff should relate to each other, this dyadic relationship in an LTC setting has undergone little systematic critical analysis. Few studies have specifically examined the distribution of power between families and nursing staff in LTC settings. Greater attention should also be given to the process of negotiating care between family members and nursing staff, with a focus on factors that influence the nature and development of family-nurse relationships in LTC settings. The present study was intended to address this paucity of data and some of the limitations of previous studies.

Method

The purpose of this study was to critically examine the relationships between families and registered nurses caring for residents of an LTC facility for war veterans in the province of Ontario, Canada. This particular facility used a primary-care approach: once residents were admitted, their care was primarily provided by the same registered nurse for the duration of their stay.

The following research questions were addressed: (1) *How do families and nurses describe their relationships?* (2) *What strategies are used by families and nurses in negotiating their caregiving work?* (3) *What are the consequences of the negotiation process between families and nurses?* (4) *What factors influence this negotiation process?*

Critical ethnography was chosen as the research method because this approach makes explicit those situations that are frequently hidden by familiarity — or taken for granted — and go unchallenged (Quantz, 1992; Thomas, 1993). In other words, critical ethnography increases our experiential capacity to see, hear, and feel. As well, a critical ethnographic approach proceeds from an explicit value-laden framework, promoting transformation and empowerment (Thomas). In this study, a critical ethnographic approach not only helps us to focus on how families and nurses are positioned and how they participate in specific power relations, but also illuminates taken-for-granted assumptions about "family-centred care" in LTC settings.

Recruiting and Sampling Methods

Following University Ethics Committee approval of the study protocol, purposive sampling was used to obtain nurse-family dyads. Registered nurses and family members were recruited from two 40-bed units in the Dementia Care Program of one LTC setting over an 18-month period using a two-phase sampling frame. All registered nurses employed (full-time or part-time) were given a letter describing the purpose and nature of the study and asking if they provided primary care to a veteran diagnosed with Alzheimer disease or a related disorder who also received regular visits (at least twice monthly) from a family member. "Family" was defined as two or more individuals who identified themselves as members of the family either by birth, marriage, adoption, or choice (Allen, Fine, & Demo, 2000). Other, ongoing, recruitment strategies included posting flyers throughout the two units and announcing preliminary findings (Ward-Griffin & Bol, 2000) at an in-service meeting. Potential nurse participants were asked to provide names of eligible family members with whom they had interacted on four or more occasions. These family members were then approached by one of the researchers to participate in the study.

Sample

Seventeen family-nurse dyads participated in the study. All dyads had known one another since the admission of the veteran to the LTC setting, which ranged from 3 months to 5 years with a mean of 1.5 years. All dyads remained the same for the duration of the stay. Most dyads saw each other weekly. The nurses ranged in age from 31 to 56 years with an average age of 45. All the nurses were women. The majority were Canadian (71%), were married (41%), held a diploma in nursing (65%), and were employed full-time (53%) (see Table 1). The family members ranged in age from 46 to 79 years with a mean age of 65. The majority were women (82%), Canadian (82%), and married (82%), held a high-school diploma (53%), and were wives of the veterans (71%) (see Table 2).

Data Collection

The main data sources used in this study were 34 in-depth focused interviews (Merton, Fiske, & Kendall, 1990) and the corresponding fieldnotes for each interview. Demographic data were also collected from each participant at the end of the interview and analyzed using descriptive statistics. The interviews were arranged at a mutually convenient time and place. With the exception of two family interviews, which were conducted in the family home, all took place in a private office on one of the LTC units. Using a semi-structured interview guide, the researcher encouraged the participant to talk about the care provided to the resident, nurse-family negotiations regarding caregiving responsibilities, and the conditions and consequences of these negotiations. In response to open-ended questions (e.g., Can you tell me what your experiences have been in caring for X? How would you describe your relationship with the primary nurse/family member?), most participants discussed their caregiving activities and relationships easily, without further prompting. The participants were also given the opportunity to raise any other issues they wished to discuss. This approach usually prompts respondents to tell their stories and provides stretches of talk that describe social relations (McKeever, 1992). The interviews averaged 60 minutes in length and were audiotaped.

Data Analysis

As suggested by Miles and Huberman (1994), prior to interviewing a provisional list of codes was drawn up based on the research questions. The categories included types of family-nurse relationships, negotiating strategies, and factors influencing negotiations and were applied to the first set of transcripts and fieldnotes, then examined for fit. Use of this method, which is situated partway between the a priori and inductive approaches to coding, helped to create codes inductively nested in each general category. Early analysis focused on key phrases and themes that emerged from the data. As common themes emerged progressively, new codes were added, producing numerous and varied codes (Lofland &

Table 1 *Nurse Demographics*

	Sex		**Nationality**		**Marital Status**			**Nursing Education**		**Employment Status**		
	M	F	Canadian	Other	Married	Single	Divorced	Diploma	Degree	Full-time	Part-time	Job-share
Nurse (*n* = 17)	0	17	12	5	7	4	6	11	6	9	7	1

Table 2 *Family Demographics*

	Sex		**Nationality**		**Marital Status**			**Education**			**Relationship to Resident**		
	M	F	Canadian	Other	Married	Single	Divorced	Primary	Secondary	Post-secondary	Wife	Son	Other
Family member (*n* = 17)	3	14	14	3	14	2	1	1	9	7	12	3	2

Lofland, 1995). Once the codes were developed, the data were read a second time and coded independently by the senior researcher and two research assistants. Differences in coded responses were discussed until consensus was reached. These codes were inserted into the text by hand and then entered into the NUD★IST software program (Richards & Richards, 1994), which facilitated the sorting and resorting of data to locate patterns in the coding categories.

Findings

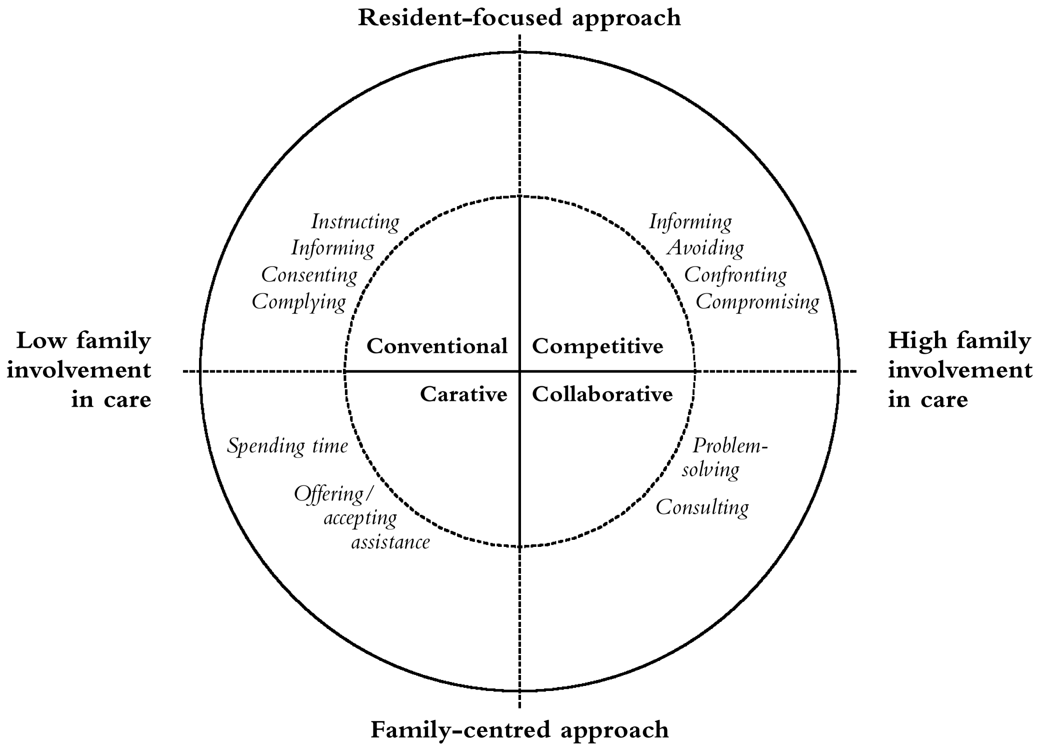
Types of Nurse-Family Relationships

Through the analytic process of coding data to locate patterns within and between dyads, four types of nurse-family relationships emerged from the data: conventional, competitive, collaborative, and "carative." Figure 1 is a graphic representation of this typology. It is important, however, to remember that these are prototypes; in reality, the dyads often engaged in more than one type of relationship, depending on the situation. The horizontal axis represents the degree of family involvement in care, ranging from low to high. Family involvement in conventional and carative relationships is low, while families in competitive and collaborative relationships are highly involved in care. The vertical axis depicts the position of the family in an LTC setting, which is either peripheral or central. Conventional and competitive relationships reflect a "resident-focused" approach to care, where family issues and concerns are seen as peripheral. In contrast, both collaborative and carative relationships reflect a "family-centred" approach, where families and family issues are central. In the next section, the four prototypes, negotiating strategies, and resulting consequences will be described.

Conventional relationship. In the conventional relationship, the nurse was viewed as the "expert" caregiver, while the family assumed a peripheral, "visitor" role. Although many of the families had once provided intense care to the resident while living at home, their role within the LTC setting was primarily providing companionship. Consequently, in this prototype the nurse was expected, by both the family and the nurse, to assume the bulk of caregiving responsibilities. On the surface, this traditional hierarchical relationship between families and nursing staff is unproblematic. However, rigid role expectations often resulted in minimal family involvement, and therefore minimal negotiations occurred between the family and the nurse. Further, this relationship was characterized by an imbalance of power and status; the nurse in the conventional relationship often used strategies to limit the family's input.

Families were not actively encouraged by the nurses to become involved in care. Nurses used their authority and status to address prob-

Figure 1 *Types of Family–Nurse Relationships*



lems affecting the resident, with minimal participation from families. As illustrated by the following comment, if input from the family was sought, it was after care decisions had already been made by the health-care team:

> *I gave her the care plan and said, "This is what was decided at the team meeting. Is there anything else that you think is important?" She wasn't at the conference, you know, when we talked.*

In order to maintain a dominant position, the nurse used controlling strategies such as instructing and informing, which resulted in family compliance:

> *I always try and explain, but she [family member] does at least know what the rules are now, and the limits, and she abides by them.*

In contrast, the family's strategies of consenting and complying reflected a passive response to the nurse's decisions. They rarely asked questions about the resident's care and did not question the nursing care being provided. As shown below, the family member would acknowledge that the nurse was in control of the care situation, especially at the beginning of the relationship:

> *When [the nurse] came in she was very up-front about what her role and responsibilities were…what she would be looking after and everything, and that's the way it is.*

Since the family member in a conventional relationship usually interacted with a team of nurses rather than with one primary nurse, family members reported feeling overpowered and outnumbered. One family member made a suggestion about her husband's care but soon realized the futility of this approach:

> *I suggested taking him [husband] home once and they said no, so I just dropped it.*

Competitive relationship. In the competitive relationship, the nurse and family member worked side-by-side in equal but competing care-giving roles. This relationship was characterized by underlying conflict. In the competitive relationship, unlike in the conventional relationship, both the nurse and the family had high role expectations of one another, in part because they were dependent on one another's care. Since the nurse relied heavily on the family to provide care, the family member was often perceived as a "necessary nuisance."

In the competitive relationship, both the nurse and the family actively engaged in strategies to gain control of the caring situation. This contrasts with the situation in the conventional relationship. Strategies used by the nurse and the family reflected a "power over" rather than a "power with" approach, including informing, avoiding, confronting, and compromising. The nurse expended a great deal of energy attempting to keep the family in their "rightful place" within the LTC setting, while the family actively resisted being put in their place. This finding suggests that competitive relationships may lead to an over-dependence on the family, a decreasing sense of accomplishment/work satisfaction amongst nurses, and a decrease in the quality of care.

In these relationships, nurses tended to inform family members of the proper care and procedures, often demanding their compliance. In order to circumvent confrontation and ensure family compliance, some nurses aligned themselves with other health-care providers, notably physicians. One nurse explained:

> *Well, usually you listen to what she has to say…but then I'll still approach the doctor as a nurse…You kind of listen and then do what you were going to do anyway, and then from there put the two together…then you can go back and say, "Well, by the way, we're doing this because of this, because the doctor feels…" So you have another one to back you [up].*

Nonetheless, avoidance and confrontation were common in this type of relationship. There were power struggles between the nurse and family; however, at times both parties attempted to avoid confrontation, with varying degrees of success. Usually the assertive behaviour of both parties led to covert or overt aggression, as expressed by one nurse:

> *Some families are very difficult to talk to and you try to avoid them. You don't mean to, you don't do it on purpose, but they kind of drive you away. When you see them, it's like there's going to be some sort of confrontation.*

When a family member monitored the nursing care, there was conflict between the nurse and the family member:

> *She [wife of resident] is concerned sometimes… If he doesn't have his creams at the bedside or we forget to take off the sticker to do a reorder she'll voice it… So when she does call you for that you better listen because she'll make sure that someone hears about it. She won't back down!*

Similarly, feelings of dissatisfaction and distrust of the nurses and the care being provided were common among family members. One family member felt the need to go behind the nurse's back to get a positive outcome. The nurse explained:

> *Usually what happens is that she'll call the dentist first and the dental hygienist will come up and look at them and see them and what not and she'll plan an in-service where — you know, we all know how to brush teeth… She'll go to whatever staff member is on too. She doesn't necessarily always just come to me.*

As well, family members supported each other in order to increase their power base:

> *Some nurses have put me off and I've had to fight for one of the other ladies… I realize that the nurses are busy but I feel that there is a lack of caring there.*

At other times, however, the two parties attempted to reach a compromise in order to ensure that care was not jeopardized. One nurse explained:

> *I think it's very important for her [family member] to feel like she's in control. She decides when…he's going to have his bath, depending on what she's doing through the week, what evenings she's here, and how much time she can spend with him. So I believe that she really has to feel that she's the guy who's in command.*

Collaborative relationship. In the collaborative relationship the nurse and family member worked together towards a common goal. This non-hierarchical relationship was characterized by mutual decision-making and a high degree of family involvement in the resident's care. Unlike in the two previous prototypes, here the family's specific contribution and expertise were recognized and valued; the nurse treated the family as a full partner in care. Rather than relegating the family-nurse relationship to secondary status in the care of the resident, both nurse and family viewed it as a central component of care. Although there was some blurring of the two roles, both parties acknowledged that some overlap was necessary for the partnership to work. Ongoing overt negotiations resulted in positive outcomes for both the nurse and the family. This finding suggests that this family-centred approach to care results in family confidence in nursing care, job satisfaction amongst nurses, and increased quality of care.

In comparison to the two previous types of relationships, in the collaborative relationship the nurse and the family solved problems by consulting with one another. The words of one family member suggest that this type of relationship is built on reciprocity, respect, and trust:

> *There's been a lot of times we talk things over, like he'll [resident] get a reaction to something and she'll ask me if he ever had it before. So we*

> *work together. There is none of this business of, well, I know better than you. We both share our own ideas.*

Similarly, another family member explained that he and the nurse worked together to find a common solution to a problem:

> *I think that it is kind of a two-way street that we're on here… I mean, it's a good relationship… we're able to arrange things for Dad together.*

The nurse within this dyad agreed with the family member's assessment of their relationship:

> *He mentioned to me not long ago that he thought his dad was having a bit more difficulty.… So together we were able to arrange physiotherapy.*

The following comment reflects the essence of the collaborative relationship; the nurse and family worked together as equals, sharing their knowledge and skills:

> *When I explained the problem that I was having and she [the nurse] explained what she was seeing, we decided then how we were going to go about it. So it was a joint effort. To date, there hasn't been one person that says, "This is how it is going to be done."*

Carative relationship. In the final type of relationship, the family was regarded as the unit of care. In other words, the nurse related to both the family member and the resident as clients in need of care. The carative relationship was characterized by a strong emotional connection between the nurse and the family member. The nurse showed genuine concern and compassion for a family member who was struggling with her/his own needs. Consequently, there were minimal expectations of the family to be involved in the care of the resident. The nurse engaged in complementary, proactive strategies such as spending time and offering assistance, while the family used passive strategies such as accepting assistance. In the words of one nurse:

> *I find usually I know the whole family history. So I'm not just dealing with the resident. I'm really dealing with the whole family unit.*

In some situations, nurses offered assistance to family members who needed help to cope with feelings of guilt or loneliness or with the deteriorating mental or physical condition of their relative. As one family member explained:

> *She [the nurse] is not just looking at me as a wife and [husband] as a patient. She's looking at both of us.*

Although this strong connection between nurse and family usually resulted in a positive outcome for the family, a carative relationship can have adverse effects for the nurse over time:

> *The wife was very alone and she would talk about that, so when she came to [the facility] she just found an ear. I was a listening ear. But there were times, and I can be honest about it…I found it draining. I was drained.*

Conditioning Factors Associated with the Development of the Nurse-Family Relationship

The development of nurse-family relationships appeared to have several conditioning factors. As illustrated in Figure 2, these were both intrinsic and extrinsic.

Intrinsic factors associated with relationship development included the nurse's philosophy of care, the family's sense of obligation to provide care, family and nurse expectations of "good" nursing care, and age relations. Nurses who appeared not to value the perceptions and expertise of the family frequently found themselves in conventional or competitive relationships. In contrast, nurses who espoused a family-centred nursing philosophy usually worked within a collaborative or carative relationship. One nurse who valued family involvement commented:

> *If you were to come in to one of our meetings, or our rounds, we don't just treat the patient. We're treating the families as well. We're thinking a lot about the families, and they're brought into a lot of the planning.*

At the same time, the family's sense of obligation and perception of nursing care influenced the development of certain types of relationships. The following comment demonstrates how a poor perception of nursing care on the part of a family member can lead to a competitive relationship in which the family provides more care than they would like:

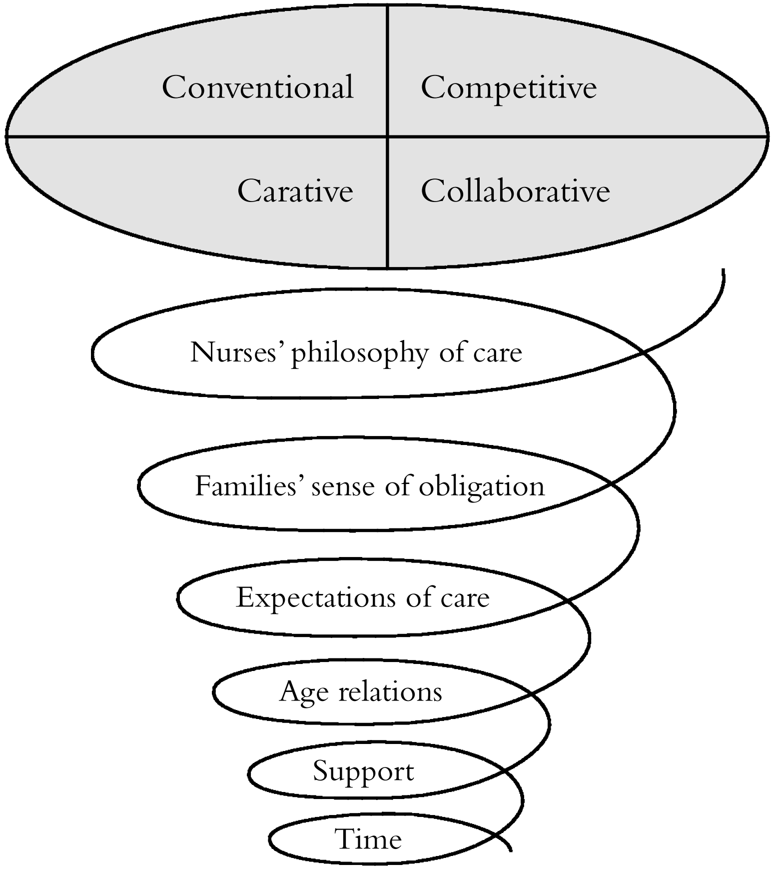
> *The nurses do take those short cuts. Once he got up from his nap and they didn't bother to make his bed; I had to be the one to straighten up his bed.*

Poorly communicated expectations between the family and the nurse also led to conflictual relations:

> *It wasn't that we were neglecting him [resident]. That's what she [family member] thought… He didn't want to be up and he was in pain… She just couldn't understand that. She thought because it was Father's Day he should be up.*

Two other nurses described their responses to family criticism of their nursing care:

Figure 2 ***Conditioning Factors Associated with Relationship Development***



> *There's a lot of nitpicky issues…at times she [family member] would come across [as] rude towards us because in her eyes his needs weren't being met. And she didn't seem to understand that there's other patients too that need our attention…saying that we don't do anything right and "my husband's suffering"… That puts us on the defensive when we're being told he's being neglected, that nothing is right.*

> *It's frustrating, when you know you're doing the best you can and he is getting good care, to always have something that is not right. Like, you never seem to get any hint of appreciation or anything like that. No pat*

> *on the back, no saying that you're doing a wonderful job and they appreciate that you're looking after him. And it's always, you could have brushed his teeth four times that day and someone trimmed a sideburn or something too short…there's always something to offset the goodness that you've done.*

Age was also associated with relationship development. In collaborative relationships the family members tended to be in the same age range as the nurse, whereas in conventional or carative relationships they tended to be older, frail women. One family member commented that being close in age to the nurse enhanced communication and trust:

> *I think that the nurse can talk to me and relate to me differently than maybe an older person — for example, an older woman or somebody that is closer to my husband's age.*

Extrinsic factors, such as the time allotted for care and administrative and collegial support, also influenced the development of family-nurse relationships.

Family members' perceptions of how the nurses spent their time varied according to the relationship. In a competitive relationship, families were often resentful of nurses' use of their time, especially at certain times of the day, and saw nurses as allied more with one another than with the resident and the family. One family member was angry because the nurses had "left" her husband in an uncomfortable situation:

> *Don't ask them to do anything at 2:30…they're sitting there all having a good lot of jokes and talking, but if you're desperate — I have changed [husband's] diaper…I found that if anything happened I'd be to fault, if he was to fall when changing his diaper.*

In the conventional relationship, in contrast, the family viewed the nurse as available to meet the resident's needs no matter how much time was required:

> *It's just unbelievable. There's no such thing as saying, "Well, we haven't time." They just seem to make time to come and do it.*

It was also evident, however, that administrative and collegial support either fostered or thwarted the development of positive nurse-family relationships. One nurse found it challenging to develop collaborative relationships with families in the face of limited administrative support for this role:

> *That's the thing, to spend as much time as you need with them…but the time you spend talking to relatives, to families, and to problem-solve, you don't get credit [from management] for that.*

Conversely, other nurses identified the type of tangible administrative and collegial support that helped them sustain a collaborative and carative relationship with families. One nurse in a carative relationship explained that support and recognition from her colleagues helped her to support the wife of a veteran who was aggressive towards other staff members:

> *I got along with the family member. The reward for that, from a colleague on that floor, was nods, approval, and saying, "It's great that you can get along with her."*

Discussion

The findings from this study extend our knowledge of family-nurse relationships in many ways. First, the identification of four prototypes of relationships between families and nurses in LTC settings — conventional, competitive, collaborative, and carative — is a significant finding in that it recognizes the mulitiplicity of family-nurse relationships in these settings. These relationships vary in terms of the nature of family involvement and degree of family-centredness. Further, the development of family-nurse relationships is conditioned by certain intrinsic and extrinsic factors. The conditioning factors described in this study provide insights into the opportunities and challenges for promoting more collaborative approaches to care.

The findings suggest that two types of family-nurse relationships reflect a family-centred approach to care, one in which the family is heavily involved (collaborative) and one in which the family provides minimal care (carative), thus indicating that the nature of family involvement does not necessarily equate with the degree of family-centred care. Although in both collaborative and competitive relationships the nurse and family were heavily involved in delivering care, only the collaborative relationship reflects a family-centred approach, with the family and nurse working together, as equal partners, in planning and implementing care. The carative relationship also featured a family-centred approach to care. Families and residents were treated as co-clients because the nurse and family focused on the needs of both families and residents. The nurse in a carative relationship did not coerce or place demands on the family to provide care to the resident.

These findings are consistent with those of Guberman and Matheu (2002), who describe three conceptions of caregiver in the family-centred approach to home care: caregiver as joint client, caregiver as resource, and caregiver as partner. The first of these is similar to the carative prototype in which family members are seen as experiencing problems linked to their caregiving role and in need of professional assistance. Caregiver as partner reflects the collaborative family-nurse relationship described in the present study. However, because of the difference in care settings, caregiver as resource — in which the responsibility for caregiving is placed mainly on the family — was not found in the present study.

The present study also identifies two types of family-nurse relationships that reflect a resident-focused approach to care, one in which the family is heavily involved (competitive) and one in which the family provides minimal care (conventional). Ward-Griffin and McKeever's (2000) co-worker prototype in home care is consistent with the competitive relationship described in this study. In these adversarial relationships, families become frustrated, since their expertise and contributions are rarely acknowledged, and families and nursing staff tend to be critical and distrustful of one another. Gladstone and Wexler (2002) describe this type of relationship in an LTC setting as "tense." Some families may be more inclined to avoid a staff member than risk conflict. In the present study, families and nurses in a competitive relationship frequently used avoidance and confrontation, which can only lead to an even more adversarial situation.

Several intrinsic and extrinsic factors appear to be associated with the type of family-nurse relationship. In the present study the nurse's philosophy of care influenced the type of relationship that was developed with the family. Also, the nurses who valued the skills and expertise of the family frequently found themselves in a collaborative relationship, while those who did not recognize nor value the knowledge and expertise of the family were often in conventional and competitive relationships. While nurses within these latter relationships generally conveyed a sense of understanding the family-centred approach, preoccupation with their status within the organizational hierarchy impeded their conscious awareness of and application of this understanding (McWilliam et al., 2001).

Intrinsic factors related to the family also played a role in developing certain types of relationships. For instance, families who felt strongly about contributing to their relative's care and who also perceived the nursing care as inadequate rarely found themselves in a collaborative relationship. Families who had years of caregiving experience tended to question procedures and policies as well as the individual nurse's knowledge and skills. Families therefore experienced many obstacles and challenges as they attempted to provide care within a hierarchical organization. It was apparent that families and nursing staff tried to influence each other's actions in order to maximize their respective interests, which resulted in a "we-they" power struggle between the parties in a competitive relationship.

The findings also suggest that certain extrinsic factors, such as time allotted to care and degree of collegial and administrative support, play a role in defining the type of relationship that will develop. As previously mentioned, data were collected from families and nurses from two units in one LTC setting. Nurses who were part of a competitive relationship rarely felt that they had enough time to spend with the family and did not feel supported by their colleagues or supervisors to do so; interestingly, this type of relationship predominated in one of the units. In contrast, nurses who were part of a collaborative or carative relationship reported the importance of administrative and collegial support.

The findings of this research provide several insights regarding the delivery of long-term care, not only to veterans with dementia, but to different populations. Since relationships in which the family is a central component of LTC appear to be beneficial for all, nurses need to reflect critically on their philosophy of care and current practices with regard to families. Any critical analysis of social relationships should consider the influence of social power. Central to this discussion is an appreciation of the types of knowledge and authority that both families and nurses bring to the relationship. Most nurses can relate to situations in which competitive relationships with families are established, and are able to differentiate these relationships from more collaborative or carative ones. By understanding the difference between "power with" and "power over" approaches, nurses will be able to develop more empowering negotiating strategies with families. Advanced practice nurses and nurse educators could play a part in this effort through educational sessions. In-service discussions that examine the intrinsic factors that shape different types of family-nurse relationships, review empowering negotiation strategies, and cite case examples can help nursing staff to develop positive relationships with families. As part of these discussions, implementation of best practice guidelines such as those published by the Registered Nurses Association of Ontario would serve to reinforce and inform changes in practice. Two sets of guidelines that would be beneficial are those relating to client-centred care (Registered Nurses Association of Ontario [RNAO], 2002a) and supporting families in care (RNAO, 2002b).

Another insight provided by this study is the importance of building relationships based on mutual respect, including respect for the knowledge and skills of both parties. In order to support families, nurses must understand that families differ in terms of their needs and desires regarding the care of their loved one. Findings from this study suggest that not all families expect, want, or feel the need to provide care and should not be coerced into doing so. On the other hand, some families wish to be active partners in care. The partnership must be flexible enough to promote a genuine sharing of both authority and expertise (Thorne, 2002). The family's motivation and comfort level should be assessed, and the meaning of family-centred care for all involved should be explored and addressed by both families and nurses.

The findings also highlight the importance of collegial and administrative support in initiating and sustaining family-centred care. The mentorship of nursing staff leaders may help to foster family-centred practices. Changes are most effective, however, when they are initiated and supported by administrative personnel in the LTC facility in collaboration with key stakeholders (Broad, 1997). Unit managers, clinical leaders, and multidisciplinary partners both in LTC settings and in the community need to develop policies that will create and sustain a culture that values family-centred approaches to care. Measures such as ensuring that adequate time and resources are spent cultivating positive family-nurse relationships, having nursing staff document all their care transactions with families, and including family-centred care as part of staff performance reviews may all help to sustain a family-centred approach to care and to achieve genuine partnerships between families and nurses. Allocation of time for family assessments, charting, and conferences, as well as sufficient funding to ensure adequate staffing, all play a role in developing a positive family-nurse relationship. Active problem-solving between families and nurses cannot occur in a vacuum; time to discuss needs and develop mutual goals must be regularly allotted within resident assignments. As well, all must support and value the time that is required by nurses and families to build effective partnerships. Thus, the philosophy, policies, and daily practices need to convey a strong commitment to building genuine partnerships between families and nurses in LTC settings.

The limitations of this study point to some directions for future research. Using a cross-sectional design, the researchers collected data at one point in time. A longitudinal design would result in a more complete understanding of the stages and changes in family-nurse relationships over time. The study was also restricted to the perspectives of registered nurses and family members in one LTC setting. No doubt the perspectives of other types of nursing staff and families in other LTC settings would differ somewhat. While the focus of this study was the development of family-nurse relationships from both perspectives, we know little about this process from the perspective of the resident. Sampling a wider range of staff, family members, and LTC residents would be helpful. As well, the influence of the work environment, such as amount of administrative and collegial support, on the development of relationships needs to be examined more fully. Finally, this study addressed the possible influence of age relations on the development of family-nurse relationships.

Since gender, race, and class are other central features of "social hierarchies" (Bury, 1995), research examining the ways in which social power is distributed between families and nursing staff is clearly warranted.

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Designer's Corner

Gerontological Nursing Research: A Challenging But Rewarding Field

Brad Hagen

> We are continually faced with a series of great opportunities brilliantly disguised as insoluble problems.
>
> — John W. Gardner (1912–)

"Good luck — you'll need it," a colleague once told me as I was embarking on one of my first research studies in a long-term-care setting. "You'll go *crazy* with all the problems of doing research in nursing homes," she added, obviously trying to discourage me from considering such research.

Well, I didn't go crazy, and that nursing-home study — one of many that would follow — was a great success. However, over the years I *have* come to appreciate some of the unique challenges of conducting gerontological nursing research, particularly with persons who are frail or in long-term care. While some of these challenges can be disheartening and even overwhelming, seeing the research through to the end is one of the many rewards that make research with older persons so satisfying. The purpose of this short article is to highlight some of the positive and negative issues confronting gerontological nurse researchers. These issues fall into three categories: ethical, recruitment and sampling, and measurement.

Ethical Issues

While research with healthy, independent older adults generally does not present unique challenges, the growing number of elderly persons with dementias such as Alzheimer disease does raise ethical concerns due to their impaired ability to provide informed consent to participate in studies (Agarwal, Ferran, Ost, & Wilson, 1996; Maas, Kelley, Park, & Specht, 2002; Moore & Hollettt, 2003; Sachs, Rhymes, & Cassel, 1993; Sachs, Stoocking, Stern, Cox, Hougham, & Sachs, 1994). These ethical concerns revolve around three issues: (1) the variability in a demented person's ability to meet the normal requirements of "informed consent"; (2) the willingness, ability, and desirability of a relative or friend to give "proxy consent" for the demented person to participate; and (3) the ethical issues raised when a demented person is excluded from research due to the problems of informed consent and proxy consent.

Regarding the first issue, researchers and research ethics boards (REBs) are faced with the thorny problem of what action to take when a person with dementia can "almost" give full and informed consent to participate in a research project (Moore & Hollett, 2003). This is a complex issue without clear guidelines. According to the Tri-Council Policy Statement, for example, "many individuals who are not fully competent are still able to express their wishes in a *meaningful* way, even though such expression may fall short of meeting the requirements for informed choice" (Tri-Council Working Group, 2000, Requirement for free and informed consent, Competence section, Article 2.7; emphasis added). The Tri-Council appears to be advising researchers and REBs that persons with dementia should have a say in whether or not they participate in research, but it offers no clear guidelines on how "meaningful" their wishes have to be to influence decisions about participation or to supersede the need for full and informed consent. Indeed, the overall issue of research consent and "competence" regarding persons with dementia remains ambiguous (Marson, Schmitt, Ingram, & Harrell, 1994), as reflected in the Tri-Council guidelines:

> Competence to participate in research, then, is not an all-or-nothing condition. It does not require prospective subjects to have the capacity to make every kind of decision. It requires that they be competent to make an informed decision about participation in particular research. Competence is neither a global condition nor a static one; it may be temporary or permanent. (Competence section, paragraph 1)

To resolve the ethical quandary over informed consent for persons with dementia, many researchers and REBs have suggested the use of proxy consent, whereby a surrogate decision-maker, usually a family member, makes a decision for the person with dementia with regard to participation in a research project. However, the use of proxy consent presents both pragmatic and legal difficulties. Pragmatically speaking, proxies can be very conservative or protective in their decision-making (Bowsher, Bramlett, Burnside, & Gueldner, 1993; Sachs et al., 1994; Warren et al., 1986), and securing their consent can be a challenging and time-consuming process. In addition, proxy consent entails important legal considerations. The laws on both competence and proxy consent vary from province to province and are often in a state of flux. Furthermore, researchers may be able to find a family member who is willing to provide consent on behalf of the person with dementia, only to discover that he or she does not have the legal right to make such a decision.

Due to some or all of these ethical difficulties, many promising research projects involving older persons with dementia simply never get off the ground. As Maas et al. (2002) state, "many older persons who are mentally infirm or institutionalized are isolated from the potential benefits of research by current ethical concerns and policies for the protection of human research participants" (p. 375). This, in turn, ironically creates another ethical concern: *the exclusion of persons with dementia from the benefits of research*, simply because REBs or nursing-home administrators may be *too* concerned about ethical matters. The Tri-Council guidelines acknowledge this issue:

> Although ethical duties to vulnerable populations preclude the exploitation of those who are incompetent to consent for themselves for research purposes, there is nonetheless an obligation to conduct research involving such people because it is unjust to exclude them from the benefits that can be expected from research. (Tri-Council Working Group, 2000, Section C: "Research Involving Those Who Are Incompetent to Consent for Themselves," paragraph 1)

Unfortunately, the Tri-Council offers no specific guidelines on how best to strike this fine balance. This remains the task of researchers, policymakers, and REBs.

One final ethical consideration in gerontological research — regardless of whether the participants suffer from dementia — is the impact of the research team's departure once the study is completed, particularly if it is conducted in a long-term-care centre. For elderly long-term-care residents, who may be experiencing monotony and loneliness, participation in a research project can be a vital source of social contact and stimulation. When the research team leaves at the end of a project, such participants can be left with feelings of loss, particularly social loss. In a recent study, Hagen, Armstrong-Esther, and Sandilands (2003) found that the withdrawal of a beneficial and enjoyable activity in nursing homes — in this case an exercise program for the institutionalized elderly — appeared to actually make people worse off than if they had never been offered the activity. While life-satisfaction scores increased as persons participated in the exercise program, after the program was stopped (because the research funding had come to an end) life-satisfaction scores fell to levels lower than those for persons who had never participated in such a program. Similarly, Higgins (1998) found that when her qualitative research study with elderly long-term-care residents ended, many residents seemed to grieve the loss of the conversation and intimacy associated with participation in the project. Clearly, researchers need to anticipate and plan for effects (and their ethical implications) associated with the termination of research projects involving the elderly.

Recruitment and Sampling Issues

Gerontological nursing research presents some challenging issues involving under- or over-representation of population subgroups. Women, certain cultural groups (e.g., Aboriginal persons), persons with dementia, and persons in rural areas are often under-represented in gerontological research samples (Bowsher et al., 1993). In addition, while large numbers of frail elderly persons live at home — many more than live in institutions — recruiting from this largely invisible population is notoriously difficult, as these people may have little contact with the formal health-care system and typically do not respond to such recruitment strategies as newspaper advertising (Hawranik & Pangman, 2002; Phillips, 1992). Thus, traditional samples for gerontological nursing research tend to be over-represented with either the well elderly living in the community or older persons without cognitive impairment living in long-term-care institutions.

Residents of long-term-care facilities also present unique recruitment challenges. The administrators of these institutions, fearful of or uncertain about the ethical and legal issues surrounding competence and informed consent, may deny access to residents and/or records even before the residents are given a say in whether they will participate (Bowsher et al., 1993; Maas et al., 2002). Further, even if administrative support for the research is forthcoming, staff members, often coping with sub-minimal staffing conditions, may find it difficult to attend to routine care needs, let alone additional research demands. Thus, the research team may not be able to count on staff for assistance with any part of the research — including recruitment of residents — and may have to adapt their research activities to the realities of staff workloads and routines.

In addition, recruitment of a sample of long-term-care residents can be challenging due to the comparatively small size of long-term-care facilities, which average approximately one hundred residents. This restriction is compounded by the fact that many residents, because of cognitive impairment or general frailty, may find the data-collection methods (e.g., interviews) too demanding, be unable to provide informed consent, or fail to meet inclusion criteria (Bowsher et al., 1993; Hawranik & Pangman, 2002). In order to obtain a sufficiently large sample, a researcher may have to consider a multi-site study, which can be complex, logistically difficult, and costly. The use of numerous long-term-care facilities to obtain an adequate sample also threatens the homogeneity of the sample, since facilities vary in terms of the kind of resident they specialize in (Bowsher et al., 1993). Finally, when recruiting samples, researchers must take into account the attrition rates for elderly research participants, which are higher than those for younger participants and can reach upwards of 25% for nursing-home samples (Bowsher et al.).

Measurement Issues

The reliability and validity of various measures used to collect data from older persons, especially the frail elderly, can be a substantial problem, particularly when the measures have been developed with younger populations (Bowsher et al., 1993; Burnside, Preski, & Hertz, 1998; Phillips, 1992). Among the frail elderly, low energy, fatigue, cognitive impairment, illiteracy, sensory deficits, and even test anxiety can all affect the reliability of a research measure. Measurement validity can be threatened as well. For example, while the commonly used mini-mental status examination may give us valuable information about certain aspects of mental status, it does not necessarily tell us how a frail older person will perform in the context of their own home — such as whether they will remember to turn off the stove (Phillips, 1992). Likewise, many outcome measures in gerontological research are based on gross screening tools that may lack the sensitivity necessary to pick up the small, subtle changes that can result from many nursing interventions with older adults. Finally, as Phillips (1992) points out, many commonly used outcome measures may in fact be inappropriate for elderly persons. As an example, a decrease in depression scores is often seen as a desirable outcome, yet for many older adults depression may actually be an effective coping strategy (Phillips, 1992).

Conclusion

This short article is intended merely to raise awareness about the various issues and challenges confronting gerontological nurse researchers. For more information, the reader is encouraged to consult some of the excellent references listed below. Despite the many challenges, particularly those of an ethical nature, gerontological nursing research is a richly rewarding and exciting field of study. Join just one of the many research teams comprising wonderful individuals who are passionate about the elderly, or attend just one meeting at which the results of your research are implemented to improve the nursing care of older persons, and you will be hooked. So give gerontological nursing research a try. And don't worry — you won't go crazy; in fact, you'd be crazy not to give it a try!

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Happenings

CIHR's Institute of Aging: Improving the Health and Quality of Life of Older Canadians

Réjean Hébert and Anne-Cécile Desfaits

In the next 25 years Canada will experience a remarkable demographic change as the senior population grows. The proportion of persons aged 65 and over will increase from 13% in 2001 to 22% in 2026 (Statistics Canada, 2003). An important question is whether this aging society will be accompanied by improved health and quality of life and by sufficient social and economic resources in terms of health services. Consequently, research on aging should be at the forefront of the health research agenda in Canada.

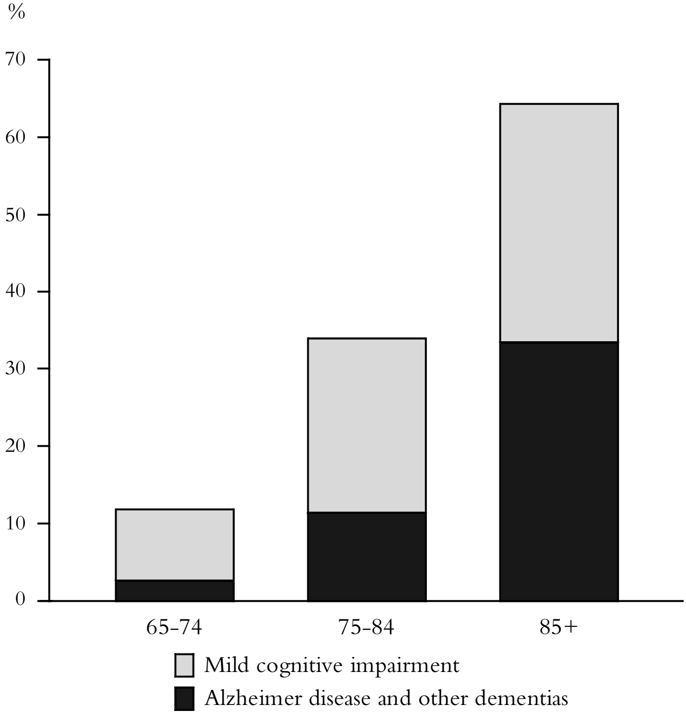
The Institute of Aging

The Institute of Aging, one of 13 institutes of the Canadian Institutes of Health Research, was created in 2001. Its goal is to advance knowledge in the field of aging to ultimately improve the health and quality of life of older Canadians. To achieve its goal, the Institute leads in the development and definition of strategic directions for Canadian research in the field of aging. The Institute also supports research on aging processes, age-related diseases and disabilities, conditions associated with aging, emerging needs of older Canadians, and health services for the elderly population. The work of the Institute encompasses the four themes of health research: biomedical, clinical, health services, and policy and sociocultural aspects of health. Through consultations with researchers and various stakeholders, the Institute has identified five priority areas for research on aging and health: healthy and successful aging, biological mechanisms of aging, cognitive impairment in aging, aging and maintenance of functional autonomy, and health services and policy relating to older people. During the first 2 years of its existence, the Institute of Aging has undertaken several strategic initiatives and programs in response to the growing needs of Canada's aging population.

Cognitive Impairment in Aging

Aging is associated with a high prevalence of cognitive impairment, including Alzheimer disease and other types of dementia such as vascular dementia (Figure 1). Cognitive impairment in aging (CIA) affects one in four Canadians over the age of 65, and the prevalence rises dramatically, to two out of three, for Canadians over the age of 85 (Canadian Study of Health and Aging Working Group, 1994). With an aging population, the number of cases of cognitive impairment is expected to double over the next 30 years. This problem not only threatens the quality of life of older people, but also has an impact on their families and caregivers, as the emotional suffering is considerable. Furthermore, cognitive impairment challenges health services and is a financial burden on the health-care system.

Figure 1 ***Prevalence of Cognitive Impairment in Canada***



Source: Adapted from Canadian Study of Health and Aging Working Group (1994).

The Institute of Aging is leading the development of a National Research Strategy on Cognitive Impairment in Aging. As part of the strategy, a CIA partnership was established in 2002 to address the need for cognitive-impairment research. The partnership brings together leading organizations from the voluntary, public, and private sectors with a shared interest in reducing the prevalence and impact of cognitive impairment. The Alzheimer Society of Canada (ASC), the Heart and Stroke Foundation of Canada, and the Canadian Nurses Foundation (CNF) are among the partners. The CIA partnership has already made notable accomplishments in the area of new funding opportunities for research in cognitive impairment. Some of the partnered initiatives that have been implemented are intended to build research capacity and include doctoral awards and Young Investigator grants. Also, the CIA partners plan to launch several Requests for Applications (RFAs), including an RFA on caregiving and Alzheimer disease. The Institute will partner with the ASC and the CNF to launch this RFA, which is aimed at supporting research into all aspects of caring for individuals with Alzheimer disease and/or their caregivers.

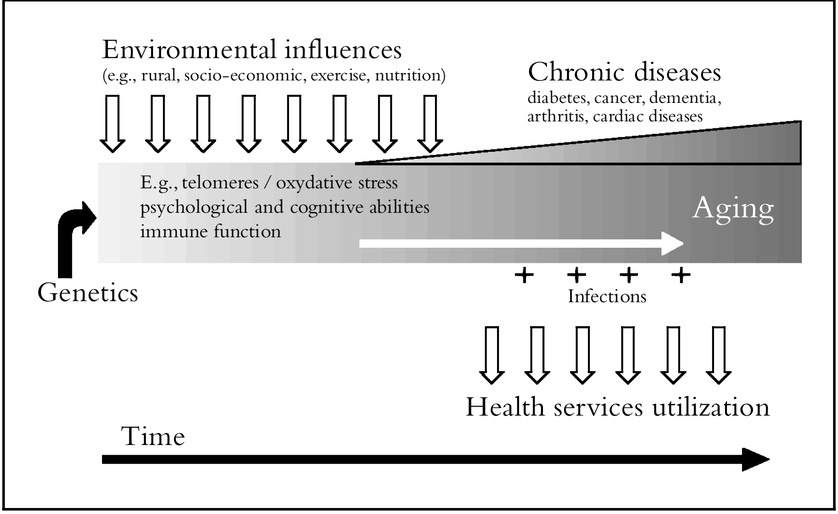
The next few years will see continued growth of the CIA partnership, with a focus on its research agenda and investment strategy.

Canadian Longitudinal Study on Aging

A framework for a Canadian Longitudinal Study on Aging (CLSA) was designed to increase knowledge in the areas of healthy aging, chronic diseases, genetics, health-services utilization, and environmental influences on health. The CLSA will assemble a large representative cohort of some 50,000 Canadians aged 45 and older who will be followed for at least 20 years as they join the senior population. The study will examine genetic, immunologic, and molecular determinants; the effects of lifestyle; the evolution of physical, psychological, and cognitive abilities; and healthcare utilization. As well, the study is expected to identify preventive strategies that will translate into practices, services, and policies (Figure 2). Ultimately, the CLSA will allow us to understand the mechanisms that underlie the process of aging and to distinguish aging from the effects of disease processes, cohort effects, and secular changes among the seniors of today and tomorrow.

Following implementation of the framework for the CLSA, a Request for Proposals for the protocol design was launched, and a team led by three principal investigators was chosen following an international review. More than two hundred collaborators and co-investigators from across the country will participate in the protocol development. It is expected that the final protocol for the CLSA will be evaluated by an international review board in early 2004.

Figure 2 ***Canadian Longitudinal Study on Aging Environment***



National Seniors' Forum on Research

Health research is essential for the provision of effective health-care and social programs. Conversing with those on the receiving end of health-care and social programs developed through research on aging was the objective of the first National Seniors' Forum on Aging, held in May 2003. This event featured interactive discussions on the Institute of Aging and recent research trends in the field of aging, the role of older people on peer review panels and ethics review boards, informed consent for participation in health research, and the gaps between research and policy. More than 80 representatives from provincial, territorial, and national seniors' organizations, as well as government officials and researchers, participated in this event organized by the Institute of Aging and its partners. As suggested at the National Forum, the Institute of Aging is now preparing five Regional Forums to be held before or during March 2004.

Capacity Building in the Field of Aging

The Institute of Aging has allocated considerable resources to building research capacity in aging. It has established a New Emerging Team (NET) grant to support the creation or development of teams of researchers undertaking collaborative multidisciplinary research in Canada. Through the NET program, the Institute and its partners are supporting several teams that have a strong component of nursing research, including NETs on end-of-life care, the care of persons with dementia in rural and remote areas, and pain assessment and treatment programs for seniors.

Funding Opportunities for Nursing Research on Aging

To meet the needs of the scientific community, research on aging has been integrated into the CIHR peer review process with the creation of two new committees, one on the biological and clinical aspects of aging and the other on the social dimensions of aging. Operating grants in the field of aging and specific strategic initiatives are now evaluated by these two committees. The Institute of Aging offers new opportunities for research funding and personnel support. For example, Pilot Project Grants in Aging are designed to support innovative ideas and to encourage established investigators to enter high-priority areas in the field of aging. In addition, the Institute recently launched a Mid-career Award in Aging to support researchers by allowing them time to devote to research and to support career reorientation for researchers who plan to enter targeted, high-priority areas of research on aging. Finally, to support health research in strategic areas in aging, the Institute, with its Priority Announcements, offers additional funding for highly rated applications that address its research priorities but did not receive funding through the CIHR open competition. It is expected that other initiatives will be proposed to the research community in aging over the coming months, and nurse researchers are encouraged to develop research within the area covered by the Institute's research priorities.

Translation and Use of Knowledge

As part of its strategic orientation, the Institute of Aging is mandated to foster the dissemination and application of research findings by end-users, including health policy-makers, health professionals, and seniors. The Institute provides support to the Annual Canadian Research Forum on Aging, which is held in conjunction with the Canadian Association on Gerontology (CAG). This forum includes a keynote speaker and symposia on timely topics in research on aging. As well, a student poster competition is organized in partnership with the CAG, the Canadian Geriatrics Society, and the Canadian Gerontological Nursing Association. The Institute will continue to facilitate the dissemination and use of knowledge for the improved health of seniors.

Since its founding in 2001, the Institute of Aging has been actively involved in leading and implementing strategic projects as part of its first strategic plan. In the coming months the Institute will assess its actions undertaken so far and will define future research priorities and strategic orientations, through consultations with stakeholders and the research community. This exercise will lead to the development of a second strategic plan to ensure the sustained growth of research on aging in Canada and its translation into better products, programs, services, and policy for the improved health and quality of life of older Canadians.

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Book Reviews

Adult Development and Aging, 3rd ed.

B. Hayslip Jr. and P. E. Panek
Malabar, Florida: Krieger, 2002. 253 pp.
ISBN 1-57524-046-7

Reviewed by Bonnie K. Lee

The third edition of Hayslip and Panek's *Adult Development and Aging* demonstrates that a textbook does not have to be a dry and neutral repository of facts and figures but can indeed have a personality. This inviting, reader-friendly, over-sized text is laid out in double columns. Boxed inserts throughout the book highlight quotations and high-interest topics. Photographs of healthy older adults at work and at play enliven the text.

An integrated, holistic conceptual framework of adult development and aging underlies the book's structure and presentation. The chapters flow naturally from the biophysiological processes of aging, then moving into its psychosocial aspects, including a discussion of personality, families, social networks, retirement, and mental health, and finally closing with death and dying. The authors discuss these various topics in a way that illustrates how changes in one stage of life weave into developments in other stages.

Multidimensionality, life-span development, and interrelatedness guide the descriptions of key issues. Physical health interacts with mental health, person with environment, socio-economic and occupational status with retirement timing and satisfaction. Examples of the pluralities of contemporary families, funeral rites, and types of mental health interventions impress upon the reader the range of options available to seniors today. Traditionally accepted definitions of normality, intelligence, learning, mental health, and family configurations are gently questioned. Although mention is made of differences in kinship networks in a few ethnic groups, the treatment of multicultural issues is cursory, especially given the authors' valuing of plurality.

The book does not treat only issues of the elderly, but covers topics across the span of adult development. Topics such as "Why Marry?," "Why Individuals Are Attracted to Each Other," and "Date Rape" are of interest to adults in their twenties. Other topics, such as "Caregiver Concerns" and "Women's Career Development," will engage middle-aged adults. However, the text is at times unclear as to how these topics pertain to aging. It is evident that the authors are appealing to readers of different ages in order to help them develop insights into their own lives and at the same time strengthen their relationships with members of another generation. Health providers will gain an appreciation of the broad spectrum of concerns facing adults across the life span.

The authors use straightforward, non-technical language in fluent narrative and avoid the use of statistical charts, graphs, and figures. Research findings are incorporated into the narratives in both a digested and a digestible form. Throughout each chapter, key terms appear in bold type in the text with periodic "Check Your Learning" sections and end-of-chapter summaries to enhance comprehension and recall. With the many interesting topical issues raised throughout, it would be a bonus to have each chapter feature questions to stimulate students to reflect, discuss, apply, assess, evaluate, compare, and synthesize the material presented. This would encourage students to take the material one step beyond recall and use the text's information for further knowledge construction and higher-level critical thinking.

The strength of this text is the authors' presentation of research-based material in a friendly and accessible way without inundating the reader with dense and overwhelming technical research details. However, this is also the text's greatest drawback in that the authors do not go into depth regarding the nature of research questions, methods, and the richness of research findings. Compared to other textbooks with a biopsychosocial orientation, this work leans towards the psychosocial. Overall, this book would make a very good introductory undergraduate text on adult development and aging due to its open, engaging style and its implicitly hopeful and positive philosophy of aging grounded in the realism of current empirical research.

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Researching Ageing and Later Life: The Practice of Social Gerontology

Edited by Anne Jamieson and Christina R. Victor
Buckingham, UK: Taylor & Francis, 2002. 275 pp.
ISBN 0-335-20821-5

Reviewed by Catherine Ward-Griffin

Researching Ageing and Later Life is the result of a collaboration between the editors, Anne Jamieson and Christina Victor, and the British Society of Gerontology to complement Sheila Peace's (1990) text on research methods in social gerontology. This book is intended to provide the reader with an update of social gerontological research in Britain and to reflect on the methodological innovations that have taken place in the last two decades.

The book has four parts. Part 1, comprising two chapters, introduces the reader to the field of social gerontology and addresses basic questions such as "the who, what and how of social gerontology." Part 2 provides examples of many different ways that researchers make use of data sources: social surveys conducted in England between the 1890s and the 1940s, photographic images of fishing communities between 1850 and 1950 in Scotland and northeast England, a mass-observation archive, and "cultural products." In addition, chapter 4 in this section is a useful overview of secondary data analysis (definition, examples of types of qualitative and quantitative data sources, advantages and limitations of secondary data analysis, types of research questions, and ethical issues). Part 3 presents five different ways of "doing research" when collecting data from individuals (longitudinal, life history, case study, use of diaries, and evaluation). Each chapter is written in a how-to style, providing practical examples of the use of the research method. Part 4, titled "The Roles and Responsibilities of the Researcher," addresses specific methodological and ethical issues in social gerontological research, such as investigating aging in different cultures and the use of gerontological research in policy and practice. Overall, the book takes a comprehensive approach to social gerontology that will be useful to educators and researchers in a variety of disciplines, including nursing.

One of the strengths of *Researching Ageing and Later Life* is its description and critique of theoretical and methodological developments in British social gerontology. Although the book does not look at comparative or global aspects of social gerontology, it addresses common theoretical and methodological trends and issues shared by social gerontologists worldwide. It is an excellent resource for both its rich descriptions of specific research studies and its practical suggestions for potential data sources and methods. Indeed, it has much to offer Canadian gerontological nurse educators and researchers. The book is a valuable resource for both senior undergraduate and graduate students with an interest in gerontology. Since many of the chapters provide extensive descriptions of gerontological research projects, students are introduced to current issues and trends in the field. For instance, a chapter by Peace illustrates the increasingly prominent role of older people in research and a chapter by Nolan and Cook addresses the challenge of having gerontological research put into practice. The participation of older people in research and the utilization of research are key issues for nurses.

Researching Ageing and Later Life is invaluable not only for established nurse researchers but also for new investigators interested in aging and health. British scholars in the field of gerontology provide detailed accounts of the potential of different data sources and research methodologies; they also provide practical examples of their research. Researchers will find this book a useful complement to more theoretically focused works on research methods.

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