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GUEST EDITORIAL

Sharpening the Focus of Research on In-Home and Community Care for Older Persons

Carol L. McWilliam

Reflecting trends in health and social policy, services, and care, this issue of *CJNR* focuses on in-home and community care for seniors. Building on the key messages of Volume 35, Number 4, published in 2003, the articles in this issue describe recent research contributions to the promotion of healthy aging, particularly emerging health and social policy and service agendas related to "aging in place."

The importance of this direction cannot be overstated. Increasingly, Canada's older citizens are aging in place. Over 90% of those aged 65 and over live in the community (Veniga, 2006). Residing at home optimizes older persons' health (Cohen, Gottlieb, & Underwood, 2001; Public Health Agency of Canada, 2006), independence, control, and sense of well-being (Chappell, 2001), as well as their social connectedness, which positively influences health (Berkman & Glass, 2000; Holmes, 2003; Kawachi, 2000; Public Health Agency of Canada, 2006).

Yet several realities continue to impede this direction. Within the persistently biomedically and institutionally focused health-care arena, in-home and community-based care still suffer from underfunding of services, underfunding of research to inform the evidence-based evolution of policy and practice, and limited consideration of the importance of comprehensive coverage for services in these sectors. Recent attention to the home care sector has fostered acute-care substitution to offset institutional downsizing, redirecting scarce resources away from the maintenance and supportive care required by frail older people, much of it essential to keeping them in their own homes. This emphasis, coupled with the sustained biomedical orientation of services, has meant that care for such major mental health challenges as cognitive impairment and depression is minimal at best. Recent attention to primary health care reform has similarly missed the mark, the focus narrowed to the organization and delivery of physician services, with little consideration given to the broader determinants of health, health promotion, and the important roles of in-home and other community-based care. Efforts to improve chronic disease management have fared no better. The movement has concentrated on the treatment of disease and self-care management, largely ignoring health promotion, secondary prevention, and *partnering* approaches between and amongst all professionals *and* people with chronic diseases.

The articles in this issue of the Journal sharpen the focus on health-oriented in-home and community care aimed at optimizing service quality rather than system efficiencies. In their Discourse contribution, Forbes and Neufeld plead for the long-overdue integration of medical, health, supportive, community, and institutional care, in order to achieve greater continuity of care relationships, and for more attention to chronic care management, social needs, health promotion, and prevention of disease and disability. In the Happenings column, Edwards and MacDonald call for new research and for knowledge translation partnerships with community agencies outside the health sector, identifying the research shifts and policy frameworks that might be targeted.

Two research articles address critical health challenges that undermine aging in place, namely dementia (Forbes et al.) and depression (Guirguis-Younger, Cappeliez, & Younger). Another two address health-care-delivery issues related to the broad determinants of health, in particular topics around service concerns in the sociocultural context of small-town Canada (Skinner et al.) and helping networks within home care (Cott, Falter, Gignac, & Bradley).

The findings of these studies, and the conclusions that can be drawn from them, point to the need for refinements to in-home and community-care policies and services for older people. Less than one third of Canada's elderly persons with dementia receive publicly funded in-home services, and just over one third receive privately funded services, while cost is ranked as the second-greatest barrier to receiving needed in-home care (Forbes et al.). A bibliotherapy intervention for treating depression amongst community-residing older people by engaging them as partners in their own care (Guirguis-Younger et al.) merits a much larger effectiveness trial and qualitative exploration of the interaction of feeling, thinking, and doing in achieving and maintaining health amongst those confronting this debilitating affliction. Discrepancies between the perceptions and the realities of health and social support in small Canadian communities invite attention to equitable access to services, the voices of older persons, and the uniqueness and diversity of Canadian communities (Skinner et al.). The fallacy of widely espoused notions of "teamwork," the traditions of hierarchical relationships, and the challenges of physically isolated, solo service delivery in the home care sector are also apparent (Cott et al.), inviting further research to test models of team functioning and related client outcomes.

The contributors to this issue of *CJNR* role model the mentoring and shared programmatic research development that is essential to sustaining and growing the efforts of gerontology researchers to inform policies, services, and practices that promote healthy aging for all Canadians. The research approaches they have used are also instructive. The articles illustrate the use of a secondary analysis of a large national survey database (Forbes et al.), single-subject experimental design for the testing and refinement of interventions (Guirguis-Younger et al.), and qualitative methodologies for exploring perceptions versus lived experience (Skinner et al.) and patterns of social interaction (Cott et al.).

So how might we proceed from here? As reflected in the following pages, gerontology researchers do have evidence suggesting directions for refining the quality and scope of in-home and community care policies, services, and practices to meet the needs of older people. To fulfil this goal, however, we need to further develop and test strategies for knowledge translation, so that our current and future efforts lead to real change. We also need to design and seek funding for larger-scale studies on in-home and community care, remaining true to a broad understanding of health and a commitment to informing refinements to relevant, quality health and social services for older people residing at home. We especially need more studies testing innovative interventions and evaluations of alternative service and delivery models. To achieve these aims, we need to consciously avoid succumbing to systemic pressures to prioritize system cost-efficiencies and accountability for scarce resources, and to focus instead on how seniors are experiencing aging in place and what that means for policies, services, and care that optimizes their health, independence, and social connectedness.

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Discourse

Looming Dementia Care Crisis: Canada Needs an Integrated Model of Continuing Care Now!

Dorothy A. Forbes and Anne Neufeld

According to the 2006 census, Canadians aged 55 to 64 are the country's fastest-growing population group (expected to reach 30% by 2017), followed by those over 80 (Statistics Canada, 2007). The 9.9 million baby boomers (those born between 1947 and 1966) are beginning to turn 60 (Foot & Stoffman, 2004). They are entering the age of greatest risk for dementia. Eight percent of Canadians 65 years of age and older and 35% of those over the age of 85 have or will have dementia (Canadian Study of Health and Aging [CSHA], 1994a). Thus, we have a narrow window of time to prevent dementia from causing a health and economic crisis of unprecedented proportions (Alzheimer Society of Ontario & Knowledge Exchange [ASO & KE], 2007).

Over the past two decades the proportion of older adults receiving care in institutions has been declining. In 2001 less than 10% of senior women and 5% of senior men resided in health-care institutions (Cranswick & Thomas, 2005). Thus, greater numbers of persons with dementia are living in their communities, with most of their care being provided by family and friends. Currently, family caregivers provide up to 90% of the in-home care for persons with dementia (Keating, Fast, Frederick, Cranswick, & Perrier, 1999). There is strong evidence that supportive services are an essential and cost-effective component of home and community-based care for persons with dementia and their family caregivers. Within the current health-care system, however, many challenges impede the delivery of high-quality care in a cost-effective manner. These challenges to in-home care call for an integrated model of continuing care that includes the dimension of continuity of relationship between care recipients and care providers (Gantert, McWilliam, Ward-Griffin, & Allen, submitted, under review; McWilliam et al., 1997).

The need for such a model, one that recognizes the contribution of home care in the context of a national framework and addresses the necessity of qualified health-care providers who are able to develop trusting partnerships (Forbes, Markle-Reid, et al., in press; McWilliam et al., 1996; McWilliam et al., 1999), cannot be overstated. Advanced dementia results in extreme functional disability, behavioural disturbances, and dependence on informal caregivers (Forbes, Markle-Reid, et al., in press). Persons with dementia eventually become dependent on others for every aspect of their care (ASO & KE, 2007). Compared to caregivers of the cognitively intact elderly, caregivers of a family member with dementia are more likely to experience chronic health problems, depression, and social isolation (CSHA, 1994b). Although the costs for home care clients are 40% to 70% less than those for patients/residents in facilities (Hollander, 2001), health-care costs will rise substantially if family caregivers are not adequately supported when caring for persons with dementia (Hux et al., 1998; Ostbye & Crosse, 1994).

The components of such a model are readily apparent. The largest community-based health service is home care, defined as "a range of health and support services received at home with costs being entirely or partially covered by a national/provincial/territorial health plan" (Canadian Institute for Health Information [CIHI], 2004, p. 2). Core program services include maintenance, rehabilitation, long-term supportive care, acute-care substitution, and end-of-life care (CIHI, 2004). Home care programs have undergone enormous growth over the last 30 years, for several reasons: the downsizing of Canada's inpatient hospital sector and the shifting of care to the home and community, medical and technological advances, and a growing elderly population. Most Canadians prefer to recover from an illness or surgery at home (Canadian Home Care Association [CHCA], 2004), and the frail elderly wish to remain in their own homes as long as possible (Forbes, 1996; Health Council of Canada, 2006). There is strong evidence for the cost-effectiveness of home care and the importance of home support services as a substitute for the more expensive services provided in long-term-care facilities (Béland, 2007; Greenwood, 2006; Hébert et al., 2007; Hollander, 2001; Hollander, Chappell, Havens, McWilliams, & Miller, 2002; Landi et al., 1999; Landi et al., 2001; Pedlar, 2006; Rigg, 2006; Scuvee-Moreau, Kurz, Dresse, & National Dementia Economic Study Group, 2002; Stuart & Weinrich, 2001; Weissert, Lesnick, Musliner, & Foley, 1997). For example, when 1,121 home care clients who received additional supportive services to remain at home were compared with similar long-term-care residents, a saving of $30 million per year was revealed (Greenwood, 2006).

However, although home care programs continue to expand, the growth has not kept pace with the demand (Forbes et al., 2003). In 2002 one in every three family caregivers identified the need for additional home care services (Decima Research Inc., 2002). An analysis of data from the 2003 Canadian Community Health Survey that examined a subset of persons with dementia found that only one third (31%) of Canadians diagnosed with dementia received publicly funded home care; a slightly higher proportion received home care not covered by government (35%) (Forbes et al., 2008). This finding is of great concern given that all were diagnosed with dementia, 42% were over the age of 80, the majority reported needing help with activities of daily living, and nearly half had difficulty dealing with an unknown person and with initiating and sustaining conversation.

Despite the clear need for home care services, Canada's spending on home care is among the lowest of all member countries of the Organisation for Economic Co-operation and Development, with only 3.5% of public health expenditures directed towards home care (Health Council of Canada, 2006). Although Canadian home care programs strive to offer broad health and social services (Shapiro, 2003), limited resources and a directive from the 2003 First Ministers' Accord on Health Care Renewal (that ignored the needs of persons with chronic conditions and their caregivers) have forced these programs to target post-acute care as a priority (CHCA, 2003; Forbes et al., 2003). As persons with dementia primarily need support services related to their cognitive impairment, not "medical" services related to physical impairment, this mismatch between needs and rationed services may be why so few survey respondents received publicly funded home care (Coe & Neufeld, 1999; Forbes et al., 2008).

Family caregivers of persons with dementia also face challenges in securing satisfactory assistance from the resources that are available. Ethnographic studies that included in-depth interviews and focus groups with female family caregivers report such difficulties as insensitive interactions, ineffective or inappropriate resources, and insufficient support (Neufeld & Harrison, 2003; Neufeld, Harrison, Hughes, & Stewart, 2007). Male caregivers were found to experience similar non-supportive interactions. Although the men valued interactions with individuals who guided them through the maze of caregiving decisions to be made, such experiences were inconsistent and sporadic. What the men wanted was a personal "coach" to assist them in negotiating all the decisions that are necessary when one is caring for a relative with dementia. They sought a person who would be consistently available to them over time, relate with sensitivity to their changing situation, facilitate the whole caregiving experience in relation to multiple sources of support, and be their advocate (Neufeld, Kushner, & Rempel, 2007). In a mixed-methods study (Forbes et al., 2008, in press) examining the role of home care services in dementia care, family caregivers reported most frequently that home care services were not accepted and were discontinued because of inconsistency of care providers (Forbes et al., in press). Other issues identified by family caregivers included insufficient information on the disease process and lack of guidance on how to handle difficult behaviours. Additional concerns identified were inappropriate treatments and provision of care; lack of respectful, gender-sensitive, and culturally sensitive care; inflexible programs, especially for employed caregivers; and the high cost of supportive services (Forbes et al, in press). All of these challenges accentuate the need for a continuity of relationship model that ensures consistency of care providers who are willing and qualified to develop trusting partnerships with persons who have dementia and their family caregivers in the home setting.

Another challenge facing provider agencies is ensuring that health-care providers are basing their practice on the best available evidence. On Canadian nurse registration examinations, the low grades for questions related to the care of persons over 80 reveal that nursing graduates are not well prepared to care for this population (Canadian Nurses Association, 2006). Undergraduate nursing programs need to place greater emphasis on the care of seniors and to integrate education programs such as P.I.E.C.E.S.™ (Hamilton, Harris, & Le Clair, 2006) throughout the curricula. Continuing education programs for home care providers (such as P.I.E.C.E.S.™ and U-First; Hamilton et al., 2006) that address ways of managing the difficult symptoms of dementia and non-supportive aspects of service provision may be costly in the short term but could offer a cost-effective way of promoting home care best practices in the long term.

A shift is needed in Canadian health-care policy, from a focus on individual sectors to a broader, integrated model of continuing care. Hollander (2003a) argues that administrative and fiscal control over a large, integrated system of care would facilitate the cost-effective substitution of home care for acute care and long-term residential care (Hollander, 2003a, 2003b, 2006). However, Chappell (2000) cautions that the provinces would have to ensure that the home care funds received from the federal government are indeed used for home care and not for the funding of other sectors.

The essence of the continuing care model is the integration of medical, health, supportive, community, and institutional care into one system. Such a model would ensure that care continues over time and across types of service (e.g., hospital to home care; Hollander, 2006). This is possible if there is a shift in values, from the current focus on acute care to an inclusive vision of home and community-based care that puts more emphasis on chronic care management (Shamian, Shainblum, & Stevens, 2006) and includes not only medical care but also social care, health promotion, and disease/disability prevention (Chappell, 2000).

A national home care framework of this nature, along with national standards to support its implementation, would ensure that all Canadians have access to appropriate, high-quality, timely services and a consistent relationship with a care provider regardless of where they live or the environment in which the care is provided. The necessary services would be available with a seamless transition between levels and settings of care for persons with dementia and their family caregivers. The national standards would address the inconsistencies across provinces and regions that now exist in program goals and in care providers, eligibility criteria, costs, and types of service. The national framework would have features such as single point of entry, comprehensive assessment of persons with dementia and their family caregivers, and care management (rather than case management) that includes the broad determinants of health. A national framework could also address the need for more professional care providers and the low wages, lack of fringe benefits, and lack of career trajectories that define the non-regulated and professional home care workforce. Ultimately, a national framework would direct more funding to home care.

As baby boomers enter the age of greatest risk, and as the demographics of family caregivers change due to fewer children, Alzheimer disease and related dementias threaten to become the health crisis of the 21st century (ASO & KE, 2007; Keefe, Légaré, & Carrière, 2007). Until governments recognize home care as a major component of the health-care system, and until they embrace an integrated continuing care model that incorporates a continuing-relationship approach, the needs of persons with dementia and their family caregivers will remain unmet. As a result, costs to the health-care system will increase, especially if family members are unable to continue in their caregiving role. There is a narrow window of time in which to address these issues. We must act now.

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Résumé

L'aide aux réseaux dans la prestation de soins communautaires à domicile aux personnes âgées : les différents types d'équipes

Cheryl A. Cott, Laura-Beth Falter, Monique Gignac et Elizabeth Badley

Les changements survenus dans la prestation des soins de santé ont entraîné une modification du lieu où sont offerts ces soins : de l'établissement de santé, il est passé à la communauté. Dans ce contexte, il est devenu nécessaire de réexaminer les modèles actuels en matière de pratiques liées aux soins de santé afin d'en déterminer l'applicabilité et la pertinence en milieu communautaire. L'objectif de cette étude était de déterminer la pertinence des modèles traditionnels fondés sur les équipes multidisciplinaires en examinant les interrelations entre les aînés de la communauté atteints d'arthrite, leur famille ainsi que les fournisseurs de soins de santé et de services communautaires (FSSSC). Des entrevues en profondeur ou des groupes de discussion ont été réalisés avec la clientèle, les membres des familles et les FSSSC. Les participants ont décrit quatre différents types d'interaction dans le réseau d'aide, dont aucun, outre les interactions avec les personnes âgées elles-mêmes, n'est apparu comme le plus courant. Trois types d'équipes sont ressortis : les équipes centrées sur le client, celles centrées sur le gestionnaire de cas, et celles par discipline. On ne trouve dans les résultats aucune mention de l'existence d'équipes interdisciplinaires conjointes structurées, les FSSSC favorisant le modèle par discipline.

Mots clés : équipes multidisciplinaires

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Helping Networks in Community Home Care for the Elderly: Types of Team

Cheryl A. Cott, Laura-Beth Falter, Monique Gignac, and Elizabeth Badley

Changes in the delivery of health care have led to a shift in the location of care from the institution to the community. This has resulted in a need to re-examine current models of health-care practice in terms of their applicability and relevance to the community setting. The purpose of this study was to determine the relevance of traditional models of multidisciplinary teams by examining interrelationships amongst community-dwelling seniors with arthritis, their families, and health and community service providers (HCSPs). In-depth interviews or focus groups were conducted with clients, family members, and HCSPs. Participants described 4 different types of interaction within the helping network, with no interaction whatsoever being the most common except for with the seniors themselves. Three types of team emerged: client-centred, case manager-centred, and discipline-specific. No evidence of formal collaborative interdisciplinary teams was found, with HCSPs most valuing the discipline-specific model.

Keywords: Multidisciplinary teams, geriatrics, home care

Introduction

Recent changes in health-care delivery have resulted in a shift in the location of care from hospital and institutional settings to the community, and more specifically the home. This shift signals a need to re-examine institutionally based models of health-care delivery and to develop models and theories that are applicable and relevant to home-based care. Care of older adults is generally modelled on a team approach, one that has been developed in institutional settings (Drinka & Clark, 2000; Qualls & Czir, 1988; Ryan, 1996) and that assumes that seniors have multiple social, psychological, and physical needs that can be met only through the close collaboration of a team of professionals (Clark, 1991, 1995). Few studies have examined issues of teams in the community, where differences in the provision of services may preclude the application of traditional multidisciplinary models (Zimmer, Groth-Juncker, & McCusker, 1985). The home is a unique clinical setting, different from acute-care or institutional environments. The home is more than just a dwelling; it has myriad meanings with respect to social arrangements, personal identity, security, and privacy (Dyck, 2001; Williams, 2004). Interactions between clients and professionals assume a different dynamic, in that professionals are now practising in the world of the client rather than in the world of the professional (Heckman & Cott, 1997). In this study we examine the relevance of the concept of health-care teams in community settings.

Literature Review

The literature examining community-based care for frail older adults emphasizes the emotional and practical support provided by family, friends, and unregulated health-care workers such as homemakers or personal support workers (Biegel, Sales, & Schulz, 1991; Neysmith & Aronson, 1996). Much of this body of work has social science rather than biomedical roots. As a result, conceptual views of elder care in the community tend to focus on social networks rather than on teams. A social network can be defined as the web of relationships that surround an individual and its characteristics such as the number of network members, the frequency of contact, and the extent to which members are interconnected (Due, Holstein, Lund, Modvig, & Avlund, 1999; Lee, 1985).

The older person with chronic illness may be part of a network of informal (e.g., spouse, children, other family members, friends) and formal care providers (e.g., family physician, nurses, rehabilitation therapists, homemakers, personal support workers) focused on helping them to manage their illness (Chipperfield & Haven, 1991; Noelker & Bass, 1989). The work of managing a chronic illness in the home encompasses more than just housekeeping and personal tasks (Neysmith & Nichols, 1994). It includes symptom management; anticipating and planning for future contingencies; coordinating and supervising the care provided by others; finding, receiving, and passing on information; and coping with disability (Corbin & Strauss, 1988). Decades of research leave no doubt that informal network members, particularly female relatives, perform the bulk of caregiving tasks for community-dwelling seniors (Frederick & Fast, 1999; Hooyman & Gonyea, 1995; Horowitz, 1985; Martin-Matthews & Campbell, 1995; Stoller & Pugliesi, 1991).

Most previous research has examined each part of the helping network separately or in dyads, looking at (for example) self-care, family support of the elderly, informal versus formal support, and relationships between seniors and service providers (Eustis & Fischer, 1991; Fischer & Eustis, 1994; McWilliam et al., 1997; Neysmith & Nichols, 1994). Studies have consistently shown that elderly persons turn to formal caregivers as a last resort, when informal networks have been exhausted (Stoller &

Pugliesi, 1991). Upon contact with formal services, the supportive relationship between older individuals and their families expands to include health-care workers who assume part of the work of managing the chronic illness. It is at this point, when health professionals are involved, that the discourse of team appears.

Ovretveit (1993) defines a community multidisciplinary team as "a small group of people, usually from different professions and agencies, who relate to each other to contribute to the common goal of meeting the health and social needs of one client or those of a client population in a community" (p. 55). He identifies three types of team in community settings: the client's team, which consists of a group of people (who may not know each other or may not meet), helping one client at a particular time; a network association team, which is a more stable grouping, often for cross-referencing clients; and a formal team, whose members meet to arrange assessments for a client population and to coordinate their work. Ovretveit does not specify the extent to which this typology of teams applies to community-dwelling seniors with arthritis who receive home care services. A few studies have examined relationships between nurses and homemakers (Ward-Griffin & McKeever, 2000), but many other health professionals, such as social workers, physicians, and therapists, also work in home care. Little is known about how this multitude of providers interact with each other and with clients and families.

A further problem with research in the community has been its emphasis on profoundly disabling conditions, such as Alzheimer disease or stroke, resulting in a body of literature that often overlooks older persons with chronic health problems who are active participants in their own care and who are likely to be in interdependent relationships within their social network. Little attention has been paid to community-dwelling seniors with chronic physical conditions such as arthritis that may require support but still allow them to be actively involved in the management of their illness. Musculoskeletal disorders like arthritis are the leading cause of disability in adults aged 65 and over (Badley, 1995). Given projected future increases in the number of Canadians with arthritis (Badley & Wang, 1998), it is important for us to find ways of enhancing the ability of these seniors to manage their disability in the home.

This study was part of a program of research examining the interrelationships between community-dwelling seniors with arthritis and their informal and formal networks, in order to develop an understanding of community-based teams. Since we were attempting to determine whether the concept of *team* is relevant in the community, we avoided using the word team in recruitment for and information about the study, instead choosing the term helping networks. Specifically, we were interested in addressing two questions: 1. *What are the patterns of interaction and communication between members of helping networks (e.g., frequency and types of contact)?* 2. *What organizational, structural, and decision-making processes are used among members of helping networks?*

Methods

We used an ethnographically framed social network analysis employing focus groups and semi-structured interviews to examine community-based helping networks from the perspective of three distinct groups: community-dwelling seniors with arthritis receiving health or social services in the community; their family members and/or friends; and health and community service providers (HCSPs) from the Arthritis Society or a Community Care Access Centre (CCAC), including regulated and unregulated health-care workers. An ethnographic approach is appropriate for studying patterns of relationships within a social group. Typically, ethnographic network mapping consists of extensive qualitative interviewing at the community level, combined with observations of people's behaviour (Cresswell, 2003; Field & Morse, 1995). It was beyond the scope of this study to conduct observations of network behaviour, so we took a focused ethnographic approach. Focused ethnography differs from traditional ethnographic approaches in that it usually relies on interviews rather than participant observation (Field & Morse, 1995).

Theoretical Perspective

We used a combination of symbolic interactionist and social network perspectives to frame our conceptualizations of interrelationships within helping networks in the community. Both of these perspectives focus on human relationships. According to symbolic interactionism, the meanings that individuals attach to the people, objects, and events in their lives develop through interaction with others. People act on the basis of their subjective perceptions of the world, which are constantly modified and negotiated through communication with others using language and other symbols (Plummer, 2000; Schwandt, 2001).

A social network approach suggests that social relations define people's roles and positions in a group. People are classified as occupying the same role or position as others in the group on the basis of having similar patterns of relations (White, Boorman, & Brieger, 1976). We define the structure of helping networks as a set of ties or relationships that occur among team members as they go about their day-to-day activities.

Context

In the Canadian province of Ontario, in-home services for seniors with arthritis are provided through CCACs and the Arthritis Society, which has community therapists who provide in-home assessment and treatment. In 1997, after a decade of less radical restructuring under New Democratic Party and Liberal governments, the Conservative government of Ontario introduced the CCAC model of service delivery. This model is based on competition, with both for-profit and not-for-profit agencies bidding for contracts to provide services for one or more of the province's 43 CCACs (Aronsen, 2002; Denton, Zeytinoglu, & Davies, 2002).

Sampling and Recruitment

To be eligible to participate, clients had to be living in the community, aged 55 or older, diagnosed with arthritis, currently receiving formal services in the home from either the Arthritis Society or a CCAC, and able to take part in an interview in English lasting 1 to 2 hours. Family members, friends, or neighbours had to be currently providing practical assistance to an older adult with arthritis currently receiving formal services from either the Arthritis Society or a CCAC in the home and be able to take part in an interview in English lasting 1 to 2 hours. HSCPs had to be currently working with older adults with arthritis who were receiving or who had received formal services in their homes through the Arthritis Society or a CCAC and be able to take part in a focus group or interview in English lasting 1 to 2 hours. We did not attempt to match HCSPs and clients during this phase of data collection, as we were interested in meanings and structures of relationships in general rather than characteristics of specific helping networks, which were addressed in another phase of the research reported elsewhere.

Potential participants were identified through the Arthritis Society (Ontario Division) and four CCACs. The overall sampling strategy was theoretical and purposive, with individuals and/or groups selected on the basis of their ability to contribute to evolving concepts. Initial contact with potential participants was made through our partners, who obtained permission to give names to the project coordinator. The project coordinator then contacted potential participants by phone, screened for eligibility criteria, and scheduled focus groups or individual interviews. Permission from the clients was required before approaching family members. Recruitment of the HCSPs was independent of client recruitment — that is, although we recruited the HCSPs and clients from the same Arthritis Society locations and CCACs, we did not specifically recruit HCSPs who were working with the clients taking part in the study.

Data Collection

Data collection with HCSPs consisted mainly of focus groups. We sampled HCSPs using break characteristics in which one samples to differentiate one group from another (Knodel, 1993). Service providers who participated in focus groups were homogeneous with respect to professional background and provision of care to community-dwelling seniors with arthritis. In some organizations, such as the Arthritis Society, where occupational therapists and physiotherapists play a similar role in the community, focus groups included members of both professions. Otherwise, separate focus groups were held, based on professional or disciplinary affiliation. Individual interviews were conducted with 10 HCSPs who were unable to attend focus groups due to scheduling difficulties (mainly the physicians) or due to insufficient numbers for a focus group (social worker and pharmacist). Table 1 summarizes the composition of the focus groups and the HCSP interviews according to profession.

We conducted individual interviews with the seniors (*n* = 11) and family members (*n* = 2) to avoid limiting the sample to those who were physically able to attend a focus group. The small number of family members interviewed reflects a methodological challenge in that family members were recruited through the seniors — that is, we asked the

Table 1 ***HCPS Focus Groups and Individual Interviews***

Provider Group	**Focus Groups**	**Interviews**
Arthritis Society physical and occupational therapists	3	
Community physical therapists	2	
Community occupational therapists	2	
Arthritis Society social worker		1
Community social worker	2	
CCAC case managers	3	
Personal support workers	3	
Nurses	2	
Family physicians		8
Pharmacist		1

seniors for their permission to interview family members, and invariably they were reluctant to provide it; as a result, the findings presented below primarily reflect the perspectives of the HCSPs and the seniors.

Procedures

The principal investigator (PI) and two research associates (RAs) conducted the focus groups following guidelines set out by Krueger (1994). The focus groups lasted an average of 80 minutes. During each focus group, one of the RAs kept a speaker log to indicate whether a particular view was expressed by a number of persons or by one person a number of times. Two trained RAs conducted the individual interviews in participants' homes or in another location of the participant's choosing. These interviews lasted approximately 60 minutes.

Interview questions were semi-structured and non-directive, to encourage participants to identify issues that were important to them. Examples of questions for HCSPs include *Who would you have contact with during a typical day?* Probes were used to elicit frequency and types of contact (e.g., *How often do you see X? What do you communicate with X about?*). The sequencing and phrasing of questions varied as the focus group or interview progressed. Prompts were used only to ask for clarification or expansion of points made by participants. As the focus group or interview progressed, the questions became more specific to teams in the community. For example, in the HCSP focus groups a more targeted question was *Would you say that you feel like you are part of a team when looking after a client's health-care needs in the home?* Similarly modified questions were posed to clients and families.

All focus groups and interviews were audiotaped and transcribed verbatim. Transcripts were checked for accuracy by the focus group leader, following which data were entered into NUD*IST Version 6.

Data Analyses

Data analyses took place concurrently with data collection and guided the sampling. We employed an iterative approach using a categorizing and editing process (Crabtree & Miller, 1999). Initially, client, family, and HCSP interviews were analyzed separately. All data sets within a particular category of participant (e.g., client, family member, or HCSP) were read and coded based on concepts, categories, ideas, and issues that emerged from the data. All the core categories were systematically related to others within that particular class of participant. Finally, comparisons were made across categories of participant (e.g., client, family, and HCSPs).

The PI and a trained RA developed the initial coding schemes for each category of participant using the following approach: first, each open-coded two or three transcripts independently; next, they met to compare and contrast codes emerging from the data, to ensure consistency; and finally, once satisfied that they were coding consistently, each coded approximately half of the remaining transcripts. Consistent with the social network approach and previous research on multidisciplinary teamwork, we were interested in identifying the nature of the ties between network members, the presence of subgroups or subunits within the network (characterized by greater interconnectedness between subgroup members), and the presence of key linking or bridging positions (people who connect subgroups).

Findings

The clients ranged in age from 69 to 88 years. Eight of the clients lived alone and three lived with a spouse. All but one reported having adult children who provided some assistance with transportation, household maintenance, and occasionally meals. All were currently receiving homemaking services from CCACs and had a family physician who saw them regularly. Most had received nursing and rehabilitation services at some point.

Patterns of Interaction and Communication between Network Members

Four types of interaction between participants emerged from the data: *direct personal, direct impersonal, indirect impersonal,* and *none at all.*

Direct personal interaction included face-to-face or voice-to-voice communication such as planned meetings, case conferences, chance meetings, and phone calls. The senior was the only person with direct personal interaction with everyone else in the network. The seniors reported seeing or talking with friends and family members more often than with HCSPs. One said, "My daughter comes nearly every day, and I have friends in the building." They reported having fairly frequent, regular contact with personal support workers/homemakers and less frequent contact with case managers and other professionals such as nurses, therapists, and physicians, although they were not always able to identify the profession of the HCSPs with whom they had contact (other than in the case of physicians). One client said, "I think she was a nurse."

Case managers were the only HCSPs to report having direct personal contact with other members of the helping network. Direct personal interaction for the other HCSPs, when it did occur, was usually by phone. Face-to-face interaction between HCSPs was rare, and usually involved a chance encounter. A physical therapist said:

> *We used to run into team members more often, and as money has gotten tighter — I mean, I have seen…one [name of agency] nurse about once*

> *in a year…but if you do run into them it's a real delight, because you do a quick little conference and solve problems that have been bugging you for ages, and you get them done a lot quicker, and [it's] a real pity…we do miss running into them.*

The organization of home care services discourages this type of encounter. HCSPs explained that they avoided scheduling clients at the same time as other providers so as not to encroach on their time, as this was seen as "double-billing."

Direct impersonal interaction was more common among HCSPs than direct personal interaction. It involved communication such as e-mail, voicemail, fax, notes, flow sheets, "communication books," formal reports, and letters. Although it was usually informal — for example, a note stuck on the fridge — occasionally there was a formal system in place:

> *In [name of city] there's a folder…it's the red folder that's usually kept on top of the fridge, and there's supposed to be a communication folder for everybody, and I've certainly seen it where the family member has written the most. It's often a caregiver who's out during the day and then comes back and has left messages, or she's out some of the day and has left messages for various members of the team, asks questions… The people who tend to write most are the personal care workers.*

Once again, the organization of services precluded the effectiveness of even this simple mechanism, as HCSPs are not supposed to read the communication books of other agencies. This regulation reflects the managed competition approach to home care. The participants gave numerous examples of how the transition to managed competition affected their interactions with clients and other HCPSs. For example, it is possible for HCSPs from different agencies to be providing services to the same client, leading to a situation of multiple communication books in the home, with HCSPs reading only the one belonging to their particular agency. In focus groups where this issue arose, participants' typical response to the question "So how many communication books might there be on top of the fridge?" was "Oh, two or three."

Some HCPSs felt that under the managed competition system other health-care workers were increasingly infringing on their practice domain. Physical and occupational therapists explained that usually only one type of therapist is sent to see a particular client, and is expected to play a dual role — that of both physical and occupational therapist. Similarly, social workers reported that nurses are now expected to perform traditional social work tasks. The clients were also aware of these issues: "It's bad to be having all this controversy over who's going to look after you and…when they are going to come and how long they can [stay]."

Indirect impersonal interaction involved the use of an intermediary. The personal support workers indicated that they had very little direct contact with other HCSPs. Aside from chance encounters, their communication with other HCSPs occurred through their supervisors. Other HCSPs confirmed that their contact with personal support workers took place through a supervisor or coordinator at the worker's agency:

> Interviewer: *Would you have any direct contact with the homemaker, or is it through —*
> Case Manager (CM): — *through the coordinator. We don't usually talk to the homemaker on the phone. Sometimes when we go to the home we see the personal support worker coming in to service and we'll meet them that way, but generally any issue is passed through the coordinator of the homemaking agency.*

Some HCSPs, particularly physicians, reported that they learned from the client about care provided by another HCSP. One family physician said:

> *I've made a referral for physiotherapy and I'll only hear from the patient that, yes, the physiotherapist is coming in 2 weeks, and they may only come for two sessions and then they won't be coming again, or the physiotherapist has discontinued their services. I'll usually hear it from the patient long before I get the note telling me that's happened.*

No interaction. The HCSPs indicated that the most common form of interaction they had with each other was none whatsoever: "We don't have contact with each other. We're basically on our own." They avoided each other so as not to encroach on each other's time with the client. When the HCSPs were asked if the notion of team was relevant to them, considering their isolation and lack of contact with other HCSPs, the response in all the focus groups was resoundingly affirmative. However, as described below, the nature and composition of teams in the community are very different to the traditional notions of health-care teams in institutional settings.

Organization, Structure, and Decision-Making among Network Members

Unlike institutional settings, where teams are generally identified through their physical proximity — for example, professionals who work with patients in a particular ward or program — community home care teams function ad hoc, according to the needs of each client. Each elderly client has a different team or group of service providers, and each service provider belongs to many different teams. In addition, over time an individual's needs change, further affecting the composition of the home care team. Based on the patterns of interaction found in the helping networks, we identified three categories of team (each with a different hub or a key linking person): *client-centred, case manager-centred,* and *discipline-specific.*

Client-centred team. The first category of team is centred around the client. The client is the hub or the link between all other team or network members, including family and friends:

> CM1: *When you're looking at a client-centred team you're looking at anyone that's providing care to that client, so whether it's physicians, pharmacists…physio, OT, homemaker, social worker, nutritionist, whoever happens to be…actually imparting some kind of care to that client or direction, they all become part of the team.*
> CM2: *Plus the client in the middle.*
> CM1: *The client is very much in the middle.*
> CM2: *Or leading.* [laughter]

These case manager comments reflect the commonly held opinion that the person with arthritis is the core of the client-centred team not only because the purpose of the team is to meet the client's needs, but also because the client is considered the primary decision-maker. The client decides what type of services he or she will accept and can, for the most part, dictate if and when providers can even enter the home. HCSPs frequently alluded to a shift in power to the client when care is delivered in the home. A physical therapist explained:

> *There's also a difference in that in hospital a patient is on your turf…[but] when you go into their home you're like a guest in their home even though you're the professional.*

However, the clients did not see themselves as part of a team, let alone as "in charge." None used the word team during the interviews, and none expressed the view that they were part of a team when asked directly. Although a few clients said they felt they were in control of their own care, most, when asked directly, stated that it was their physician who made the decisions about their care. When asked who made the decisions regarding their arthritis management, one client answered, "I guess the doctor."

Case manager-centred team. This category of team was focused on decision-making about the sorts of services that can be provided given the economic realities of delivering care in the community. It comprised the HCSPs and did not include family and friends. Participants identified the case manager as the central communicator among HCSPs. Case managers were the only network members, aside from the clients themselves, who reported frequent direct personal or direct impersonal contact with all of the other members. The case manager–centred team was hierarchical, with decision-making revolving around financial concerns rather than patient-care concerns. An occupational therapist explained:

> *With regard to the client and the leader of the team, I think that there's a dichotomy of practice, for me anyway, because we're taught very clearly that it's client-centred — the client is the leader of the team — but practicalities and the realities of the situation are economic…it's economic driven, or… there's some sort of outside force that's really dictating who is in fact the leader of the team and who is calling the shots.*

Authority clearly rested with the case managers, mainly because of their role in managing scarce financial and human resources:

> Focus group leader: *And who ultimately would make the decisions in that team?*
> OT: *[The] case manager.*
> Focus group leader: *Why is that?*
> OT: *They control the dollars and cents.*

The clients were also cognizant of the role of the case manager in controlling resources. One senior said that the case manager "tells you if you can have a therapist, or a VON [home care nurse], or a homemaker or so forth." However, they also were aware of the scarcity of resources and limited their requests accordingly. Another client explained that the case manager

> *is really limited because they've cut her down so much…. I could use a therapist right now, with my back and everything, but I haven't talked to [case manager] about it because I know it's hard for her to have people come in… The government [doesn't] want us.*

Discipline-specific HCSP team. This category refers to workers with the same professional or disciplinary affiliation employed by the same organization. In contrast to client-centred teams, these teams were described by most HCSPs as highly valued and as central to home care. Members of discipline-specific teams interacted on a fairly regular basis, both formally during staff meetings or educational sessions and informally during social events. Such direct personal, face-to-face interactions allowed them to discuss common issues, thus fostering professional development, and to problem-solve on specific cases. In addition, direct personal contact among members of the discipline-specific team provided much needed social support and helped to alleviate feelings of isolation. An Arthritis Society therapist said:

> *I think in terms of team. When our group refers to team, we're talking about almost, like, our emotional team, not a client treatment team… I think when we talk about team it's kind of the emotional resource for us, not necessarily for the client.*

Participants expressed regret that, due to recent changes in community care, routine interaction with other HCSPs was less frequent. For example, under the CCAC structure, many health-care providers no longer have a designated office where they can routinely interact with co-workers.

Discussion

Three categories of home care teams emerged in this study: client-centred, case manager-centred, and discipline-specific. Of these, the case manager-centred team most closely resembles the empirically supported hospital-based multidisciplinary team in that it is hierarchical, with a group of professionals and unregulated staff members reporting to a team leader. In the case of the manager-centred team, as with the hospital-based multidisciplinary team, unregulated staff members in the community are excluded from decision-making and goal-setting (Cott, 1997, 1998) and are discouraged from interacting directly with other HCSPs. Unlike the hospital-based multidisciplinary model, however, team composition differs for each client, and HCSPs in the community are members of multiple teams.

Returning to the types of community teams described by Ovretveit (1993), the case manager-centred and client-centred teams fall into the category of client teams: Members of the network may share the goal of assisting the client but have little if any interaction with each other. Overall, we found little indication of formal teams or of functional collaborative teamwork.

According to social network theory, the relationships that develop within teams are based on various types of proximity: physical, professional, task, social, and formal or organization-created. In other words, individuals who work in close physical proximity, in the same formal organizational unit, doing similar tasks, with people who share similar professional backgrounds and social contacts, are more apt to function collaboratively (Cott, 1997, 1998; Farris, 1981). Given that HCSPs do not work in close physical proximity in the community, are actually discouraged from interacting with each other, and belong to multiple teams, it is hardly surprising that we found little evidence of collaborative teams.

This study reveals the emergence of a new team leader in the health-care field: the case manager with a background in nursing or social work. Case managers have the authority to make decisions regarding services to be provided in the community. According to the HCSPs who participated in the study, including physicians and clients, case managers have the final say in treatment decisions, mainly because they control the purse strings.

Unlike the case manager-centred team, the discipline-specific team is non-hierarchical. It most often includes colleagues from the same discipline employed by the same organization. HCSPs identified most strongly with their discipline-specific team because it was a source of emotional support and job satisfaction. With advances in communication technologies, it is likely that in the future many home care workers will not be based at a central location and will have even less contact with their peers. In their study with home care workers in Ontario, Denton, Zeytinoglu, Davies, and Lian (2002) found that those who felt supported by their peers were more likely to be satisfied with their jobs and less likely to experience work-related stress. Home care organizations need to encourage interaction among colleagues through activities such as team meetings, professional training sessions, and planned social events, in order to enhance quality of work life and staff retention.

The HCPSs in the present study felt that clients had greater control over treatment decisions in the community because the health-care encounter took place in their home. For the HCPSs, the shift in power from the professional to the patient was a defining characteristic of the client-centred home care team. However, the clients who participated in the study did not echo this belief. Other researchers have also found that even though clients may have more control in the home setting their power is still limited vis-à-vis the health professionals (Oudshoorn, Ward-Griffin, & McWilliam, 2007). It was beyond the scope of the present study to determine absolute power relations, but the HCPSs' perception of increased client control has implications for the way in which they approach their practice: They may have to modify their approach to ensure that they develop trusting, effective relationships with clients (Heckman & Cott, 2005).

Our findings highlight the impact of the health-care system on team structure. The managed competition approach to care appears to be actually hampering the development of effective teams in the community. The loss of job security and competition among HSCPs, combined with severely limited communication, has exacerbated role-boundary tensions and created a work environment that discourages collaboration. Other researchers have also found that changes in service delivery have implications for the ability of home care workers to provide high-quality personalized care (Aronsen, 2006; Aronson & Neysmith, 1996; Denton, Zeytinoglu, & Davies, 2002). No doubt lessons could be learned from jurisdictions with a different approach to home care delivery. As health care increasingly shifts from institutions to the community, it will be crucial for decision-makers and researchers to examine whether models of service delivery based on cost-effectiveness are not counterproductive in terms of quality and long-term effectiveness.

Overall, this study reveals a lack of collaboration, a hallmark of effective teamwork, in the community. Participants, particularly HCSPs, believed the word team applied mostly to discipline-specific teams and felt most emotionally engaged with these teams. These teams, although an important source of support for health-care workers, were self-isolating. The lack of opportunity for interdisciplinary exchange, with powerful socialization into the discipline-specific view of the world, can be a barrier to the development of effective interprofessional teamwork. The two other types of team are also problematic. For example, the client-centred team is plagued by a lack of communication among members and inconsistency of membership. The case manager–centred team is rigidly hierarchical, with decision-making revolving around financial rather than patient-care concerns. This lack of collaboration in community care for the elderly with arthritis raises concerns about the quality of care available to this population, as collaborative goal-setting and decision-making are considered essential for the management of chronic conditions (Hall & Weaver, 2001).

Our inability to recruit a sufficient number of family members to include their perspectives in this phase of the research was disappointing. Ironically, our decision to focus on those seniors with arthritis who are likely to be capable of taking part in the management of their condition probably precluded our ability to recruit family members. This in itself may be an indication of the role of family when older adults are able to be active participants in their own care. Community-based teams may differ for groups of patients with conditions other than arthritis or for patients in other age groups. Future studies could examine community-based teamwork for clients of other ages and with other diagnoses.

Despite these limitations, the present study extends our understanding of community-based teams. By examining the meaning of *team* from many perspectives, including those of clients and both regulated and unregulated health-care workers, the study uncovers three types of team that, although bearing some resemblance to institutionally based teams, are unique to the home care setting. The structure of teams and their function in the community will become more critical in the future, as demographic trends in fertility, migration, and marriage limit the availability of informal caregivers and an increasing number of seniors come to rely on health and support services provided in the home (Neysmith & Aronson, 1996).

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Résumé

Différences entre les genres en ce qui a trait à l'utilisation et la disponibilité des services à domicile et services communautaires destinés aux personnes atteintes de démence

Dorothy A. Forbes, S. Lynn Jansen, Maureen Markle-Reid, Pamela Hawranik, Debra Morgan, Sandra Henderson, Beverly Leipert, Shelley Peacock et Dawn Kingston

L'étude avait pour objet d'examiner la disponibilité des services à domicile et services communautaires, de même que leur utilisation par les hommes et les femmes atteints de démence, en s'appuyant sur les données de l'*Enquête sur la santé dans les collectivités canadiennes* de 2003. Les variables d'intérêt, définies selon le modèle d'Andersen et Newman, étaient les variables de prédisposition, de capacité, de besoin et d'utilisation des services de santé, les besoins en soins de santé et soins à domicile non comblés perçus, ainsi que la disponibilité des services de santé à domicile et communautaires. Les femmes ont fait état d'une meilleure santé et recevaient davantage de soins de soutien, mais leurs besoins en soins à domicile non comblés étaient plus importants que chez les hommes. Ainsi, les soignants des hommes atteints de démence (souvent leurs épouses) étaient particulièrement exposés aux résultats négatifs, car les personnes prises en charge étaient en moins bonne santé mais recevaient moins de services. Il conviendra de prendre en compte ces différences entre les genres, dans l'élaboration des politiques et programmes, dans l'évaluation des besoins des personnes prises en charge et des soignants, de même que dans la prestations des services.

Mots clés : Enquête sur la santé dans les collectivités canadiennes

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Gender Differences in Use and Availability of Home and Community-Based Services for People with Dementia

Dorothy A. Forbes, S. Lynn Jansen, Maureen Markle-Reid, Pamela Hawranik, Debra Morgan, Sandra Henderson, Beverly Leipert, Shelley Peacock, and Dawn Kingston

The purpose was to examine the use and availability of home and community-based services by men and women with dementia using data from the 2003 Canadian Community Health Survey. Variables of interest were based on the Andersen and Newman model and included predisposing, enabling, need, and use of health service variables, perceived unmet health and home care needs, and availability of home and community-based health services. Women reported better health and received more supportive care yet had more unmet home care needs than men. Thus, the caregivers of men with dementia (often their wives) were particularly vulnerable to negative outcomes, as their care recipients had poorer health yet received fewer services. These gender differences should be considered when policies and programs are developed, the needs of care recipients and caregivers are assessed, and services are provided.

Keywords: Canadians with dementia, gender differences in use of community-based services, supportive home care, Canadian Community Health Survey

The numbers of persons over the age of 85 and the corresponding numbers with dementia are increasing in all developed countries. In Canada, 8% of persons 65 and older and 35% of persons over 85 have dementia for an average of 6.7 years for women and 4.6 years for men (Canadian Study of Health and Aging Working Group, 1994). Almost two thirds of persons with dementia are women (Hopkins & Hopkins, 2005; Tranmer, Croxford, & Coyte, 2003). With declining proportions of older women (< 10% in 2001) and men (5% in 2001) residing in health-care institutions (Cranswick & Thomas, 2005), larger numbers of persons with dementia are living in their communities, with up to 90% of their care provided by family and friends (Keating, Fast, Frederick, Cranswick, & Perrier, 1999).

Advanced dementia results in extreme functional disability, behavioural disturbances, and ultimately dependence requiring a caregiver (Forbes et al., in press). Historically, caregiving has been provided primarily by female family members. In recent years, the proportion of men providing care to a family member has increased. In 2005, 46% of caregivers were men and 54% were women (McCloskey, 2005). Compared with their male counterparts, female caregivers report greater physical (e.g., sleep disturbances), psychological (e.g., depression), social (e.g., loneliness), and financial (e.g., putting their careers on hold) consequences of caregiving (Fast, Forbes, & Keating, 1999). In general, women and men require home and community-based services for different reasons, at different times in their lives, and at different levels of intensity. Their ability to secure access to home care services varies on the basis of their sex and corresponding social and economic gender differences (Maritime Centre of Excellence for Women's Health, 1998). How women and men with dementia use home and community-based services, and their satisfaction with the availability of these services, is not well understood. Are there individual, contextual, and societal differences between women and men with dementia that influence use and availability of home and community-based services?

Community-based programs offer a variety of services to persons with dementia: Day-Away programs, Alzheimer support groups, Meals on Wheels, and health professionals (e.g., physicians, dentists, nurses, therapists). However, home care programs make up the largest component of community-based care. In Canada, home care is defined as "a range of health and support services [such as housekeeping, meal preparation, bathing, and basic medical functions; Cohen et al., 2006] received at home with costs being entirely or partially covered by a national/provincial/territorial health plan. These services enable clients incapacitated, in whole or in part, to live in their home environment" (Canadian Institute for Health Information [CIHI], 2004, p. 2). Core services include maintenance, rehabilitation, long-term supportive care, acute-care substitution, and end-of-life care (CIHI, 2002).

Home care programs have undergone enormous growth over the last 30 years. Between 1995 and 2002 the number of home care recipients increased by 60%. However, the annual average aggregate funding for home care decreased to 9.2% per year in the period 1996 to 2001 from an average of 15% in the period 1900 to 1995 (Canadian Home Care Association, 2004). The allocation of funding has not kept pace with demand (Forbes et al., 2003; Shamian, Shainblum, & Stevens, 2006). As a result, supportive home care services have been reduced or eliminated, resulting in decreased ability to meet the continuing care needs of long-term clients, such as those with dementia, and a shifting of responsibility for care and cost to the clients themselves or their family members and other unpaid caregivers (Cohen et al., 2006; Forbes et al., 2003).

The purpose of this study was to examine the differences between Canadian men and women with dementia in their use of home and community-based services, their unmet health and home care needs, and their perceptions of the availability and quality of health services in their community. Thus, a gender perspective was used throughout the study. Gender is defined as the array of socially constructed roles and relationships, personality traits, attitudes, behaviours, values, relative power and influence that society ascribes to the two sexes on a differential basis (Women's Health Bureau, Health Canada, 2003).

The Andersen and Newman Behavioural Model of Health Services Use (Andersen & Newman, 1973) and a modified version of the same model (Andersen, 1995) provided a framework for the organization of the study, selection of variables, presentation of results, and discussion. In recent years the Andersen and Newman model has been used almost exclusively to conceptually organize health services utilization research, providing benchmarks for examining service use and permitting comparison of results across studies (Gill, Hinrichsen, & DiGiuseppe, 1998). The model outlines three domains that influence service use: predisposing variables that reflect premorbid propensities to use services indexed by demographic, social, structural, and attitudinal factors (e.g., sex, age, living arrangement); enabling characteristics that encompass an individual's ability to secure services because of personal, community, or social resources (e.g., education, income, social relationships); and need characteristics that mirror the nature and severity of the illness as perceived by the person or the proxy respondent (e.g., self-rated and objective measures of health). Recognizing the important role of family caregivers of persons with dementia in accessing and using health services, Bass and Noelker (1987) add caregivers' characteristics to the predisposing, enabling, and need variables of the Andersen and Newman model.

Literature Review

The predisposing variables age and sex are strongly related to use of home care services. Historically, 85% of home care clients were 65 or older (National Advisory Council on Aging, 1994). However, the figure fell to 53% in 2007 (Bell, 2007). This finding perhaps reflects the changing focus of home care programs to post-acute clients. However, as Canadians age they are more likely to receive home care services: 42% of those 85 or older report receiving home care services, compared with 20% of those aged 75 to 84 and 8% of those aged 65 to 74 (Carrière, 2006). Women 85 or older (45%) and women between 75 and 84 (23%) account for a larger proportion of home care admissions than men of similar ages (36% and 18%, respectively; Rotemann, 2006). Men are twice as likely to receive nursing services through home care programs and women are twice as likely to receive homemaking services, implying that men are more likely to need professional services (e.g., nursing care following hospitalization) and women are more likely to need long-term support services (Forbes et al., 2003). Persons living alone are more likely to receive supportive home care than those living with others (Forbes et al., 2003; Wilkins & Park, 1998). Persons with dementia living in rural areas are just as likely to receive home care as their urban counterparts. However, the types of services vary. Those living in rural areas are more likely to receive housework assistance, while those living in urban areas are more likely to receive nursing services (Forbes, Morgan, & Janzen, 2006).

The enabling variables income, education, and social support vary in their association with home care use. Increasing income levels have an inverse relationship to receiving supportive home care (Forbes et al., 2003; Wilkins & Park, 1998), whereas levels of education and perceived social support are not associated with use of home care (Forbes et al., 2003).

Need varibles, such as functional disability, have been reported as the strongest single predictor of home care use (Carrière, 2006; Forbes et al., 2003; Hall & Coyte, 2001; Wilkins & Park, 1998). A diagnosis of dementia has also been shown to increase the liklihood of receiving home care (Forbes et al, 2006). However, Toseland, McCallion, Gerber, and Banks (2002) report that enabling variables are as important as need variables in predicting use of community services by family caregivers of persons with dementia. 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, 1998).

Research Objectives

The research objectives were: (a) to describe and compare the attributes of male and female Canadians diagnosed with dementia, (b) to examine and compare use of health services and publicly funded home care services by male and female Canadians diagnosed with dementia, and (c) to examine and compare unmet health and home care needs and perceived availability of health services in their communities by male and female Canadians diagnosed with dementia.

Method

The cross-sectional survey design used data from the 2003 Canadian Community Health Survey Cycle 2.1 (Statistics Canada, 2004). The

CCHS covers 98% of the Canadian community-dwelling population aged 12 or older but excludes persons living on Indian reserves, on Crown lands, on Canadian Forces bases, in institutions, and in some remote areas (Béland, 2002). A multistage stratified cluster sampling design was used to collect data between January and December 2003, incorporating both in-person and telephone interviews. The response rate was 80.6%, yielding a sample of 135,573 (Carrière, 2006). This study included only those respondents who reported a diagnosis by a health professional of dementia (*N* = 467: males = 247; females = 220).

Data on the dementia variable were not released in the Public Use Micro Data File for reasons of confidentiality; thus data were accessed and analyzed at the Statistics Canada Research Data Centre, University of Western Ontario. Consistent with the Andersen and Newman model (Andersen, 1995; Andersen & Newman, 1973), the predisposing variables were sex, age, living arrangement, and rural/urban residence. The enabling variables were education, income adequacy (household income), and types of care provided by family members. The need variables were dementia (all types) diagnosed by a health professional, other comorbidities such as stroke and diabetes, need for help with everyday activities, perceived health, and the Health Utility Index (HUI) scale (a measure of functional health based on eight attributes such as mobility, emotion, and cognition) — a single numerical value up to one was provided, with higher scores reflecting better health (Roberge, Berthelot, & Wolfson, 1995); test-retest reliability of .77 was obtained for the HUI scale (Boyle, Furlong, Feeny, Torrance, & Hatcher, 1995). Variables related to health services used in the preceding 12 months included overnight hospitalization, publicly funded and privately funded home care, and consultations with a health professional (e.g., physician, nurse, dentist). Respondents' unmet health and home care needs during the preceding 12 months were captured by a dichotomous yes/no response, reasons for not receiving these services were reported, and availability and quality of health services in their community were rated on a five-point Likert scale (1 = poor; 5 = excellent) (Statistics Canada, 2004).

Data Analyses

The CCHS Public Use Microdata File Documentation guidelines were followed (Statistics Canada, 2004). Sampling weights, which took into account the sampling design, were calculated for each respondent, permitting generalizability to the Canadian population and the reporting of population estimates. For persons with dementia who were incapable of participating fully due to their cognitive impairment (54%), as assessed by the trained interviewer, a knowledgeable household member served as proxy. The problem of missing data was resolved by using the "nearest neighbour" imputation method (Béland, 2002). The unit of analysis is considered to be the combination of proxy and non-proxy responses, as use of home and community-based services pertains to both the person with dementia and members of his or her household. Predisposing, enabling, and need variables, use of services, unmet needs, and availability and quality of health services in the home and community, for men and women with dementia, were described using SPSS® 15. Differences between men and women with dementia were examined using chi-square analyses of contingency tables for dichotomous data and one-way analysis of variance for continuous data. Relationships between the variables were determined using Pearson *r* correlations. The level of significance was set at .05.

Results

Predisposing, Enabling, and Need Variables

The predisposing, enabling, and need variables of the respondents are described, followed by statistically significant differences between the men and women. As shown in Table 1, nearly half the respondents were 80 years of age or older and 13% lived alone. The mean score on the Health Utility Index was 0.359 (*SD* = 0.394) and nearly half the respondents rated their health as worse than it had been 1 year earlier. The majority reported needing help with finances, housework, and meals, nearly half reported needing help with personal care, and nearly one quarter reported needing help with moving about the home. In addition, nearly half had difficulty initiating and sustaining conversation and dealing with an unknown person. The majority received assistance from family members with housework, meal preparation, shopping, and personal care, one third received nursing care, and one fifth received respite care.

There were several significant differences between men and women with dementia (Table 1). The women reported greater difficulty moving about the home and were more likely to receive personal care and respite care from family members. Men were more likely to report low scores on the HUI and to suffer the effects of a stroke.

Use of Home and Community-Based Services

As shown in Table 2, most respondents reported having a family doctor. Less frequently consulted health professionals were other physicians, eye specialists, dentists, nurses, and social workers. Approximately one quarter had been hospitalized during the preceding year. Only one third received publicly funded home care. Of those who did receive home care, the

Table 1 *Variables by Sex of Persons with Dementia*

Estimated Population	**Female (n = 43,202)**		**Male (n = 48,394)**		**Total (N = 91,596)**	
	Frequency	**%**	**Frequency**	**%**	**Frequency**	**%**
Predisposing Variables						
Aged 80+	19,916	46.1	18,205	37.6	38,121	41.6
Living alone	6,917	16.0	4,846	10.0	11,763	12.8
Rural area	8,890	20.6	8,634	17.8	17,524	19.1
Enabling Variables						
Education (completed ≤ secondary)	1,573	7.8	2,312	12.0	3,885	9.9
Income adequacy (lower [levels 1,2,3/5])	3,367	9.5	4,121	9.5	7,488	9.5
Family members provided care	12,645	74.3	12,108	81.5	24,753	77.6
Types of care provided by family members						
Housework	10,232	81.9	8,288	75.5	18,520	78.9
Meals	9,906	79.3	8,542	77.8	18,448	78.6
Shopping	9,019	72.2	6,428	58.5	15,447	65.8
Personal care	7,565	60.5*	4,651	42.4*	12,216	52.0
Nursing care	4,234	33.9	3,087	28.1	7,322	31.2
Respite	3,456	27.6*	1,453	13.2*	4,909	20.9

Continued next page

Table 1 (cont'd)

Estimated Population	**Female (n = 43,202)**		**Male (n = 48,394)**		**Total (N = 91,596)**	
	Frequency	**%**	**Frequency**	**%**	**Frequency**	**%**
Need Variables						
Needs help with finances	28,711	66.7	28,361	59.2	57,072	62.8
Needs help doing housework	27,638	64.2	28,549	59.0	56,186	61.4
Needs help preparing meals	26,249	61.0	27,420	56.7	53,669	58.7
Needs help with personal care	21,867	50.9	21,234	43.9	43,101	47.2
Needs help moving about home	11,908	27.7*	8,555	17.7*	20,463	22.4
Difficulty with conversation	18,942	44.4	20,92	42.7	39,134	43.5
Difficulty with unknown people	18,962	45.1	18,250	38.5	37,212	41.6
HUI (mean, *SD*)	0.457*	(0.405)	0.279*	(0.369)	0.359	(0.394)
Self-perceived health (somewhat worse to much worse)	18,818	44.0	23,978	49.8	42,796	47.1
Suffers effects of a stroke	7,167	16.7*	11,888	24.6*	19,055	20.9
Has diabetes	5,267	12.2	7,619	15.7	12,887	14.1

* $p < .05$

types of services, in order of frequency, were: nursing, personal care, housework, meal assistance, and respite care. A slightly higher proportion (35%) received privately funded home care.

Women were more likely than their male counterparts to be hospitalized overnight and to receive personal care and housework assistance through publicly funded home care programs. Men were more likely than women to visit an eye specialist and a dentist.

Unmet Needs and Availability of Home and Community-Based Services

Nine percent of respondents reported that their health care and home care needs were unmet (Table 3). The reasons for not receiving needed health care were: not available in the area (34%), the wait was too long (21%), cost (15%), and considered the service to be inadequate (14%). The reasons for not receiving specific home care services were: service not available (33%), cost (21%), decided not to seek care (20%), and did not know where to go (11%).

Nearly half of the respondents rated the availability of health services in the community as fair to poor and one quarter rated the quality of those services as fair to poor (Table 3). Although women reported receiving more services and rated the availability of community services higher than their male counterparts, they also reported greater unmet home care needs than the men (Table 3). Pearson *r* correlations revealed that those who reported less availability of community health services tended to have additional comorbidities; to have difficulty dealing with unknown people; to have cognitive, emotional, or mobility problems; to have pain or incontinence; to need help with activities of daily living; and to receive nursing services through home care; whereas those who reported greater availability of community services tended to be women and to receive home care support services. The rating of *quality* of community services was significantly correlated with *availability* of community services (Table 4).

Limitations

The Anderson and Newman model (Andersen, 1995; Andersen & Newman, 1973) includes additional variables that may influence use of home and community-based services that were not captured in the 2003 CCHS cycle 2.1. Excluded, for instance, were the amount and duration of home care received and whether the received services were necessary or appropriate, information on respondents' informal caregivers, their coping strategies, and perceived self-efficacy in managing and accessing services. Also not captured were societal costs related to the use of health and social services as well as direct costs (e.g., for support services,

Table 2 *Use of Home and Community-Based Services by Sex of Persons with Dementia*

Estimated Population	**Female (n = 43,202)**		**Male (n = 48,394)**		**Total (N = 91,596)**	
	Frequency	**%**	**Frequency**	**%**	**Frequency**	**%**
Consultations with health-care providers (1+ visits)						
Family doctor	41,960	97.1	46,128	95.3	88,087	96.2
Other physician	18,442	43.3	21,707	45.3	40,150	44.4
Eye specialist	19,018	44.1⋆	26,786	55.5⋆	45,804	50.1
Dentist	14,917	34.5⋆⋆	22,987	47.8⋆⋆	37,904	41.5
Nurse	10,592	25.6	16,164	33.7	26,756	30.0
Social worker	6,917	16.2	10,859	22.4	17,776	19.5
Hospitalized in previous year	15,594	36.1⋆⋆⋆	9,822	20.3⋆⋆⋆	25,416	27.8
Received publicly funded home care	14,487	33.5	13, 601	28.1	28, 088	30.7
Types of home care received						
Personal care	7,956	54.9⋆	5, 211	38.3⋆	13,167	46.9
Nursing care	6,776	46.8	6, 673	49.1	13,448	47.9
Housework	6,462	44.6⋆	3, 529	25.9⋆	9,991	35.6
Meal assistance	3,107	21.4	2, 136	15.7	5,243	18.7
Respite care	3,095	21.4	2, 105	15.5	5,200	18.5
Received privately funded home care	17,028	39.4	14, 852	30.8	31,880	34.9

⋆ $p < .05$; ⋆⋆ $p < .01$; ⋆⋆⋆ $p < .001$

Table 3 ***Satisfaction with Home and Community-Based Services by Sex of Persons with Dementia***

Estimated Population	**Female (n = 43,202)**		**Male (n = 48,394)**		**Total (N = 91,596)**	
	Frequency	**%**	**Frequency**	**%**	**Frequency**	**%**
Perceived unmet health-care needs	4,720	11.1	2,934	6.2	7,654	8.5
Perceived unmet home care needs	5,599	13.0**	2,930	6.1**	8,529	9.3
Availability of health services in your community						
Good to excellent	8,266	72.0**	6,706	44.7**	14,972	56.6
Fair to poor	3,218	28.0**	8,285	55.3**	11,504	43.5
Quality of health services in your community						
Good to excellent	9,241	80.5	10,140	67.7	19,382	73.2
Fair to poor	2,242	19.5	4,840	32.3	7,082	26.8

** $p < .01$

Table 4 ***Significant Associations between Variables and Availability of Community Services***

	Availability of Services
Predisposing Variables	
Sex (female)	.30***
Need Variables	
Difficulty with unknown people	-.24**
Difficulty with conversation	-.25**
Cognitive problems	-.49***
Emotional problems	-.52***
Mobility problems	-.63***
Activity prevented by pain	-.56***
Urinary incontinence	-.31***
Suffers from a stroke	-.42***
Needs help with meals	-.27**
Needs help with personal care	-.40***
Needs help with finances	-.29**
Needs help getting to appointments	-.22*
Needs help with heavy chores	-.33***
Use of Community Services	
Received government home care	-.23**
Received nursing care	-.52**
Received housework assistance	.56**
Received meal assistance	.39*
Rating of quality of community services	.44***

* $p < .05$; ** $p < .01$; *** $p < .001$

medications, supplies) and indirect costs (e.g., the caregiver's reduced hours of employment) incurred by the respondents. Several variables of interest, such as social support, access to medical specialists, tests, health information, routine or ongoing care, and quality of care in hospital and quality of care provided by a physician, were optional questions that resulted in inadequate sample sizes for analysis. The overall small sample size precluded the conduct of multivariate analyses such as multiple regression and logistic regression. The CCHS excludes persons living on Indian reserves, on Crown lands, on Canadian Forces bases, and in some remote areas (Béland, 2002). Thus, not all Canadians (e.g., Aboriginal populations living in rural and remote areas) have an equal opportunity to participate in the CCHS and to give their perspectives, even though their health-care needs may be great and they may have limited access to health services (Mitura & Bollman, 2003). In addition, the use of a cross-sectional design and correlational analyses precludes the drawing of causal connections between variables. However, the benefits of using Statistics Canada data outweigh the limitations, as these data are of high quality and the resources required to collect, clean, and manage them are not available to individual researchers.

Discussion

The Andersen and Newman model (Andersen, 1995; Andersen & Newman, 1973) serves as a useful framework for a broad, practical understanding of the variables associated with use of home and community-based services. Unfortunately, not all of these variables of interest were included in the 2003 CCHS cycle 2.1. However, the findings from this study shed considerable light on the relationships between the predisposing, enabling, and need variables of men and women with dementia and use of health services, unmet needs, and availability of health services in the community.

All of the respondents were diagnosed with Alzheimer disease or related dementia by a health professional. Because these are self-reported data, it is likely that the numbers of those with dementia are underreported, as many who are afflicted with dementia have not been diagnosed by a health professional (Teel & Carson, 2003). The essential symptoms of dementia are "an acquired impairment in short and long-term memory, associated with impairment in abstract thinking, impaired judgment, other disturbances of higher cortical function, or personality changes" (Robillard, 2007, p. 293). These symptoms were reflected in the respondents' need for assistance with activities of daily living and with communication. As "baby boomers" approach the age of greatest risk for dementia in 2012 (Alzheimer Society of Ontario & Knowledge Exchange, 2007), there will be increased demand on community-based programs, and specifically home care, to support informal caregivers of those with dementia (Forbes et al., 2004). Persons with dementia have complex needs that are often difficult to interpret and manage, requiring a consistent health-care provider who is well informed about the process and management of the disease and is sensitive to the wants and needs of the care recipient and his or her caregiver (Forbes et al., in press); this includes sensitivity to the gender differences of persons with dementia and their caregivers.

Historically, caregiving has been female-dominated (e.g., Fast et al., 1999). However, recent research has revealed that 54% of caregivers are female and 46% male (McCloskey, 2005). In the present study, community-dwelling men with dementia were more likely to report suffering from a stroke and to have poorer health than their female counterparts. Thus, men with severe dementia and comorbidities were living in their homes longer than women with dementia. This implies that although men with dementia are in poorer health, their caregivers (usually their wives and/or other family members) are willing and able to care for them longer than those who are caring for women with dementia. However, although the health of men with dementia was rated lower on the HUI scale, women with dementia were more likely to receive assistance with personal care and respite from family members and to use formal services (e.g., overnight hospitalization, personal care and housework assistance) than their male counterparts, perhaps because of their greater difficulty moving about the home and their caregivers' willingness to accept help. Female respondents may have been cared for by their husbands, who tend to receive more emotional support from children and more practical assistance from formal sources such as home care than caregiving wives (Bedard et al., 2005; Miller & Guo, 2000). Female caregivers, on the other hand, are socialized into a nurturing role and often assume a caregiving role even when experiencing poor health themselves (Bedard et al., 2005).

An interesting finding is that women with dementia visited the dentist and eye specialist less frequently than men. This result requires further exploration. Persons with dementia would not likely be able to visit an eye specialist or dentist on their own, but would be dependent on the willingness and ability of their caregivers to accompany them.

Only a third of the respondents received publicly funded home care. This finding is cause for concern given that all respondents were diagnosed with dementia, 42% were over the age of 80, the majority reported needing help with activities of daily living, and nearly half had difficulty dealing with an unknown person and with initiating and sustaining conversation. Although home care is intended to address both health and social needs (Shapiro, 2003), Canadian home care programs, due to a lack of resources, have targeted post-acute clients with predominately physical needs and have reduced their support services (Forbes et al., 2003). However, as revealed in this study, persons with dementia primarily need support services related to their symptoms of impaired memory and judgement, abstract thinking, and behavioural disturbances or personality changes. Perhaps home care programs and providers are equipped to meet the physical needs better than the emotional and cognitive needs of persons with dementia (Parent, Anderson, & Neuwelt, 2000), resulting in few respondents receiving publicly funded home care. This finding suggests a mismatch between needs and the availability of corresponding resources, which can result in the use of more specialized and (often) costlier resources (Contrandiopoulos, Tessier, & Larouche, 1986).

Nine percent of respondents reported that their health care and home care needs had not been met in the preceding year. When asked why their home care needs were unmet, one third reported that the services they needed were not available, followed by cost, decided not to seek care, and did not know where to go. Other studies (Forbes et al., in press; Markle-Reid & Browne, 2001; Neufeld & Harrison, 2003; Neufeld, Harrison, Hughes, & Stewart, 2007) reveal possible reasons for unavailability of services (e.g., rural or remote geographic location, insufficient services, inflexible provision of service) and for deciding not to seek services (inconsistency of providers, providers who are uninformed about the assessment and treatment of dementia, providers who are insensitive to the needs of persons with dementia). Caregivers may require information about available services and support in making the decision to accept assistance (Forbes et al., in press; Markle-Reid & Browne, 2001) and in navigating the health-care system (Neufeld, Kushner, & Rempel, 2007). Single points of entry and a 24-hour, 7-days-a-week 1-800 hotline, providing access to information and to a network of other caregivers (VON Canada, 2006), would promote caregivers' ability to navigate the health-care system.

Cost ranked as the second-greatest barrier to receiving needed home care. Although there is no cost for professional home care, there may be a cost for the support services that are often required by those with dementia to remain in their homes (Forbes et al., in press). As well, the slightly higher proportion of respondents (35%) who received home care not covered by government is a disturbing trend, as those who cannot afford to pay may be doing without (Cohen et al., 2006; Hollander & Tessaro, 2001). Elimination of this barrier and establishment of more appropriate support for persons with dementia could serve to reduce the need for costly institutionalized care.

Respondents who were receiving support services (e.g., assistance with meal preparation and housework) were more likely to report availability of health services in the community, as their health-care needs were being met. When these services were not received, perhaps because support services were not available or because cost was a barrier, the respondents tended to rate the availability and quality of health services in the community as fair to poor. Although women with dementia reported receiving more services and rated the availability of community services higher than their male counterparts, they also reported greater unmet home care needs than men. The accumulating evidence is that in the Canadian national system of health and social insurance, the most expensive services being provided are those that are not tailored to people's needs (Browne et al., 2001). To address these unmet needs, the Ontario government recently announced a $700-million Aging at Home Strategy, including enhanced home and community support services such as homemaking, meals, transportation, adult day programs, and caregiver support (Ontario Ministry of Health and Long-Term Care, 2007). However, the success of this initiative relies upon every aspect of home care being strengthened and integrated with other health services and the development of national standards to ensure that all Canadians are getting the right care at the right time regardless of where they live or the environment in which care is provided (Scarrow, 2007).

Future quantitative studies could explore what models of service delivery would best meet all the needs of persons with dementia and their caregivers. Qualitative research approaches are needed, in order to explore the decision-making processes of persons with dementia and their caregivers in seeking formal home and community-based services as well as why and how specific service delivery models and practice approaches do or do not meet their needs.

Conclusion

The Andersen and Newman model (Andersen, 1995; Andersen & Newman, 1973) provided a useful framework for this study describing and comparing the relationships between predisposing, enabling, and need variables of men and women with dementia and use of health services, unmet needs, and availability of health services in the community. Women with dementia reported better health yet received more personal care assistance from family members and more formal personal care and housework assistance. As well, their caregivers (often their husbands) were more likely to receive respite services. Even though women were receiving more services, a greater proportion of women than men reported that their home care needs were not being met. Men with dementia, on the other hand, had lower HUI scores than women — that is, poorer overall health status (likely related to more severe dementia). This implies that their caregivers (often their wives) were providing more care and receiving less informal and formal support. Thus, those caring for men with dementia may be particularly vulnerable to negative health outcomes. Home care policy, program planners, home care assessors, and health-care providers should acknowledge the vulnerability of these caregivers, who are currently supplying up to 90% of the care provided in the home (Keating et al., 1999), and ensure that they receive the support services they require to prevent the need for costly specialized services and premature institutionalization of the person with dementia or their caregiver (Cohen et al., 2006; Contrandiopoulos et al., 1986). Governments must demonstrate their commitment by providing the funding and resources necessary to enable home care programs to meet the long-term needs of persons with dementia and their informal caregivers. This calls for Canadian home care programs to receive a greater proportion of governments' health-care budgets. In 2003 only 4% of all public health-care spending went to home care, compared with 30% to hospitals and 17% on medications (Scarrow, 2007).

The time has come to adequately fund Canadian home care programs, so that other sectors, such as acute care and long-term care, are not overburdened by persons with dementia who require support services only. This move will not only ensure that women and men with dementia and their family caregivers receive the care they need in the comfort of their own homes, but also address some of the greatest challenges facing the health-care system.

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Résumé

Une intervention communautaire pour traiter la dépression chez les personnes âgées

Manal Guirguis-Younger, Philippe Cappeliez et Alastair Younger

Dans le cadre de ce projet, on a piloté et raffiné une intervention communautaire de nature comportementale destinée aux personnes âgées déprimées. Fondée sur l'ouvrage de Lewinsohn intitulée Control Your Depression, l'intervention consistait ici en une bibliothérapie adaptée à la population visée, nécessitant un contact moindre assuré par l'entremise d'infirmières de soins à domicile. On a testé et raffiné l'intervention grâce à une série de trois études de base comportant des caractéristiques multiples et deux participants chacune. Chaque série comprenait six séances de thérapie hebdomadaires de base et un suivi de trois mois. La série A a servi à vérifier la faisabilité de l'intervention. La série B a servi à étudier le rôle des activités agréables en tant que point d'ancrage du traitement. La série C a servi à reproduire les conclusions de la série B et à tester l'intervention dans sa version définitive. On a constaté une réduction de la dépression au terme du troisième mois du suivi. Ces résultats indiquent que ce type d'intervention peut être réalisé par des infirmières à domicile auprès de populations mal desservies et sujettes à la dépression.

Mots clés : bibliothérapie, dépression, personnes âgées, populations mal desservies

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A Community-Based Intervention for Treating Depression in Seniors

Manal Guirguis-Younger, Philippe Cappeliez, and Alastair Younger

This study piloted and refined a community-based behavioural intervention for depressed seniors. The intervention, based on Lewinsohn's *Control Your Depression,* was administered in bibliotherapy format adapted for seniors. It was delivered in a minimal-contact format by home care nurses. The intervention was tested and refined in a series of 3 multiple-baseline studies, each with 2 participants. Each series consisted of baseline, 6 weekly treatment sessions, and 3-month follow-up. Series A tested the feasibility of the intervention. Series B examined the role of pleasant activities as a pivotal part of the treatment. Series C replicated the findings of series B and tested the final version of the intervention. In all the series, there was a reduction in depression that remained at 3-month follow-up. The results indicate that this form of intervention can be supported by home care nurses working with an underserved population that is prone to depression.

Keywords: Aging, bibliotherapy, care delivery, cognitive behaviour therapy, depression, elder health, underserved populations

Although older adults are an extremely heterogeneous group, there are some commonly anticipated life changes that occur with advancing age. One of the most significant changes is alteration in overall health and functional ability (Karel, 1997). Poor health and functional impairment tend to be associated with depression and loss of the ability to engage in enjoyable activities (Freyne, Keogh, Kelley, & Wrigley, 2005; Zarit, Femia, Gatz, & Johansson, 1999). Depression is one of the most common psychological disorders among seniors (Rapp, Parisi, Walsh, & Wallace, 1988) and is reported to be three times greater among seniors with physical disabilities than those without (Turner & Noh, 1988). While it might be tempting to conclude that it is disability that leads to depression, the relationship may be bidirectional: Depression itself may actually increase the risk of disability and hamper recovery from temporary conditions (Freyne et al., 2005; Turner & Noh, 1988).

Some researchers have suggested that functional impairment constitutes the mediational link between physical illness and depression. Williamson and Shaffer (2000) propose an Activity Restriction Model of depressed affect, arguing that physical impairment restricts one's ability to engage in routine and pleasant activities, a disruption that can lead to depression. In a similar vein, Zeiss, Lewinsohn, Rohde, and Seeley (1996) postulate that physical impairment, by interfering with activities that are reinforcing, may create susceptibility to depression. Moreover, there is evidence that re-engaging in activities can help alleviate depression in older adults (Greaves & Farbus, 2006).

Lewinsohn has proposed a model (e.g., Lewinsohn, 1976; Lewinsohn & Gotlib, 1995) that is useful for understanding the links between disability and depression. According to this model, a low rate of positive reinforcement in the person's environment is an antecedent for a depressive state. For example, a negative life event, such as bereavement or disability, can set in motion a series of situations whereby the person's environment lacks positive reinforcement and become fraught with daily troubles. Certain negative life events, such as disability, restrict the potential for corrective behaviours. Lewinsohn has argued that a reinstatement of positive activities could disrupt this downward spiral of depression and inactivity. Lewinsohn's treatment model entails a reinstatement of positive activities.

A serious problem for depressed seniors, however, is access to treatment, and this problem is magnified by disability. Efforts to modify traditional therapy for use with older adults (e.g., Floyd et al., 2006; Scogin, Hamblin, & Beutler, 1987) have primarily taken two forms: self-administration, and delivery by non-mental health professionals. For example, Scogin et al. (1987) have introduced a more deliverable self-administered alternative to depressed seniors. In their "bibliotherapy" intervention (i.e., in which written material is used as a form of treatment), participants follow the exercises in Burns's (1980) book, *Feeling Good: The New Mood Therapy.* Scogin et al. (1987) report a significant reduction in depressive symptoms among their participants. Other "minimal contact" interventions have also involved the training of non-mental health professionals to deliver treatment. Such interventions have been found to be effective (e.g., Lamer, Jonkers, Bosma, Diederiks, & van Eijk, 2006; Lichtenberg, Kimbarow, MacKinnon, Morris, & Bush, 1995; Thompson, Gallagher, Nies, & Epstein, 1983). Self-administered bibliotherapy has also been found to be effective in increasing self-management ability and preventing age-related decline in frail older persons (Frieswijk, Steverink, Buunk, & Slaets, 2006).

Cognitive-behavioural interventions have been found to be particularly efficacious when delivered in a self-administered bibliotherapy format (e.g., Cuijpers, 1998; Floyd et al., 2006; Floyd, Scogin, Kendree-Smith, Floyd, & Rokke, 2004; Scogin, 1997; Scogin et al., 1987; Scogin, Jamison, & Gochneaur, 1989). This minimal-contact model is a positive contribution to the provision of mental health services: It is innovative, cost-effective, efficacious, and flexible.

In line with this evidence, the present study was designed to implement and evaluate an alternative form of intervention for the underserved depressed elderly. This intervention combines various elements of previously validated treatment approaches to target this group, with the support of home care nurses. Cognitive-behavioural treatment was chosen because of its particular suitability for older adults with the dual affliction of depression and functional impairment. Drawing from Lewinsohn, Munoz, Youngren, and Zeiss's (1986) self-help book, *Control Your Depression,* we developed a bibliotherapy intervention to be self-administered in six sessions, with a suggested rate of one session per week. The topics covered in each of the six sessions are as follows:

1. What is depression?
2. How thoughts and actions influence the way we feel.
3. Keeping track of pleasant activities.
4. Increasing pleasant activities.
5. Decreasing negative thoughts.
6. How to maintain the gains made.

The treatment was designed to be implemented by nurses who provide a community link to underserved older persons with medical conditions, physical impairment, and depression. The fundamental goal of the intervention was to reduce depression. Our research piloted a community-based intervention delivered by nurses to a difficult-to-reach population. We hypothesized that the intervention could benefit seniors with health problems who are assisted by nurses through home care agencies or medical-aid programs but who are unlikely to seek psychological care on their own.

For this project, we partnered with a home care organization active locally, the Victorian Order of Nurses (VON). The VON is a national agency serving the underreached elderly. Although its assistance is medical in nature, the agency maintains close links to a sub-population of elders who are particularly vulnerable to developing depressive disorders. Its personnel are health professionals, typically registered nurses, who deliver the service in patients' homes. Medical services are extended to older persons who do not require hospitalization for their medical condition but do require outpatient health maintenance. The nature of the service varies according to the client's needs. VON nurses enjoy good rapport with their clients and it was believed they could easily incorporate a psychological treatment as an element in their established routines.

Method

Design

The study involved a multiple baseline design of the across-subjects variety. The multiple baseline approach is a single-subject experimental design used to infer a cause-effect relationship between an intervention and a dependent measure (Goodwin, 2007; Ray, 2006). It is used frequently when a reversal-replication (or ABAB) type of single-subject design is unfeasible because the changes produced by the intervention cannot be reversed by withdrawal of treatment (Goodwin, 2007; Ray, 2006). This was the case with the present study, in which the skills taught could not subsequently be "untaught" in a withdrawal phase. The procedure consisted of collecting a baseline measure of depressed mood, then introducing the six-session bibliotherapy intervention and assessing changes in mood concurrent with its implementation. The across-subjects version of the multiple baseline design requires a minimum of two participants in a series. Finally, a follow-up assessment of mood was made 3 months after completion of the intervention.

The study consisted of three series, presented here as A, B, and C. Series A was designed to examine the feasibility and effectiveness of the bibliotherapy intervention. Series B examined the unique role of reinstating pleasant activities as a key element in the intervention. Series C was designed to replicate the results observed in series B. In each series, VON nurses identified two individuals suitable as research participants and spent about 15 minutes per week with each, providing support with and clarifying the program material.

Participants

The participants were six VON clients who were receiving home medical care for a variety of chronic and acute health conditions. They were referred to the study by the VON because of presenting depressive symptoms. The study was approved by the university's research ethics board, which required informed written consent by all participants and nurses. Individuals receiving other forms of psychotherapeutic intervention were excluded from the study, with the exception of those who had been stabilized on pharmacological treatment. Other exclusion criteria were definitive cognitive impairment and serious suicidal tendency. It should be added that none of the participants experienced interruption of VON medical services during the course of the intervention.

Measures

Screening instruments. Participation in the study required that seniors be depressed but have no cognitive impairment. The Nurses' Observation Scale for Geriatric Patients (NOSGER; Spiegel et al., 1991) was used to guide nurses in identifying depression in their clients and in making appropriate referrals to the study. The Modified Mini-Mental State Examination (3MS; Teng & Chui, 1987) was used to screen for cognitive impairment. This instrument assesses the following domains: orientation to time and place, registration, attention, memory, language, and visual construction. These two instruments were administered once prior to commencement of the study. In addition, seniors were asked to rate their mood on a daily basis using a nine-point Likert-type scale ranging from *extreme sadness* to *feeling great*. This mood rating was used to establish a baseline of mood prior to treatment, to satisfy the criteria of the multiple baseline design. Participants were instructed to complete this mood rating once a day at the same time of day, preferably at bedtime.

Outcome measures. The following two measures of depression were used to track depressive symptoms throughout treatment and at follow-up: the Geriatric Depression Scale (GDS; Brink et al., 1982), a self-report measure of depressive symptoms; and the Hamilton Rating Scale for Depression (HRSD; Hamilton, 1960; Moritz, Meier, Hand, Schick, & Jahn, 2004), a clinician rating scale for indexing severity of depressive symptoms. Both measures were completed weekly and also at 3 months post-treatment.

Procedure

Clients suspected of experiencing depression, as identified by the VON nurses using the NOSGER, were invited to take part in the study on a voluntary basis. Those who agreed to take part were seen for a first interview to determine their suitability for the study. During this session, they were administered the 3MS. The study began 1 week later, when the six participants were asked to begin their daily mood ratings. In addition, the participants completed the full GDS on a weekly basis.

Establishment of a baseline. The collection of baseline data began immediately following completion of the screening assessments. The baseline was established on the basis of the daily mood rating and was considered stable if the rating did not fluctuate by more than a single scale point in either direction within a given week.

Treatment phase. Once the baseline had stabilized, participants were introduced to the 6-week self-administered treatment. Throughout both the baseline and treatment phases, the GDS and HRSD were administered weekly and the mood rating was administered daily.

Post-treatment phase. Post-treatment assessment of depression using the GDS and the HRSD took place immediately following completion of treatment, as well as 3 months after the end of treatment, at the participants' homes (with the exception of one participant, who mailed in his GDS).

Analysis of Results

Analysis of the results of multiple baseline studies typically involves visual examination of the graphical depiction of the results. Two criteria are frequently employed to assess changes in the graphical form of the data: level and latency (see Kazdin, 1982, 1998). Change in level refers to an abrupt change in the dependent variable associated with the end of one phase and the beginning of another. Change in latency refers to the time lag between the commencement of treatment and the appearance of changes in behaviour. Other criteria considered in visual comparison include the variability of the behaviour of interest in a given phase, persistence of trend, and level changes across subjects.

Findings

Series A

Participant 1 was an unmarried 62-year-old man who lived alone and had no children and no contact with close relatives. Participant 2 was an 84-year-old widow who lived alone, having lost her husband 1 year prior to the study. She had two adult children, who were in frequent contact with her.

Participant 1. Figure 1 shows participant 1's weekly assessments on the GDS and the HRSD throughout the baseline and treatment phases as well as at 3-month follow-up. Before treatment, this man's GDS and HRSD scores were 29 and 18, respectively, indicating moderate levels of depression. Following treatment, his scores were 20 and 6, respectively. The HRSD score indicated recovery; however, the GDS remained elevated, pointing to the presence of some residual depressive symptoms. At 3-month follow-up, his GDS was 26 and his HRSD 10. His HRSD score indicated recovery; however, the GDS score continued to suggest the presence of some residual depressive symptoms.

As Figure 1 indicates, however, participant 1's reduced GDS and HRSD scores did not coincide precisely with the introduction of treatment. There was a lag of 3 weeks between the introduction of treatment and a detectable change in symptoms. During the first 3 weeks mood was consistently rated as "often sad," but after 3 weeks it was rated as fluctuating yet increasingly positive. This trend in subjective mood ratings was mirrored by the HRSD scores, which showed a decline at about the same point in time.

Participant 2. Figure 2 shows participant 2's weekly GDS and HRSD assessments throughout the baseline and treatment phases as well as at 3-month follow-up. Before treatment, this client's GDS and HRSD scores were 15 and 17, respectively, placing her in the mild range for depression.

Figure 1 ***Participant 1: GDS and HRSD Scores as a Function of Baseline and Treatment Periods and at 3-Month Follow-up***

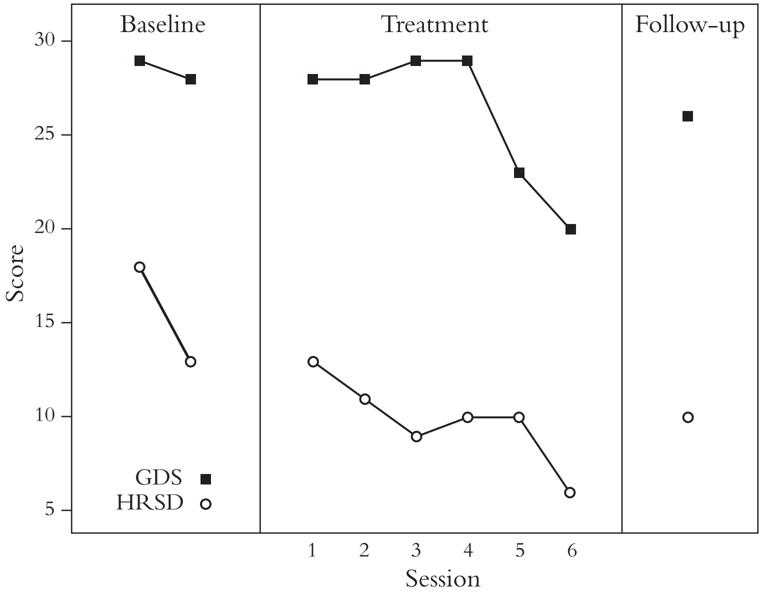
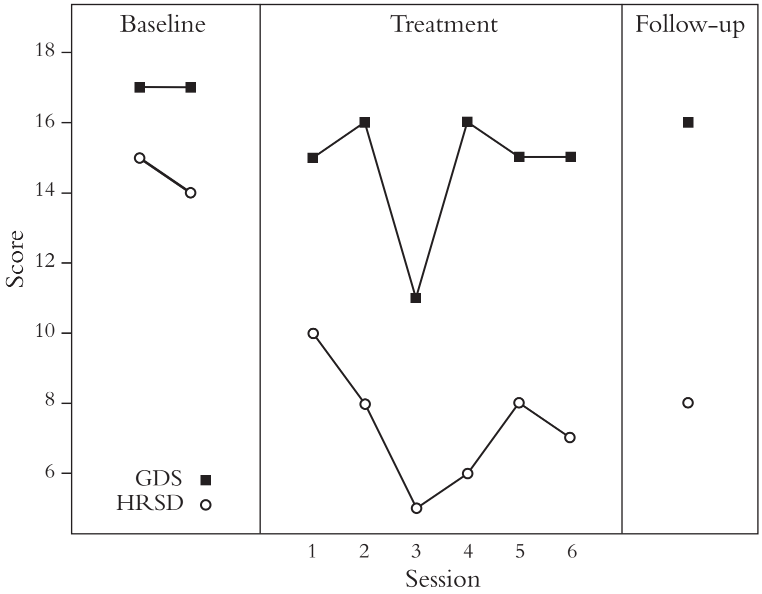


Figure 2 ***Participant 2: GDS and HRSD Scores as a Function of Baseline and Treatment Periods and at 3-Month Follow-up***



There was a decline in depressive symptoms indicated by these two measures over the treatment period, with improvements in mood most apparent at week 3, followed by a slight increase in symptoms. However, the pattern of these data does not seem to indicate a clear latency period. At 3-month follow-up, participant 2's GDS and HRSD scores were 16 and 8, respectively, indicating that gains made since pre-treatment had been retained after 3 months.

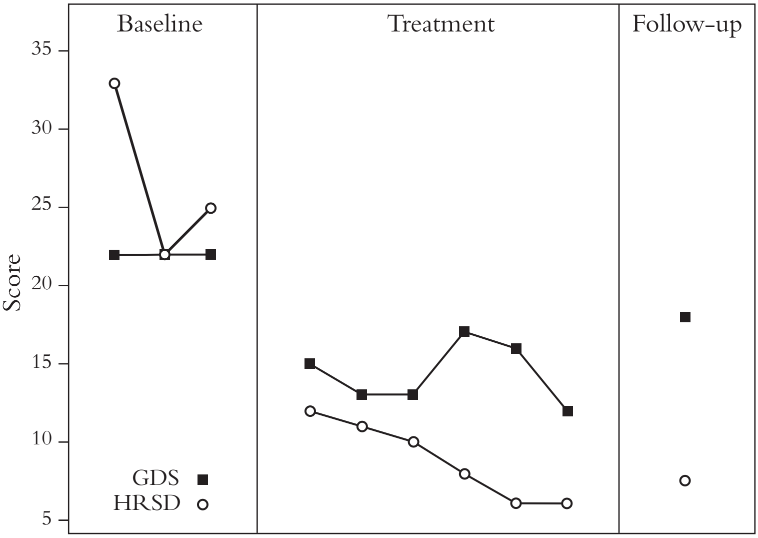
Discussion of series A. Both participants showed some signs of recovery across the course of the study. Interestingly, in both cases recovery showed a delay of several weeks. This delay may correspond to the point in treatment where engaging in "pleasant activities" began. As discussed earlier, it may well be that the reintroduction of pleasant activities constitutes a powerful active ingredient in this treatment. In the case of participant 1, there were strong indications that recovery began 3 weeks into the treatment, around the time when pleasant activities were introduced. In contrast, participant 2 did not seem motivated to integrate new activities into her daily routine. This can be considered an implementation weakness and may have been responsible for her delayed response to treatment. The delay in recovery, however, might also reflect a gradual change in behaviour and subsequent change in mood, a process to be expected when complex life changes are needed. These competing explanations were put to the test in a second study — series B.

Series B

The pattern of results in series A raised the question of the importance of pleasant activities to the alleviation of negative mood symptoms. The 3-week delay in response to the treatment coincided with the introduction of the session designed to reinstate pleasant activities. In order to determine whether the 3-week lag was in fact linked to the implementation of pleasant activities, rather than simply a gradual change resulting from the treatment in general, we modified the sequence of the sessions. The pleasant activities material was switched from session 3 to session 1. As with series A, the VON identified two suitable clients as participants in series B. Participant 3 was a 70-year-old married man who had experienced his first episode of depression in his late sixties when he was diagnosed with cancer. He reported that his retirement had left him feeling unproductive and useless, contributing to his negative mood. Participant 4 was a 72-year-old woman who had experienced two distinct episodes of depression in the past. The first episode of sadness took place around the death of her mother and lasted for several years. The second occurred following the sudden death of her son.

Participant 3. Figure 3 shows participant 3's weekly assessments on the GDS and the HRSD throughout the baseline and treatment phases as well as at 3-month follow-up. Before treatment, this man's GDS and HRSD were 22 and 33, respectively, indicating severe depression. Following treatment, they were 12 and 6, respectively. These scores, particularly the GDS, indicated improvement yet suggested the possible presence of mild residual symptoms. At 3-month follow-up, his GDS and HRSD were 18 and 10, respectively, indicating recovery, although some residual depressive symptoms remained. As can be seen in Figure 3, a drop occurred in both scores immediately after the introduction of treatment (i.e., after session 1, pleasant activities). The pattern of these data does not indicate the presence of a latency period between intervention and positive treatment effects, such as that found in series A.

Figure 3 ***Participant 3: GDS and HRSD Scores as a Function of Baseline and Treatment Periods and at 3-Month Follow-up***



Participant 4. Figure 4 shows participant 4's weekly assessments on the GDS and HRSD throughout the baseline and treatment phases as well as at 3-month follow-up. Before treatment, this woman's GDS and HRSD scores were 20 and 23, respectively, indicating moderate depression. Her post-treatment scores were 6 and 4, respectively, indicating that she was free of depressive symptoms. At 3-month follow-up, the GDS

score was 14 and the HRSD 5, indicating some residual symptoms. There were substantial changes in GDS and HRSD scores for this participant, with the greatest response occurring directly after the introduction of treatment (introduction of pleasant activities). Once again, no latency between intervention and positive treatment effects was observed. This participant's mood rating demonstrated a tremendous degree of fluctuation during the course of the study. This was partially the result of a setback due to illness. The intervention was interrupted for several weeks when she was hospitalized for health problems. Upon her return home, her subjective ratings were again alternating between *fair* and *good.*

Discussion of series B. The intervention was modified in the sense that the pleasant activities material was introduced right at the beginning — that is, in sessions 1 and 2 rather than in sessions 3 and 4 — in order to explore the reasons for the 3-week lag in positive response to treatment observed in series A. Both participants showed substantial mood improvements immediately after the intervention was introduced. This finding suggests that the introduction of pleasant activities was responsible for the improvement in depressive symptoms.

Series C

As in series A and B, the VON identified two clients as suitable participants. Participant 5 was a 71-year-old married man with nine adult children. During the preceding 2 years he had become increasingly depressed, especially because of his deteriorating health and multiple disabilities. Participant 6 was an 85-year-old married man who had a son and a daughter from his first marriage. His first marriage of 30 years ended when his wife died of cancer. His current marriage had lasted 19 years and was described as extremely happy and loving. Following the death of his first wife, he reported experiencing extended grief and guilt, as well as depression. This condition disappeared after his remarriage but returned about 9 months prior to the initiation of the study.

Participant 5. Figure 5 shows participant 5's weekly assessments on the GDS and the HRSD throughout the baseline and treatment phases as well as at 3-month follow-up. At pre-treatment, his HRSD score of 14 indicated a moderate level of depression, whereas his GDS score of 24 indicated a higher level of depression. At post-treatment, these scores had dropped to 1 for the HRSD and 5 for the GDS, indicating recovery. At 3-month follow-up, his GDS and HRSD scores were both 3.

Participant 6. Figure 6 shows participant 6's weekly assessments on the GDS and HRSD. At pre-treatment assessment, his GDS and HRSD scores were 29 and 16, respectively. Following treatment, they were 22 and 11. His GDS showed great fluctuation (ranging from 2 to 30) during treatment, but in general was lower during the treatment observation

Figure 4 ***Participant 4: GDS and HRSD Scores as a Function of Baseline and Treatment Periods and at 3-Month Follow-up***

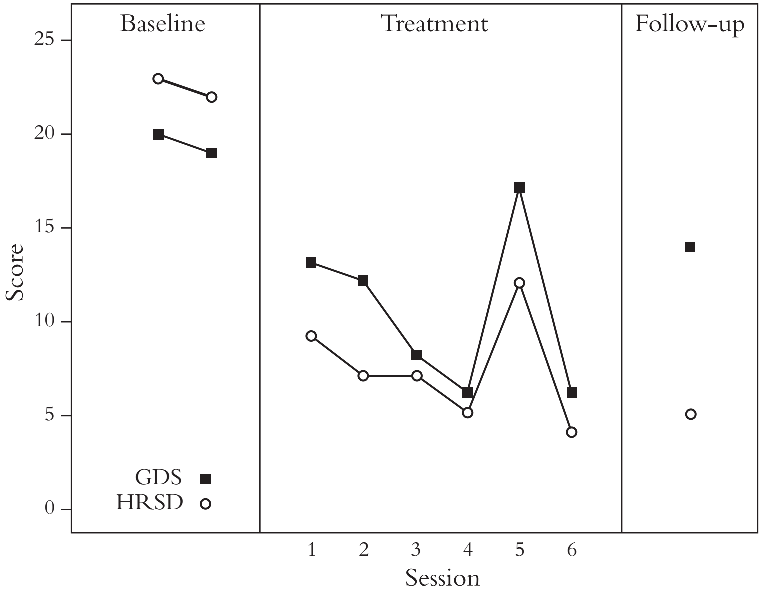


Figure 5 ***Participant 5: GDS and HRSD Scores as a Function of Baseline and Treatment Periods and at 3-Month Follow-up***

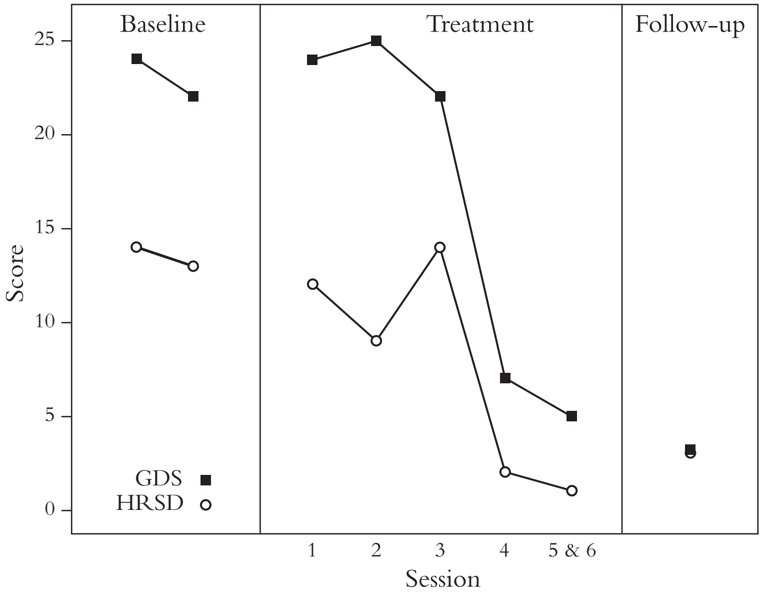
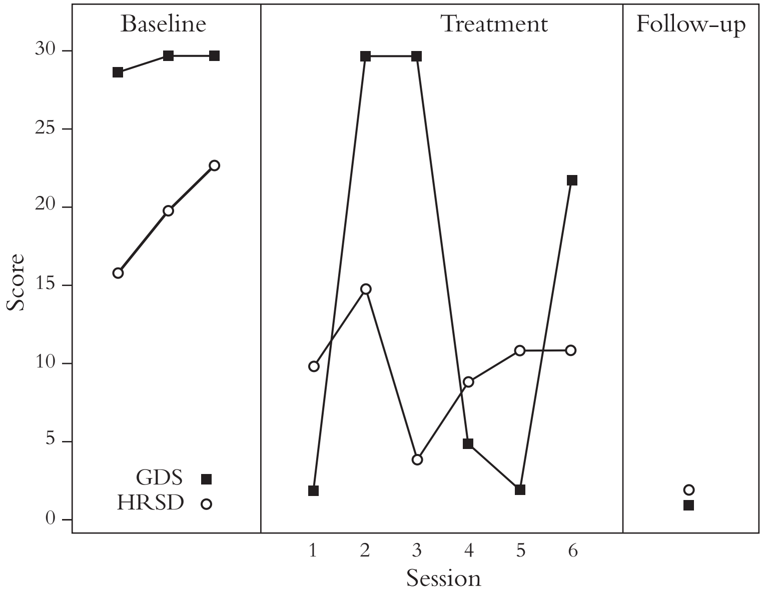


Figure 6 ***Participant 6: GDS and HRSD Scores as a Function of Baseline and Treatment Periods and at 3-Month Follow-up***



period than during baseline. At 3-month follow-up his GDS and HRSD scores were 1 and 2, respectively, indicating the absence of depression. As can be seen, there was a substantial change in the weekly GDS and HRSD scores immediately after the introduction of treatment. Most of these fluctuations were in response to physical setbacks that interfered with his preferred activities. Nevertheless, participant 6's mood improvements were clinically meaningful and had a strong impact on his quality of life. At follow-up, his gains appeared even stronger. His mood was normal on all mood indices and he reported a high level of pleasant activity and hopefulness.

Discussion of series C. This series was conducted as a replication of series B, with the addition of gathering estimates of the level of pleasant activities at a baseline to provide a point of comparison for levels observed during the treatment period. Both participants estimated a low level of pleasant activities at baseline. The first reported a gradual increase in activity level, with a notable increase at session 4. While this client seemed to agree with the idea of reinstating pleasant activities, he did not feel that he was able to alter his own life. However, he appeared to test the idea slowly, making small steps and then increasing his efforts as he saw the positive effects on his mood. In contrast, the second participant and his wife became convinced of the efficacy of reinstating pleasant activities and devoted a great deal of effort to bringing about a change. There was no latency in his response to treatment, as his reported pleasant activities increased and his negative mood symptoms decreased immediately after the introduction of treatment. For both participants, the implementation of pleasant activities and mood improvements occurred close together in time. This provides further support for our findings in series B.

Discussion

This study was undertaken to meet a pressing need of community older adults with depression. The combination of depression and disability creates a deteriorating spiral for an already underreached group. Although this special population presents with high risk for depression, the solutions are scarce, due in part to the challenge of barriers to treatment. The present study was directed by the desire to develop a solution that was therapeutically efficacious and deliverable at low cost, could be administered by nurses, and was acceptable to and usable by the elderly.

We integrated all of these aims into an alternative form of intervention. First, we chose a behavioural treatment on the basis of its demonstrated efficacy and suitability for older persons. Second, the treatment was administered in a simple written form — bibliotherapy, with examples relevant to the life and issues of the older person. This manner of administration allowed the participants to manage their own therapy with the support of a home care nurse — that is, to think about and develop their own behavioural adjustment and then carry out the change. This placed the control with the individual. Third, the issue of treatment barriers was addressed by finding a connection with a community-based service, the Victorian Order of Nurses, an organization that has a unique relationship with this high-risk population. The VON was able to deliver this type of treatment at very low cost in terms of both money and time. As the intervention was designed for self-administration with minimal contact, we aimed to express a clear therapeutic philosophy that was easily understood by the participants. The VON played a key role in delivering the intervention and serving as a resource for participants. Fourth, this approach to the treatment of depression in the home is unlikely to carry the stigma associated with seeking mental health care and is embedded in the existing rapport between VON nurses and their clients.

Results from series A indicated that the treatment was successful at the fundamental level — that is, it was feasible to coordinate the intervention with VON visits and to commission the nurses with its administration and support. With these issues of workability settled, the efficacy of the treatment approach was examined. Although the intervention produced marked reductions in the participants' depression levels, it was not clear from series A which of its components were most useful. There was some delay (i.e., latency) before reductions in negative mood symptoms were observed, with most improvements occurring in the last 2 to 3 weeks of the intervention.

In series B we altered the order of the sessions so that the apparently more effective ingredients of the intervention, in this case hypothesized to be pleasant activities, were introduced immediately after the baseline period. Results produced in series B were favourable. Both participants experienced a meaningful reduction in negative mood symptoms, retaining most of these changes up to 3 months after the termination of treatment. Perhaps the most interesting finding was the absence of a latency period. We found it remarkable that such substantial changes could occur so rapidly. Nevertheless, reports from the VON and occasionally from significant others corroborated this change and named the increased participation in pleasant activities as its catalyst.

Our data provide strong evidence that pleasant activities were the active ingredient in this intervention. We became aware of the importance of pleasant activities in the results of series A, where changes in mood appeared to occur concurrently with the pleasant activities component of the intervention. We experimentally tested the hypothesis that pleasant activities were particularly potent in reducing self-reported symptoms of depression in series B and C by introducing this component earlier in the treatment. Three of the four participants in these two series showed mood improvements that closely followed the pleasant activities session. The fourth participant had difficulty implementing pleasant activities and required several weeks to achieve this goal. His mood, consequently, showed more gradual improvement. These results underline the importance of reinstating pleasant activities in interventions focused on treating depression in seniors with medical problems.

Some participants were eager to reinstate pleasant activities into their lives and proceeded to take immediate action. Others, however, required more time to make the changes and needed more encouragement from the nurses. Individual differences in initiative and enthusiasm may affect the speed with which participants make the behavioural changes.

Questions regarding adherence to treatment are not new. In this case, activity level was advocated and coached by the reading material and monitored by the nurses. There are many issues, however, that can affect the inclination to change. First, we capitalized on some of the inherent qualities of behavioural intervention. The behavioural formula of change is simple but powerful. In our case, much effort was made to enhance face validity and also to maintain the simple presentation of the bibliotherapy material. This issue is particularly pertinent when one is working with older adults. Acceptability of treatment, and ultimately its implementation, is facilitated if the proposed changes are reasonable, attainable, and mindful of the limitations of older persons. In addition, this intervention was administered in the context of a medical care model, which contributed to its credibility; while this does not preclude non-medical interventions, it is a generational preference that must be accepted as a possible factor in treatment success.

It should be noted that while the data strongly suggest that pleasant activities are an important component of the treatment, the idea of reinstating pleasant activities was supported by sessions focusing on the participants' cognitions. An awareness of the link between thinking and feeling, as well as the ability to cope with negative thinking, may help participants to maintain their gains after the termination of treatment. Seniors with functional impairment may find it difficult to keep up the effort of deliberately participating in pleasant activities. It may be less difficult if they know that their recovery depends in large part on their ability to take the initiative and combat negative thoughts with continuous effort.

Maintaining therapeutic gains is an important issue for any intervention. Most participants in this study maintained their gains well. In fact, many continued to improve during the 3 months after treatment and showed further gains at follow-up. Many reported reading the material over again to refresh their memory, and some continued to use the exercises included in the treatment package.

One of the strongest features of this intervention is its flexibility and sensitivity — it can be tailored to fit the needs of any given VON client. For example, since all six sessions are relatively self-contained, there is freedom to concentrate (either with the nurse or alone) on readings that appear to be particularly relevant to the problem behaviour. Some participants did this naturally. For example, one participant found the session on negative thinking quite helpful and continued to read it in conjunction with other sessions. Certainly, if the VON nurses were administering this intervention without the restrictions imposed by research control, they would have the flexibility to let clients choose helpful components, and perhaps drop any that seem superfluous. Further, some parts of the intervention can be left to self-administration and others can be discussed with the nurse, depending on each client's needs and resources. Frequently, participants needed assistance with problem-solving in order to engage in pleasant activities. For example, one man wanted to plan activities that were quite a distance from his home and found it difficult to use public transportation. The VON nurse, who was familiar with community resources, was able to arrange for a special adapted vehicle for him. This service allowed him to extend his functional mobility and arrange pleasant activities at locations of his choice.

In the same vein, modifications can be made while the intervention is in progress. For example, participants may terminate early if their depressive symptoms have disappeared and the essential parts of the intervention have been covered, particularly sessions on pleasant activities and negative thinking. Also, since sessions are only several pages in length, they can be combined in a coherent way for participants who prefer a more a rapid pace. These modifications are recommended only in cases where there is reasonable justification for varying the tested intervention (i.e., participants' requests or special circumstances). It is recommended that the intervention initially be presented to clients in the form finalized and examined in the final series of our research (series C).

The flexibility of this intervention is highly advantageous, especially with respect to seniors with health problems. Some of the unforeseen events that occurred during the intervention centred around complications of the health condition and medication irregularities. In three cases, such disruption occurred during the treatment period. One participant became ill and was hospitalized for several weeks, an event that caused a serious setback in terms of her mood. Another participant began to anticipate a relocation, which to him meant that he would have to abandon all of the social and community contacts he had worked hard to build. The participant's difficulty coping with this situation affected his progress during the observation period. A third participant, although stable on medication at initial interview, had a sudden change in medication, causing serious side effects that contributed to agitation and negative mood. The results must be interpreted in the context of these unforeseen events, which pose a problem in a short observation period. However, future research must anticipate such irregularities, as their absence is difficult to imagine in older persons with unstable health. It must be kept in mind that the core goals of the intervention are, or should be, considered as independent of these fluctuations — that is, the intervention can be continued and worked around such events or resumed when the client is ready. This is a judgement that very much depends on the situation of the individual and the nature of the life event.

This study contributes to our knowledge on the nature of depression in seniors and also provides an innovative treatment for use with under-reached older persons. Our results indicate that in some seniors depressive symptoms may be related to diminished engagement in pleasant activities imposed by physical limitations. We found that the nurses working with these seniors were in an opportune position to introduce the treatment and assist with its implementation. The seniors likely would not have pursued treatment otherwise. Because of their trusting relationship with patients, nurses are able to provide considerable moral and instrumental support with treatment. They are able to encourage problem-solving, helping seniors to come up with and implement reasonable pleasant activities substitutes. Although the treatment is designed to be self-administered, the nurses played an important role in its implementation. Their knowledge of the patients' physical limitations, combined with their access to community resources, supported seniors in finding innovative solutions to their activity restrictions and ultimately reducing their symptoms of depression.

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Authors' Note

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Résumé

Les services fournis aux personnes âgées dans les petites villes du Canada : le paradoxe de la communauté

Mark W. Skinner, Mark W. Rosenberg,
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Il existe une idée répandue selon laquelle les petites villes rurales compensent le manque de services structurés qui les caractérise par la création de liens serrés entre leurs habitants ainsi que par une compréhension commune de la notion de communauté. À partir d'une recherche effectuée dans neuf petites villes situées un peu partout au Canada, les auteurs examinent l'application du concept de communauté en ce qui a trait à la prestation de soins à domicile et communautaires aux aînés. L'analyse se fonde sur des entrevues réalisées avec 55 informateurs clés provenant d'organismes gouvernementaux, d'agences de santé et de services sociaux ainsi que de groupes du secteur bénévole et communautaire locaux. Les résultats révèlent le paradoxe de la croyance conventionnelle selon laquelle les communautés rurales peuvent compenser le manque de services offerts aux personnes âgées, cette croyance ne tenant pas compte de la capacité d'adaptation incertaine des secteurs informels locaux. Les auteurs mettent au défi les décideurs en matière de politiques sur la santé dans les régions rurales, les chercheurs et les fournisseurs de services de démolir certaines présomptions à propos des services offerts aux personnes âgées dans les régions rurales du Canada.

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Services for Seniors in Small-Town Canada: The Paradox of Community

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There is a prevailing argument that what small towns lack in formal services they make up for in close ties among rural people and a shared understanding of the notion of community. Drawing on research undertaken in 9 small towns across Canada, the authors examine how the concept of community operates with respect to the provision of in-home and community care for seniors. The analysis is based on interviews with 55 key informants from local governments, health and social care agencies, voluntary sector organizations, and community groups. The findings reveal the paradox of the conventional belief that rural communities can compensate for lack of services for seniors while failing to take into account the uncertain coping ability of the local informal sectors. The authors challenge rural health policy decision-makers, researchers, and providers to debunk assumptions about services for seniors in rural Canada.

Keywords: Aging, gerontology, rural and remote health, social support, theory

Introduction

The popularity of ideas like social capital, voluntarism, and the rural idyll propel the argument that what small towns lack in formal services they make up for in close ties among rural people and a shared understanding of the notion of community. Key debates within rural health policy, research, and practice raise critical questions about such conventional wisdom, especially as it relates to the provision of services like in-home and community care for seniors in rural and small-town settings (e.g., Hanlon, Rosenberg, & Clasby, 2007; Joseph & Martin-Matthews, 1993; Keating, Keefe, & Dobbs, 2001). Indeed, among those involved in the provision of in-home and community care, there is a sense of uncertainty surrounding the ability of rural communities to support aging in place (e.g., Stewart et al., 2005). This is encapsulated in the words of a provider interviewed as part of our ongoing research on aging communities across Canada:

> *There's a sense that in smaller, rural communities where we don't have an agency and don't provide services, people know one another, they know their neighbours, and even if they live miles and miles away, they know people through church, so services can be provided at an informal level at the very least,* but I'm not convinced that's really the case. *[emphasis added]*

To address this ambiguity, we examine how belief in community operates with respect to the provision of in-home and community care for seniors living in rural Canada. Drawing on interviews with key informants involved in providing services in rural areas, we analyze (1) how belief in community is manifested at the local level, (2) whether those who provide services share this belief, and (3) the implications for delivery of services to seniors in rural and small-town settings. In doing so, we hope to contribute to the limited literature on rural health care in Canada (Kulig, 2005b) and to the even smaller body of geographical work on in-home and community care for rural seniors (Andrews, McCormack, & Reed, 2005). The research is part of a national project in which key informants from local governments, health and social care agencies, voluntary sector organizations, and community groups across Canada are interviewed about service provisioning for seniors and what it takes to create a healthy and service-rich community (Rosenberg et al., 2005).

The article is presented in three parts. First, we review the literature on community, rurality, and service provisioning, which serves as a framework for our analysis of belief in community as it relates to the provision of in-home and community care for seniors. Next, to demonstrate the utility of our approach, we describe the qualitative research design and report findings from 55 semi-structured interviews in nine rural communities across Canada. We then discuss the key findings as they relate to the conventional understanding of rural service provisioning. We conclude by challenging decision-makers, researchers, and providers to debunk assumptions about services for seniors in rural Canada.

Community, Rurality, and Services for Seniors

We contend that understanding in-home and community care for seniors living in rural areas and small towns requires an appreciation of the link among community, rurality, and service provisioning. Three bodies of literature reveal the gap in our understanding of services for seniors at the local level as complex and diverse phenomena. The first informs us about how the concept of community relates to health and social care. The second informs us about the contested nature of rurality and how it shapes our view of rural and small-town settings. The third informs us how the challenges of the rural service environment affect the provision of in-home and community care for seniors. The integration of these bodies of work provides a three-part theoretical context that guides the analysis that follows.

Community is a complex and evolving concept. It has been defined as a social network of interacting individuals grounded in material conditions and cultural expressions of particular places (Panelli, 2005). Key studies of health and social care argue that central to developing a proper appreciation is the role of people in producing communities and the role of place in shaping them (e.g., Hanlon, Halseth, Clasby, & Pow, 2007). In this sense, community can be understood as the shared meanings (or beliefs) that people ascribe to the spaces and structures that make up where they provide and receive care. The important role of people in producing community has not gone unnoticed in health policy. Indeed, policy debates have recognized the social nature of community as contributing to health and social care (e.g., Helliwell, 2001), not to mention the targeting of local communities for government downloading, particularly as it relates to the needs of seniors aging in place (Cloutier-Fisher & Joseph, 2000). Underlying the emphasis on community is the growing literature on social capital, which contends that enhancing the social linkages within communities has the potential to improve health status (Veenstra, 2002). While there is evidence that social capital affects health through the development of socially cohesive communities that promote supportive efforts and positive health behaviour (e.g., Veenstra et al., 2005), there is scepticism about whether such arguments are valid for already underserved rural and small-town settings and the increasingly at-risk seniors who inhabit them (Ramsey & Beesley, 2006).

The link between community and rurality stems from traditional assumptions about the nature of rural society. "Rurality" has long been idealized as encapsulating a peacefulness and social cohesion that is missing in urban environments (i.e., the rural idyll) (Cloke, 2005). While the rural idyll has remarkable staying power in popular culture and in government policies and programs, commentators point to the growing disparities between conventional views of rurality and the material realities of rural life (e.g., Pitblado, 2005). Indeed, rural health studies are showing that the lives of rural people are lived in a multidimensional, place-specific context (Hanlon & Halseth, 2005). The small-town milieu is characterized by dispersed settlements, uneven development, social deprivation, and an aging population — features that combine to pose distinct challenges for service provisioning (Halseth & Ryser, 2007). However, despite the burgeoning of rural health studies in Canada (e.g., Canadian Institute for Health Information [CIHI], 2006), including a recent special issue of this journal on rural health research (Kulig, 2005a), the rural dimension of services for seniors is still not fully understood.

The increasing demand for services associated with Canada's aging population exacerbates the longstanding problems surrounding the availability and accessibility of services for rural seniors. Rural service provisioning has been described as the double burden of caring for increasingly vulnerable rural seniors in increasingly vulnerable rural places (Joseph & Cloutier-Fisher, 2005). The difficulty of providing cost-effective services to small numbers of rural seniors is compounded by the failure of governments to acknowledge the unique challenges associated with the small-town milieu, such as geographic, socio-economic, and technological barriers and a limited pool of health professionals and volunteers (Skinner & Rosenberg, 2006). These limitations raise questions about whether the needs of rural seniors are being met and whether rural households and communities are a sustainable source of care (Skinner, in press). Indeed, the literature suggests that recent restructuring demands that families and community members play an increasing role in supporting seniors in order to cut government costs (e.g., Cloutier-Fisher & Skinner, 2006). Yet, in contrast to the widely held beliefs about community and social cohesion in rural areas, researchers have found that seniors draw from a range of sources for their care and that most rural care networks are small and in danger of being overwhelmed (e.g., Fast, Keating, Otfinowski, & Derksen, 2004); as a result, a greater burden is likely being placed on rural seniors' formal and informal caregiver networks (Keating et al., 2001), challenging the conventional argument that small towns, by their very nature, are able to cope.

Taken together, the literatures on community, rurality, and service provisioning in rural Canada reveal a wide gap between belief in community and how communities actually function with respect to supporting seniors. It is this gap that our research on aging communities sought to address.

Methods

To determine how belief in community relates to in-home and community care, we turned to an empirical investigation of services for seniors in different parts of rural Canada. Informed by the threefold theory, we analyzed the results of in-depth interviews with key informants in a series of case studies undertaken for a project funded by the Canadian Institutes of Health Research, Aging Across Canada:

Comparing Service Rich and Service Poor Communities (Rosenberg et al., 2005). The interviews provided an invaluable "insider view" of the complex and dynamic ways in which services for seniors are manifested at the local level.

The Aging Across Canada studies were intended to reveal how and why communities "age" differently and what it takes to create a healthy and service-rich community that allows seniors to age in place. Fourteen qualitative case studies were conducted between 2002 and 2004 by a team of regional investigators. The study sites were selected following an analysis of demographic, population health, and health services data that produced distinct types of aging communities across the country based on population size and levels of income, social deprivation, and community health (Table 1) (see Rosenberg, Moore, Skinner, & Lovell, 2004). Nine of the case studies were defined as representing rural Canada (i.e., either small towns or larger centres serving a rural area) and were purposively selected for analysis here. Based on the studies available, our empirical focus was confined to the collective perceptions of services for seniors in small towns located in rural Prince Edward Island, New Brunswick, Quebec, Manitoba, Saskatchewan, Alberta, and British Columbia. By combining the results of the case studies, we were able to examine the changing service provision environment for rural seniors across the country (Stake, 2005).

The research featured in-depth interviews with a variety of key informants in order to capture the complex dimensions of change and the various sectors involved in providing services for rural seniors across Canada. In each case, a purposive sampling strategy was employed to recruit people with extensive knowledge and experience in providing services for seniors in their communities. Approval was obtained from the research ethics boards of the investigators' universities and health authorities. Informed consent was obtained prior to the interviews. To guarantee confidentiality, the names of individuals and any identifying information are withheld.

In total, 110 interviews were conducted with senior administrators from a wide range of government offices (economic development, municipal council, recreation, transportation), health and social care institutions (hospitals, long-term-care facilities, in-home and community care agencies), voluntary sector organizations (not-for-profit housing corporations, social planning councils, in-home and community care providers), and community groups (community centres, seniors' associations, service clubs), of which 55 are included in this analysis. The number of interviews at the study sites depended primarily on the size of the community but also on variations in how communities are

Table 1 *Profile of Aging Across Canada Studies*[a]

Location	Region	Population[b]	Study Type[c]	Interviews
St. John's, N.L.	Atlantic Canada	99,182	3	9
Sydney, N.S.	Atlantic Canada	105,968	6	7
Summerside, P.E.I.	**Atlantic Canada**	**14,654**	**5**	**6**
Moncton, N.B.	**Atlantic Canada**	**61,046**	**6**	**8**
Chicoutimi, Que.	**Central Canada**	**60,008**	**4**	**10**
Kingston, Ont.	Central Canada	114,195	3	14
Toronto, Ont.	Central Canada	2,481,424	1	15
Dauphin, Man.	**Prairie Canada**	**8,085**	**6**	**6**
Neepawa, Man.	**Prairie Canada**	**3,325**	**5**	**5**
Thompson, Man.	**Prairie Canada**	**13,256**	**7**	**4**
Prince Albert, Sask.	**Prairie Canada**	**34,291**	**6**	**1**
Calgary, Alta.	Western Canada	878,866	2	10
Lethbridge, Alta.	**Western Canada**	**67,374**	**4**	**9**
Prince George, B.C.	**Western Canada**	**72,406**	**4**	**6**
				Total 110

[a] Case studies featured in this article are highlighted in bold ($N = 55$ interviews).

[b] Based on the 2001 census.

[c] Typology based on Rosenberg et al. (2004):

1. Major metropolitan centres with high immigration, above average income, high SD, above average CH.
2. Large cities with high income, moderate immigration, low SD, good CH.
3. Medium-sized cities with average income, SD, CH.
4. Semi-rural regions with above average income, low SD, low CH.
5. Semi-rural regions with average income, low SD, good CH.
6. Semi-rural regions with low income, high SD, below average CH.
7. Northern region with low income, high proportion of Aboriginal population, high SD, poor CH.

SD: social deprivation; CH: community health.

organized administratively across the country. For instance, in one case sufficient information was collected from a single informant who played multiple leadership roles in providing services for seniors in the community.

All of the interviews were conducted using a common interview questionnaire and protocol designed to ensure data consistency throughout the case studies. In meetings lasting between 30 and 120 minutes, the informants responded to a series of semi-structured questions about the current service environment for seniors in their community, with particular reference to strengths and weaknesses and any constraints on the capacity for improved services (see Table 2). The interviews were conducted by research assistants trained in qualitative data collection at a location convenient for the participant. They were audiotaped and transcribed verbatim to ensure authenticity of the data.

Using a grounded theory approach, the investigators performed a content analysis on the qualitative data. This allowed for the identification of themes throughout the primary data by means of continuous interaction (or "checking") with the objectives of the research (Strauss & Corbin, 1998). The first author coded each transcript to identify categories of manifest and latent messages, which were then organized into an interpretive summary based on the identification of themes throughout the entire database (Cope, 2005). Rigour and reliability of data analysis were ensured through a process of checking the categories and themes with the other investigators and the research assistants (Bradshaw & Stratford, 2005). It was through this analytical process that *belief in community, small-town milieu,* and *services for seniors* emerged as themes.

Findings

The findings on rural and small-town Canada are organized according to the three themes, with specific attention to their constituent categories (Table 3). While some of the categories relate to service provisioning in Canada's urban and metropolitan settings, they are all part of the multidimensional context of service provisioning in rural communities. Direct quotes from the transcripts are used throughout, to illustrate the perspectives of the informants and to ensure authenticity of their voices in the interpretation of the findings.

Belief in Community

The concept of community as it relates to service provisioning for seniors was evident throughout the interviews. The 10 different categories that emerged explain the informants' belief in community (i.e., what it is) and how it is manifested at the local level (i.e., what it does).

Table 2 *Aging Across Canada Common Interview Questionnaire*

General Topics	**Questions**
Current dimensions of services for seniors in the community	• Please explain what services and facilities are available in your community. • Please describe the organizations that provide services in your community. • Please explain how services in your community are delivered. • Please describe the overall scope of operation for services in your community. • Please explain how services for seniors in your community are co-ordinated. • Please explain the relationship between the services that are provided in your community and the local/regional health authority.
Information about service organizations	• What services does your organization provide to seniors in your community? • What is the administrative structure of your organization? • To whom does your organization report? • What are the roles and responsibilities of your organization with respect to seniors in your community? • What capacity does your organization have to provide services for seniors? • From where does the funding for services provided by your organization come?
Impressions of services for seniors in the community	• What is your overall impression of the current services available for seniors in your community? • What are the strengths of the services that are currently provided to seniors? • Which services in your community work well? Please explain why.

	• What are the weaknesses of the services that are currently provided to seniors? • Which services in your community do not work well? Please explain why. • What services do you think your community needs most? Please explain why. • Do you think your community is attractive to seniors? Please explain why. • Do you think your community is supportive of seniors' independence? Please explain why. • Does your community actively try to encourage seniors to remain in the community? • Does your community actively try to encourage seniors to move into your community as a retirement destination? • What difficulties do you think your community has in attracting seniors? • What difficulties do you think your community has in supporting seniors' independence? • What initiatives have been taken to deal with difficulties regarding services in your community?
Perceptions of service-rich versus service-poor community	• How would you define a service rich community? • How would you define a service poor community? • What constraints does your community face in becoming more service rich? • Do you believe that your community is service rich or service poor with respect to seniors? Please explain why. • How would you compare your community with others with respect to it being service rich or service poor?

Table 3 ***Major Themes and Categories from Transcript Content Analysis***

Belief in Community	**Small-Town Milieu**	**Service for Seniors**
• Nature of community • Sense of belonging • Family and informal relations • Shared values and meanings • Small-town identity • Voluntarism • Local agency • Formal partnerships • Informal networks • Local churches and clubs	• Rural culture • Social issues • Quality of life • Rural health status • Economic change • Political restructuring • Rural policy • Size of community • Distance, travel, and isolation • Climate and weather	• Service deficiency • Lack of infrastructure • Professional services • Service coordination • Advocacy • Ageism • Aging volunteers • Aging in place • Frail elderly • Seniors' independence

Starting with the *nature of community,* the informants conveyed a positive perception of small towns across Canada. For instance, they suggested that small towns "might be lacking [formal] services, but there is lots of community" and that rural communities feature "a strong sense of self-sufficiency and helping each other out." This optimistic view of community points to a *sense of belonging* in small towns. Informants indicated that there is a feeling of closeness in small towns and that this is especially important for seniors: "This is their home; their roots are here." At the same time, they remarked on the exclusionary nature of their communities: "It's difficult for outsiders to relate with the community."

The *importance of family* was cited by informants as defining small-town settings. There was a strong perception that seniors thrive in communities where they have family — "As long as they have family here, seniors stay here" — and that in small towns everyone is considered family regardless of biological ties. One informant said, "Strangers are related to everybody else as if they were family here." The same person noted the *importance of informal relationships.* Other informants also made this point, highlighting the informal power base of leadership and networking in small towns as well as seniors' dependence on one another: "While seniors may be isolated here, they rely on each other more." They expressed the view that family and neighbours are more likely to look in on one another in rural communities than elsewhere.

Underlying these perceptions of community were *shared values and meanings* centred on relationships of trust and a communal service ethos: "People pull together here, and it makes us stronger." A sense of community was also evident in the informants' identification with individual small towns. Several informants referred to their community as able to resolve its own problems — "We get things done without much fanfare" — while others commented on the resourcefulness associated with "the North." The importance of *small town identity* was particularly evident when small towns were compared with cities: "Rural communities have a stronger community service ethic, [which] we lose as we become more urbanized and sophisticated."

While the informants indicated that a sense of community is central to small-town life, they also raised a number of issues relating to how belief in community operates at the local level. *Voluntarism,* for instance, emerged as a dominant feature of service provision in small towns. While informants mainly spoke positively about voluntarism in their communities, some admitted that it increasingly posed a challenge. Informants highlighted the positive relationship between volunteers and community, with one saying, "Because we have a strong volunteer base here, there's a good support system within the community," and others pointing to the ability of volunteers to supplement the formal service environment: "There are a large number of people involved on a voluntary basis to offset the professional help we're losing." Those informants who mentioned the challenge posed by the use of volunteers focused on their declining availability: "[The volunteers are] getting older and burning out."

Informants indicated that local solutions had been developed to meet service needs. Initiative and leadership emerged as key components of communities' ability to maintain services: "Developing more services would not happen without local vision." More importantly, *local agency* was seen as a central feature of how small towns cope with the lack of resources: "There are fewer resources here, so we've got to be more creative and innovative with solutions." The development of local solutions highlights the importance of *formal partnerships* and *informal networks* between the various stakeholders in a community. One person said, "Service providers have to partner with each other in order to have things happen," explaining that there was interest in developing private partnerships (i.e., between the municipal government and for-profit or not-for-profit agencies) to meet local needs. Informants also referred to the crucial role played by the informal sector in small towns: "[In the absence of] a formal system, informal connections are the things that make community services work."

The last aspect of community identified was the role played by *local churches and service clubs*. Informants indicated that the church represents both a spiritual institution and a focal point for accessing and delivering community services. They referred to the traditional nature of their communities, with more than one commenting on the role of the church: "Most of our residents are connected to the church." "It's not just religion," said an informant, "the church is actively involved in providing services." Local service clubs were also viewed as important providers of community services. However, several people stated that service clubs are struggling to cope with the growing demand for services in small towns: "Out here, services clubs, just like churches, are losing membership and funding."

Small-Town Milieu

Permeating the responses was an overall concern for the rural service environment, from which 10 additional categories emerged, all associated with the sociocultural, political-economic, and material realities of the small-town milieu.

The informants cited both positive and negative aspects of rural life, as captured under the category *rural culture*. Some indicated that their communities were traditional and homogeneous — "We all speak the same language here" — while others pointed to the transient nature of their populations and the lack of closeness in their communities: "We're as diverse as they come." Taken together, these two perceptions reflect the complexity and diversity of Canada's rural communities, which was also evident in the informants' perceptions of *social issues,* such as the overall sense of safety versus the lack of privacy inherent in close-knit rural communities.

Linked to rural culture and social issues was the view that *quality of life* is an important aspect of rurality. Many of the informants referred to the advantages of small-town life, from the practical issue of a lower cost of living — "For those of us on a fixed pension, your dollars go further here" — to the more ephemeral sense of the rural idyll — "We have a more relaxed, more laid-back lifestyle." Some, however, articulated a nuanced view of rurality, acknowledging that not everyone shares equally in the benefits of small-town life. These informants raised the often overlooked issue of rural poverty: "Some people live here because they can't afford to move."

There was clear evidence of an association between quality of life and health status in rural Canada. The informants demonstrated a sophisticated understanding of the underlying issue of *rural health.* They described the effects of the various determinants of health, such as income, education, employment, personal health, and health services, on the relatively poor health status in rural areas, as noted in the literature (CIHI, 2006). "People in the North [and other rural areas] aren't as healthy," said one informant, "and we don't have the capacity to change that." The informants suggested, however, that there is a sense of resiliency in small towns: "While health care is a serious issue here, an awful lot of our seniors aren't sick because they're tough."

Economic change was associated with all the small towns in the study. Informants pointed to the widespread impact of a decline in agriculture, fishing, forestry, mining, and other resource-based industries on small towns across the country. Some cited the unemployment and out-migration due to economic decline: "All the small villages are being deserted because there are no jobs." Others commented that they were starting to see symptoms of social disintegration in their communities: "Crime is becoming a serious problem — homelessness and alcoholism too." Reflecting the variety of small towns featured in the research, some informants expressed a positive view of the economic changes taking place, noting that their communities were retirement destinations and seeing the in-migration of older populations and retirement-oriented businesses as a boost to the local economy.

Along with the economic transition, the informants referred to *political restructuring* as a source of systemic change in their communities. They discussed the impact of broad-scale changes to public services, such as centralization of health authorities, downloading of ambulance services to the local level, and municipal reorganization through amalgamation. One informant cited the "lack of political clout" in rural areas and another suggested that recent restructuring was worsening this situation. Informants bemoaned the *lack of rural policy* in general, which one referred to as "a forgotten issue" and went on to explain, "We are disadvantaged because we are far away from decision-makers in the city."

The perception that the economic impact on the lives of rural people was heightened by the small *size of their communities* was virtually universal among the informants. Informants brought up the difficulty of developing economies of scale for the full range of services in rural and small-town settings. One explained that "sometimes it's hard to put together the resources to meet needs, because we don't have the volume...." Another said, "There's no critical mass of population to demand services," which exacerbated the resource scarcity associated with small towns. Informants also pointed to *distance, travel,* and *isolation* as significant barriers to accessing services in rural areas: "Distance is a big problem for those who have a 2-hour drive to get treatment because of a lack of physicians here." While the informants attributed the isolation of small towns to physical location — "We're just one remote community that the Regional Health Authority serves" — they also raised the social isolation of seniors within the community itself as an issue: "There aren't enough services here to get [seniors] out amongst other people, so they stay inside"; "Sometimes we find them dead."

While weather is not unique to rural environments, there was a strong perception that the challenges posed by *climate and weather conditions,* especially during the winter season, served to exacerbate those of providing and accessing services for seniors in small towns. Informants from across the study sites viewed winter and snow as particular barriers. Some related them to the issue of seniors being homebound — "Some of our older people can only get out of their homes in the summer" — and to the strain on already limited services — "Winter limits access to community services"; "If there's a snowstorm, we really shut down — not like other places, where you just hop on the bus or subway." As with other aspects of the small-town milieu, there was a minority perspective that emphasized the positive aspects of climate and weather in rural areas, consistent with the rural idyll: "It's part of our outdoor recreation and fresh air."

Services for Seniors

Specific issues and challenges surrounding the provision of services like in-home and community care for seniors were captured in 10 final categories relating to the overall availability of services in rural areas and the particularities of the aging rural population.

There was a general perception that insufficient funding and resources hinder the availability of services in rural and remote regions, and that these areas already have minimal levels of service compared to urban communities. Informants also referred to the narrow range of service options available: "Services that *are* available here are good, but we don't have the entire continuum…over the life cycle." *Service deficiencies* also reflected ongoing problems of service provision in rural areas and related to specific issues in small towns, such as the *lack of general infrastructure*. Informants cited the lack of municipal infrastructure, such as public transportation, as weakening seniors' access to services: "We're like a poor country cousin, with poor roads." Similarly, in terms of the availability of health and social care, people referred to the dearth of *professional and specialized services* in small towns. Along with the longstanding need for more general practitioners in rural areas, they pointed to the growing need for geriatric care, long-term care, and mental health services in their communities. These issues are exacerbated by the difficulty of recruiting and retaining professionals in small towns: "It's hard to attract health professionals [to our community] and to find trained staff here — they don't want to come north."

In addition to the service deficiency in small towns, *service coordination* was seen as a challenge for rural service provisioning. Informants explained that management of the disparate and limited services in rural areas is crucial for local service providers and for seniors; however, they also pointed out that, because of limited resources and staff in small towns, such coordination is usually informal and sometimes insufficient: "There's a need to network between different groups, to ensure better program management in the community…but there aren't that many of us around." In addition, although not necessarily unique to the rural context, awareness of what services are available for seniors in the community was seen as a challenge: "Sometimes people don't get the services they need because they don't know where to go." Similar to the need for service coordination, there was a perception that lack of information serves only to exacerbate the accessibility challenges facing seniors living in relatively isolated rural settings: "Most seniors don't know what's out there for them…so they go without."

Limited coordination and awareness became even more important when issues surrounding *advocacy* for seniors in small towns were raised. Informants suggested that service availability is undermined by a general lack of concern for the needs of older people, especially those living in rural areas: "Seniors need someone to champion their issues"; "There has to be someone to assess, support, and determine their needs." Consequently, there was a perception that responsibility for advocacy lies with family members and with the seniors themselves. Compounding this issue, the informants pointed to *ageism* in the rural service environment. Some noted that seniors are not a priority in the planning process, while others suggested that seniors' fear of being labelled in the rural setting, where privacy is sometimes lacking, restricts their use of the services that are available: "There's a stigma with using the Handi-Van — an admission of being old." It was also suggested that many younger residents do not look upon seniors as active, contributing members of the community despite the fact that, according to the informants, it is seniors who do the majority of volunteering.

Many of the informants were concerned about the implications of relying on older volunteers. They reported that people in both paid and voluntary positions are "wearing out" as they get older. One informant put it very succinctly: "There's a lot of burnout in the senior population." This was a significant issue for the informants, who viewed voluntarism as a key component of the service environment in their towns: "Our volunteers are getting older, slowing up, and sickness takes them over too." *Aging volunteers* in particular were viewed as a challenge for the study communities, which were seen as growing old more rapidly than their urban counterparts. One person said, "We have no one left but older volunteers, with the young ones leaving [the community] for work and all."

The challenge of *aging in place* emerged as a key feature of the small-town milieu. Along with the larger proportions of older people in rural areas presenting a challenge for service provision, the informants noted that increasing demand for services to help seniors remain in their homes and communities is taxing existing services: "We're struggling to catch up to the older population." In addition, some informants connected the impact of aging in place to other demographic trends in their communities, including the out-migration of the younger population and the shrinking support networks of seniors due to a combination of demographic trends. "The loss of young people is really affecting service provision in the community," lamented one informant.

Several people also cited the need to differentiate among the generations of seniors living in their communities. One person commented on the demands associated with newly retired, active seniors versus those associated with the "frail elderly" (those seniors over 80 years of age). According to another informant, the growing numbers of frail elderly in rural areas pose a problem because "their needs are getting more complicated than we have time for." The informants viewed the oldest seniors as presenting additional challenges: "We see seniors who are stuck in the old system…it's impossible for some old seniors to think about online banking…or taking cabs."

Ultimately, the ability of seniors to remain in their own homes and communities was viewed as a critical challenge for the provision of services. Informants suggested that rural settings often serve to hinder *seniors' independence* because of the lack of home care support. They saw the lack of intermediary resources, such as Meals on Wheels and caregiver respite programs, as particularly significant, because "some people who aren't ready for long-term-care residences are forced to go there anyway." Other informants, in contrast, looked upon the active involvement of seniors in the community — as volunteers, for instance — as a sign of their independence.

Discussion

The three-part analysis presented above sheds light on how the concept of community is manifested in terms of in-home and community care for seniors in rural Canada. These descriptive findings show that belief in community, rurality (the small-town milieu), and service provisioning are important yet complex themes for understanding the health and social care of seniors living in small towns. Unique categories of each theme were distinguishable in the informants' perspectives on services in their communities (e.g., sense of belonging, quality of life, service deficiencies), and many aspects, such as the growing reliance on voluntarism, were linked to more than one theme. Other issues seemed to transcend the rural context (e.g., the importance of local solutions, the implications of weather and an aging population), suggesting that the empirical reality of rural service provisioning is much more complex than is apparent in the literature.

Three potential sources of this complexity emerge from the findings. First, the rural service environment in general and the specific challenges of providing services for seniors influenced the informants' perspectives on the concept of community. For instance, issues surrounding the nature of community (e.g., self-sufficiency) and small-town identity (e.g., the North) stem directly from traditional perceptions of rurality in Canada. In addition, issues surrounding the importance of family and informal relations link directly with service availability and accessibility challenges for rural seniors. The second source of complexity is the strong presence of belief in community in the informants' perspectives on their local service environment. On the positive side, they highlighted the role played by aspects of community linked to social capital, such as local agency (e.g., leadership) and institutions (e.g., the church), in creating a service-rich community. On the negative side, they acknowledged the barriers, such as lack of infrastructure, to the provision of services for seniors in small towns. The third source of complexity is the ambiguity regarding the ability of rural communities to support aging in place. While the informants indicated that they believed in community, they had concerns about community-based, informal means of providing services. Positive perceptions of community (i.e., what it is) contrasted with the realities of how communities function (i.e., what they do). For example, on the one hand the informants drew attention to the role of voluntarism in strengthening the local service environment and on the other hand they cited the limitations of voluntarism in rural and small-town settings.

The findings thus confirm a sense of uncertainty among service providers who, as we stated at the outset, remain unconvinced that the close ties among rural people and their shared sense of community can compensate for the lack of formal in-home and community care. It must be acknowledged, however, that the findings represent only the perspectives of small-town service providers. The research did not cover the perspectives of providers in Canada's urban and metropolitan settings nor the voices of seniors themselves (i.e., the user perspective). This is a limitation because there may be other arguments and evidence as to the importance of belief in community for sustaining the independence of rural seniors (e.g., see Cloutier-Fisher & Joseph, 2000). These other user and provider perspectives lay beyond the scope of this analysis.

We also acknowledge the limitation of the combined case study approach, which allows for the presentation of generic findings of service provisioning in the nine small towns across Canada but does not account for the place-specific ways in which belief in community plays out among the different sites. Not addressed in the research were the significant sociocultural, political-economic, and geographical distinctions among the small towns, such as anglophone versus francophone communities, resource-based versus retirement communities, and prairie versus coastal communities. Neither were the comparable experiences of services for seniors in other types of aging communities across Canada considered (e.g., does belief in community play out similarly in urban and metropolitan settings?). These issues notwithstanding, the findings serve to narrow the gap in our understanding of how belief in community functions, with respect to creating supportive and service-rich environments by deconstructing the complex and diverse ways in which community, rurality, and service provisioning interact at the local level.

Concluding Comments

The conventional view that what small towns lack in formal services they make up for in the supportive nature of the rural community continues to influence health policy, research, and practice. Using findings from interviews with key informants in nine small towns across Canada, we examined the interrelationships among the concepts of community, rurality, and the specific issues surrounding services for seniors. Our objective was to determine whether this perspective reflects the reality of in-home and community care in rural communities. We conclude that the integration of these concepts has provided a useful approach for exploring in-home and community care for seniors in rural and small-town settings. Given the regional focus of the Aging Across Canada studies upon which the analysis was based (Rosenberg et al., 2005), and given the growing calls to address the under-theorized and under-researched issue of rural health care in general (Kulig, 2005b), we view our approach as at least partially transferable to the study of service provisioning in other parts of rural Canada and in rural parts of other Western countries facing similar challenges.

Reflecting on the prevailing argument in the literature, the research reveals that there is a strong belief among service providers that, despite the limitations associated with the rural service environment, communities are able to provide for their seniors. The results suggest, however, that assumptions about community, rurality, and services for seniors are predicated on positive perceptions of community in small towns, not to mention a belief that families, friends, and neighbours can mediate the reality of the lack of formal services in rural areas. This contradiction resonates with concern for the ability of rural communities and their informal sectors to cope, especially given the shift in public policy towards in-home and community care, which risks further entrenching service deprivation in rural areas. Indeed, there is a paradox between the conventional notion that the social nature of community can compensate for lack of services and concern about the lack of informal networks in rural areas. How seniors living in small towns are imagined (or romanticized) remains a fundamental question, and we challenge decision-makers, researchers, and providers to debunk assumptions about services for seniors in rural Canada. In closing, we warn of the very real danger that belief in community will continue to justify health policies and programs, further prejudicing the situation of rural seniors and their caregivers.

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Happenings

Nurse Researchers Contributing to Seniors' Independence in the Community

Nancy Edwards and Jo-Anne MacDonald

Canadian nurse researchers have made substantial contributions to the field of health services and policy research with seniors. The realities of an aging population are now on the agenda of policy-makers. Thus new challenges and promising opportunities await nurse researchers.

First, we present a brief overview of some pivotal nursing research with older adults in Canada. Next, we offer an example of an evolving program of research targeting falls among seniors. Finally, we describe how emerging policy frameworks provide direction for future research.

Canadian nurse researchers have made longstanding contributions to health issues among seniors. The following examples illustrate the breadth and depth of their research. Mohide and Pringle led early studies of support and respite services for caregivers of older adults with disabilities and cognitive impairments (Mohide, 2002; Mohide et al., 1990). Other investigators are advancing this research, identifying the impacts of service delivery that emphasizes self-reliance, autonomy, and supportive environments (Forbes & Janzen, 2004). Predictors of health among male caregivers are a focus of investigation by Ducharme, Lévesque, Lachance, Vézina, and Zarit (2005). Other researchers have explored the influence of gender on the health practices of elderly immigrant populations (Oliffe, Grewal, Bottorff, Luke, & Toor, 2007). Brown, Markle-Reid, and colleagues have examined the cost-effectiveness of community-based health service delivery for frail elderly home care populations (Markle-Reid et al., 2003), while McWilliam's studies have provided insights into the value of interdisciplinary work and the impact of the culture of home care nursing on client outcomes (Gantert & McWilliam, 2004; Hall & McWilliam, 2006). The development of practice guidelines for the assessment and management of leg ulcers and wounds has been shaped by Harrison's work (Graham, Harrison, Cerniuk, & Bauer, 2007; Harrison et al., 2005), while Skelly and colleagues have advanced our understanding of urinary incontinence (Swanson, Kaczorowski, Skelly, & Finkelstein, 2005; Swanson, Skelly, Hutchison, & Kaczorowski, 2002) and researchers on the west coast have focused on the prevention of falls (Gallagher & Scott, 1997; Herman, Gallagher, & Scott, 2006; Scott, Votova, Scanlan, & Close, 2007).

Although there are many examples of innovative knowledge translation strategies developed by these and other nurse researchers, there has been a tendency to concentrate such efforts on changes in the health-care sector. If we are going to substantially help seniors to age in place, new partnerships for research and knowledge translation will have to be developed with community agencies and policy-makers outside the health-care sector.

Our work on falls prevention illustrates the need for a shift in both research questions and knowledge translation strategies. Research in the late 1980s focused on risk factors for falls, a significant precursor for intervention research. Many intervention strategies have now been tested, including those that focus on individual behaviour change and those that target the larger community. In the late 1990s we decided to concentrate our efforts on modifications to the built environment. Falls on stairs and in bathrooms were of particular interest as these represent a large proportion of all falls and of falls with higher rates of injury. Consistent with a population health approach, we identified building codes as a critical focus for our knowledge translation efforts. This was new territory for us, and it called for the development of skill in working with other disciplines and sectors, including biomedical engineering, the housing and construction industry, and those responsible for modifications to the codes. Although our early intervention studies encouraged seniors to install bathroom grab bars and to examine the safety features of their indoor and outdoor stairs, providing input on the building codes required a different set of research questions. Specifically, we needed to determine (a) whether there were differences in the use of grab bars that were universally installed versus those installed by the owner of a home, (b) what configuration of grab bars seniors found easier to use, and (c) what features of indoor and outdoor stairs seniors found hazardous. Addressing these questions necessitated an expansion of our research team to include those with backgrounds in engineering and ergonomics. Our research portfolio grew to include laboratory studies. Gaining familiarity with the national and provincial processes for changes to building codes was essential as we refined our knowledge translation strategies. We used invitational symposia to obtain the input of decision-makers on the processes required to make changes to building codes. This helped us to gain a better view of how we might bring our research findings to the policy table. More recently, Edwards's

Table 1 *Examples of Provincial Frameworks for Aging*

Province/Territory	**Framework**	**Policy Elements**
Nova Scotia	Continuing Care Strategy for Nova Scotia: Shaping the Future of Continuing Care	Supporting individuals and families and community solutions, investing in providers, strengthening continuing care services, and investing in infrastructure (Nova Scotia Department of Health, 2006)
Newfoundland and Labrador	Provincial Healthy Aging Policy Framework	Improving access to prescription drugs, increasing the seniors' benefit, eliminating the mandatory retirement age, and placing a focus on health promotion (Government of Newfoundland and Labrador, 2007)
Manitoba	Advancing Age	Coordinated and comprehensive framework of legislation, public policy and programs designed to address health care, community living, and security (Manitoba Seniors and Healthy Aging Secretariat, 2003)
Ontario	Aging at Home Strategy	Integrated continuum of community-based services: facilitating seniors to reach their health potential, improving access to services, building system capacity and responsiveness, and expanding housing options (Ontario Ministry of Health and Long-Term Care, 2007)
Saskatchewan	Provincial Policy Framework and Action Plan for Older Persons	Strategic directions for housing, transportation, health care, active living and lifetime learning, safety and security, and recognition of the contributions of older persons (Saskatchewan Provincial Advisory Committee for Older Adults, 2003)

membership in a group responsible for making recommendations regarding changes to national building code standards for stairs, ramps, guards, and handrails has provided an avenue for putting research findings into action.

As nurse researchers consider priorities for research in the next decade, it is important that they be aware of policy frameworks for older persons announced in several provinces. Examples are shown in Table 1.

These frameworks remind us of the many sectors that influence seniors' independence and health status. They also highlight the importance of knowledge translation strategies that address the array of services and policies required to support seniors' independence. Thus the next generation of research undertaken by nurse researchers calls for the establishment of strategic intersectoral links and the identification of opportunities to bring evidence to the iterative and often long-term processes of policy formulation and implementation.

Canadian nurses have made substantial contributions to research with community-dwelling seniors. Much work still needs to be done. As governments become aware of the impact of demographic shifts on our social structures and health-care systems, they are developing policy frameworks to address these challenges. It is essential that we consider both what research questions arise from these frameworks and what knowledge translation strategies are needed to inform policy. The renewed interest in policies that support independent living for older adults in the community presents a critical opportunity for nurse researchers. There is no doubt that we are poised to address this challenge.

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Book Review

Healthy Aging: A Lifelong Guide to Your Physical and Spiritual Well-Being

Andrew Weil, M.D.
Toronto: Random House, 2005, 358 pp.
ISBN 978-0-307-27754-1

Reviewed by Elaine M. Gallagher

It was with scepticism that I approached the task of reviewing a book on aging by a physician who is known to be a regular guest on such television programs as *The Oprah Winfrey Show* and *Dr. Phil.* Not that the guests on these shows do not have valuable ideas to share, but pop culture today is full of myths and fantasies about what one can do to prevent the very natural process of aging. Many of the preachers are motivated by market incentives of various types, and it can be difficult to separate the proven remedies from the ones that are based on poor or minimal research.

At first glance, Dr. Weil appeared to hold more credence than many writers who claim special knowledge or wisdom on various topics. With undergraduate and medical degrees from Harvard, he is the founder and Director of the Program in Integrative Medicine at the College of Medicine, University of Arizona, where he also holds the positions of Clinical Professor of Medicine, Professor of Public Health, and Lovell-Jones Professor of Integrative Rheumatology. I was inspired to continue reading.

Healthy Aging is one of 10 books authored by Dr. Weil on a variety of subjects based on his beliefs and research findings concerning our ability to improve our minds, bodies, and spirits in natural, holistic ways. The focus of this book is the later stages of life. The key messages stem from his premise that it is never too early or too late to start caring for your body, and that does not mean plastic surgery, Botox, expensive face creams, or medications of various sorts. This "Dr." has a new set of "prescriptions," including:

- get regular exercise
- enjoy better sleep
- prevent flu and cold infections
- learn to eat well (an anti-inflammatory diet is outlined in detail) and choose proven dietary supplements

- live with altered sexuality and other stresses in healthy and creative ways
- have regular screening checks and treat precursors to illness (like hypertension or hyperglycemia) early
- maintain healthy mental, social, and intellectual patterns

Now, this is not rocket science and it is information that many nurses know intuitively and in fact are taught in health promotion classes as part of undergraduate curricula. However, the scientific backing for many of these ideas has been beautifully woven throughout the book in an informative yet easily understood way. Thus the book reads less like a textbook for a course and more like something you would want to keep by your bedside for inspiration and guidance. It is a book to give as a gift to one's aging parents, a book to recommend to the girls' book club, a book to use as a reference for those nursing courses.

Perhaps Dr. Weil's most compelling message is around the notion of embracing one's aging, recognizing the normality of many of the changes one undergoes and not trying to stop or interfere with the process. Dr. Weil suggests we "use the experience of aging as a stimulus for spiritual awakening and growth." He also recommends journaling one's encounter with aging and sharing the knowledge one has gained with others one cares about.

Some may find that he stretches his analogies somewhat by providing detailed descriptions of the values of aged whisky, wine, cheese, beef, violins, and antiques. So be it. I found that aspect of his book refreshing, although as I near that magic age of 65 myself, I think I want to be thought of more as "graceful swan" than as ancient chest of drawers. That aside, the book will appeal to many readers, particularly health practitioners of all backgrounds. While respecting the role that genetics and the environment play in determining our life course, *Health Aging* provides guidance on those elements of our aging that we can control — our lifestyle. It includes practical tips on how to carry out the recommended lifestyle changes as well as additional reading and resources to assist one in making those changes. I will read this book again.

Elaine M. Gallagher, RN, PhD, is Director, Centre on Aging, University of Victoria, British Columbia, Canada.

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Résumé

Validation de deux échelles de dépistage de dépression postpartum auprès d'un échantillonnage de femmes des Premières Nations et de femmes métisses

Pamela J. Clarke

L'étude a pour objectif de déterminer la prévalence de la dépression postpartum (DPP) et d'examiner l'utilité de l'échelle de dépistage de dépression postpartum [Postpartum Depression Screening Scale – PDSS] et de l'échelle de dépression postnatale d'Edinburgh [Edinburgh Postnatal Depression Scale – EPDS] chez les femmes des Premières Nations et les femmes métisses, dans la province canadienne de la Saskatchewan. Un total de 103 femmes qui ont accouché dans une période de un à douze mois précédant l'enquête ont été recrutées dans la ville de Regina et dans des centres de santé desservant les Premières Nations de cette province. Des outils d'autoévaluation servant à dépister la DPP ont été remis dans le cadre d'une entrevue clinique structurée pour identifier la présence d'un trouble de l'axe 1 du DSM-IV (SCID) et dépister la DPP. Des 103 femmes, 17 % ont reçu un diagnostic de DPP. Les résultats confirment la validité des échelles PDSS et EPDS comme outils de dépistage de DPP chez les femmes des Premières Nations et les femmes métisses. L'auteure discute de la nécessité de mettre en place des professionnels de la santé primaire, y compris des infirmières, pour offrir des services de dépistage postnataux aux femmes risquant la DPP.

Mots clés : dépression postpartum, DPP, Premières Nations, femmes, validation, dépistage

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Validation of Two Postpartum Depression Screening Scales with a Sample of First Nations and Métis Women

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The purposes of this study were to determine the prevalence of postpartum depression (PPD) and to examine the utility of the Postpartum Depression Screening Scale (PDSS) and the Edinburgh Postnatal Depression Scale (EPDS) in First Nations and Métis women in the Canadian province of Saskatchewan. A total of 103 women who had given birth in the preceding 1 to 12 months were recruited from the city of Regina and from First Nations health centres in Saskatchewan. Self-report screening instruments assessing PPD were administered along with a structured clinical interview for DSM-IV Axis I disorders (SCID) to confirm the diagnosis of PPD. Of the 103 women, 17% were diagnosed with PPD. The findings support the validity of the PDSS and the EPDS as measures of PPD in First Nations and Métis women. The author discusses the need for primary health care professionals, including nurses, to offer postnatal screening for women who may be at risk for PPD.

Keywords: Postpartum depression, PPD, First Nations, women, validation, screening

Pregnancy and childbirth are remarkable events in the course of a woman's life. Although for many women the transition to motherhood is a precious time that brings excitement and joy into the home, new motherhood is a vulnerable time for the development of postpartum mood disorders (Miller, 2002). Postpartum depression (PPD) is the most frequent and serious clinical mood disorder among women postpartum (Beck, 1995). Although PPD has been identified as a major public health concern across cultures, Yonkers and colleagues (2001) report that nearly 80% of their sample of impoverished women with PPD remained undiagnosed due to associated stigmas and lack of screening by health-care providers.

Research conducted with samples from different cultures has found prevalence rates for PPD to vary from 13% to 50% (Affonso, De, Horowitz, & Mayberry, 2000). Westernized countries such as Australia and Sweden have the lowest levels of PPD, whereas selected Asian and South American sites have the highest. The lower levels of depressive symptomatology found in Australia and Western European countries may be the result of mental health assessment and intervention programs; higher levels of PPD in Asian and South American samples implies less recognition of the disorder as a major health concern (Affonso et al., 2000).

As Canada becomes increasingly multicultural, PPD prevalence rates provide an empirical basis for determining vulnerability to maternal depression among diverse cultural groups. Awareness of and knowledge about PPD, particularly in underserved and minority populations, could assist in its detection in the immediate postpartum period (Dennis & Ross, 2006). Given the increasing awareness of the cognitive, behavioural, and emotional sequelae of PDD for women, their children, and their families, it is imperative that reliable and culturally valid screening procedures be employed (Boyd, Pearson, & Blehar, 2002).

Over the last two decades, a number of PPD screening instruments have been developed and validated in community and clinical samples in several countries (Boyd et al., 2002). The Edinburgh Postnatal Depression Scale (EPDS; Cox, Holden, & Sagovsky, 1987) is one of the most researched and widely used PPD screening instruments (Eberhard-Gran, Eskild, Tambs, Opjordsmoen, & Samuelsen, 2001). During development and validation of the EPDS, Cox and colleagues (1987) found that a cutoff score of 12 yielded optimal predictive power in differentiating women who were depressed postpartum from those who were not. Specifically, a cutoff score of 12 produced sensitivity (i.e., true positive rate) of 86% to identify screened women with PPD, specificity (i.e., true negative rate) of 78% to identify screened women not depressed, and a positive predictive value (PPV) (i.e., identifying women who were depressed given a positive screen) of 73% to identify women who were depressed given a positive screen. Although subsequent cross-cultural studies (e.g., Ghubash, Abou-Saleh, & Daradkeh, 1997) reported similar diagnostic utility (i.e., predictive values) when employing a cutoff value of 12, other studies (e.g., Zelkowitz & Milet, 1995) have found a cutoff value of 12 to be less than optimal. Zelkowitz and Milet (1995) reported 91% sensitivity when employing a cutoff value of 10 in their community sample of postpartum women in Canada. These discrepancies suggest that different cutoff scores may be required for different cultural groups or selected populations (i.e., clinical vs. general). Furthermore, scores of 9 or 10 may be indicative of subclinical levels of PDD, whereas a higher cutoff value of 12 may be more predictive of those who meet diagnostic criteria for PPD (Lawrie, Hofmeyr, De Jager, & Berk, 1998).

A second recently developed measure of PDD is the Postpartum Depression Screening Scale (PDSS; Beck & Gable, 2000). In their validation study with 150 American women with PPD, Beck and Gable (2001) compared the screening utility of the PDSS to that of the EPDS. The

PDSS demonstrated better predictive and construct validity. Construction of receiver operating characteristic (ROC) curves indicated that a cutoff score of 80 yielded sensitivity of 94%, specificity of 98%, PPV of 90%, and negative predictive value (NPV) (i.e., identifying women who were not depressed given a negative screen) of 99%. Beck and Gable (2001) report that the PDSS yielded better validity than reported by Cox et al. (1987) in their validation study of the EPDS.

To date, the PDSS has been validated in predominantly Euro-American middle-class populations, with few samples drawn from minority or underrepresented populations. Beck and Gable (2003) recently validated a Spanish version of the PDSS in a sample of 150 Hispanic postpartum women in the United States. They found that a cutoff score of 60 was optimal in identifying PPD despite obtaining slightly lower psychometric values than found for the English version of the PDSS. In a sample of Native American women (Baker et al., 2005), the PDSS identified 23% of the sample as having PPD and revealed a history of depression to be a risk factor for PPD. Although there is a dearth of available data examining the utility of the PDSS in minority populations, Beck and Gable (2001) report that the PDSS captures many facets of PDD and is a more valid measure than the EPDS.

In Canada, rates of general depression in First Nations and Métis adults have been found to be three to four times higher than those for non-Aboriginal adults (O'Nell, 1996). However, no studies to date have published data examining prevalence of PPD in First Nations and Métis women, nor have they validated PDD instruments in that population despite the high rates of general depression and the known link between general depression and PPD. The present study is the first to explore PPD in Canadian First Nations and Métis women. The purposes of this study were to determine prevalence rates of PPD in a sample of First Nations and Métis women in the province of Saskatchewan and to compare and validate the PDSS and EPDS in this sample. Findings from the study will assist nurses to provide culturally appropriate screening procedures for PPD in Canadian First Nations and Métis women.

Methods

Sample

Ethical approval was obtained from the University of Regina and the Regina Qu'Appelle Health Region. A total of 103 English-speaking First Nations and Métis women who were 18 years of age or older and had given birth to a live infant in the previous 1 to 12 months were recruited from postnatal and parenting groups and via notices posted in various locations (e.g., hospital maternity wards, community health centres) in

Regina and in First Nations health centres in Saskatchewan. Despite the higher rates of teenage pregnancy among First Nations and Métis females compared to the general Canadian population (20% vs. 5.6%; Health Canada, 2001), adult women (i.e., aged 18 years and older) form the majority of the childbearing population. Because some emotional reaction in puerperium is apparent in 50% to 80% of women following birth (Glangeaud-Freudenthal, Crost, & Kaminski, 1999), a 1-month period was used to allow for the dissipation of symptoms commonly associated with "baby blues" (Yawn, 1996). Furthermore, onset of depressive symptoms can occur any time within the first 12 months after giving birth (Stowe & Nemeroff, 1995), thus supporting the inclusion of women up to 12 months postpartum.

Measures

The EPDS (Cox et al., 1987) is a 10-item, self-report, paper-and-pencil measure that assesses symptoms such as sadness or misery, inability to laugh, inability to look forward to the enjoyment of things, anxiety and tendency to worry, fear or panic, difficulty sleeping, and thoughts of harming oneself. In the present study, the internal consistency of the EPDS was $\alpha = 0.87$.

The PDSS (Beck & Gable, 2000) is a 35-item, self-report, paper-and-pencil measure that assesses seven dimensions of PDD: Sleeping/Eating Disturbances, Anxiety/Insecurity, Emotional Lability, Mental Confusion, Loss of Self, Guilt/Shame, and Suicidal Thoughts. In the present study, the internal consistency of the PDSS was $\alpha = .95$.

The BDI-II (Beck, Steer, & Brown, 1996) is a widely used 21-item clinical instrument that assesses cognitive, somatic, and affective symptoms of depression. Although use of the BDI-II as a measure of PPD requires careful interpretation (i.e., inflated scores; Affonso et al., 2000), the BDI-II is widely used in PPD research and has demonstrated good concurrent validity with measures of PPD (Beck & Gable, 2001). The BDI-II was used as a comparison tool for assessing the construct validity of the EPDS and the PDSS. In the present study, the internal consistency of the BDI-II was $\alpha = 0.85$.

Procedure

After written informed consent to participate had been obtained, participants completed a background information sheet and then the depression screening scales. The screening scales were administered in a counter-balanced manner. Once the background information sheet and depression questionnaires were completed, the author interviewed each mother privately using the Mood Disorder Module of the Structured Clinical Interviews for DSM-IV Axis I Disorders (SCID; First, Spitzer, Gibbon, & Williams, 1997) to confirm the diagnosis of PPD. The author had received instruction and training in administering the SCID by a licensed clinical psychologist.

Data were entered into SPSS 11.0. Data-analysis procedures used in this study included descriptive statistics, correlations, and logistic regression. ROC curves were also constructed for the PDSS and the EPDS.

Results

Sample

Of the 103 mothers, 17 (17%) were diagnosed with PPD based on the SCID. The mean age of the sample was 23.8 years (*SD* = 4.73), with a range of 18 to 42 years. Of the participants, 48% (*n* = 49) had given birth between 1 and 4 months before completing the measures. Approximately 58% (*n* = 59) reported not completing high school and 59% (*n* = 61) reported a family income of less than $10,000. Nearly 62% (*n* = 63) resided in the city of Regina and 33% (*n* = 34) resided in reserve communities. Of the mothers, 28% (*n* = 29) were single, 10% (*n* = 10) married, 53% (*n* = 55) partnered, and 4% (*n* = 4) divorced. Of the sample, 87% (*n* = 90) had delivered vaginally and 21% (*n* = 22) reported complications during delivery. As for infant-feeding method, 29% (*n* = 30) of the women reporting breastfeeding, 41% (*n* = 43) bottle-feeding, and 30% (*n* = 31) a combination. Of the sample, 43% (*n* = 45) experienced feelings of sadness or depression in the antenatal period and 52% (*n* = 53) had a previous history of depression.

Construct Validity: Correlations

Correlational data were analyzed to examine the construct validity of the EPDS and the PDSS. The EPDS was correlated with BDI-II, $r\ (94) = .71, p < .01$, and the PDSS was correlated highly with both the BDI-II, $r\ (94) = .75, p < .01$ and the EPDS, $r\ (101) = .80, p < .01$, indicating that the three instruments measured similar aspects of depression.

Construct Validity: Logistic Regression

Separate hierarchical logistic regression analyses were performed to compare the ability of the EPDS and the PDSS to predict SCID-depressed versus non-depressed status. The BDI-II was entered first for both analyses, as this instrument correlated with both PPD screening instruments and thus was used as a control to screen for depressive symptoms. The regression models for depressive status are shown in Table 1. The first model, with the BDI-II as the only predictor in the first block, discriminated those depressed from those not depressed, $\chi^2\ (1, N = 95) = 30.65, p < .001$, odds ratio = 1.24, and accounted for 47% (Nagelkerke

Table 1 ***Summary of Logistic Regression Analyses for Variables Predicting Depressive Status (N = 95)***

First Model	β	Wald Test (*z* ratio)	Odds Ratio	Nagelkerke R^2	95% CI
Block 1					
BDI-II score	.22**	17.70	1.24	.47	1.12–1.38
Block 2 – first model					
BDI-II score	.13*	4.42	1.14		1.01–1.28
PDSS score	.05*	5.30	1.05	.55	1.01–1.10
Block 2 – second model					
BDI-II score	.12	3.42	1.12		.99–1.27
EPDS score	.30**	6.28	1.35	.58	1.07–1.71

* $p < .05$; ** $p < .01$

R^2) of the variance in depression classification. The PDSS was then added in the second block of the first model. The second block discriminated the depressed from the not depressed, χ^2 (1, N = 95) = 6.24, p = .012, odds ratio = 1.10, and together the BDI-II and PDSS accounted for 55% (Nagelkerke R^2) of the variance in diagnostic classification of PPD. Taken together, the overall correct classification rate for the PDSS and the BDI-II was 88% for depressed versus non-depressed.

The second hierarchical logistic regression analysis was conducted using the BDI-II and the EPDS as predictor variables. As in the preceding analysis, the BDI-II was entered as the only predictor in the first block of the model. Entry of the EPDS in the second block of the second model discriminated those depressed from those not depressed, χ^2 (1, N = 95) = 8.65, p = .003, odds ratio = 1.35. Together, the BDI-II and EPDS accounted for 58% (Nagelkerke R^2) of the variance in diagnostic classification of PPD. The overall correct classification rate after combining the EPDS and the BDI-II was 92% for depressed versus non-depressed. In comparing the variance accounted for over and above the BDI-II, the EPDS accounted for an additional 11% (Nagelkerke R^2), whereas the PDSS accounted for slightly less additional variance of 8%.

Sensitivity, Specificity, and Predictive Values

ROC curves were generated using SPSS 11.0 to examine the sensitivity, specificity, and predictive values over a range of cutoff scores for the PDSS and the EPDS. Sensitivity (i.e., true positive rate) is the ability of a screening measure to identify correctly all screened women who have PPD; specificity (i.e., true negative rate) is the ability of the screening scale to identify correctly all screened women who do not have PPD (Jekel, Elmore, & Katz, 1996). There is a tradeoff between sensitivity and the specificity of a screening instrument when optimum cutoff scores are constructed (Fletcher, Fletcher, & Wagner, 1996). When either sensitivity or specificity is increased, it is at the expense of the other.

Predictive values yield information about the predictive power of a measure while considering the prevalence of a particular disorder within a population (Jekel et al., 1996). PPVs are used to determine the probability that an individual is disordered given that the measure has screened that individual as having the disorder. NPVs are used to determine the probability that an individual is non-disordered given that the particular measure has screened that individual as not having the disorder. Thus, predictive values produce information different from sensitivity or specificity regarding the diagnostic utility of the screening measure (Fletcher et al., 1996).

Figure 1 ***Sensitivity and 1-Specificity of the PDSS and EPDS***

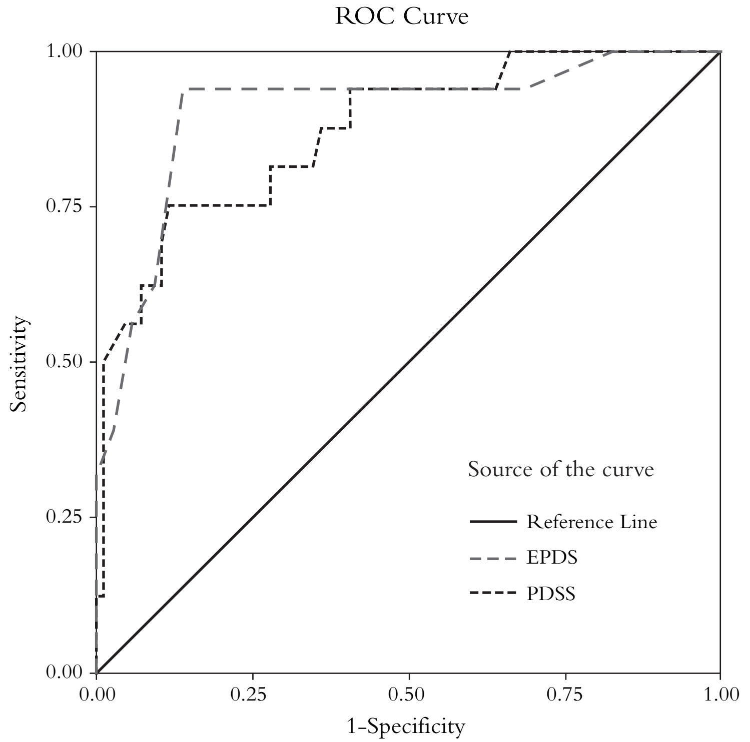

Table 2 ***Performance of the PDSS and EPDS over a Range of Cutoff Scores Using DSM-IV PPD Criteria***

Cut-off Score	**Sensitivity (%)**	**Specificity (%)**	**PPV[a] (%)**	**NPV[b] (%)**
PDSS				
71.5	94	59	31	98
80.5	81	72	37	95
93.0	77	88	56	95
EPDS				
11.5	94	86	56	99
12.5	81	88	56	96

[a]Positive predictive value; [b]Negative predictive value.

Figure 1 represents the accuracy of the PDSS and the EPDS in screening for PPV. The area under the ROC curve for the PDSS is = .87 (*SD* = .05), which is considered very good (Zweig & Campbell, 1993). The area under the ROC curve for the EPDS is excellent, at .90 (*SD* = .05). Both curves are statistically significant ($p < .001$).

Table 2 illustrates the sensitivity, specificity, and positive and negative predictive values for a range of cutoff scores for both the PDSS and the EPDS. For example, based on the ROC curve for the PDSS, a cutoff score of 71.5 produced sensitivity of 94%, specificity of 59%, PPV of 31%, and NPV of 98%. Beck and Gable (2001) recommend a higher cutoff score of 80. In the present sample, use of a similar cutoff score of 80.5 produced lower sensitivity (i.e., true positive rate) value of 81%, higher specificity value of 72%, PPV of 37%, and NPV of 95%.

Based on the ROC curve for the EPDS, a cutoff score of 11.5 produced sensitivity of 94%, specificity of 86%, PPV of 56%, and NPV of 99%. Cox and colleagues (1987), among others (e.g., Ghubash et al., 1997), report an optimal cutoff score of 12 or 13. In the present sample, however, measures of validity produced when using a cutoff score of 12.5 included lower sensitivity of 81%, slightly higher specificity of 88%, PPV of 56%, and lower NPV of 96%.

Discussion

Postpartum depression has been researched extensively across cultures and is reported to be a serious mental health problem (Oates et al., 2004). Researchers have not investigated prevalence rates of PPD nor tested the validity of the PDSS and the EPDS in Canadian First Nations and Métis women postpartum. The aims of the present study were to determine prevalence of PPD and to evaluate the validity of these two PPD screening measures in a sample of First Nations and Métis women in Saskatchewan. Of the sample, 17% were diagnosed with major PPD. This prevalence rate is consistent with reports of major PPD prevalence rates cross-culturally of between 10% and 20% (O'Hara & Swain, 1996). Extant research indicates that depression rates among American Indian and First Nations cultures are upwards of 45% (O'Nell, 1996). Because women in the present study were recruited through Aboriginal health centres that offered prenatal, postnatal, and parenting groups, one possible explanation for the lower PPD rates in the sample is that First Nations and Métis women were provided supportive, caring environments by nursing staff within the health-care setting.

The study compared the ability of two PPD screening instruments to differentiate between women with and without PPD. Separate logistic regression analyses were performed to determine the ability of the PDSS and the EPDS to classify correctly depressed and non-depressed mothers. In the first analysis, the addition of the PDSS to the BDI-II accounted for an additional 8% of the variance. In the second analysis, the addition of the EPDS to the BDI-II accounted for an additional 11% of the variance.

Based on the sensitivity and specificity values of the PDSS, Beck and Gable (2001) recommend a cutoff score of 80, which generated for their sample a sensitivity value of 94% and a specificity value of 98%. For comparison purposes, a cutoff score of 80.5 for the present sample yielded a sensitivity value of 81% and a specificity value of 72%. However, a PDSS cutoff score of 71.5 resulted in identification of a higher percentage of the women with PPD.

Cox and colleagues (1987) report that a cutoff score of 12.5 yielded the highest measures of validity in their validation study of the EPDS. For comparison purposes, the present study employed a similar cutoff score of 12.5 for the EPDS to determine measures of sensitivity and specificity. This cutoff score was associated with a sensitivity value of 81% (vs. 86% reported by Cox et al.) and a specificity value of 88% (vs. 78% reported by Cox et al.). However, a lower cutoff score of 11.5 in the present sample generated a sensitivity value of 94% and a specificity value of 86%. Therefore, a cutoff score of 11.5 for the EPDS was optimal in obtaining satisfactory psychometric properties (i.e., sensitivity and specificity) in First Nations and Métis women in Saskatchewan.

Although sensitivity and specificity provide useful information about the quality of a measure, these properties do not take into consideration the prevalence or the pretest probability of a disorder or disease (Fletcher et al., 1996), nor do they provide practical information on the diagnostic ability of a measure as a general screening tool (Jekel et al., 1996).

Predictive values, on the other hand, consider the prevalence rates of the disorder being studied (Fletcher et al., 1996). Screening tools that have lower positive predictive power inflate the incidence of a particular disorder (false positives), whereas screening tools that have lower negative predictive power miss those who are disordered (false negatives).

The prevalence rate of 17% for PPD in this sample of First Nations and Métis women is consistent with previously reported prevalence rates of between 10% and 20% (O'Hara & Swain, 1996) and supports the efficacy of predictive values in comparing the PDSS and the EPDS. Recommended cutoff values for the PDSS and the EPDS in the present sample were 71.5 and 11.5, respectively. Although both instruments demonstrated utility as general screening tools, the EPDS yielded better predictive power (25% PPV and 1% NPV over and above) than the PDSS. The EPDS is a time-efficient measure that can be quickly scored and interpreted by nurses and other health-care practitioners. The EPDS is available without cost from Dr. Cox. Although the PDSS captures many facets of PPD (Beck & Gable, 2001), it takes considerably longer to complete, is more cumbersome to score, and must be purchased. Despite these administrative differences, both measures demonstrated adequate clinical utility in the present study.

Conclusions

Postpartum depression affects many women, including those of First Nations and Métis descent. This is the first study to provide evidence for the utility of the EPDS and the PDSS as general screening instruments in postpartum First Nations and Métis women in Saskatchewan. The results support the need for primary health care professionals, including nurses, to offer postnatal screening for women who may be at risk for PPD. Nurses may also be in a position to provide information regarding risk factors and prevalence rates associated with PPD. This information can be communicated during initial home visits following birth or during the infants' routine immunization appointments. This open dialogue would serve to educate women about the nature of PPD and assist in the transition to motherhood by encouraging women to attend support groups and develop social networks.

The study had a few limitations. It recruited women from health centres that provided postpartum and parenting support. Prevalence rates of PPD obtained in the sample may be lower than those for the general population of postpartum First Nations and Métis women. Also, the study did not include First Nations and Métis women from northern Saskatchewan, whose PPD experiences could well differ. The results of the study reflect primarily the postpartum experiences of Cree women in southern

Saskatchewan. The conclusions of the study should be applied with caution to postpartum women of First Nations descent outside of Saskatchewan. Nearly 50% of First Nations women in Canada hold either a bachelor's degree or a non-university certificate or diploma (Stout & Kipling, 1998). In contrast, only approximately 20% of the present sample had some postsecondary education. Differences between this sample and First Nations women across Canada, in terms of education and other variables, suggest that one should be cautious in generalizing the results to all postpartum First Nations women in Canada. These limitations should be addressed in future research.

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Résumé

L'effet de l'anxiété sur les résultats d'apprentissage post-PAC

Suzanne Fredericks, Souraya Sidani et Daniel Shugurensky

Les patients ayant subi un pontage aortocoronarien (PAC) requièrent des interventions éducatives ayant pour objectif d'aider à leur rétablissement et de prévenir les complications chirurgicales postopératoires. Toutefois, l'efficacité de ces interventions est discutable, le stress lié à l'hospitalisation pouvant entraîner une augmentation de l'anxiété capable d'affecter leur réussite. L'objet de la présente étude était d'examiner la relation entre l'anxiété et la réussite d'apprentissage, le recours aux comportements d'autosoins et la gestion des symptômes. Un modèle de corrélations descriptives a été employé, ce qui incluait un échantillon de commodité. Les résultats montrent des corrélations statistiquement significatives entre l'anxiété et les résultats recherchés. Les implications sur la pratique seront de réaliser les interventions éducatives aux moments de faible anxiété.

Mots clés : anxiété, comportement d'autosoins, gestion des symptômes

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The Effect of Anxiety on Learning Outcomes Post-CABG

Suzanne Fredericks, Souraya Sidani, and Daniel Shugurensky

Post-operative coronary artery bypass graft (CABG) patients require educational interventions to support recovery and prevention of surgical complications. However, the effectiveness of these interventions is questionable, as stress related to the hospitalization process can result in increased levels of anxiety that may impact on the success of the education. The purpose of this study was to examine the relationship between anxiety and the achievement of knowledge, use of self-care behaviours, and management of symptoms. A descriptive correlation design was used, which included a convenience sample. Results indicate statistically significant correlations between anxiety and the outcomes of interest. Implications for practice include provision of educational interventions at times when anxiety levels are low.

Keywords: Anxiety, descriptive design, CABG patient education, self-care behaviour, symptom management

Introduction

Cardiovascular diseases are defined as diseases and injuries of the cardiovascular system, which includes the heart and the blood vessels (veins and arteries) throughout the body and within the brain. Coronary artery bypass graft (CABG) is a common surgical treatment for cardiovascular disease. In Canada each year, an average of one in every one thousand individuals undergoes a CABG procedure (Canadian Institute for Health Information, 2001). Usually, patient education programs are provided just prior to hospital discharge to support recovery and prevention of surgical complications. The effectiveness of these programs is questionable, however: The stress related to the hospitalization process can result in increased levels of anxiety that may affect the success of the educational initiative.

During hospitalization, the CABG patient is inundated with laboratory tests and procedures, the introduction of numerous caregivers, and adaptation to frequent changes in physiological state following surgery (Wheby & Brenner, 1999). These stressful events, along with the environmental factors associated with hospitalization, such as increased noise, unfamiliar surroundings, and lack of privacy, can lead to increased anxiety (House & Stark, 2002). Anxiety can interfere with the effectiveness of education by altering one's ability to be attentive and to retain information (Grayson, 2000). Grayson reasons that if patients are unable to retain educational content, they will have no stored information upon which to draw in order to engage in the desired self-care behaviours or therapies after discharge. Yet these self-care behaviours are critical to the patient's symptom management and recovery.

The effect of anxiety on knowledge, self-care, and symptom experience has not been extensively examined in a CABG population. The potential impact of anxiety on learning suggests the need for continued examination of anxiety and its relationship to CABG patients' knowledge of self-care behaviours, adoption of self-care behaviours, and symptom experience. Identification of the extent to which anxiety influences learning has implications for the design of educational interventions and the timing of their implementation following surgery. The purpose of this study was to examine the relationship between anxiety and the achievement of outcomes expected of educational interventions in patients who have undergone CABG surgery.

Literature Review

Patient teaching usually takes place during hospitalizaton, 24 to 48 hours prior to discharge (Marshall, Penckofer, & Llewellyn, 1986; Moore, 1996; Moore & Dolansky, 2001; Steele & Ruzicki, 1987). Beckie (1989), Moore (1996), Moore and Dolansky (2001), and Weaver and Doran (2001) report moderate levels of anxiety in all hospitalized patients, assessed 24 to 48 hours before discharge. These authors argue that the presence of anxiety just prior to discharge may interfere with learning, as suggested in various studies (Beckie, 1989; Feshbach & Loeb, 2003; Rosenstein, 2003).

Beckie (1989) investigated the relationship between CABG patients' level of knowledge of self-care behaviours and anxiety during the first 6 weeks after discharge. Anxiety was assessed using Spielberger's (1995) State Anxiety Scale. Beckie found a statistically significant inverse relationship between participants' level of knowledge, assessed after exposure to educational intervention, and anxiety scores in the control group ($r = -0.61, p < 0.05$) and the experimental ($r = - 0.31, p < 0.05$) group. She states that the findings support the theoretical proposition that anxiety has a negative impact on knowledge acquisition.

The effect of anxiety on learning has also been assessed in university students. Rosenstein (2003) evaluated the effects of anxiety on learning outcomes (specifically, knowledge of content covered in class) in 400 first-year psychology students. The author began by administering the Mandler-Sarason Test Anxiety Questionnaire (TAQ) as a means of anxiety arousal. Anxiety was assessed using the Palmer Sweat Index. The participants were then given an educational intervention that consisted of lectures from their psychology class. Post-teaching, the students' levels of knowledge and anxiety were assessed. Results indicated that higher levels of anxiety were related to lower levels of knowledge (r = -0.79, $p < 0.01$).

Feshbach and Loeb (2003) also assessed the effect of anxiety on knowledge retention in first-year psychology students (N = 45). A design similar to that used by Rosenstein (2003) was employed, in that anxiety was aroused using the Mandler-Sarason TAQ and evaluated using the Taylor Scale, then a teaching intervention was delivered, followed by assessment of knowledge and anxiety. Similar results are reported, with higher levels of anxiety inversely related to lower levels of knowledge (r = -0.68, $p < 0.01$).

Although the studies differed in context, target population, design, and measures, the results are consistent. They indicate that anxiety interferes with learning, where highly anxious persons gain minimal knowledge following an educational intervention. The extent to which this inverse relationship between anxiety and knowledge is applicable to patients who have had CABG surgery was investigated in the present study.

Study Framework

The concepts of interest for this study include patient education, self-care knowledge, self-care behaviours, symptom experience, and anxiety. The conceptual definitions of each concept and the proposed relationships among them are presented based on the results of an integrative review of the theoretical and empirical literature.

Rankin (2001) defines patient education as the "communication of information to enact change in knowledge, performance of self-care behaviours, and physical functioning" (pp. iv–v). Patient education provides the patient with information that can be used to enhance self-care knowledge, promote self-care behaviours, and improve symptom experiences (Orem, 2001; Rankin, 2001; University of California Symptom Management Group [UCSMG], 1994). In the present study, patient education was given to patients who underwent surgery. The intervention covered information that patients needed in order to manage their condition following discharge from hospital. The specific topics addressed included complications, activities, medication, symptom management and control, and psychological symptoms.

The expected outcomes of the educational intervention were self-care knowledge, adoption of self-care behaviours, and improved symptom experience. Rankin (2001) defines knowledge as a body of facts and principles that are learned through life experiences or are taught.

Knowledge is enhanced through educational interventions and is manifested by cognitive indicators such as recall or self-report of information (Rankin, 2001). In the present study, knowledge pertained to self-care, such as how to prevent complications, engaging in appropriate activities, preventing the onset of symptoms, and practising proper nutrition. It was hypothesized that patients would demonstrate an increase in self-care knowledge following exposure to the intervention, as reported in the literature (Beckie, 1989; Moore, 1996; Moore & Dolansky, 2001).

Orem (2001) describes self-care as "the practice of behaviours that individuals initiate and perform on their own behalf in maintaining or enhancing their health" (p. 35). For Orem, self-care encompasses self-reported actions that "contribute in specific ways to human development and health" (p. 37). It is a process involving selection and implementation of treatment strategies to enhance or maintain functioning, or to alleviate or prevent the onset of symptoms, and evaluation of treatment strategies to determine whether to continue with the intervention, stop treatment, or adopt a new strategy. Orem states that before patients can engage in these behaviours they must have knowledge of how to do so; the length of time required for an individual to transform the information gained through self-care instruction into deliberate action varies between immediately and 1 week post-teaching. In the present study, the following self-care behaviours were of interest: deep breathing and coughing exercises, walking and climbing stairs, care of surgical incisions, medication administration, interaction with physician, salt and fluid restriction, and symptom management. A small increase in use of these behaviours was expected after delivery of the intervention.

The University of California Symptom Management Group (UCSMG, 1994) defines symptoms as "subjective experiences reflecting changes in a person's bio-psychosocial function, sensation, or cognition" (p. 272). The way in which symptoms are experienced is influenced by how the patient perceives them and the frequency of the experience. Perception of symptoms is described as whether an individual notices a change from the way he or she usually feels or behaves, which generally occurs over the course of 1 to 2 weeks (UCSMG). Patients who have had CABG surgery often report fatigue, trouble sleeping, shortness of breath, chest and body pain, constipation, edema, nausea, and dizziness within 1 week post-discharge. However, it was proposed that the severity of the symptoms would be low to moderate after the educational intervention, which informs patients about strategies for managing symptoms.

Anxiety has been defined as "a state characterized by subjective, consciously perceived feelings of apprehension and tension, accompanied by activation of cognitive impulses that block judgment of various situations" (Spielberger, 1995, p. 17). This blocked judgement serves to impede the process of learning and of engaging in specific behaviours (Orem, 2001). Patients' level of anxiety varies across settings and experiences. The individual's perception of anxiety is assessed via self-report (Rankin, 2001; Spielberger, 1995). Anxiety has been assessed at various points throughout the course of an individual's recovery. Beckie (1989), Moore (1996), Moore and Dolansky (2001), and Weaver and Doran (2001) report moderate levels of anxiety in CABG patients 24 to 48 hours prior to discharge. In addition, Rankin (2001) states that knowledge levels are significantly reduced in the presence of heightened levels of anxiety. This proposition is supported empirically by three studies assessing the effects of anxiety on learning, specifically knowledge retention (Beckie, 1989; Feshbach & Loeb, 2003; Rosenstein, 2003).

Based on the relevant literature, it was proposed that patients' level of anxiety, reported prior to exposure to the educational intervention, is (1) negatively associated with low levels of self-care knowledge and use of self-care behaviours, and (2) positively related to symptom experience following the intervention.

Methods

Design

This study was part of a large randomized clinical trial evaluating the effectiveness of an individualized patient education intervention, delivered by telephone 1 to 2 days pre- or post-discharge, in enhancing CABG patients' knowledge of self-care behaviours, adoption of self-care behaviours, and symptoms experienced (Fredericks, Sidani, Watt-Watson, & Shugurensky, under review). Institutional Review Board Approval was received from three institutions: the University of Toronto, the University Health Network, and Ryerson University.

For this study, data obtained at pretest and post-test were analyzed. At pretest, which took place 1 to 2 days prior to delivery of the intervention, data were collected on anxiety and the three outcomes: self-care knowledge, use of self-care behaviours, and symptoms experienced. Post-test data were collected within 1 week after implementation of the intervention. The change scores from pretest to post-test were used to represent achievement of the outcomes. The change scores were then correlated to the anxiety scores measured just prior to delivery of the intervention.

Intervention

The intervention used in the larger study consisted of an individualized patient education program. The intervention was administered verbally over the telephone by a research nurse trained in its delivery using one-on-one nurse-patient interaction. Delivery began with an assessment of the patient's learning needs, addressing such topics as complications, activities, medication, symptom management, and psychological symptoms. The assessment began with the client being contacted by the research nurse, via telephone, at a prearranged time. The nurse introduced herself by giving her name, her position (research nurse), the name of the study, and the purpose of the call. She then asked if the patient had any questions about the purpose of the call. If questions arose, she responded appropriately. The nurse then read the instructions for the learning needs assessment questionnaire selected for the study. This was followed by completion of the questionnaire over the telephone by the patient. Patients were asked to rate the degree to which they perceived the topics on the questionnaire as important for learning. Any topic identified as important or very important for learning was discussed with the patient. Depending on the topic identified, the nurse used the educational material contained in the post-discharge intervention (developed for the study based on an extensive critical review of available evidence) to discuss the behaviours that the patient needed to adopt to enhance his or her symptom experience and recovery. If all topics were identified by the patient as important or very important, all content areas of the intervention were discussed. The average length of time for delivery of the intervention, if all topics were identified as important or very important, was 20 to 30 minutes.

Setting and Patient Population

The setting for the study was a cardiovascular surgical (CVS) unit at a university-affiliated teaching hospital in a large Canadian city. The accessible population comprises approximately 1,500 CABG patients per year. These individuals undergo CABG surgery accompanied by one to four grafts. Patients also undergo combined surgeries in which a CABG procedure is performed in unison with a ventricle repair. The average length of stay in the unit is 5 days. The average age is 68 years. The male/female ratio is 3 to 1. The patients are ethnically diverse. Approximately 70% of the accessible population met the eligibility criteria.[1]

Sample

Patients who met four eligibility criteria were invited to take part in the study: (1) underwent CABG surgery for the first time, with no additional surgical procedures (such as valve replacement or repair, Maze procedure, pacemaker insertion, stent insertion, or procedures related to stem cells);

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[1] The figures in this paragraph were obtained from the Department of Cardiovascular Surgery, University Health Network, in September 2003.

(2) literate in English; (3) oriented as to time, place, and person; (4) have access to a telephone.

Dunstan and Riddle (1997) and Wang, Fennie, He, Burgess, and Williams (2003) state that the more an individual has experienced an event or treatment the greater his or her likelihood of having been exposed to a patient teaching intervention related to the topic. Hence, second- or third-time CABG patients will have additional self-care knowledge, obtained through experience and previous hospitalization, which will confound the effects of the intervention under investigation in the study. Selection of individuals who have experienced only one CABG reduces random heterogeneity of the participants on the outcomes of knowledge, thereby increasing the power to detect significant intervention effects (Cook & Campbell, 1979). The identification of patients who had recently undergone CABG surgery for the first time was determined in consultation with the unit nurse, physician, or manager.

Individuals who are unable to speak the language in which the education is being provided and are cognitively not oriented to person, place, or time will not benefit from an educational intervention, as they will not be able to understand the information being presented. Hence, only patients literate in English and cognitively alert and oriented were considered. Identification of these characteristics was determined in consultation with the unit nurse, physician, or manager. Participants had to have access to a telephone.

Convenience sampling, whereby available consenting patients are entered into the study until the desired sample size is reached, was used. The number of patients who consented to take part in the large randomized clinical trial was 150. Of these, 20 dropped out of the study, yielding a 13.3% attrition rate. In total, 130 patients completed the pretest and post-test data. This sample size was adequate to detect a moderate-to-high correlation (≥ 0.60) between anxiety and self-care knowledge, setting the alpha at 0.05 and the beta at 0.80 (Cohen, 1988). A moderate-to-high correlation was anticipated based on theoretical evidence (Redman, 1997) and empirical evidence (Beckie, 1989; Colagiuri, Colagiuri, deBlieck, & Naidu, 1994; Jaarsma et al., 2000; Wright, Kravitz, Kaplan, & Meyers, 2001).

Measures

Demographic data were obtained using standard questions. Established instruments were employed to measure the concepts of interest. However, since these instruments were being used for the first time in the CABG patient population, their content validity and reliability were evaluated as part of the large randomized clinical trial. Self-care knowledge was measured using the 15-item Knowledge Inventory developed by McHugh-Schuster, Wright, and Tomich (1995). The Inventory assesses patients' knowledge of self-care strategies to be implemented at home for managing incision and chest pain, nausea, vomiting, fatigue, sleep disturbance, constipation, and edema/water retention, as well as taking medications and engaging in usual activity. The total score represents the number of correct responses to the 15 items. A maximum score of 15 indicates knowledge in all areas of self-care. The higher the score, the greater the CABG patient's knowledge of self-care behaviours. McHugh Schuster and colleagues state that the Inventory was reviewed by three cardiac rehabilitation professionals (nurses and exercise physiologists) for clarity, content, and face validity. They report an internal consistency reliability coefficient of 0.71. In the present study, the content validity index (CVI), representing the percentage of items rated as relevant or very relevant by at least 80% of the participants, was 100%. The internal consistency reliability coefficient was 0.64 at pretest. The rather low coefficient was due to minimal variability of participants' responses to the item.

Self-care behaviours were measured using the Revised Heart Failure Self-Care Behaviour (RSCB) scale developed by Artinian, Magnan, Sloan, and Lange (2002). This scale is a 29-item, self-report, Likert-type scale describing behaviours that patients with heart failure must engage in, to some degree, in order to regulate their own functioning. The behaviours relate to management of post-operative CABG complications, incision and chest pain, nausea, vomiting, fatigue, sleep disturbance, constipation, edema/water retention, emotional reactions, and self-care strategies for medication administration. Participants are asked to indicate how often they engaged in each of these behaviours in the preceding few days on a scale ranging from *none of the time* (0) to *all of the time* (5). The total score is calculated by summing the scores across items. It ranges from 0 to 145. Higher scores indicate more frequent use of self-care behaviours. Artinian et al. report that content validity (CVI = 0.86) was demonstrated through evaluation by a panel of experts, including two nurse practitioners and two self-care experts. They also state that the tool demonstrated convergent validity, as evidenced by a positive correlation between a tool assessing self-care behaviours and the RSCB scale and internal consistency reliability (Cronbach's alpha coefficient = 0.8).

In the present study, the RSCB scale showed content validity (CVI = 100%) and internal consistency reliability (Cronbach's alpha coefficient = 0.79).

Symptoms were assessed using the Symptom Inventory developed by Artinian, Duggan, and Miller (1993), which is a 19-item self-report checklist that measures symptoms commonly experienced during the post-CABG recovery period. These symptoms include tiredness, trouble sleeping, trouble breathing or shortness of breath, chest pain, chest incision pain or discomfort, leg incision pain or discomfort, shoulder, back, neck, or abdominal pain/discomfort, incision redness, increased tenderness at incision site, constipation, edema or swelling in arms and legs, nausea, anxiety, feeling emotionally drained, vomiting, shortness of breath, dizziness, and irregular heartbeat. Participants are asked to describe the frequency of a given symptom during the previous week (1 = *not at all,* 2 = *once,* 3 = *rarely,* 4 = *sometimes,* 5 = *often,* 6 = *usually,* 7 = *always*). The total score is calculated by summing the item scores. It ranges from 20 to 140, with a higher score indicating greater frequency. Artinian et al. report an internal consistency reliability coefficient of 0.78. They report that content validity for this tool has been demonstrated; however, they do not describe the process through which the instrument's content validation was conducted. In addition, the authors state that construct validity is supported by a positive correlation between the symptom inventory and another tool that assesses symptoms similar to those experienced by CABG patients.

In this study, CABG patients rated the Symptom Inventory as content valid (CVI = 100%). This instrument also demonstrated high internal consistency reliability (Cronbach's alpha coefficient = 0.92).

Anxiety was assessed using Spielberger's (1995) State Anxiety Scale, a 20-statement scale that identifies feelings. Participants respond using a four-point scale ranging from *not at all* to *very much so.* The total scale score ranges from 20 to 80, with a high score representing high levels of anxiety (Spielberger, 1995). The scale is reliable (internal consistency reliability coefficient ranging from 0.83 to 0.92 and a test-retest reliability coefficient ranging from 0.16 to 0.54) in a CABG population (Beckie, 1989; Spielberger, 1995). The low test-retest reliability coefficient was expected for this scale, as it reflects the changes in anxiety over time (Spielberger, 1995). Beckie (1989) reports acceptable content validity using a panel of cardiovascular experts to assess the relevance of each item to the CABG population; however, she does not provide specific data to support this claim. Furthermore, Beckie reports convergent validity (Pearson r = 0.81) with a similar unidentified instrument that assesses anxiety for the tool when used with a CABG population.

This instrument demonstrated acceptable internal consistency reliability (Cronbach's alpha coefficient = 0.84) in CABG patients who participated in the study.

Procedures and Data Collection

Patients who met the eligibility criteria were approached, within 24 to 48 hours of admission to the CVS unit, to participate in the study. The unit staff were provided with the inclusion criteria and were asked to use these in identifying eligible patients. Staff members used a standardized script to inform eligible patients about the study and ask if they wished to hear more about it. The researcher approached patients who expressed an interest in hearing more, to describe the study in detail, answer any questions, and obtain written consent.

Pretest data related to the outcomes were collected once consent was obtained (24–48 hours after admission to the CVS unit) via face-to-face interaction. Data on number of bypasses and comorbidity were obtained from the patient's chart. Completion of the pretest instruments took between 20 and 30 minutes. Anxiety data were collected at pretest. Three weeks after delivery of the intervention, patients received the post-test instruments for assessing the outcomes by mail.

Data Analysis

Descriptive statistics (i.e., measures of central tendency and dispersion) were used to characterize the sample in terms of demographic and illness-related characteristics. The Pearson correlation coefficient was used to examine the relationships between anxiety levels measured at pretest and the change score reflecting changes, between pretest and post-test, in self-care knowledge, use of self-care behaviours, and symptom experience. Change scores were computed as the difference between the data collected at time two (1 week post-intervention) and time three (3 weeks post-intervention).

Results

Demographic Profile and Health Status

The participants had an average age of 63.4 years (*SD* = 9.3) and were predominantly married (84.0%), male (80.0%) high school graduates (58%). Most participants had three bypass grafts and three comorbid conditions. The most frequently reported comorbid conditions were high blood pressure, high cholesterol, diabetes, arthritis, and visual impairment.

Outcomes Measured at Post-test

Anxiety scores were found to be moderately high at pretest (*mean* = 34.78, *SD* = 19.80). Results indicate a statistically significant inverse correlation between anxiety and change in knowledge (r = -0.185, p = 0.033) and self-care (r = -0.275, p = 0.001) and a statistically positive correlation between anxiety and change in symptom frequency (r = 0.498, p = 0.000). These change scores were correlated with the pretest anxiety scores.

Discussion

The general characteristics of the sample were similar to those of the accessible and target populations (Beckie, 1989; Marshall et al., 1986; Moore, 1996; Moore & Dolansky, 2001; Steele & Ruzicki, 1987; Weaver & Doran, 2001). Moderate levels of anxiety were reported at pretest. The hospitalization process for the CABG patient, which is characterized by laboratory and diagnostic tests and procedures (routine chest X rays and daily blood work); the introduction of numerous caregivers; adaptation to frequent changes in physiological state; and environmental factors associated with hospitalization, such as increased noise, unfamiliar surroundings, and lack of privacy, are possible explanations for the moderate anxiety scores reported at pretest (House & Stark, 2000). Hence, the moderate levels of anxiety were consistent with expectations and with previous findings in similar and different patient populations (House & Stark, 2000).

As well, self-care knowledge scores and use of self-care behaviours increased from pretest to post-test, while symptoms decreased over time, reinforcing the notion that increased levels of anxiety impact on knowledge acquired, behaviours adopted, and symptoms experienced.

Inverse moderate correlations between anxiety at pretest and self-care knowledge and self-care behavioural change scores and a moderate positive correlation with symptoms experienced were also identified. Therefore, with increased anxiety there is minimal gain in knowledge after education delivery, minimal use of appropriate self-care behaviours, and an increase in the presence of symptoms 3 weeks after discharge. These findings are consistent with those of Beckie (1989), Moore (1996), Moore and Dolansky (2001), and Weaver and Doran (2001), who report similar correlations between anxiety and knowledge, self-care, and symptoms.

Practice and Research Implications

Moderate to high levels of anxiety were present at pretest and influenced outcome achievement. Health educators are encouraged to be cognizant of the presence of anxiety prior to teaching and the potential negative effect of anxiety on knowledge retention, self-care behaviour, and symptom experience. Specifically, nurses are encouraged to assess patients' anxiety levels prior to conducting educational sessions. If moderate or high levels are evident prior to teaching, implementation of the educational session could be postponed until anxiety levels have been reassessed and are low. Alternatively, psycho-educational interventions could be implemented, whereby the patient's psychological/emotional (i.e., anxiety) status is assessed and addressed prior to teaching. This type of intervention combines health education with behavioural counselling (Rankin, 2001). The health education component could focus on the nature of anxiety and the counselling component on behaviours tailored to manage anxiety. Specific behaviours to manage anxiety include breathing activities, exercise, and meditation (Rankin, 2001). This type of intervention can help to decrease anxiety prior to self-care education and enhance the patient's acquisition of knowledge (Rankin, 2001).

Future research could focus on determining the most appropriate time to implement CABG educational interventions. Such interventions are usually delivered prior to hospital discharge (Beckie, 1989; Moore & Dolansky, 2001; Wheby & Brenner, 1999). Since the hospitalization process has been found to be characterized by moderate levels of anxiety, which serves to impede knowledge acquisition, behavioural change, and the management of symptoms, an alternative time for the delivery of CABG educational interventions should be evaluated in terms of effectiveness in producing the outcomes of interest. A randomized clinical trial could be carried out to compare the effectiveness of a CABG educational intervention delivered at two different times (e.g., 48 hours pre-discharge and 48 hours post-discharge). The findings could be used to draw up best practice guidelines for the timing of CABG educational initiatives.

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Résumé

La nature, les sources et l'impact de l'information sur la capacité d'adaptation des aidants naturels : un projet pilote

Hélène Lefebvre, Marie Josée Levert,
Diane Pelchat et Jérôme Gauvin Lepage

L'information transmise aux patients et aux familles aux prises avec des troubles de santé comme un traumatisme crânien ou un accident vasculaire cérébral (AVC) s'ajoute à ce que ces personnes savent déjà pour former un corpus de connaissances. Cette étude avait pour objectif d'identifier les besoins des aidants naturels en matière d'information, leurs sources d'information, leurs stratégies de cueillette d'information et l'impact de celle-ci sur leur capacité d'adaptation et leur lien avec les professionnels de la santé. Des groupes de discussions auxquels participaient des proches parents de personnes atteintes de traumatisme crânien ou d'un AVC ainsi que des professionnels de la santé de diverses disciplines travaillant avec cette clientèle ont été menés. Les besoins en information des proches parents portaient sur l'impact du handicap de la personne atteinte sur leur vie quotidienne. Selon le point de vue des professionnels, les besoins des proches portaient sur les incapacités de la personne, leurs stratégies d'adaptation et leurs sources d'information. L'expérience de la vie constituait la principale source de connaissances. Des recommandations en matière d'intervention en soins actifs et de réadaptation ont été émises à partir des résultats de l'étude.

Mots clés : familles, connaissances, santé, professionnels de la santé, traumatisme crânien, AVC

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Nature, Sources, and Impact of Information on the Adjustment of Family Caregivers: A Pilot Project

Hélène Lefebvre, Marie Josée Levert,
Diane Pelchat, and Jérôme Gauvin Lepage

The information conveyed to patients and families dealing with a health problem such as traumatic brain injury or stroke combines with what they already know to form a new pool of knowledge. The aim of this pilot study was to describe the information needs of family caregivers, their sources of information, their strategies for gathering information, and the impact of the information on their adjustment and their relationship with health professionals. Focus groups were held with close relatives of persons who had sustained a traumatic brain injury or a stroke and with health professionals from various disciplines working with theses clienteles. The information needs of relatives concerned the impact of the person's disabilities on their everyday lives. From the professionals' point of view, the information needs of close relatives concerned the person's disabilities, their coping strategies, and their information sources. Life experience was the main source of knowledge. The results form a basis for recommendations regarding interventions in acute care and rehabilitation.

Keywords: Families, knowledge, health, health professionals, head injury, stroke

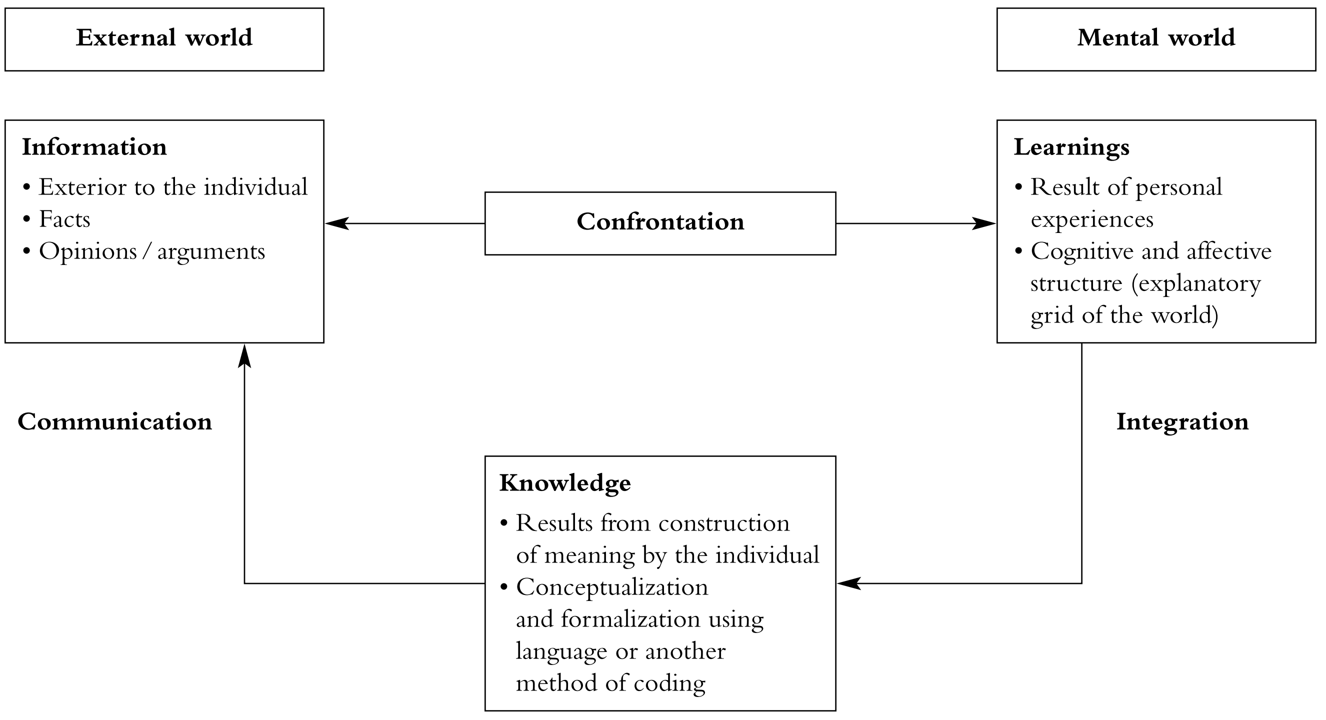
Introduction

In a health situation, the information conveyed to the patient and family helps to ensure the transfer of new knowledge and skills to daily life. This information is integrated with existing knowledge to form a new body of knowledge that gives people a degree of control. Knowledge acquired in a contextualized setting leads individuals to integrate new skills that make them more autonomous in their choices with respect to the situation (Bouchard, 1999; Vygotsky, 1985).

Family caregivers glean their information from various sources — for example, from health professionals, discussions with relatives or friends, and print or electronic media (Tooth & Hoffmann, 2004). The Internet is a major new source of informal knowledge that can enrich daily life and serve to empower (Fostier, 2005; Journal du Net, 2002).

Accordingly, it is essential to ensure that patients and family caregivers are properly informed, and above all that the information they receive matches their needs and concerns and is easily transferable to their daily

Figure 1 ***Astolfi's (1992) Construction of Knowledge Model (Adapted)***



lives (Rodgers, Bond, & Curless, 2001). Health professionals have to recognize people's knowledge, be receptive to their reality, and make sure they are satisfied with the information they receive (Tooth & Hoffmann, 2004). The increasingly structured involvement of family members in the management of the rehabilitation process is redefining the dynamic of discussions with professionals, who are now coming to view the knowledge of family caregivers as credible (Bouchard, 1999).

Yet, surprisingly, in contrast to the situation in oncology, psychiatry, and cardiology, there is hardly any literature on the information needs of individuals who have suffered a traumatic brain injury (TBI) or stroke (cardiovascular accident, or CVA) and their families. Research findings show that even though these two clienteles are very different and experience distinct repercussions, they have similar information needs. Family caregivers require information on prevention; TBI or CVA; medical and rehabilitation interventions; short, medium, and long-term prognoses; strategies for coping with stress; social support; experiences of family members of other TBI or CVA patients; how to reintegrate daily living; and long-term services for TBI patients (Lefebvre, Pelchat, Gélinas, Michallet, & Levert, 2005; Lefebvre, Pelchat, Swaine, Gélinas, & Levert, 2005; Paterson, Kieloch, & Gmiterek, 2001) and CVA patients (Garrett, & Cowdell, 2005; O'Connell, Baker, Prosser, 2003; Pierce, Finn, & Steiner, 2004; Van Veenendaal, Grinspun, & Adriaanse, 1996). Research findings show that many of these needs are not being met (Garrett & Cowdell, 2005; Lefebvre, Pelchat, Gélinas, et al., 2005; Lefebvre, Pelchat, Swaine, et al., 2005; O'Connell et al., 2003; Paterson et al., 2001; Pierce et al., 2004; Van Veenendaal et al., 1996). Moreover, studies comparing the perceptions of family caregivers with those of health professionals have revealed several differences (Lefebvre, Pelchat, Swaine, et al., 2005; Van Veenendaal et al., 1996).

Overall, there is little evidence about the information needs of family caregivers of TBI or CVA survivors, their sources of information, and the impact of the information they do receive. Moreover, almost no studies have investigated the comparative perceptions of family members and health professionals. Therefore, a pilot project on this subject was conducted in summer 2005.

Conceptual Framework

The conceptual framework for the study was Astolfi's (1992) Construction of Knowledge Model (Figure 1), which provides guidelines for understanding and analyzing the role of information in the acquisition of the knowledge necessary to care for a person with TBI or stroke. For Astolfi, knowledge is an articulated and organized group of learnings and information. The learnings are connected to an individual's unique history (personal experiences, cognitive and affective structure) and the information is external to the individual (facts, opinions, and arguments). Therefore, the purpose of information is to increase learnings and then knowledge. Communication is the instrument of this process.

Purpose and Objectives

The purpose of the study was to document, from their own perspective and that of the health professionals working with them, the information needs of families grappling with a medical situation (TBI, CVA). More specifically, the project sought to identify, from the points of view of families and health professionals: (1) the information sources and strategies used by family caregivers for obtaining information, (2) the nature of the information sought and obtained, and (3) the impact of this information on the adjustment of family caregivers and on their relationship with health professionals.

Methods

This qualitative pilot project followed the tradition of exploratory empirical research and used co-construction of reality in an interdisciplinary approach (Van der Maren, 1995). The research results stemmed from (i.e., were co-constructed from) the interaction between the participants during focus groups. This method provided an opportunity to ascertain, reflect on, and examine the points of view of different people in order to understand the experience of each participant. The study fell within the constructivist paradigm, with the co-construction of comments stemming from the interaction between the researchers and the participants (Guba & Lincoln, 1989).

Sample

The convenience sample consisted of six family caregivers of individuals who had suffered a TBI or CVA and eight health professionals working with these clienteles. Although they are very different and have distinct repercussions, these two clienteles (TBI and CVA) were selected because the health situations are sudden and unexpected. Furthermore, no studies have investigated the information needs of TBI populations. Participation was purely voluntary. Sample size was determined by institutional constraints with respect to recruitment (feasibility) and data saturation in the context of a pilot project (Pirès, 1997). Participants were recruited by internal collaborators based on precise criteria, at a functional rehabilitation centre (i.e., aimed at recovery of physical, cognitive, and sensorial abilities) and a rehabilitation centre specializing in social reintegration (i.e., focused on the resumption of social roles and daily living activities), both in the Greater Montreal area.

For family caregivers, inclusion criteria were: be living with or responsible for an adult who had suffered a TBI or CVA; be aware of the person's diagnosis; be fluent in French; reside in Greater Montreal; and be over 18 years of age. The individuals for whom they were caring had to have completed the functional rehabilitation phase and experienced social reintegration; this criterion was used because the type of information needed in order to adapt to a health situation varies with each phase of care (Lefebvre, Pelchat, Swaine, et al., 2005). Inclusion criteria for health professionals were: be employed at a rehabilitation centre for TBI or CVA patients and their families; and have worked with one of these clienteles for more than 2 years.

All the family caregivers taking part in the study were women (N = 6). Most were the spouse of a person who had suffered a TBI or CVA an average of 3 years earlier (range = 1–5 years). The family caregivers were aged 27 to 66 (mean age = 49.7). Most were university graduates. Their employment status varied: employed full time, retired, unemployed.

The health professionals taking part in the study (N = 8) were mostly women and their mean age was 39.4 (range = 29–55). Their professional disciplines were physiotherapy (n = 2), psychology (n = 3), and social work (n = 3). Most worked in a rehabilitation centre specializing in social reintegration. They had 2 to 24 years' clinical experience (mean = 13.8) and 2 to 22 years' experience with the TBI or CVA clienteles (overall mean = 9.2).

Data Collection

Focus groups were used to collect the data because of their potential for eliciting an abundance of diverse information from many people at once and encouraging the spontaneous expression of ideas (Krueger, 1994; Merton, Fiske, & Kendall, 1990). Participation in a focus group made family caregivers and professionals more aware of the problem; this in turn stimulated their desire to structure their actions with a view to self-managed development. The researchers met with the family caregiver and health professional groups separately, to ensure that no bias was introduced through interaction between the two categories.

A semi-structured interview guide was developed. It was divided into three themes, corresponding to the study objectives and emerging from the literature review: nature of information sought and obtained, sources of and strategies for finding information, and effects of information on the adjustment of family caregivers and on their relationship with the health professionals.

The groups were led by a researcher assisted by a research professional, who played an observer role and made notes on both verbal and non-verbal data (Dilorio, Hockenberry-Eaton, Maibach, & Rivero, 1994). Moderation of the group adhered to the principles of group dynamics described by Mucchielli (1983). The focus groups, which lasted 2 hours on average, were audiotaped and transcribed verbatim.

Participants were asked to fill out forms specifying their sociodemographic characteristics. Analytical notes (questions, ideas, wonderings, curiosities, examples, categories, codes, etc.) were made for each focus group. A research log was also kept on the evolution of the project: the researcher's thoughts and feelings and concerns about bias; the research situation (what was done, by whom and when); articles read.

Ethical Considerations

Ethics approval was obtained from the Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal, with which the participating rehabilitation organizations were affiliated. Before commencement of data collection, the participants were asked to complete a research consent form. They were informed that if they found it upsetting to recall the events associated with the themes discussed, they could be put in touch with a health professional for assistance. In addition, it was explained that the results would be confidential and that they were free to withdraw from the study with no consequences for themselves or their relative with the medical condition. Confidentiality was ensured by assigning each participant a numeric code. The researchers alone have access to identifying information and will not release it to a third party unless required to do so by law. Videotapes were kept under lock and key in the researcher's office at the research centre and were destroyed upon completion of the project.

Data Coding and Analysis

Focus group proceedings were transcribed *in extenso*. A content analysis approach was used (Mayer & Deslauriers, 2000). The data were then vertically analyzed for thematic content (i.e., specific to each focus group). Each statement was coded by unit of meaning and grouped by theme, in order to reduce the amount of data and to extract the meaning of the statement. The researcher read and approved the transcriptions and data coding. Inter-group triangulation of the results (family caregiver results, health professional results) enabled the researchers to synthesize the information needs of families in the context of the health situation. The process was iterative — that is, analysis was built upon and fine tuned as it proceeded, supported by consulting the log and the analytical, methodological, and theoretical notes.

Four basic analytical categories were established beforehand. *Nature of the information* covered statements relating to all information sought. *Sources of information* comprised statements concerning sources other than the health professionals. *Search strategies* were the means by which people obtained information, such as the media or relatives. *Impact of the information* covered how the information affected people's adaptation and their relationship with the professionals, as well as what they found satisfactory or unsatisfactory.

Scientific Criteria

Methodological rigour was based on the following criteria (Guba & Lincoln, 1989; Laperrière, 1997): (1) credibility (similar to internal validity), which was ensured by triangulation of data sources, obtaining of consensus on data analysis (interrater reliability of transcript coding), and validation of meeting reports by the head researcher at regular intervals; and accuracy of data, which was verified by the audio- and videotapes; (2) transferability (similar to external validity), which was ensured by describing the study's context in detail so that the reader could identify and predict a similar situation in a similar context; and (3) consistency (similar to reliability), which was ensured by entering in the log any changes in the research process.

Results

Opinions of Family Caregivers

The results show that the families needed mostly information about the impact of the deficits on daily life and ways of dealing with this as well as the long-term consequences of the health condition. To acquire this knowledge, family caregivers consulted health professionals, written information, the media, and the Internet. The information they obtained helped them to understand the deficits, develop coping strategies, and collaborate with the professionals. The fact remains, however, that people were still not entirely satisfied. Their main complaint was lack of information and the way in which information was conveyed.

Nature of the information. The results show that the information needs of family caregivers had to do with how the person's deficits would affect day-to-day life. Family caregivers needed information about strategies for dealing with the deficits (difficulty organizing one's personal life, scheduling various appointments, planning social activities, etc). Most family caregivers also said they were anxious about the person's future and the long-term consequences of the health condition.

Family caregivers reported that information obtained from health professionals concerned the diagnosis, the prognosis, and rehabilitation but that what had the most impact was the professionals' advice about issues arising in day-to-day life.

Information search strategies. In their quest for information, many family caregivers surfed the Internet, watched television programs about the medical condition, and read books on the subject. Some said they had to press hospital staff to give them the information they wanted, especially in acute care.

They reported that they consulted the Internet when the health problem first arose but gradually abandoned this strategy or used it only occasionally. Information found on the Internet mainly concerned progress and medical innovations.

Consulting with health professionals enabled family caregivers to bridge the information gap and find out about care and services. Some people got their information from talking to the professionals because they were unaware of other sources.

Impact of the information. The information obtained by family caregivers gave them a fuller understanding of the health condition and enabled them to mitigate the person's deficits; sometimes it helped them to collaborate more closely with the health professionals. For example, reading books, articles, and brochures helped them to learn more about the health condition. The knowledge they acquired made them aware of the most recent advancements that might improve their life situation and the patient's condition.

Advice, tools, and methods provided by professionals played a prominent role in the family caregivers' adjustment to the new life situation. People said they had modified their daily activities and lifestyle based on the person's capacities and incapacities.

Finally, the knowledge of family caregivers sometimes contrasted with that of the professionals from whom they sought solutions. When people brought their own information to an appointment, it sometimes helped to forge collaboration between the family caregivers and the professionals.

The results show that some family caregivers were unhappy about the way in which information was conveyed to them, especially in acute care, and felt they had been left all alone with their uncertainties. Regarding services offered after rehabilitation, some family caregivers reported that they did not get all the information they needed about financial aspects or resources available. Also, many people said they were unaware of a brochure issued by the Quebec automobile insurance board about traumatic brain injury and how it affects day-to-day living. Others had never heard of the Association québécoise pour les traumatisés crâniens (Quebec's brain injury association) or had only vaguely heard about it, had never consulted it, and could not recall receiving information about it. The lack of information was sometimes due to the emotional shock of being told of the diagnosis and the subsequent refusal to accept the situation. One person deplored the fact that the professionals hardly asked what the family caregivers were experiencing in caring for the affected person.

Lastly, family caregivers said they would have liked to see more videos about the condition of their loved one and to talk things over with peers; they also felt that the public should be better informed about what life is like for people in disability situations.

Opinions of Health Professionals

From the point of view of health professionals, the information needs of the family caregivers were associated mainly with the deficits resulting from the medical condition, strategies for dealing with the condition, and the long-term consequences of the condition. The health professionals identified various strategies used by families, such as consulting the Internet, the media, and written materials and talking with health professionals and peers. Life experience seemed to be the main source of knowledge. Participation in therapies was a useful means of transferring knowledge, but the professionals who were interviewed reported that family caregivers played little part in this process. The results also show that information obtained by the family caregivers had an impact on their adjustment to the health situation and on their relationship with the health-care team. The professionals acknowledged that lack of information was a source of frustration for family caregivers.

Nature of the information. The results show that the information needs mentioned by family caregivers to the professionals during appointments concerned mainly the functional aspects of the health condition (walking, talking, working, etc.) and the long-term prognosis. Relatives were also concerned about possible interventions (medical innovations, alternative medicine, etc.) and treatment methods.

The professionals said they gave patients and their families various kinds of information: general information (medical facts about the health condition, written material), personalized information ("because the whole book does not apply to the injured person"), information about the impact of the deficits ("what the relative is going to go through in this process"), and information concerning the future ("for later, what will become of them"). A lot of the knowledge conveyed to the family concerned ways of making things easier for caregivers — for example, making them aware of the risk of exhaustion — repeated as often as necessary to ensure that it was applied in practice, fostering better integration.

Information search strategies. The health professionals identified various strategies used by the family caregivers to meet their information needs. People consulted the Internet, the media (newspapers, television), and articles, books, and brochures, talked with their peers, and interacted with the health professionals. According to the professionals, however, the most effective way people acquired knowledge was through their own life experience; this was more effective than searching for information.

The health professionals regarded the Internet as a major source of information: A family caregiver can go on the Internet and contact specialists all around the world; they can obtain exhaustive information on a topic and discuss it with health experts. Yet the professionals said their clienteles did not often use the Internet, for a number of reasons: lack of access, lack of skills in information and communication technology, stability of the condition such that further search was not deemed necessary, and the nature of the information found.

The professionals reported that, with regard to knowledge acquisition by family caregivers, their approach was to suggest strategies and guide them in the direction of appropriate resources. They also pointed patients and their families to the most relevant sources of information for their particular needs.

The professionals tended to view family caregivers' participation in workshops and therapies as a positive strategy, promoting the flow of information between health professionals and family caregivers. However, they deplored the fact that relatives hardly ever took part in information activities or intervention planning meetings; they noticed increased involvement by the relatives when the patient's file was about to be closed. In general, the family caregivers did not proactively seek out information, even when the information would have been very helpful.

Impact of the information. The comments of the professionals reveal that information can have an impact on family caregivers' adjustment to the health situation and on their relationship with the health-care team.

With regard to the possible repercussions of information, the professionals identified a number of barriers to adaptation. Some pointed out that inaccurate or contradictory information can undermine adjustment and rehabilitation. One professional cited problems caused by misconceptions: When information is incorrect, professionals have to set the record straight; this entails qualifying and supplementing information found in the media, such as the accessibility and high cost of equipment featured on Web sites.

Information also affected the relationship with the professionals. When family caregivers brought information to an appointment, it provided a starting point for discussion and debate. As the family caregivers became more knowledgeable about the health condition, they tended to become more demanding in terms of professional expertise. A number of health professionals believed that the family caregivers' trust in and respect for their professional competence materialized in a relational framework. They indicated that this trust in the other's expertise was reciprocal. They valued the family caregivers' knowledge in that hands-on expertise is key to the adjustment and rehabilitation process. This attitude seemed to be appreciated by family caregivers.

The results show that for communication to be effective one must first ascertain what information the family caregivers have and whether they have absorbed it. All the professionals agreed that a key factor is how and when information is conveyed. They stressed the importance of sounding upbeat and focusing on positive aspects, successes, and abilities. Normalization and the questioning of restrictive beliefs were part of the positive approach adopted by these professionals.

Finally, the results show that the lack of information referred to by the families was also acknowledged by the professionals. The fact that a definitive long-term prognosis was not possible created a sense of uncertainty among family caregivers. The professionals also reported that talking to specialists during the acute-care phase is often no simple matter; the specialists tend to be short of time and uncomfortable breaking the news of a poor diagnosis or disclosing information involving bad news.

However, the professionals tended to qualify these explanatory factors. The family caregivers' sense that they lacked information was also caused by their difficulty remembering or understanding the information because of their sketchy medical knowledge (vocabulary, roles of the various professionals, how the system works) and their emotional state.

Discussion

The goal of this pilot project was to document the information needs of family caregivers in the context of a health situation (TBI or CVA), from their own point of view and that of the relevant health professionals. The results show that the points of view of the families converged with those of the health professionals. They enable us to draw an integrated analytic profile of the information needs of family caregivers and how these mesh with the interventions used. These findings have major clinical implications that translate into communication and collaboration, to provide family caregivers with information that meets their needs and fosters their adjustment to the situation.

Profile of Information Search by Family Caregivers

The results of the study highlight the consistent nature of family caregivers' information needs, regardless of the health problem (TBI or

CVA). The concerns of these people — the health condition, its long-term consequences (anticipation of behaviours, capacities and deficits, coping strategies, etc.), and what will happen to the patient day to day — have been pinpointed as key elements in the process of adjusting to a health situation (Hummelinck & Pollock, 2006).

A central finding of the study is the homogeneity of strategies used by family caregivers in different health situations. According to the literature, increasingly family members wish to be informed and to receive justification for and explanation of any intervention that is proposed. The media, the Internet, and scientific articles offer an array of information on a wide range of health situations (Ensemble parlons autrement des cancers, 2001). Age, socio-economic status, and educational level all appear to influence the search strategy (Doumont & Sandrin-Brethon, 2001). The present results suggest that the amount of time elapsed since the onset of the health condition is also a factor.

Although dissatisfaction with information was sometimes glaring, the professionals believed that some families tended to be passive in their quest for knowledge. Research and clinical experience show that knowledge usually stems from experience (Lacroix & Assal, 2003). Such experience-based knowledge (Jarvis, 1992) is rooted in the day-to-day lives of family caregivers as they cope with the limitations and abilities of the affected person. When people face a problem in their daily lives, they wonder about possible solutions, seek useful information, and try things out to see if they work. The resulting knowledge is then incorporated into their existing knowledge in the context of the present experience. This finding could explain why family caregivers' concrete, objective strategies seemed (to the professionals) to be somewhat limited and passive, when in fact the knowledge-acquisition process takes place first and foremost in a subjective register.

Another explanatory factor for this seemingly passive approach is the family's state of shock or even psychological trauma at the time of acute care. Families and professionals alike realize that the sense of having insufficient information is intimately linked to diminished receptiveness, which hinders retention of information (Davis, Kristjanson, & Blight, 2003).

The information needs of family caregivers may be difficult to determine because they can vary from one individual to another and are often identified in retrospect and therefore cannot be met at the time of consultation. Also, the information has to be relevant for the recipients at the time it is conveyed, in order for them to absorb and integrate it (Hummelinck & Pollock, 2006).

In addition to the above reasons why the families felt they lacked information, we should bear in mind a reality intertwined with the adjustment process: Lack of information breeds uncertainty and insecurity for the relatives and the disabled person alike (Lefebvre, Levert, David, & Pelchat, 2007). Information is seen as having a positive impact on adaptation by giving the family a sense of being in control of the situation and of their environment. This is fundamental to the process whereby people learn and transform themselves positively as they work through the ordeal. Being informed gives patients and their relatives the confidence they need to participate in the care process (Bouchard, 1999; Pelchat & Lefebvre, 2005).

Profile of Communication in a Context of Collaboration: Information to Meet the Needs of Family Caregivers

The health professionals and family caregivers stressed that the communication of information was affected by both the manner in which it was conveyed and the point at which it was conveyed (Deccache & Meremans, 2000; Paterson et al., 2001). The effects will be beneficial or detrimental, depending on whether the professionals' approach is characterized by openness, circularity, and reciprocity or simply involves a one-way transmission of information (Ramritu & Croft, 1999). The role of professionals is therefore paramount. The contribution of professionals was part of the experience-based learning process identified by family caregivers as both the most common and the most effective strategy for knowledge acquisition. A relationship of trust founded on discussion, collaboration, and valuing of people's knowledge was key to getting them involved and maximizing their adjustment.

The health-care team should use its expert knowledge as a guide in helping patients and their relatives to address a difficult situation, while at the same time acknowledging their expertise and competence in finding, implementing, and evaluating solutions. The patient and relatives should be the focal point of interventions and be regarded as partners whose knowledge is crucial to improving their quality of life (Buttet, 2002; Camden, Baril, & Tétreault, 2005). This process involves first *identifying the knowledge* of family caregivers. By being open to subjective experience, the professional can probe their knowledge and beliefs. This knowledge has to be *recognized as valid* or at least *qualified*. While the print and electronic media are major sources of information, they are secondary and should be used discerningly, because information that is rapidly obtained, plentiful, and readily accessible is not necessarily reliable and accurate (Fostier, 2005). Once the relatives' knowledge is confirmed as valid, the professionals *value it as supporting expertise* (Bouchard, 1999). Communication then becomes circular and reciprocal, with each person's expertise being pooled to form a common body of knowledge that is highly instructive for all. This type of communication promotes absorp-

Table 1 ***Recommendations***

Experience of Family Caregivers	**Recommendations**
Information search strategies	
• Experience-based learning is the main source of knowledge. • Consultation with professionals is a major source of information.	• Be aware that you are the family caregiver's preferred source of information. • Provide information anchored in the family caregiver's subjective experience.
Communication of information	
• Information is often believed to be insufficient, unclear, contradictory, and overloaded. • The terminology is unfamiliar. • Information does not always correspond with what one is concerned about here and now.	• Communicate the information at the right time. • Communicate information addressing issues the family caregiver is concerned about here and now. • Use clear, simple language. • Provide written information as a backup to verbal information. • Repeat and explain information as often as needed.
Collaboration	
• One has a sense of assurance and control when one's opinion is taken into account. • The attitude of professionals has an impact on the quality of interactions and adjustment.	• Forge a relationship of trust based on exchange, listening, and empathy. • Be open to the family caregiver's knowledge (identify, recognize/qualify, value). • Engage in reciprocity of knowledge.

tion of information and facilitates adaptation (Driscoll, 2000; O'Mahoney, Rodgers, Thomson, Dobson, & James, 1997).

Information addressed to individuals coping with a health situation and their families must be adapted to their needs. For information to be retained and seen as relevant by family caregivers, it has to be *proffered at the right time* (Paterson et al., 2001). Too often, professionals communicate information systematically, regardless of the immediate needs of family caregivers. For information to be conveyed effectively, it has to *correspond with their immediate concerns*. The only way for the professional to ensure this is to co-construct the intervention with the family, exploring their knowledge and concerns as well as their objective and subjective experience in the particular situation — in other words, their otherness. The information must be *repeated or explained at the right moment* — that is, when the family caregivers so request, or when they reach a particular stage in their journey (Lefebvre, Pelchat, Swaine, et al., 2005; Paterson et al., 2001). All of these considerations have to be supported by the care and service structures.

The results of this study lead to a number of recommendations to support the experience of family caregivers (see Table 1).

Limitations

The fact that this was a pilot project with a small sample limits the generalizability of the results, which reflect the specific experiences of family caregivers and health professionals. Generalizability is also limited by the characteristics of the sample (homogeneous, predominately female university graduates). Therefore, the findings may not be useful in situations where the caregiver is male or is less educated. Although all participants related their stories willingly, some people found certain events difficult to discuss and their perception of these events, when they did discuss them, may have been altered by the passage of time. It is also possible that, for all sorts of contextual reasons, participants censored their comments about their present or past experiences. Moreover, it is often difficult to remember exactly what happened in a specific situation because, as time passes and other events occur, one's original perception may be altered (Baribeau, 1996; Van der Maren, 1995). However, the inter-group triangulation of the results validating the interpretation of the data helped to reduce these biases and promoted scientific rigour.

Conclusion

The above findings point to the importance of developing and implementing a communication approach that fosters adjustment through a learning process based on collaboration and focusing on the patient-professional relationship (Deccache & Meremans, 2000). This depends on all the actors being actively involved in the quest for information. Individuals have to be proactive in their search for information and in their interactions with health professionals, who in turn should encourage and elicit such behaviour and give people the opportunity to discuss their own experience and knowledge in order to pinpoint the family's needs and tailor their responses accordingly. In addition, verbal communication backed up by written information appears to be an effective means of communication; health professionals should move in this direction.

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