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

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

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The purpose was to examine the use and availability of home and communitybased 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 communitybased 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).

CJNR 2008, Vol. 40 Nº 1

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

CJNR 2008, Vol. 40 Nº 1

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 $(n = 4)$	18,394)	Total $(N =$	91,596)
	Frequency	%	Frequency	%	Frequency	0%
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
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Table 1 (cont'd)						
Estimated Population	Female $(n =$	43,202)	Male $(n = 4)$.8,394)	Total $(N = 9$	1,596)
	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
* <i>p</i> < .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. 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-B	ased Services by	Sex of Pers	ons with Deme	entia		
Estimated Population	Female (n =	43,202)	Male $(n = 4)$	8,394)	Total $(N = 9$	1,596)
	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 Com	munity-Based S	ervices by 3	Sex of Persons	with Dem	entia	
Estimated Population	Female (n =	43,202)	Male $(n = 4)$	8,394)	Total $(N = 9$	1,596)
	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
** <i>p</i> < .01						

Table 4 Significant Associations between Variablesand 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 communitybased 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 longterm 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.

References

- Alzheimer Society of Ontario & Knowledge Exchange. (2007). Projected prevalence of dementia: Ontario's Local Health Integration Networks. Retrieved September 13, 2007, from http://alzheimerontario.org/local/files/ Web%20site/Public%20Policy/Projected-Prevalence-of-Dementia-LIHNs-April-2007.pdf.
- Andersen, R. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Science*, 36(March), 1–10.
- Andersen, R., & Newman, J. F. (1973). Societal and individual determinants of medical care utilization in the United States. *Milbank Memorial Fund Quarterly. Health & Society*, 51, 95–124.
- Bass, D. M., & Noelker, L. S. (1987). The influence of family caregivers on elders' use of in-home services: An expanded conceptual framework. *Journal of Health and Social Behavior, 28,* 184–196.
- Bedard, M., Kuzik, R., Chambers, L., Molloy, W. D., Dubois, S., & Lever, J. A. (2005). Understanding burden differences between men and women caregivers: The contribution of care-recipient problem behaviors. *International Psychogeriatrics*, 17(1), 99–118.
- Béland, Y. (2002). Canadian Community Health Survey: Methodological overview (Statistics Canada Catalogue #82-003.) *Health Reports*, 13(3), 9–14.
- Bell, D. (2007, April 19). Providing services in the community. Presentation at Research into Policy, Career Scientist Seminar Series, Ontario Ministry of Health and Long-Term Care, Toronto.
- Boyle, M. H., Furlong, W., Feeny, D., Torrance, G. W., & Hatcher, J. (1995). Reliability of the Health Utilities Index-Mark III used in the 1991 Cycle 6

Canadian General Social Survey Health Questionnaire. *Quality of Life Research*, *4*, 249–257.

- Browne, G., Roberts, J., Byrne, C., Gafni, A., Weir, R., & Majumdar, B. (2001). The costs and effects of addressing the needs of vulnerable populations: Results of 10 years of research. *Canadian Journal of Nursing Research*, 33(1), 65–76.
- Canadian Home Care Association. (2004). *Home care: A national health priority. Visionary leadership can make it happen.* Ottawa: Author.
- Canadian Institute for Health Information. (2004). Final project report: Development of national indicators and reports for home care. Ottawa: Author.
- Canadian Study of Health and Aging Working Group. (1994). Canadian Study of Health and Aging: Study methods and prevalence of dementia. *Canadian Medical Association Journal*, 150(6), 899–913.
- Carrière, G. (2006). Seniors' use of home care (Statistics Canada Catalogue #82-003). *Health Reports*, 17(4), 43–47.
- Cohen, M., McLaren, A., Sharman, Z., Murray, S., Hughes, M., & Ostry, A. (2006). *From support to isolation: The high cost of BC's declining home support services.* Vancouver: Canadian Centre for Policy Alternatives.
- Contandriopoulos, A., Tessier, G., & Larouche, D. (1986). The effects of Quebec home aid services on the utilization profile of sociosanitory resources: A substitution study. *Social Science and Medicine*, 22(7), 731–736.
- Cranswick, K., & Thomas, D. (2005, Summer). Elder care and the complexities of social networks. *Canadian Social Trends* (Catalogue #11-008). Ottawa: Statistics Canada.
- Fast, J. E., Forbes, D., & Keating, N. C. (1999). Contributions and needs of informal elder care providers in Canada: Evidence from Statistics Canada's 1996 General Social Survey on social support. Edmonton: Health Promotion and Programs Branch, Health Canada.
- Forbes, D., Markle-Reid, M., Hawranik, P., Peacock, P., Kingston, D., Morgan, D., et al. (in press). Availability and acceptability of Canadian home and community-based services: Perspectives of family caregivers of persons with dementia. *Home Health Care Services Quarterly.*
- Forbes, D.A., Morgan, D., & Janzen, B. (2006). Rural and urban Canadians with dementia: Use of health care services. *Canadian Journal on Aging*, 25(3), 321– 330.
- Forbes, D., Neufeld, A., & Reutter, L. (2004). Health and well-being in youngold and old-old Canadians: A comparison of two time periods. *International Journal of Canadian Studies*, 28(Fall), 39–62.
- Forbes, D., Stewart, N., Morgan, D., Anderson, M., Parent, K., & Janzen, B. (2003). Individual determinants of home-care nursing and housework assistance. CJNR, 35(4), 14–36.
- Gill, C. E., Hinrichsen, G. A., & DiGiuseppe, R. (1998). Factors associated with formal service use by family members of patients with dementia. *Journal of Applied Gerontology*, 17(1), 38–53.
- Hall, R., & Coyte, P. (2001). Determinants of home care utilization: Who uses home care in Ontario? *Canadian Journal on Aging*, 20, 175–192.

CJNR 2008, Vol. 40 Nº 1

- Hollander, M., & Tessaro, A. (2001). Evaluation of the maintenance and preventive function of home care. Retrieved July 19, 2001, from http://www.hollander analytical.com/downloads/preventivehomecarereport.pdf.
- Hopkins, R. W., & Hopkins, J. F. (2005). Dementia projections for the counties, regional municipalities, and districts of Ontario. Geriatric Psychiatry Programme, Clinical Research Bulletin, 15. Kingston, ON: Providence Continuing Care Centre Mental Health Services.
- Keating, N., Fast, J., Frederick, J., Cranswick, K., & Perrier, C. (1999). *Eldercare in Canada: Context, content and consequences*. Ottawa: Statistics Canada.
- Markle-Reid, M., & Browne, G. (2001). Explaining the use and non-use of community-based long-term care services by caregivers of persons with dementia. *Journal of Evaluation in Clinical Practice*, 7(3), 271–287.
- Maritime Centre of Excellence for Women's Health. (1998). *Home care and policy: Bringing gender into focus.* Retrieved March 8, 2006, from http://www.acewh. dal.ca/eng/reports/HC-intro-e.htm.
- McCloskey, D. (2005). Caregiving and Canadian families. *Transition Magazine*, 35(2), 1–17.
- Miller, B., & Guo, S. (2000). Social support for spouse caregivers of persons with dementia. *Journal of Gerontology: Social Sciences, 55B,* S163–S172.
- Mitura, V., & Bollman, R. (2003). The health of rural Canadians: A rural-urban comparison of health indicators (Statistics Canada catalogue #21-006-XIE). *Rural and Small Town Canada Analysis Bulletin, 4*(6).
- National Advisory Council on Aging. (1994). *Aging vignette #30*. Ottawa: Author.
- Neufeld, A., & Harrison, M. J. (2003). Unfulfilled expectations and negative interactions: Nonsupport in the relationships of women caregivers. *Journal of Advanced Nursing*, 41(4), 323–331.
- Neufeld, A., Harrison, M. J., Hughes, K., & Stewart, M. (2007). Non-supportive interactions in the experience of women family caregivers. *Health and Social Care in the Community*, 15(6), 530–541.
- Neufeld, A., Kushner, K. E., & Rempel, G. (2007, November 1–3). *Men negotiating the maze of care for a relative with dementia*. Paper presented at Chinook Winds: Shaping the Landscape of Aging, 36th Annual Scientific and Educational Conference of the Canadian Association on Gerontology, Calgary.
- Ontario Ministry of Health and Long-Term Care. (2007, August 28). *McGuinty government transforming community living to help seniors live independently at home.* [News release.] Toronto: Author.
- Parent, K., Anderson, M., & Neuwelt, B. (2000). Home care and people with psychiatric disabilities: Needs and issues. Toronto: Queen's University Department of Rehabilitation Medicine and Canadian Mental Health Association.
- Roberge, R., Berthelot, J. M., & Wolfson, M. (1995). The Health Utility Index: Measuring health differences in Ontario by socioeconomic status. *Health Reports*, 7(2), 25–32.
- Robillard, A. (2007). Clinical diagnosis of dementia. *Alzheimer's and Dementia*, *3*, 292–298.

- Rotemann, M. (2006). Seniors' health care use (Statistics Canada catalogue #82-003). *Health Reports*, 16(Supp.), 33-45.
- Scarrow, J. (2007). Bringing health care home. Registered Nurse Journal, 19(6), 12–16.
- Shamian, J., Shainblum, E., & Stevens, J. (2006). Accountability agenda must include home and community based care. *Healthcare Papers*, 7(1), 58–64.
- Shapiro, E. (2003). Perspectives on the Romanow Commission: The Romanow Commission Report and home care. [Editorial.] *Canadian Journal on Aging*, 22(1), 13–17.
- Statistics Canada. (2004). CCHS Cycle 2.1 (2002–2003): Public Use Microdata File Documentation. Ottawa: Author.
- Teel, C. S., & Carson, P. (2003). Family experiences in the journey through dementia diagnosis and care. *Journal of Family Nursing*, 9(1), 38–58.
- Toseland, R. W., McCallion, P., Gerber, T., & Banks, S. (2002). Predictors of health and human services use by persons with dementia and their family caregivers. Social Science and Medicine, 55, 1255–1266.
- Tranmer, J. E., Croxford, R., & Coyte, P. C. (2003). Dementia in Ontario: Prevalence and health services utilization. *Canadian Journal on Aging*, 22(4), 369–379.
- VON Canada. (2006). VON Canada's submission to the House of Commons Standing Committee on Finance in preparation for budget 2007. Ottawa: Author.
- Wilkins, K., & Park, E. (1998). Home care in Canada. *Health Reports, 10*(1), 29–37.
- Women's Health Bureau, Health Canada. (2003). *Exploring concepts of gender and health*. Ottawa: Minister of Public Works and Government Services Canada.

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