

ABSTRACT

The aim of this paper is to document interest in support strategies among caregivers of elderly persons. We used data from the Canadian Study of Health and Aging caregiver questionnaire which included 43 informal caregivers of elderly persons living with dementia and 145 informal caregivers of elderly persons not living with dementia. While the study assessed interest in attending support groups (10.4%), receiving telephone support from either a professional (44.9%) or a fellow caregiver (41.0%), receiving a newsletter (40.5%), receiving volunteer support (24.2%), and interest in support via computer (14.8%), there were no significant differences between the two groups with regard to interest in any of the support services. Implications for program delivery are discussed. Planners may want to consider adding telephone support and newsletters to other supports already available for caregivers.

ABRÉGÉ

Afin de documenter l'intérêt des pourvoyeurs de soins aux personnes âgées à l'égard de diverses stratégies de soutien, nous avons utilisé les données du questionnaire aux soignants de l'Étude sur la santé et le vieillissement au Canada, administré notamment à 43 soignants informels de personnes âgées atteintes de démence et à 145 soignants informels de personnes âgées non atteintes de démence. Notre étude évaluait leur intérêt à participer à des groupes de soutien (10,4 %) ou à recevoir du soutien téléphonique d'un professionnel (44,9 %) ou d'un collègue (41,0 %), un bulletin d'information (40,5 %), du soutien bénévole (24,2 %) et du soutien par ordinateur (14,8 %). Nous n'avons toutefois constaté aucune différence significative entre les deux groupes. L'étude aborde aussi les incidences possibles sur l'exécution des programmes. Les planificateurs pourraient envisager l'ajout d'un soutien téléphonique et de bulletins d'information aux ressources déjà offertes aux soignants.

What Support Do Caregivers of Elderly Want? Results from the Canadian Study of Health and Aging

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The Canadian Study of Health and Aging¹ has indicated that almost 50% of the elderly in Canada are already assisted primarily by informal caregivers (unpaid family and friends) in a community setting. This has great public health implications in light of the projected increase of our elderly population. There is a need to explore a variety of means to support these caregivers in ways that are acceptable to them. A dearth of research is available on the preferences of these caregivers for different types of support.

A recent study conducted among community-living caregivers of persons with dementia indicated a stronger interest in receiving support via telephone and newsletter than through support groups or via computer. Little is known of the preferences of these types of support (or other types of support such as the use of volunteers)²⁻⁵ among larger samples of caregivers. The aim of this paper is to describe how interested caregivers of seniors are in various support strategies using a large national sample of caregivers. We compare the preferences of caregivers of persons with dementia with other caregivers since there is strong evidence that dementia care is different from other types of family caregiving.⁶

METHOD

Subjects

We used data from a national sample of caregivers from the 1996 second wave of

the Canadian Study of Health and Aging (CSHA-2). A more detailed description of the methodology is found elsewhere.¹

Included in our sub-sample were primary caregivers of a senior in the community who had indicated that they were "informal", that is a friend or relative of the senior.¹ Two hundred and eighty-seven (287) of the 1,129 caregivers in this sample were community-living informal caregivers and therefore fit our criteria for inclusion. Unfortunately, because the survey questions relevant to our study were added to the CSHA-2 caregiver questionnaire as an appendix, 64 subjects did not complete these queries and were, therefore, excluded from the analysis. There were no significant differences between the 64 who did not participate and the caregivers that did. The remaining 223 were categorized into three groups: caregivers of seniors with dementia, caregivers of seniors without dementia, and caregivers of seniors with cognitive impairment but no dementia (CIND). For the purpose of this research, we were only interested in caregiver-care-recipient dyads in which the care-receivers were clearly living with or without dementia. The 35 caregivers who were caring for a person with CIND were excluded from the analysis. Our sample, therefore, consisted of 188 senior-caregiver dyads, 43 of whom comprised the dementia group and 145 of whom comprised the non-dementia comparison group.

Variables measured

1) Characteristics of the caregiver measured were socio-demographic (age at interview, gender, questionnaire language and relationship to care-recipient), degree of perceived burden as measured by Zarit Burden Inventory⁷ and depressive symptomology evaluated using the Center for Epidemiological Studies Depression Scale (CES-D).⁸

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2) Characteristics of the care-recipient measured were socio-demographic (age and gender), limitations in activities of daily living as measured by the Fillenbaum rating scale.⁹

Support variables

Support or Self-help Group

Participants were asked whether they would be interested in participating in a support or self-help group. Those respondents who indicated that they were not already involved with such a group, but would be interested, were then queried about barriers that would make attendance in such a group difficult. Caregivers who responded in the affirmative were asked about the following barriers: transportation, time constraints, respite, and other.

Telephone Support

Respondents were asked to indicate whether they would be interested in utilizing a service that would allow them to phone in to get advice or support by a professional or fellow caregiver over the phone at no cost.

Information Via Newsletter

Caregivers were queried as to whether they would be interested in receiving a newsletter that would deal with issues related to caring for persons with dementia.

Help from Volunteers

Participants were questioned about whether they would be interested in volunteers coming to their home in order to provide help in any of the following areas: emotional support, caring for the caregiver's friend/relative, helping with other household tasks, helping with any other areas of need.

Support by Computer

Respondents were asked whether they owned or had access to a computer. Respondents were asked whether they would be interested in receiving, via computer, information that was related to caring for someone with dementia, and whether they would be interested in communicating with other persons who were caring for someone with dementia.

TABLE I
Comparative Characteristics of Study Sample

	Dementia Group (n=43)		Comparison Group (n=145)		Total (N=188)		p value
Caregiver Characteristics	M	(SD)	M	(SD)	M	(SD)	
Age at CSHA-2	61.8	(12.5)	64.2	(13.9)	63.7	(13.6)	0.31*
Zarit Score at CSHA-2†	21.8	(15.2)	9.0	(10.1)	11.9	(12.6)	0.0001*
CES-D Score at CSHA-2	8.2	(10.1)	5.9	(7.9)	6.5	(8.5)	0.1808*
Care-recipient Characteristics							
Age at CSHA-1	87.3	(6.2)	83.1	(5.4)	84.0	(5.9)	0.0002**
Fillenbaum Rating‡	3.9	(1.2)	1.8	(1.0)	2.3	(1.4)	0.0001**

* wilcoxon
** t-test
† A higher score is indicative of more burden
‡ A score of 1 indicates no ADL impairment and a score of 5 indicates complete ADL impairment

TABLE II
Summary Statistics of Study Sample

	Dementia Group (n=43)		Comparison Group (n=145)		Total (N=188)		p value
Characteristics	n	(%)	n	(%)	n	(%)	
Sex of Caregiver							
Male	9	(22)	40	(30.1)	49	(28.2)	
Female	32	(78)	93	(69.9)	125	(71.8)	0.312***
Sex of Subject							
Male	21	(48.8)	49	(33.8)	70	(37.2)	
Female	22	(51.2)	96	(66.2)	118	(62.8)	0.073***
Caregiver's Relationship to Care-recipient							
Wife	12	(27.9)	31	(21.4)	43	(22.9)	
Husband	0	(0.0)	21	(14.5)	21	(11.1)	
Daughter	16	(37.2)	46	(31.7)	62	(33.0)	
Son	9	(20.9)	23	(15.9)	32	(17.0)	
Other	6	(14.0)	24	(16.5)	30	(16.0)	0.10***
Questionnaire Language (Caregiver)							
English	35	(81.4)	119	(82.1)	154	(81.9)	
French	8	(18.6)	26	(17.9)	34	(18.1)	0.92***
# of Caregivers Depressed (scored 16+ on CES-D)							
Depressed	7	(16.3)	18	(12.4)	25	(13.3)	
Non-depressed	36	(83.7)	127	(87.6)	163	(86.7)	0.512***

***chi-square

Statistical analyses

Frequency counts at both levels of care-recipient cognitive status were computed for all outcome variables. Differences in interest between the two groups were assessed using a chi-square test. To control for an inflated type I error rate, the p value for all comparisons in the paper was set at 0.01.

RESULTS

Care-recipients in the dementia group were significantly older and more functionally impaired while caregivers of persons living with dementia reported significantly more perceived burden (See Tables I and II). There were no significant differences between these groups on any other characteristics.

In the dementia group, 4.65% (2/43) of caregivers were involved in a support/self-help group and 2.33% (1/43) of caregivers were participating in a phone service manned by professionals. None of the dementia group respondents indicated that they were currently using a phone service manned by fellow caregivers or receiving a newsletter specifically about issues related to caring for persons with dementia. One (1/145) of caregivers of persons not living with dementia (0.7%) replied that they were currently a member of a support/self-help group and no respondents replied that they were currently utilizing any type of telephone support service. Interestingly, 2.07% (3/145) of the caregivers of persons not living with dementia reported receiving a newsletter.

TABLE III
Interest in Support Groups, Phone Support and Newsletter

	Dementia Group		Comparison Group		Total		p value
Services	n	(%)	n	(%)	n	(%)	
Support Group	7/40	(17.5)	11/133	(8.3)	18/173	(10.4)	0.10***
Phone Support by Professional	16/40	(40.0)	64/138	(46.4)	80/178	(44.9)	0.48***
Phone Support by Fellow Caregiver	18/43	(41.9)	55/135	(40.7)	73/178	(41.0)	0.90***
Newsletter	19/43	(44.2)	56/134	(41.8)	75/177	(42.4)	0.78***

***chi-square

TABLE IV
Interest in Volunteer Support

	Dementia Group		Comparison Group		Total		p value
Type of Volunteer Support	n	(%)	n	(%)	n	(%)	
Emotional	4/43	(9.3)	22/136	(16.2)	26/179	(14.5)	0.27***
Help with Caring	12/41	(29.7)	31/137	(22.6)	43/178	(24.2)	0.77***
Help with Household Tasks	9/42	(21.4)	32/138	(23.2)	41/180	(22.8)	0.82***
Help with Other Needs	6/42	(14.3)	21/136	(15.4)	21/178	(15.2)	0.86***

***chi-square

TABLE V
Interest in Computer Support

	Dementia Group		Comparison Group		Total		p value
Computer Support	n	(%)	n	(%)	n	(%)	
Access to a Computer	16/43	(37.2)	62/138	(44.9)	78/181	(43.1)	0.38***
Receiving Information via Computer	7/42	(16.7)	19/134	(14.2)	26/176	(14.8)	0.69***
Communicating with Other Caregivers	5/42	(11.9)	16/134	(11.9)	21/176	(11.9)	0.99***

***chi-square

Seventeen percent (7/40) of caregivers in the dementia group who were not participating in a support/self-help group indicated that they would be interested in doing so. Moreover 8.3% (11/133) of caregivers in the comparison group were interested in such a program. Since the total number of caregivers who were interested in support/self-help groups was relatively low, and the difference between the groups with regard to interest was not significant, we collapsed the data across the 2 levels of cognitive status in order to examine potential barriers to attendance. Among those who displayed interest in self-help/support groups, 55.6% (10/18) indicated that there were circumstances that could make attendance in such a group difficult. Five of the 18 (27.8%) suggested transportation was a barrier, 33.3% (6/18) reported time constraints and 22.2% (4/18) reported lack of respite.

Both the dementia and comparison groups displayed considerable interest in

telephone support manned by professionals or fellow caregivers. Approximately 45% (80/178) and 41.0% (73/178) of all caregivers indicated that they would be interested in receiving telephone support by a professional and fellow caregiver respectively. Forty-four percent (19/43) of these caregivers of persons living with dementia indicated that they would be interested in receiving a newsletter about dementia, as did 41.8% (56/134) of the caregivers of persons not living with dementia. For a summary of interest in support groups, telephone contact, and support via newsletter, please see Table III.

Interest in volunteer services

(See Table IV). Four (9.3%) of caregivers in the dementia group and 16.2% (22/136) of caregivers in the comparison group suggested that they would be interested in having a volunteer come to their home to provide emotional support. In

this sample, 29.7% (12/41) of dementia group caregivers and 22.6% (31/137) of comparison group caregivers expressed interest in assistance from volunteers to help care for the senior. Twenty-one percent (9/42) of people caring for a person who was living with dementia and 23.2% (32/138) of people caring for a person who was not living with dementia indicated that they would be interested in volunteers who would help with other household tasks. Six (14.3%) caregivers in the dementia group and 21 (15.4%) caregivers in the comparison group responded that they would be interested in assistance with other areas of need. None of the chi-square comparisons between the dementia group and the comparison group in the above 4 variables were significant.

Interest in information via computer

Access to a computer ranged from 37% (16/43) in the dementia caregiver group to approximately 45% (62/138) in the comparison group. This difference was not statistically significant. Approximately 17% (7/42) of caregivers in the dementia group also expressed a marginal amount of interest in obtaining information related to caring for someone with dementia via computer, compared to 14.2% (19/134) of caregivers of persons not living with dementia. Approximately 12% (5/42) were interested in the possibility of communication, by computer, with other persons who were caring for someone with dementia, similar to the 11.9% (16/134) of caregivers for non-dementia persons. Table V provides an overview of interest in receiving information via computer.

DISCUSSION

Our findings on the level of interest in each type of support service replicate patterns found in a convenience sample of community-based caregivers of persons living with dementia.^{5,10} In both studies, the highest level of interest displayed among caregivers who were not currently using the target service was for telephone support (provided by a professional or fellow caregiver) and newsletter support. Less interest was expressed for support groups, volunteer support or support by computer.

The low level of interest in support groups in this sample of older caregivers replicates that of other national Canadian studies that have found very low participation rates in support groups among the elderly.¹¹ Time constraints, lack of respite, transportation and health issues have all been cited as barriers to participation by caregivers and should be taken into account by persons developing such programs.¹⁰ Our findings indicate that caregivers are most interested in instrumental types of support from volunteers, such as help with caring and household tasks. Despite the high mean age of caregivers, a notable percentage had access to a computer and were interested in support via computer. In the coming decades, as computers become a part of everyday culture, it is likely that caregivers will be more familiar with computers and, therefore, more willing to utilize computer-based services.

Although our sample was obtained through a national study of aging, our total number of dementia caregivers was quite small, which may have led to non-significant differences. The caregivers of people living with dementia expressed similar interest in support despite describing more burden. These findings are in accord with other studies that have shown that dementia caregivers do not use more services and may underutilize services despite the greater demands placed on them.¹ Public health administrators and other professionals assisting community-living caregivers of persons with dementia should consider providing information via telephone/newsletter as part of a flexible menu of services. Where such services do not exist, we recommend that officials consider developing such programs. With regard to support groups, we are not advocating that profes-

sionals abandon such services. Rather, we are suggesting that professionals evaluate the barriers to participation and tailor their services accordingly.

More research should be conducted to discern the specific types of telephone services that would be most appropriate for different sub-types of caregivers over the course of a caregiver's career. For instance, needs of caregivers in rural communities, who may stand to benefit the most from telephone/newsletter support, may be different from those who live in well-served metropolitan areas, and needs will change as the severity of dementia progresses. Moreover, interest in a service is not necessarily commensurate with use of that service. Therefore the acceptability of various types of telephone support needs to be explored. Finally, the interest of different ethnic groups for alternative forms of support also warrants further investigation.

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