Archives of Gerontology and Geriatrics 52 (2011) 202–205

Contents lists available at ScienceDirect

Archives of Gerontology and Geriatrics

journal homepage: www.elsevier.com/locate/archger

Information needs and sources of family caregivers of home elderly patients

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ARTICLE INFO

Article history:
Received 2 October 2009
Received in revised form 12 February 2010
Accepted 14 March 2010

Keywords:
Home care
Information needs
Information sources
Dementia
Family caregivers

ABSTRACT

Meeting the information needs of family caregivers in a timely and appropriate way is a key concern of home care. The present study aimed to explore the following two areas: (a) the priority information needs and sources of family caregivers of home elderly patients and (b) the differences in information needs according to severity of dementia. The subjects were 475 family caregivers of home elderly patients residing in Nagoya city. Data was collected through questionnaires. Severity of dementia was evaluated according to the criteria of the public long-term care insurance policy (levels 0–5). The top 3 items they perceived as of most concern were dementia, first aid, and available public long-term care insurance services. A few respondents felt the need for information on public long-term care insurance services. Nearly half of the caregivers were interested in food and nutrition. The respondents were more likely to receive information from their care managers or physicians than any other source. Caregivers of elderly dependents with severe dementia reported a greater need for information on the spread of dementia, dementia-specific care, or the negative effects of dementia on family and neighborhood. Our results provide useful information on how family caregivers should be educated.

1. Introduction

The continuous growth of the elderly population in Japan has led to an increase in chronic morbid conditions, such as dementia or stroke. Due to the decreasing number of hospital beds, as well as the changing preferences of elderly patients and their families, greater numbers of frail elderly people are now opting to spend their last years of life at home (Hashimoto, 2001). Home care is therefore an essential component of long-term care for Japanese elderly patients, and good home care requires appropriate support to the family caregivers of elderly patients with a chronic disease such as dementia, which can be a burden at different levels.

Effective communication based on reliable and comprehensive health information between health professionals and elderly patients and families is an important part of home elderly care (Seematter-Bagnoud and Santos-Eggimann, 2007; Donohue et al., 2009). While television and newspapers have traditionally been common sources of health information among the general population, an increasing number of people are now turning to the internet to gather information (Dutta-Bergman, 2003; Bates et al., 2006; Lemire et al., 2008). However, because elderly patients vary widely in terms of health conditions and activities of daily living (ADLs), the issues surrounding their care are often complex; thus, relaying accurate and tailored information to them is crucial. Therefore, meeting the information needs of family caregivers in a timely and appropriate way is a key concern of home care, and the information needs and sources of family caregivers should be well documented.

Also, although the trend toward home care for elderly people is part of a social movement designed to improve long-term care in Japan (Kawamoto et al., 1999; Hirakawa et al., 2006), family caregivers for the demented elderly still have two major concerns: caregiver burden and their ability to provide care (Kameda et al., 2001). Because dementia is a progressive disease, family caregivers need information on how to better assist demented elderly according to the severity of cognitive impairment (Hirakawa et al., 2008). Especially, it is important to educate them concerning dementia-specific care including the behavioral and psychological symptoms of dementia (BPSD) care. The development of BPSD is associated with a more rapid rate of diminished quality of life and is often the reason for placement into residential care (Haupt et al., 2000). Thus, the nature of the dementia requires family caregivers to learn about the disease, make difficult decisions regarding the ensuing care, and cope with the consequences of the illness.

The present study aimed to explore the following two areas: (a) the priority information needs and sources of family caregivers of home elderly patients and (b) the differences in information needs according to severity of dementia.

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doi:10.1016/j.archger.2010.03.019

2. Subjects and methods

The subjects in this study were family caregivers of home elderly patients residing in Nagoya city (Central Japan). Subjects were provided various formal home care services from the Nagoya City Health Care Service Foundation for Older People which comprises 16 care-managing centers. Data was collected through self-reported, structured questionnaires covering the following: (i) areas in which a need for education was perceived, and (ii) information sources which were frequently utilized (Tables 3 and 4). Data on the characteristics of elderly dependents and their family caregivers was also collected from center records. The presence of various comorbid conditions of elderly dependents was recorded if documented in the visiting nursing station records. Severity of dementia was evaluated according to the criteria of the public long-term care insurance policy, which recognizes six levels of dementia (levels 0–5) (Onishi et al., 2005). ADL limitation was evaluated according to four ranks of ADL of disabled elderly, identified by the Japanese government as follows: Rank J, independent in ADL; Rank A, house-bound; Rank B, chair-bound; Rank C, bed-bound (Hirakawa et al., 2005). The questionnaire was drawn up following interviews with several leading members of the Nagoya City Health Care Service Foundation for Older People. The family caregivers were asked to describe the perceived need for specified items and indicate the information sources they most frequently used.

To evaluate the differences in information needs according to severity of dementia, we divided the participants according to the condition of their elderly dependents into three mutually exclusive categories: (1) no dementia; (2) mild dementia (levels 1–2), and (3) severe dementia (levels 3–4). Because level 5 includes severe cognitive impairment caused by severe physical ailments (Onishi et al., 2005), we excluded level 5 dependents from the present analysis. The data was analyzed using SPSS17.0. The differences in information needs among the dementia categories were assessed using the Kruskal–Wallis test. $p < 0.05$ levels were considered to be significant. The research protocol was reviewed and approved by the Nagoya University School of Medicine Research Ethics Board.

3. Results

Four hundred and seventy-five family caregivers responded. Tables 1 and 2 show the general characteristics of family caregivers and their dependents. The average age of respondents (family caregivers) was 65, and three-fourths of them were female. Two-thirds of the respondents were high school, college, or university graduates. The majority of them lived with their elderly dependent. Approximately half of them reported that they felt that the caregiver burden was severe.

Table 1
Characteristics of family caregivers ($n = 475$).

Variables	Categories	n/mean	%/SD
Age (year)		64.9	12.2
Sex	Women	366	77.1
Kinship	Spouse	205	43.2
	Child (incl. daughter/son-in-law)	235	49.5
	Others	29	6.1
Living together		423	89.1
Job		157	33.1
Level of education	Junior high	39	8.2
	High school	200	42.1
	College/University	97	20.4
Subjective caregiver burden	Severe	86	18.1
	Moderate	192	40.4
	Light	176	37.1
	No	9	1.9

Table 2
Characteristics of elderly dependents ($n = 475$).

Variables	Categories	n/mean	%/SD
Age (year)		81.2	8.7
Sex	Women	254	53.5
Feeding	Independent	287	60.4
	Partly dependent	123	25.9
	Dependent	48	10.1
Communication with others	Independent	165	34.7
	Partly dependent	265	55.8
	Impossible	80	16.8
ADL scale of disabled elderly	J	43	9.1
	A	189	39.8
	B	167	35.2
	C	58	12.2
Severity of dementia	0	81	17.1
	1	146	30.7
	2	115	24.2
	3	79	16.6
	4	32	6.7
	5	7	1.5
Illness	Cerebrovascular disease	157	33.1
	Hypertension	107	22.5
	Diabetes	73	15.4
	Cardiopulmonary disease	59	12.4
	Neoplasia	41	8.6
	Osteoarthrities	40	8.4
	Kidney disease	34	7.2

Half of the elderly dependents were female and 80 years old in average. One-third of the elderly had a past history of stroke, and one-fourth had a history of hypertension. The majority of dependents had ADL limitation, communication disability, or swallowing disorder, and one-third was using a nurse's home visit service. Approximately half of the elderly had mild dementia ($n = 261$) while one-fourth had severe dementia ($n = 111$).

Table 3 shows the family caregivers' perceptions of their own educational needs. The top 3 items they perceived as of most concern were dementia, first aid, and available public long-term care insurance services. A few respondents felt the need for information on public long-term care insurance services, particularly on home and institutional care services. Few respondents perceived an educational need for consumer-related issues, such as problems with consumer products and contracts. Nearly half of the caregivers were interested in food and nutrition.

Table 4 shows the main sources of information of family caregivers. The respondents were more likely to receive information from their care managers or physicians than any other source.

Table 3
Family caregivers' perceptions of their own information needs ($n = 475$).

Variables	Categories	n	%
Dementia	Overall	309	65.1
	Care	233	49.1
	Spread of disease	191	40.2
	Treatment	189	39.8
	Family impact	142	29.9
	Chance of recovery	109	22.9
First aid		281	59.2
Public long-term care service	Overall	261	54.9
	Institutional care	186	39.2
	Home care	177	37.3
Food and nutrition		224	47.2
Life related disease		203	42.7
Stress management		196	41.3
When to transfer patient to hospital		187	39.4
Problems as a consumer		60	12.6