

UNDUE CONCERN FOR OTHERS' OPINIONS DETERS CAREGIVERS OF IMPAIRED ELDERLY FROM USING PUBLIC SERVICES IN RURAL JAPAN

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ABSTRACT

Objective. To determine whether opinions of others may discourage the use of public services for the elderly.

Design. Users and non-users were compared regarding several variables including caregivers' concerns about opinions of others.

Setting. Matsuyama Town, located in a rural area of northern Japan.

Subjects. Seventy pairs of (1) elderly persons in need of care assessed by the procedure employed by the Ministry of Health and Welfare, and (2) their respective family caregivers.

Measures. Cognitive function (Hasegawa Dementia Rating Scale), diagnosis of dementia, activities of daily living (ADL: Barthel Index), caregivers' burden (Zarit Caregiver Burden Interview), behavioral disturbances (Dementia Behavioural Disturbance Scale), caregiver interviews.

Results. A logistic regression analysis revealed that those who looked after the elderly with severe dependency in ADL were three times more likely to use public services (OR = 3.33, 95% CI = 1.02–10.88, $p = 0.04$). Those concerned about what others think or say were less likely to use public services (OR = 0.22, 95% CI = 0.06–0.78, $p = 0.01$) than those who did not.

Conclusions. Caregivers' undue concern for the opinions of others apparently deterred them from using public services. The overriding notion of care for the elderly as a family duty is still prevalent in rural Japan. It would be useful for the government to launch a public awareness programme to help caregivers understand the benefits of services available for the elderly. Copyright © 2000 John Wiley & Sons, Ltd.

KEY WORDS—caregivers; Japan; elderly; attitude; service use

INTRODUCTION

Caring for the disabled elderly has proved to be a burden on family caregivers (Zarit *et al.*, 1980; Baumgarten *et al.*, 1994). It is also acknowledged that for caregivers the utilization of services such as day care or respite care has lessened the caregiver burden (Lawton *et al.*, 1989; Kosloski and Montgomery, 1995; Arai *et al.*, 1998a). Nonetheless, caregivers make little use of public (formal)

services (Caserta *et al.*, 1987; Collins *et al.*, 1991; Braithwaite, 1998). Collins *et al.*, for example, characterized such caregivers' attitude by several factors, e.g. concern for the opinion of others and pride in family independence.

In Japan, reluctance to use public services among the general public has been clearly demonstrated (Watts, 1998). First, according to a survey by the Japanese government in 1995, 20% of the elderly stated that caregivers should not use public services; another 36% held that only a minimum amount of public services should be used and only when caregivers are about to reach burnout (Office of Management and Coordination Agency, 1997). Second, it was shown that 42% of the healthy elderly did not want their family members to use formal services, even if they were to suffer from dementia (Arai *et al.*, 1998b). In such cir-

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cumstances, caregivers in Japan have found it extremely difficult to apply for public services.

Despite this prevailing negative attitude toward the use of services, the new public long-term care (LTC) insurance scheme will be fully operational from the year 2000 in Japan, following Germany and Holland. In this scheme, the level of service provision will be decided entirely by the patients' impairment, not by the amount of available informal care (Arai, 1997). Currently, the Ministry of Health and Welfare (MHW) has stated that health visitors and practice nurses in each municipal authority should identify the number of 'elderly in need of care', i.e. 'Yokaigo roujin' who are eligible for public services (e.g. home-help service, day care, etc.). The MHW has defined 'elderly in need of care' as those who are either 'semi-bedridden' (i.e. 'home-bound': those who are immobile but not bedridden within their own homes), or 'bedridden' (Miura *et al.*, 1997). The elderly in need of care in Japan are thus encouraged to use services provided by the municipal government, i.e. public services.

However, it is feared that the above-described negative attitude towards utilizing formal services may lead to a failure in implementation of the new public LTC insurance scheme. Once the scheme is in place, each elderly person in need of care will be assessed in terms of the severity of his or her disability and be allowed to receive public services accordingly. However, there will be caregivers who may hesitate to utilize services. Thus, it is urgent and important to investigate (1) what proportion of eligible elderly and caregivers are using public services when accessibility and availability of public service are not problematic; and (2) if concerns about opinions of others are related to the decision of using services among caregivers.

METHODS

The present study was conducted between June and August 1998 in Matsuyama Town, located in Miyagi Prefecture, in northern Japan. The quantitative method and subsequently the qualitative method were employed for a sub-sample of the subjects.

Subjects

Subjects were drawn from the list of 'registered disabled elderly' from Matsuyama Town (popu-

lation: 7126). Some 1586 people in the town were older than 65 years of age, which was slightly higher than the national average. Currently, once registered as an elderly person in need of care (i.e. Yokaigo roujin), these people are given explanations of all the services provided by the municipal government by practice nurses, as well as the most appropriate services for them.

The elderly in need of care were identified in the procedure employed by the MHW (Miura *et al.*, 1997). First, all 1586 elderly residing in the town were given the Assessment of Independence Level in Daily Living established by the MHW. This is a self-administered questionnaire to evaluate their level of physical independence such as eating, bathing and dressing. According to the guidelines of this assessment, the subjects were categorized into independent, semi-bedridden, i.e. home-bound, or bedridden. Consequently, 135 elderly were identified as home-bound or bedridden and thus, 'elderly in need of care'. They were, therefore, eligible for public services.

These 135 elderly were comprised of 29 institutionalized elderly, 18 elderly residing in their home alone, and 88 elderly residing with caregivers. Since the purpose of our study was to investigate the caregivers' decision to utilize services, 88 registered elderly persons and their respective caregivers were identified as subjects. All 88 elderly persons and their respective caregivers agreed to take part in the study. Among them, 70 elderly and their caregivers returned the completed questionnaire.

In Matsuyama, the following six public services were available for those in need of care: home-help (housekeeping); home nurse visits; respite care; meals on wheels; bathing service; and day care center. Currently, services are available to the elderly according to their disability assessment; there are few problems of accessibility and/or availability. All of these 88 elderly and their caregivers were invited to participate by a letter explaining the project, which has also been fully endorsed by the ethical committees of both Matsuyama Town and the National Institute of Longevity Sciences.

Measures

The caregivers of the 88 elderly were asked to complete the following questionnaires in relation to their burden and caregiving situation: (1) the Japanese version of the Zarit Burden Interview (ZBI; Arai *et al.*, 1997); (2) questions regarding

demographic variables of the caregivers and patients; and (3) their use of various services. For service use, the respondents were asked about their current use of the above-described six types of services within the previous 4 weeks. The response for each service was either 'use' or 'no use'. Caregivers were also asked the following question: 'Are you concerned about what others would think or say to you when using public services?' Caregivers were asked to choose either 'yes' or 'no'.

Caregivers' burden was assessed by the Japanese version of ZBI, a 22-item self-report inventory that examines the burden associated with functional/behavioral impairments in the home care situation (Arai *et al.*, 1997). The ZBI is one of the most common scales for assessing the burden of caregiving (Zarit and Zarit, 1990).

Cognitive impairment of the elderly was rated by the revised Hasegawa Dementia Rating scale (HDS-R), which was equivalent to the Mini-Mental Test and has been widely used in Japan. HDS-R is a Japanese screening test for dementia that measures overall cognitive function, including verbal orientation and memory, with scores ranging from 0 to 30 (Kato and Hasegawa, 1991). The diagnosis of the dementia was made by the principal investigator (Y.A.) employing the DSM-III-R.

Disability of the elderly was assessed by: (1) activities of daily living (ADL) of the patients, i.e. Barthel Index (BI) (Davies, 1996); and (2) their behavioral disturbances if any. First, the practice nurses assessed the patients on their visits by the BI, which is a widely used 10-item ADL scale. It was reported that a cut-off point of 9 on the BI represented the threshold between moderate and severe dependence. Thus, in the present study, the elderly were divided into the following two groups: those whose BI was less than 10 (severely dependent) and those whose BI was 10 or more (moderately dependent) (Davies, 1996).

Second, in order to determine whether the elderly had behavioral disturbances associated with dementia, we asked the caregivers to fill in the Dementia Behavioral Disturbance (DBD) scale (Baumgarten *et al.*, 1990). The Japanese version of the DBD scale has been validated (Mizoguchi *et al.*, 1993).

Analyses

The caregivers in the present study were divided into two groups: those who used at least one

service (i.e. users) and those who did not use any services (i.e. non-users). First, a χ^2 or Mann-Whitney test was conducted to determine the differences between the two groups (i.e. associations between ZBI and the variables concerned). Second, a multiple logistic regression analysis was employed to see which of the remaining variables was significantly related to the caregivers' decision to use services. Variables found to be statistically significant in the above univariate analyses were entered as independent variables in this multiple logistic regression analysis. The Statistical Package for Social Science (SPSS, version 8.01) was used for the above statistical analyses (Norusis, 1993).

Qualitative study

Seven caregivers were randomly selected from among those who expressed concerns about what others would think or say regarding the utilization of formal services. The principal investigator (Y.A.) conducted semi-structured interviews (in Japanese). The content of the interview was analyzed by adapting the procedures outlined by Silverman (1994). First, the audiotapes of all the interviews were transcribed. Second, significant statements were set in bold type in each of the transcripts. Third, these bold face statements were re-read and prevalent themes were identified.

RESULTS

Characteristics of subjects

Tables 1 and 2 show the characteristics of the caregivers and registered elderly who participated in the study. As shown in Table 1, the mean score of the BI was 9.1, indicating that the elderly in the present study were severely disabled. Also, the mean score of the HDS-R was 13.8, indicating

Table 1. Characteristics of elderly persons and caregivers (total number = 70)

	Variables	Mean	SD
<i>Elderly person:</i>	Age	80.1	8.0
	BI	9.1	6.5
	HDS-R score	13.8	9.2
	DBD score	1.3	2.1
<i>Caregiver:</i>	Age	59.5	13.7
	ZBI score	34.9	17.9

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