

[REVIEW ARTICLE]

Caregiver Burdens, Health Risks, Coping and Interventions among Caregivers of Dementia Patients: A Review of the Literature

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Abstract:

Over 55 million people reportedly suffer from dementia worldwide. In Japan, it is estimated that 1 in 5 people over 65 years old will have dementia by 2025, of which more than 20% will live with symptoms that require home/nursing care. Given the lack of effective medical treatments for dementia, informal caregivers play essential roles in allowing dementia patients to live with dignity. Our review focusing on caregiver burden showed that this burden has not been sufficiently addressed, despite having negative effects on caregivers' health, employment, and finances. It is important to consider non-pharmacological interventions that contribute to effective coping strategies for mitigating the caregiver burden. Online communication tools may be a viable intervention measure to educate caregivers on the importance of sharing resilient coping strategies to reduce their stress so that they can continue to provide care for their loved ones.

Key words: caregiver, burden, caregiving, health, coping, interventions, dementia

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Introduction

The number of dementia patients is increasing as the population ages. Dementia is a progressive disease characterized by a global decline in cognition, followed by deterioration of additional aspects of memory and skills that enable a person to act independently in daily life, such as language, planning, and organization (1, 2). It has been reported that more than 55 million people suffer from dementia worldwide, and nearly 10 million new cases occur every year (3). The global population of dementia is expected to increase from 35.6 million in 2010 to 115.4 million in 2050 (4).

In Japan, a national survey of dementia conducted by the Ministry of Health, Labour and Welfare of Japan found that the prevalence of dementia was more than 15% among individuals ≥ 65 years old in 2009 (5). The number of dementia individuals ≥ 65 years old in 2012 was estimated to be 4.62 million nationwide, and this number is expected to reach

more than 7 million by 2025 (6). There were 1.19 million people ≥ 65 years old who were considered to have conditions requiring dementia care as of 2019 (7). Thus, developing strategies to deal with various issues related to dementia has increasingly been viewed as the most important agenda in health and social care.

Given the abovementioned background, the Japanese government aims to disseminate and establish community-based integrated care systems in all local municipalities by 2025, where a care package of housing, health care, long-term care, preventive care, and support for a living can be provided (8). The government has ordered an appropriate number of hospital beds be set aside to meet the needs for medical care of these patients according to the Medical Service Law (9). However, local health authorities have not yet implemented any effective interventions to meet the increasing demand for community-based care of dementia individuals (10, 11), and the shortage of formal care to be provided under the long-term care insurance (LTCI) scheme remains a

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critical health and social care concern (11).

In these circumstances, families of dementia individuals remain major sources of informal caregiving, as shown in previous reports (2, 12). Such care is provided by non-professional people, such as a spouse, other family members, and friends in a home setting. Indeed, of the families living with dementia in Japan, about 50% have been reported to be the primary caregivers of their loved one (13).

Caregiver burden is defined as a multidimensional response to caregiving responsibility incurred on the informal caregivers of dementia patients (14-16). Informal caregivers are likely to experience a greater caregiver burden in their daily lives than non-caregivers. Despite being expected to serve in this role for many years, even after the patients move to assisted living and nursing facilities (17, 18), most have neither professional knowledge nor sufficient training to cope with the various behavioral and psychological symptoms that dementia patients exhibit. Therefore, they cannot deal with the caregiver burden well and are significantly more likely than non-caregivers to experience symptoms of depression and anxiety (19) due to combined physical and psychological stressors, which are influenced by psychosocial factors like kinship, the social environment, and the general culture (20).

As informal caregivers are an important resource for taking care of community-dwelling dementia patients, it is essential to support these individuals. The present study therefore reviewed the literature related to caregiver burden and its coping strategies and interventions and summarized the burdens experienced by caregivers, types of burdens, coping strategies, and interventional tools that can be implemented in real clinical settings.

We hope that this article will provide concise and well-founded resources to be read by those involved in the care of dementia patients.

Caregiver Burden

What is “caregiver burden”?

Caregiving for dementia patients has become a global problem, partly because of the worldwide demographic change into an aging population (4-6).

Many variables have been identified as being associated with caregiver burden. Caregiver burden can be understood as a multidimensional definition encompassing caregiver struggles in fiscal, physical, psychological, emotional, and social well-being aspects (13, 14). There are mainly two dimensions that cause caregiver burden: the characteristics of the patients and the characteristics of the caregivers. The characteristics of the patients include the type of dementia, extent of personality change, and presence of behavioral and psychological symptoms of dementia (BPSD). Regarding the characteristics of the caregivers, the systematic review by Chiao et al. revealed that these characteristics could be grouped into three categories (21): socio-demographical fac-

tors (including caregivers’ monthly income, gender, educational level, cohabitation with the patient, and ethnicity), psychological factors (including psychological health, perceived well-being, depressive symptoms, religious coping skills, and anxiety), and caregiving-related factors (including patient care load and family functioning). Of these, the review study reported that socio-demographical factors and psychological factors were most frequently cited as factors associated with caregiver burden, and subjects with characteristics negatively related to socio-demographical and/or psychological factors experienced greater burden from their caregiving than others (21).

Burdens influenced by cultures

The level of caregiver strain perceived by caregivers might be influenced by variations in culture and social support. Studies have shown that family caregiving remains a predominantly feminine obligation under traditional culture, where women’s work roles are viewed as being centered in their own home, and female caregivers tend to spend more time caregiving, assume more caregiving tasks, and care for someone with cognitive, functional and/or behavioral problems than male caregivers (2, 22, 23). Female caregivers have thus been reported to be at greater risk for the caregiver burden than male caregivers (2), although another study did not find any marked differences between men and women in these aspects (23).

Regarding difference based on ethnicity, Caucasian caregivers were reported to appraise caregiving as more stressful than African Americans (24). Individuals raised in Asian cultures often feel greater responsibilities for older family members than others and are reluctant to reveal family problems related to dementia (25). They therefore tend to avoid accepting social and emotional support for caregivers, eventually bearing markedly heavier burdens across their cultures than others. Such may be the case with caregivers in Japan. However, a previous study comparing the burden in Japan with that in Western countries reported that the average Japanese caregiver felt less of a burden than their Western counterparts thanks to social support (26).

In any case, understanding the cultural and social influences on the attitude toward informal caregiving and caregiver burden is vital for addressing this important issue in dementia care.

The current situation of the burden in Japan

Before and after the implementation of the LTCI system in Japan, caregiver burdens felt by informal caregivers have long been acknowledged. Compared with Western countries, a lower caregiver burden has been reported by caregivers in Japan, partly because of Japan’s over-reliance on institutions (26). However, the Japanese government stopped subsidizing high-cost care, such as nursing homes, after the revisions of the LTCI (27), which promoted an overall trend of shifting from institutional care to domiciliary care. This means that family caregivers must rely on community-based

services in the future, which can never resolve the caregiver burden as long as caregiving is necessary.

Under the LTCI, there are seven assessed levels of care need certification: support levels 1 and 2 and care need levels 1 (least disabled) to 5 (most disabled). The coverage of services provided within the insurance scheme differs by the certified level. The benefits encourage informal caregivers to mainly use in-home long-term care services. Direct rewards for family caregivers, such as cash, pension, and workers' compensation, are not available in Japan, although these are available in Germany and some other countries (28).

The LTCI system has thus turned family members entrusted with the burden of taking care of their dementia patients at home into primary caregivers. As already reported, these individuals will face many health risks and a reduced quality of life. Adequate support to help alleviate the burden of care should therefore be determined (15) by evaluating caregivers' stress in accordance with each level of long-term care certification in Japan.

Health and Financial Impact of Caregiving

Caregiver health

Most caregivers are spouses of dementia patients (2) and may therefore be in the same age range, which means that they may have health problems of their own to manage. As the symptoms related to dementia worsen, family caregivers may often have to cope with difficulties communicating with patients because of their loss of orientation, understanding, and adequate judgment (2). Difficulties coping with them may increase emotional stress, leading to a depressive mood. The stress of caregiving is likely to damage the health and well-being of caregivers, resulting in a reduction in the quality of sleep (29), an impaired immune function (30), and health problems such as coronary heart disease (31) and stroke (32). A recent meta-analysis of studies regarding the biological mechanism suggested that dementia caregivers were characterized by slight reductions in the immune function and elevated inflammatory marker levels (33). In addition, they were unable to spend much time maintaining their own health (34) due to the burden of having to care for patients with dementia. Some studies have reported that spousal caregivers are at an increased risk of all-cause mortality (35, 36), although a study of physiological changes caused by caregiving reported that there was no notable change in levels of inflammatory biomarkers among dementia caregivers, except for tumor necrosis factor- α receptor 1 (37). However, another study reported that caregiving tasks had a positive effect of keeping caregivers physically active. It was then suggested that, when comparing the difference in physical activity between caregivers and non-caregivers, activities performed during routine caregiving tasks should be taken into account (38).

In terms of depression and mental health, caregiving stress is considered to be associated with depression. Espe-

cially when dementia patients had depression, behavioral disturbances, and/or a low functional status, caregivers' increased depressive symptoms were associated with the risk of visiting an emergency room and hospitalization (39). Another previous study showed that spousal caregivers might experience cognitive decline and had a six-fold higher risk of developing dementia (40). In Japan, however, the prevalence of depression and anxiety was reported to be low among caregivers. One possible explanation for this reduced depression/anxiety prevalence is that Japanese families tend to subscribe to traditional values, including accepting the role of caregiving as an aspect of filial piety (26). As we mentioned in the section "*Burdens influenced by culture*", inherent cultural differences, such as religion, spirituality, and caregiving appraisals, might influence the mental health outcomes as well as the burdens.

Caregiver employment and finances

According to the 2018 Japan National Health and Wellness Survey, caregivers of dementia patients had a greater impairment in their work productivity due to having experienced depression and anxiety than non-caregivers (41). Their greater work impairment despite having no health problems was attributed to a greater number of reduced working hours due to their care responsibilities (12).

From a financial perspective, a survey conducted in the United States showed that dementia caregivers spend nearly 20% of their income on caregiving expense, including costs of medical care, personal care, and household expenses for the person with dementia, as well as personal expenses and respite services for the caregivers themselves (42). Furthermore, another study in Japan reported that caregivers' incomes decrease by 40-50% when they changed jobs owing to caring for the patient (43).

Caregivers' burdens, including related health problems, depleted caregivers' incomes and finances by disrupting employment and requiring paying for health care or other services for caregivers themselves as well as their dementia patients (2), thus making the caregivers no longer able to fulfill important roles in their households.

Coping Strategies

Of note, not all caregivers experience negative health outcomes from dementia caregiving, meaning that caregivers' coping strategies influence the consequence of the caregiver burden (44-47). Coping strategies are defined as specific behavioral and psychological efforts to mitigate and control stressful events that caregivers respond to in interaction with the environment when they try to handle external and internal demands that exceed their resources (48, 49).

Caregivers' coping strategies consist of three domains: 1) emotion-focused (i.e. to ameliorate depression symptoms, anxiety, stress, and burden using thoughts and indirect actions), 2) problem-focused (i.e. to alter or control them actively and constructively) (44-47), and 3) dysfunctional (i.e.

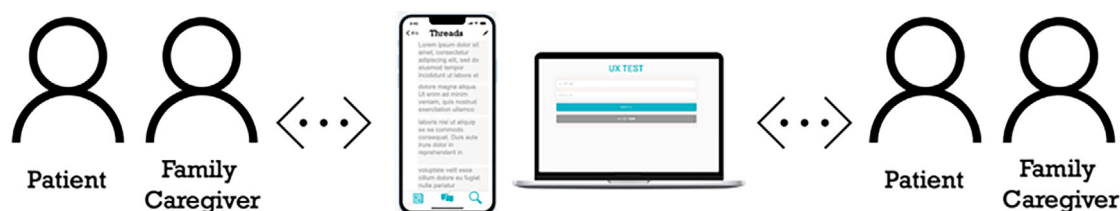


Figure. Design of web application system. Web application where dementia patients and their caregivers build a virtual social network by connecting with other patients and caregivers for communicating in a virtual, secure, private salon.

to relieve them by confrontation, escape, and avoidance) (46, 47). The problem-focused strategies were found to be effective when dealing with specific problems (44, 46), although there was no clear suggestion regarding which coping strategy was most effective for maintaining a healthy mental condition. Therefore, considering the varying effectiveness of different coping strategies, it seems important to select an adequate coping strategy against a specific stressor in a general stressful situation. It was reported that the most effective strategies were a combination of passive and active strategies (49). However, caregivers employing emotion-focused strategies, such as stoicism and wishful thinking, might tend not to look for help from others, in which case such caregivers are more likely to suffer from depression. Furthermore, dysfunctional strategies are considered harmful to the management of dementia patients (46).

In addition, self-efficacy may influence coping strategies (51). If caregivers have stronger self-efficacy and take time for themselves, their burden will decrease, and they may enjoy a greater quality of life (51, 52). Therefore, caregiver self-efficacy and coping strategies are important factors to consider in order to control the caregiver burden.

Interventions

Non-pharmacological interventions

Non-pharmacological interventions for caregivers should be attempted before pharmacological ones. Non-pharmacological interventions can be divided into two groups (53): (a) those aimed at reducing the objective amount of care provided by caregivers (i.e. respite) and (b) those aimed at improving the caregiver's well-being and coping skills (e.g. psychosocial and/or psychoeducational interventions). The approaches in group (b) are particularly important for delaying nursing home placement (2), resulting in reduced costs of long-term care.

Among the multifactorial interventions that have been found to be effective (54, 55), psychoeducational intervention is the most frequently used intervention for addressing caregivers' well-being, providing caregivers with information about their role and information on available resources (53, 56). This intervention, which focuses on the development of problem-focused coping strategies, includes

lectures, discussions, written materials, and accessing online resources, while psychosocial intervention addresses the development of emotion-focused coping strategies. Therefore, psychoeducational intervention may help caregivers prepare themselves to cope with problematic symptoms (i.e. BPSD) by understanding what they are and how to deal with them.

More studies will be required to define which interventions work for specific situations and how to capitalize on those interventions (2, 56, 57).

Online tools as interventions

Recent advances in information and communication technologies (ICTs) have enabled us to anonymously provide psychoeducation and support programs to caregivers online. Even in Asia, where the culture negatively influences the caregiver burden, previous reports have mentioned that participation in the social network can moderate the caregiver burden (58, 59) by allowing caregivers to obtain information about how to deal with dementia patients, how to cope with caregiving stress, etc. Not just exchanging information but also sharing an understanding of the burden of caregiving with others may help caregivers mitigate psychological distress (60), such as feeling like "I am the only one suffering." Given that some aspects of the caregiver burden may be alleviated, such online communication tools are desired, as they meet caregivers' demand for specific information or a communication opportunity during which they can share their feelings. These tools should prevent so-called "familism," meaning less delegation of caregiving responsibilities to outsourced caregivers (61, 62). In short, these tools are expected to enable and enhance communication with healthcare providers and other caregivers whenever important information needs to be shared in order to provide care for dementia patients, regardless of geographic distance (62). Studies from the United States and China have suggested that internet technology may succeed in reducing caregiver depression and the caregiver burden (63, 64).

Future directions

Caregiving for dementia patients has a negative impact on the psychological and physiologic health outcomes of caregivers. However, some caregivers may escape such negative outcomes by adopting adequate coping strategies against specific stressors under stressful situations. Such positive

coping strategies, increased levels of personal mastery, and self-efficacy seem to have a protective effect on health outcomes for caregivers of dementia patients (65).

Given most caregivers are family members and not professionals, it is important to teach them how to mitigate the impact of chronic stress on their health outcomes. Interventions including psychoeducation may not only prevent informal caregivers from becoming physically and/or mentally ill due to the stress of caregiving but may also delay institutionalization of the dementia patients, helping reduce the costs of long-term care (56).

Online communication is a candidate interventional tool for facilitating the interaction between healthcare professionals and/or other caregivers, regardless of geographic distance (62). By engaging in online virtual communities where caregivers of dementia patients can easily receive psychoeducation, they may continue providing care for their loved ones while maintaining their own psychological well-being. To this end, we are presently conducting research (registered as No. jRCT1042210111) utilizing a Web Application (Figure) to investigate whether or not involvement with a virtual online community can reduce the sense of caregiver burden (66).

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