

# Research Trends into Support for Families Coping with Dementia in Japan

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## Abstract

In Japan, there is a growing need for family support of elderly patients with dementia because the number of sufferers is expected to increase over coming years. We conducted a review of 92 studies into the support provided to the families of patients with dementia in Japan. They were reviewed by care setting, study focus, and study design. Most studies were in home settings, followed by hospital settings, with the fewest in long-term care facilities. A wide range and quality of studies were performed in home settings, including quantitative descriptive and interventional studies; however, qualitative descriptive studies and case studies predominated. We identified a need to perform additional studies to verify support programs at home. Concerning family support in hospitals, studies were mainly performed in relation to early diagnosis of dementia and early discharge from hospital, and we observed a clear need to investigate the development of new support programs. Finally, although the need for family support is estimated to be high in long-term care facilities, we found only a few studies investigating this issue. In particular, more studies are needed on the topic of end-of-life care. To offer support that meets the needs of families in various care settings, there is an urgent need to accumulate evidence about patients and their families in each setting.

**Keywords:** family nursing, dementia, family support, review

## 1. Introduction

### 1.1 *The Scale of the Problem Posed by Dementia*

The growth in the size of Japan's elderly population is much faster than that of any other country. In 1970, the elderly accounted for only 7.2% of the total population of Japan, but by 1994, this had almost doubled to 14.1%. Whereas this increase took only 24 years in Japan, comparison with other countries with large elderly populations show marked differences, with comparable increases taking 62 years in Italy, 85 years in Sweden, and 115 years in France. These clearly highlight the rapid progress of demographic aging in Japan. In 2014, there were 31.9 million elderly people in Japan, which accounted for 25.1% of the population (Soumushyoutoukeikyoku [Statistics Japan], 2014).

Against this backdrop, the prevalence of dementia is also increasing rapidly. In August 2012, the Health and Welfare Bureau for the Elderly (Japanese Ministry of Health, Labour and Welfare, 2012) published a report indicating that the estimated number of elderly persons with dementia could increase to as much as 4.70 million by 2025. If these trends hold true, the disease will then be present in about 13% of the elderly population, affecting more than one in ten elderly people (Kouseiroudousyou [Ministry of Health, Labour and Welfare], 2014)

### 1.2 *The Importance of Ensuring Proper Family Support*

Due to this increase in the number of people with dementia, there is an increasingly urgent need to develop and provide high-quality support, not only for patients with dementia but also for their families. In response to this problem, the Japanese government formulated a "Five-year Plan for Promotion of Measures against Dementia" (Ministry of Health, Labour and Welfare, 2014). Enhancement of support for the families of elderly people with dementia was included in this plan. A report from the Ministry of Health, Labor and Welfare (2010) indicated that approximately 1.4 million elderly people with dementia were living at home, 1.01 million were living in

long-term care facilities, and 0.38 million were living in medical institutions (Kouseiroudousyou [Ministry of Health, Labour and Welfare], 2014).

The problems of the families of patients with dementia are becoming better recognized, not only for those caring for patients at home but also for those caring for patients in long-term care facilities and medical institutions. These problems are distinct from those faced by the caregivers of elderly people without dementia, because dementia is also associated with memory loss and recognized behavioral and psychological symptoms, such as wandering and irritability. Therefore, families have unique dementia-specific problems that differ by care setting, and we must recognize these as differing needs when seeking to provide high-quality support for patients and families who are in the midst of dealing with dementia.

### 1.3 Aim

In this review, we aimed to obtain a general overview of the studies concerning support for the families of patients with dementia in Japan. We also planned to clarify the trends and issues raised by such studies, as stratified by care setting, study focus, and study design.

## 2. Method

### 2.1 Design

We conducted a literature review using the database of the Japan Medical Abstracts Society (ICHUSHI), and reviewed articles identified on support for the families of elderly people with dementia. The ICHUSHI database contains information about articles published in approximately 5000 medical, dental, pharmaceutical, nursing, and related periodicals in Japan.

### 2.2 Search Terms and Methods

A search was performed for original articles published from January in 2000 to December in 2016 using the key words “dementia” AND “family support” OR “family care.” All identified articles were reviewed manually. Those with content focusing on support for the families of patients with dementia were included in the final review. When analyzing the studies, we focused on three aspects: 1) the care setting, 2) the study focus, and 3) the study design.

## 3. Results

A total of 159 related studies were identified. Among these, 92 focused on support for the families of patients with dementia, and are summarized in Table 1. As shown in the table, 54 studies (59%) focused on home settings, 25 (27%) on medical institutions, and 13 (14%) on long-term care facilities. The studies under review conducted from 1998 to 2015.

Table 1. Identified studies by care setting and design

Study design	Home care setting	Medical setting	Long-term care setting
Qualitative descriptive study	19	8	8
Case study	15	10	1
Quantitative descriptive study	7	2	4
Interventional study	7	2	0
Correlational study	3	2	0
Questionnaire development	1	0	0
Literature review	2	1	0
Total	54	25	13

Description: this table summarizes the numbers of studies on support for the families of people with dementia in Japan by study design and care setting (N=92)

### *3.1 Research Design and Study Focus for Support in Home Care Settings*

Analysis of the research design of studies on home care revealed a wide range of studies. Although these included quantitative descriptive studies and interventional studies, most were qualitative descriptive studies or case studies.

The case studies tended to analyze single or multiple difficult cases by retrospective assessment of family support issues and it was shown that the family's lack of understanding of dementia leads to a negative response to elderly people with dementia, which has led to the deterioration of family relations; however, this relationship could be improved by the involvement of nursing (Tanaka, Akagi, Takushima, & Yamaguchi, 2007) (Iwaki, Tamekuni, Maekawa, & Sasaki, 2002).

The qualitative descriptive studies investigated various issues, which are clarified. Although the family caregivers try to rectify behaviors of elderly people with dementia that they cannot take their eyes off, that attempt worsens their relationship with the elderly, which in turn allows families to realize the sense of self-reproach and the pointlessness of their trial. Subsequently, it changes the family caregiver to allow the behavior of the elderly that does not cause inconvenience to other people (Watanabe & Watanabe, 2015) (Suzuki, Matsuda, & Sakurai, 2015). The Elderly Dementia Patient Family Association provides emotional support in relation to others and provides opportunities to the family caregiver to obtain information, but its significance depends on the caregiver's view of life (Omori, Kimura, Sano, Mine, & Matsumoto, 2007) (Matsumura & Kawagoe, 2001). Families continue long-term care while they reorganize the family livelihoods, thereby deepening their ties with the elderly and acquiring new learning (Tanaka, Fukuhara, Shimamoto, Takata, & Ikezoe, 2012) (Nishiyama, 2005). Male family caregivers find it difficult to deal with people with dementia, but they also feel anxious about housework, embarrassment to neighborhoods, social isolation, and their own health (Nagasawa, Yamamura, & Iwashimizu, 2015) (Matsumoto, Osono, & Morikawa, 2014). These have studies promoted a multifaceted understanding of the families of patients with dementia.

Quantitative descriptive studies show that the stress coping patterns of family caregivers of the elderly with dementia have features such as watching over, lowering the expectation value, and devising preventive measures (Nagai, 2011); male family caregivers have a high ability to cope with health problems and utilize social resources, but their relationship adjustment ability is low (Kawano, Hirano, Torii, & Hishiyama, 2008); the service provider related to the elderly with dementia collects the information about family as important information (Yamamura, Lee, & Kase, 2012).

In the interventional studies, the effects of different family support programs were verified. As a result, it was demonstrated that the support intervention program, which consists of providing knowledge on dementia, providing information about the care condition of the elderly in day care services, and exchanging information among family caregivers (Kamijou, Nakamura, Nto, & Ogihara, 2009), and the intervention program regarding structured stress management, including relaxation training (Hosaka & Sugiyama, 2003), could improve the caregivers' burden or the behavioral and psychological symptoms of dementia of the elderly.

In addition, there were several correlation studies that investigated the relationships between family caregivers' burdens and either family health-related quality of life (Fujiwara, Yamaguchi, Koike, Hirao & Kamijyou, 2010), family function (Fujiwara, Kamijyou, Komatsu, Edo, & Sukanuma, 2011), or the methods used for coping with the behavioral and psychological symptoms of dementia (Kusumoto, Yokokawa, Ikeda, Suzuki, & Kondou, 2007). These studies show that there is a relationship between family caregivers' burden and family function or their physical and mental health; the lower understanding of the family caregiver about how to cope with the patients' behavioral and psychological symptoms of dementia leads to a higher sense of the caregivers' burden .

### *3.2 Research Design and Study Focus for Support in Medical Care Settings*

In total, 18 of the 25 studies conducted at medical institutions were case studies or qualitative descriptive studies. The research tended to focus on the influence of early diagnosis of dementia on families (Ikehata et al., 2009), the status of families during hospitalization (Taniguchi, 2003) (Sugiyama, Yuasa, & Takahashi, 2009), the process of building trust with families (Maeshiro, 2010), the support offered during discharge (Hatada, 2011) (Ojima & Kimura, 2011), the support given to help families make surrogate treatment decisions (Ooki, Ogata, & Matsuo, 2015), and the difficulties faced by nurses when coping with families (Matsuo, 2011).

These studies demonstrate that nurses have difficulty when dealing with families that cannot understand the condition of patients with dementia during hospitalization (Matsuo, 2011), but the diagnosis of dementia and the behavioral and psychological symptoms of the elderly are unacceptable for family members, and it takes time to understand (Taniguchi, 2003) (Sugiyama, Yuasa, & Takahashi, 2009). While the care burden of family caregivers

is reduced during the hospitalization period, family members have a different sense of burden when deciding the place to live for the elderly after the discharge, complaints and anxiety about hospital care and treatment, anxiety about deterioration of the patient's physical symptoms, burden regarding visiting, and restraints accompanying hospitalization (Taniguchi, 2003) (Sugiyama, Yuasa, & Takahashi, 2009). When family members cannot understand the patients' behavioral and psychological symptoms of dementia, the relationships with the elderly tend to worsen, and it is important that nurses understand the feelings of the families and deepen their understanding of dementia (Maeshiro, 2010).

In addition, it is shown that in hospital discharge support, nurses understand that families are puzzled by the fact that their family member has developed dementia; have an attitude to wait and provide emotional support by listening to their story so that the families can take the care role; as well as provide the information about care techniques for the elderly persons with dementia, response to accidents, and utilization of social resources after discharge to their home (Ojima & Kimura, 2011). With such support, an elderly person with dementia could be able to be discharged to his/her home (Hatada, 2011).

Furthermore, when families cannot understand the characteristics of dementia and the course followed, it is difficult for the families to forecast the situation after choosing the treatment even in surrogate decision making in case of medical treatment, and the families suffer from anxiety (Ooki, Ogata, & Matsuo, 2015).

### *3.3 Research Design and Study Focus for Support in Long-term Care Settings*

Most of the 11 studies on family support in long-term care facilities were qualitative or quantitative descriptive studies, and they focused on end-of-life care. The needs of families engaged in such care (Kawakita, 2015) (Tanaka, Ishii, & Matsumoto, 2011) or the process of supporting decision-making (Futagami, Watanabe, & Chiba, 2010) were explored in several studies. As a result, it is clarified that families feel a deepened relationship with the elderly by being involved in terminal care, but through the process that leads to the death of elderly people with dementia, families also have stress during the care and have anxiety of whether surrogate decision making in medical practice accompanying life extension of the elderly reflects the intention of the elderly.

Investigations were also performed into the actual state of family support by facilities (Morioka, 2000), the level of satisfaction of the families with facilities (Nakajima, Nagata, & Hirabayashi, 2006), and the experience of families on admission of their elderly relatives to facilities (Kobayashi, 2004). These studies show that the duration of stay of elderly people with dementia at the institution is longer than that of those without dementia, and family support is insufficient. On the other hand, families have a high satisfaction level for living and services at facilities and have expectations for the elderly to be able to live their own life; however, there is still need for family support for the elderly as they go out. In addition, families have anxiety about the adaptation of the elderly to the life at the institution and guilt of placing the elderly in long-term care facilities.

## **4. Discussion**

This review indicates that there was a greater number of studies on support for the families of patients with dementia in home settings, and that the state of research was more advanced in this setting when compared with other care settings. According to studies in home settings, it is suggested that intervention so that families can better understand dementia is important because the lack of understanding of dementia results in the deterioration of family relations and quality of family care giving (Tanaka, Akagi, Takushima, & Yamaguchi, 2007) (Iwaki, Tamekuni, Maekawa, & Sasaki, 2002) (Watanabe & Watanabe, 2015) (Suzuki, Matsuda, & Sakurai, 2015). Although the research was primarily descriptive, some interventional studies had been performed to verify the effects of family support programs at home. In the studies on the effects of family support programs, various programs for reducing the burden of home care on caregivers were reviewed (Kamijou, Nakamura, Nto, & Ogihara, 2009) (Hosaka & Sugiyama, 2003). However, these programs are still under development, so additional verification will be needed in the future to develop more effective programs. Overall, there was clear evidence that research has focused on the burden of home care on families, but that some findings should be verified in the future.

As for studies in hospital settings, there were only a few studies, and these studies tended to focus on the socially important topics of support for early diagnosis and discharge. Indeed, these reflect the health policies promoted in Japan; equally, the focus on research into care at home reflects the focus on developing medical services to support living in local communities. Those studies indicated that even in the case of early diagnosis and discharge support, dementia and its behavioral and psychological symptoms of the elderly are unacceptable for the families (Taniguchi, 2003) (Sugiyama, Yuasa, & Takahashi, 2009) (Ojima & Kimura, 2011); therefore, emotional support is important for the families. Unfortunately, however, much of the research on these important topics was in the form of case studies or qualitative descriptive studies, and it has therefore been limited to

describing the phenomena. In the future, it will be necessary to perform studies using more robust research designs to assess the status of support and to develop support methods for families coping with early diagnosis and early discharge from hospital.

We must remember that many elderly people with dementia are also admitted to long-term care facilities. One of the studies in this care setting shows that families have anxiety about the adaptation of the elderly to life at the institution and guilt of placing the elderly in long-term care facilities (Kobayashi, 2004). Because family care for these elderly patients does not cease with admission (Woods, Keady, & Seddon, 2008), there may be a missed need to support the families of patients at these facilities. However, the smallest number of studies in this review focused on family support in long-term care facilities. Moving forward, it will be necessary to perform more studies in long-term care facilities, starting with descriptive studies that provide accurate quantitative and qualitative assessment of the present status. In these long-term care settings, research attention has often focused only on the needs and difficulties of families engaged in end-of-life care, consistent with the increased prevalence of elderly patients with dementia with a high dependence on medical care. Further studies on this particularly important subject are needed.

In conclusion, in this review, we found that family acceptance of the fact that elderly people (their family members) develop dementia and support of the elderly people based on the understandings of characteristics of dementia are important not only for the elderly but also for family relations. In addition, it is important to reduce the burden of family care giving. Therefore, it was suggested that there is a need for nursing intervention to provide knowledge on dementia and emotional support to families. The development of support programs for families and its verification are underway in the home care setting. However, if we are to offer support that meets the needs of the families of patients with dementia in different care settings, there is an urgent need to accumulate evidence using robust study designs in each setting.

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