

Support Provided to Dementia Patients by Caregivers and the Community

JMAJ 54(5): 301–304, 2011

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Abstract

Japan is currently experiencing an unprecedented aging of society and decline in the birth rate. According to the White Paper published by the Ministry of Health, Labour and Welfare, the number of dementia patients in Japan is estimated to reach 2.5 million by 2015, and so community understanding and response to dementia are expected to become increasingly important.

Depending on the cause, the symptoms of, drug therapies for, and responses to dementia differ, and so first of all it is necessary to know diagnostic information that leads to treatment policies. With regard to the epidemiology of dementia, we present a study conducted in Nakayama Town in Ehime Prefecture. Furthermore, it is possible to divide the symptoms of dementia into core symptoms and peripheral symptoms such as behavioral and psychological symptoms of dementia. With core symptoms, it is important that the characteristics of the symptoms and prognosis be sufficiently explained using images and tests of cognitive function. With peripheral symptoms, the burden of care on caregivers is even greater than that with core symptoms. Here we present a brief overview of delirium, hallucinations, delusions, agitation/aggression, apathy/indifference, roaming, stereotypy, and eating abnormalities. In future, it is envisaged that the involvement of not only health professionals but also members of the community as a whole in dementia care will be extremely important.

Key words Dementia, Core symptom, Behavioral and psychological symptoms of dementia (BPSD), Community

Introduction

As the aging of Japanese society progresses, the number of dementia patients is increasing. According to the 2009 White Paper published by the Ministry of Health, Labour and Welfare, the number of elderly people in Japan requiring some form of nursing care or support and having dementia is estimated to increase to 2.5 million by 2015 and 3.23 million by 2025. Accordingly, further measures for treating dementia need to be prepared and primary care physicians also require an understanding of medical care for dementia patients.

Interest in dementia by society as a whole is increasing, with dementia-related issues being reported in the media virtually every day and even becoming the subject of films. However, in the everyday treatment of dementia, it is not uncommon to see situation in which it appears that dementia is thought to equal Alzheimer's disease (AD). Accordingly, it is vital to promote better understanding and response to dementia amongst the general public.

Epidemiology of Dementia

First of all, because in dementia treatment meth-

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This article is a revised English version of a paper originally published in the Journal of the Japan Medical Association (Vol.139, No.10, 2011, pages 2149–2151).

ods and responses differ depending on the cause of the condition, it is necessary to know that the causes of dementia are diverse.

Here, in regard to the epidemiology of dementia, we present a study conducted by our research laboratory in Nakayama Town in Ehime Prefecture. The Nakayama Town Study is an epidemiological survey conducted in Nakayama Town in Iyo County (now Iyo City), Ehime Prefecture, beginning in 1997.¹ The study took the form of an inventory survey targeting the community-dwelling all 1,438 elderly aged 65 years and older. In phase I, the elderly residents were surveyed directly following education activities by specialists in geriatric psychiatry; in phase II, a family medical history was taken in addition to neurological examinations and psychological symptom evaluations. Subjects deemed to have dementia or suspected of having dementia based on the results of phase II underwent head CT scans and blood tests as phase III. As a result of this testing, 60 subjects (4.8%) were diagnosed with dementia, 21 subjects with AD, 28 subjects with vascular dementia (VaD), 1 subjects with both AD and VaD, 3 subjects with normal pressure hydrocephalus, 2 subjects with frontotemporal lobar degeneration (FTLD) (Pick's disease, etc.), and 1 subjects with dementia with Lewy bodies (DLB). From these results we found that AD and VaD each comprised approximately 40% of all dementia patients, together comprising approximately 80% of all dementia cases.

This study was performed in 1997, but due to the remarkable advances in treatments for hypertension and other conditions that have been achieved in recent years, it is anticipated that today the proportion of AD cases is increasing.

Core Symptoms and Peripheral Symptoms (Behavioral and Psychological Symptoms of Dementia)

Dementia symptoms can be divided into “core symptoms”—such as impaired memory, disorientation, and aphasia—and “peripheral symptoms”—such as delusions and roaming. In recent years, peripheral symptoms have come to be referred to as Behavioral and Psychological Symptoms of Dementia (BPSD). Here we provide an outline of responses to each symptom.

Response to core symptoms of dementia

In AD, impairment of episodic memory and disorientation can be observed from the early stages of their diseases; as the disease progresses, visuospatial agnosia begins to appear, and the final stages of the disease are accompanied by personality changes and aphasia. Caregivers often say that the patient “remembers people and events from the past really well, but cannot remember recent events.” In contrast, in VaD the symptoms vary depending on the area of the vascular lesion, and the disease may not be recognized in some cases as the degree of memory impairment is mild. With the core symptoms of dementia, it is important to convey to caregivers the results of imaging examinations and tests of cognitive function while also adequately explaining the characteristics of the causative disease and the prognosis.

Response to BPSD

BPSD place an even greater care burden on caregivers than core symptoms and are factors that lead to early admission to nursing facilities. For this reason, it is imperative that BPSD be explained to caregivers at the onset.

Delirium (disturbance of consciousness)

Delirium is a state in which mild impaired awareness overlap with behavioral anomalies. Patients often see a doctor because their caregivers have “suddenly begun to forget things” and their language and/or behavior have become “strange.” Symptoms include impaired attention, disorientation, visual hallucinations (mainly at night), and somnolence during the day. Delirium can easily be caused by physical diseases such as infectious disease and dehydration, and attention must be paid to the fact that it can be activated in some cases by drugs such as benzodiazepines, H2 receptor antagonists, and antiparkinsonian agents. In addition to treating the physical disease and ceasing administration of the causative drug, caregivers should be instructed to keep the patient awake during the day to maintain the sleep-wake rhythm. Although delirium itself is not dementia, patients frequently mistake it for dementia when they go to the doctor for an examination.

Delusions

The delusion that most commonly accompanies dementia is the “delusion of theft” that occurs in AD. Suffering from impairment of episodic memory, the patient forgets where they put

something important, then claim, for example, that their “daughter-in-law stole it.” In many cases, patients claim that their purses/wallets or bank passbooks have been stolen. Since in such cases it is common for the primary caregiver to be the object of the delusion, this condition is one factor that can wreck home nursing. It is possible to lighten the burden on caregivers by explaining to them the possibility of the “delusion of theft” appearing from the very early stages of dementia, when the delusions have not yet appeared. Furthermore, caregivers should also be told that searching for a lost item together can diminish the delusion in the case that the patient tells the caregiver that “something has gone missing.” If the burden on the caregiver is not lightened through these measures, the patient can be administered a small dose of an atypical antipsychotic drug.²

Hallucinations

In DLB—the next most common dementia after AD and VaD—patients frequently experience recurrent visual hallucinations. The condition is characterized by the ability of patients to explain their visions in detail: “A dead relative was sitting in the wardrobe”; “A child was sitting under the chair”; “There was something white, like a snake, wriggling on the tatami matting.” Caregivers should of course be provided with explanations of the main symptoms of the disease, but in many cases drug therapy is required and cholinesterase inhibitor, such as donepezil, is a remarkably effective treatment.³ Moreover, in the case of hallucinations observed in delirium, the patient often does not remember the hallucination, and so this is an important point of differentiation.

Agitation/aggression

Agitation/aggression is a symptom of all forms of dementia, such as AD and VaD. In the case of agitation/aggression caused by the delusions and/or hallucinations discussed above, priority is given to treatment of the causative psychological symptoms. In the case that the patient becomes excitable in certain situations, such as when someone points out their mistakes to them in daily life, the symptom can be alleviated by gathering information through meticulous observation and making every effort to avoid triggering situations. In some cases, use of social resources such as daycare services and short stays is recommended in order to establish an environment and relieve the burden on the caregiver.

Apathy/indifference

Because apathy/indifference do not strongly affect the care burden on caregivers, these symptoms are often overlooked. However, if these symptoms continue over a prolonged period, they may activate impaired awareness or trigger disuse syndrome, greatly affecting the quality of life of the patient, and therefore they require close attention. Use of day services and other services to increase the patient’s daytime activity can be expected to alleviate these symptoms.

Roaming

Roaming is a symptom that is common in AD from the intermediate stage of the disease onwards. Because of the large burden placed in caregivers, this symptom can easily become a factor that wrecks home nursing care. Two causes of roaming are thought to be the effects of locational disorientation and visuospatial agnosia. In particular, nighttime roaming can easily occur due to diminishing of the visual information received by the patient, increasing the care burden on caregivers. In many cases, this symptom can be alleviated by increasing the patient’s daytime activity through the use of day services, encouraging sufficient natural sleep during the night. In some cases, use of short stays of several days to one week duration can also be effective.

In the case that daytime roaming is conspicuous, the caregiver should be advised to accompany the patient while roaming if possible and guide them back home after an appropriate time has passed. Recently use of mobile telephone with GPS functions has become widespread, and the use of such mobile telephones can also be recommended as a means of avoiding dangers while the patient is roaming.

Stereotypy

Stereotypy is a distinguishing symptom of FTLD. In this case, the patient lives each day in a fixed rhythm, preferring certain meals and repeating the same conversations and actions. Stereotypy itself does not directly affect increases in the care burden of caregivers, but in the case that the stereotypy is restrained by others around the patient, agitation and violent behaviors can easily appear. In such cases, it is desirable to create an environment in which the stereotypy is recognized but unrestrained. Although the patient intends no harm, at times socially problematic stereotypy may appear, such as the patient sometimes taking (stealing) the same product at the

same store. In such cases, routinization therapy to help the patient acquire another stereotypy appropriate for him/her—conducted short-term as in-patient treatment at a specialist hospital—is effective.⁴

Eating abnormalities

In DLB, disturbed eating behavior caused by dysphagia due to parkinsonian syndrome can occur from the early stages of the disease onwards, and is also a symptom of VaD. Because dysphagia is a symptom that is directly linked to life prognosis as it can lead to such conditions as aspiration pneumonitis and asphyxia, it is vital that the caregiver be asked about the presence of this symptom at the onset of treatment. In the case that the symptom is present, it is important that the patient undergo swallowing training with a speech therapist and food menu guidance with a nutritionist as part of their treatment.

In FTLD, eating abnormalities such as changes in food preferences and allotriophagy occur. These symptoms can be treated effectively through environmental coordination and the above-mentioned routinization therapy.

Community Support

Training for specialist physicians is provided by the Japanese Psychogeriatric Society (<http://www.rounen.org/>) (in Japanese) and the Japan Society for Dementia Research (<http://dementia.umin.jp/>) (in Japanese), which have their specialty in dementia. Moreover, the National Caravan Mate Federation (<http://www.caravanmate.com/>) (in Japanese) provides training for “Caravan Mates” who act as “Dementia Supporter Training Course” instructors through in collaboration with local government agencies, national professional organizations, business groups, and other organizations. As of March 31, 2010, there were more than 1.7 million dementia supporters nationwide, and education activities currently are being carried out with a target of 4 million dementia supporters.

Concluding Remarks

In this paper we have provided an overview of the epidemiology of dementia, ways of treating to core symptom and BPSD, and community support. Today, with the number of dementia patients expected to increase, it is important that not only health professionals but also the community residents become involved in the treatment of dementia.

References

1. Ikeda M, Hokoshi K, Maki N, et al. Increased prevalence of vascular dementia in Japan: a community-based epidemiological study. *Neurology*. 2001;57:839–844.
2. Shigenobu K, Ikeda M, Fukuhara R, Komori K, Tanabe H. A structured, open trial of risperidone therapy for delusions of theft in Alzheimer disease. *Am J Geriatr Psychiatry*. 2003;11:256–257.
3. Mori T, Ikeda M, Fukuhara R, Nestor PJ, Tanabe H. Correlation of visual hallucinations with occipital rCBF changes by donepezil in DLB. *Neurology*. 2006;66:935–937.
4. Tanabe H, Ikeda M, Komori K. Behavioral symptomatology and care of patients with frontotemporal lobe degeneration—based on the aspects of the phylogenetic and ontogenetic processes. *Dement Geriatr Cogn Disord*. 1999;10 (Suppl 1):50–54.