Factors Decreasing Caregiver Burden to Allow Patients with Cerebrovascular Disease to Continue in Long-term Home Care

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Background: This study attempted to assess continued long-term home care by examining patients' independent activities of daily living (ADLs) and caregivers' free time. *Methods:* We surveyed the main caregivers of 52 patients with cerebrovascular disease with continuous home care from 1999 to 2010. Survey items were patients' ADLs, the frequency of use of care services, care requirements, and caregiver sense of burden. We compared the survey results between years. *Results:* ADLs of excretory control, verbal expression, verbal comprehension, and range of activities showed significant deterioration from 1999 to 2010. Patient need for care increased significantly but use of care services did not. Main caregivers were typically spouses who aged together with the patients. Main caregivers rarely changed; occasionally, a son or daughter-in-law became the main caregiver. Patients typically required less than 3 hours of care daily, which did not change over time. Caregivers had significantly more difficulty maintaining their own health in 2010 than 1999. However, they did not identify increases in difficulties with housework or coping with work. They felt that caregiving was a burden but did not indicate that the family relationship had deteriorated. *Conclusions:* Regardless of degree of independence of patients' ADLs, caregiver burden was severe. To decrease caregiver burden, it is necessary to use care services, reduce care time, and allow caregivers free time. In addition, it is possible to continue long-term home care by maintaining their relationships. **Key Words:** Caregiver burden—cerebrovascular disease—home care.

Introduction

Populations in countries such as Japan, the United States, and Europe are aging rapidly, and it is becoming a serious problem.[1] In Japan, the long-term care insurance system was introduced in 2000 to support elderly people's independent living and to reduce their caregivers' burdens. As a result, home care services and number of patients living at home have increased.

The city of Tokyo held a "Tokyo Home Care Promotion Meeting" in October 2010, highlighting problems and future directions in promoting more home care.[2] Movements to promote home care have been developed by various local governments and Tokyo. However, various problems can occur with care in the family environment, such as the declining birthrate, trend toward smaller family size, elderly care by elderly persons, and increases in amount of care time.[3] In addition, problems with patients can occur with home care, such as the prolongation of their care periods by medical improvements[3] and decreases in terminal severity of patients' disabilities.

In these situations, it is useful to examine the current conditions of home care from the perspectives of both the patients and caregivers. This enables evaluation of

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the social resources needed for current and future aging society. The importance of promoting home care is obvious, but the factors that support continuous home care are not clear. The caregiver burden seems to be severe. Therefore, we examined 2 possible factors that could affect continued long-term home care: caregivers' free time and degree of independence in patient's activities of daily living (ADLs). One objective of this study was to determine changes in caregivers' senses of burden over the long term (>10 years). We also examined the factors that support continuous long-term care by analyzing changes in survey contents between 1999 and 2010.

Materials and Methods

Subjects

Subjects were 436 patients with acute stroke consecutively admitted to the Department of Neurology at the Kitasato University Hospital between 1993 and 1997. In 1999, surveys were mailed to 406 patients (30 patients had been admitted more than once or had died). The survey was completed by the main caregiver, and 294 completed responses were obtained.[4] We surveyed these 294 individuals again in 2010. Of those, 99 were eliminated (because of unknown address or death). Surveys were mailed to 195 patients, and responses were obtained from 86 (response rate of 44.1%). Of these, 52 provided complete responses; these patients and main caregivers were the final sample (Fig 1).

Methods

The postal survey was addressed to the patients. The request to the patients and an inner envelope for caregivers were placed in the outer envelope. The request explained the purpose of our study to the patients. If they agreed, they gave the inner envelope to caregivers. The inner envelope contained a request, a study manual, and a self-addressed envelope. If they agreed, the caregiver completed the survey. The study manual indicated that reply (rather than signature) constituted informed consent.

The 1999 survey comprised 6 pages. It was developed from questionnaires of Japan's Ministry of Health, Labour, and Welfare cardiovascular disease–sponsored research[5] and physical exercise guidelines.[6] We modified the 1999 survey by changing "public service" to "care

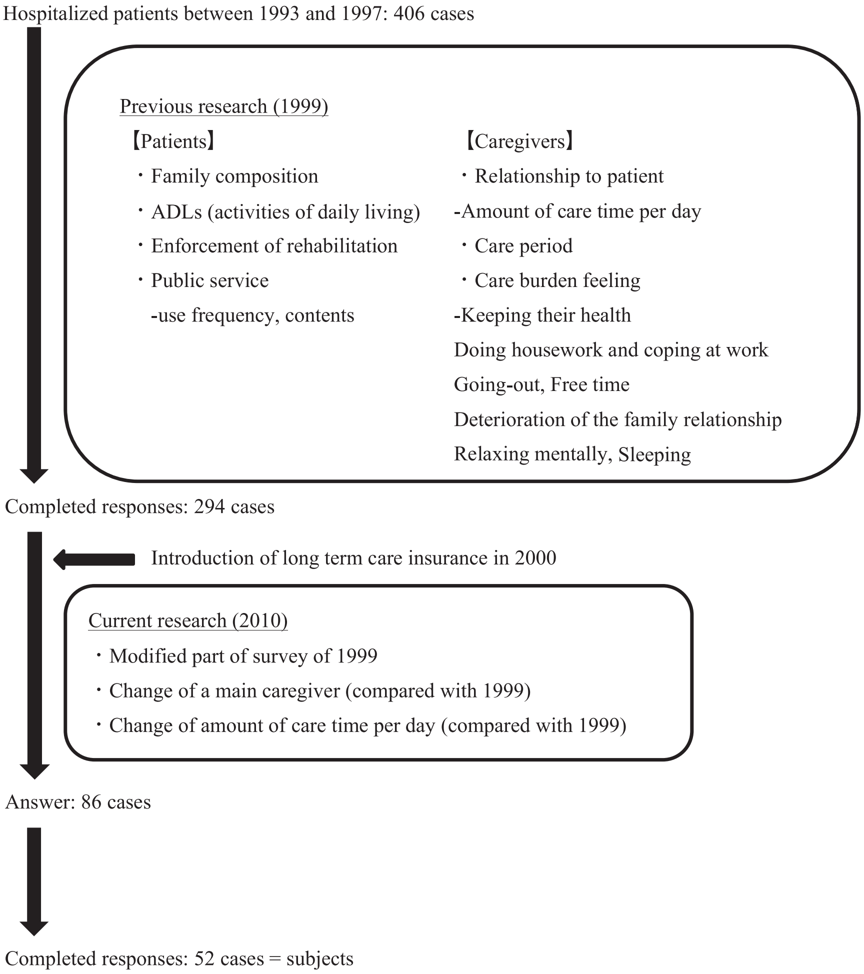

Figure 1. *We surveyed ADL and care situations in 1999 and obtained 294 completed responses from the patients' main caregivers. Then, long-term care insurance was introduced in 2000. We surveyed these 294 cases again in 2010 and obtained 86 answers. Of these, 52 cases were completed responses used for this study. Abbreviation: ADL, activity of daily living.*