

Survey of caregiver burden in families of adults with higher brain dysfunction

Toru Takekawa, Shu Watanabe, Masahiro Abo

Department of Rehabilitation Medicine, The Jikei University School of Medicine

Abstract

Background & Objective: The recovery of patients with higher brain dysfunction depends on the extent of brain injury, clinical management, and follow-up rehabilitation, as well as care given by family members. Based on a questionnaire, the present study was designed to assess and analyze the factors that affect the caregiver burden in families providing support for individuals with higher brain dysfunction. **Methods:** We conducted a questionnaire survey of families caring for 964 patients with higher brain dysfunction. The caregiver burden was evaluated by the short version of the Zarit Caregiver Burden scale (J-ZBI_8), we analyzed the correlation of J-ZBI_8 with patients' cognitive behavioral disorders (4-point Likert scale), activities of daily living (ADL, Barthel index, BI), social interaction and employment status. **Results:** The study included 964 patients (776 males), with age at injury of 34.5±17.4 (0-85) years (mean±SD), current age 47.1±14.1 (19-89) years, and time from injury of 12.6±9.2 (0-60) years. The main causative conditions were cerebrovascular accidents and brain trauma. The survey indicated that 866 (89.8%) of the patients lived with somebody, of whom 377 (43.5%) lived with their spouses. The BI was 86.9±21.9 (0-100), with scores 85 points or more in 727 cases (75.4%). The J-ZBI_8 correlated with presence of behavioral disorders, unemployment and social isolation.

Conclusions: Our results suggested that the burden on family members who provide care to individuals with higher brain dysfunction can be reduced by clinical management of cognitive behavioral disorders, securing employment for the affected individuals and enhancement of community interaction.

Keywords: Brain injury, chronic, caregivers, cognitive dysfunction, family nursing, neurobehavioral manifestations, rehabilitation, return to work, social participation, stroke, surveys and questionnaires

INTRODUCTION

Higher brain dysfunction is often caused by cerebrovascular accidents and trauma and often exhibits symptoms of attention deficits, executive dysfunction, memory problems, and neurobehavioral problems.¹ Japan's effort to support people with higher brain dysfunction began in 1996 when the Diet first addressed issues related to acquired intellectual disabilities associated with various conditions, including brain trauma and hypoxic encephalopathy in young people. The 1996 opinion statement was formulated to overcome the problem of young people who could not obtain any legal remedy because of mild physical disability even though they are suffering from severe emotional and behavioral disorders. Along with persistent lobbying by patients and family

groups; in 2001, the Japanese Ministry of Health, Labor and Welfare established various higher brain dysfunction support initiatives, selected 10 institutions in Japan as model hospitals (facilities) for supporting people with higher brain dysfunction, and started a fact-finding survey on higher brain dysfunction, evaluation methods, community support, and research on employment support. This was followed in April 2004 by the establishment of standard diagnostic criteria of "higher brain dysfunction" and the inclusion of this clinical entity in the Government-supported Medicare system. Furthermore, in 2006, following the implementation of the Act on Support for the Independence of Persons with Disabilities, a project that provides life support and publicity for subjects with higher brain dysfunction was established by various prefectures. Thus, the

Address correspondence to: Toru Takekawa, MD, PhD, Department of Rehabilitation Medicine, The Jikei University School of Medicine, 3-25-8 Nishi-Shimbashi Minato-ku, Tokyo 105-8461, Japan. Tel: +81-3-3433-1111, Email: bamboo@apricot.ocn.ne.jp

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last 25 years have been a significant increased recognition of “higher brain dysfunction” in Japan and emergence from the institutional “ice age”.

With regard to the actual life of people with higher brain dysfunction, the burden on the families who care for individuals with higher brain dysfunction became more apparent, and it was felt that the time had come to modify the system created over the last 25 years. Specifically, memory problems, attention deficits, executive dysfunction, and especially neurobehavioral problems were found to have a strong impact on the care burden of persons with higher brain dysfunction.² Thus, neurobehavioral problems, such as decreased spontaneity, depressive symptoms, and easy anger, are considered among the major factors that inhibit social reintegration, resulting in increased mental burden on the families.¹ It is also reported that the discrepancy in recognition of higher brain dysfunction between the person with higher brain dysfunction and the family caregivers increases the burden on the caregivers.^{3,4} Thus, in Japan, there was recent increased awareness of the burden on family members caring for persons with higher brain dysfunction.^{2,5}

How have other countries dealt with this problem? In many western countries, support for families who care for persons with higher brain dysfunction is provided by the Governments and also by family associations, such as the Headway - the brain injury association⁶ in the UK, the Brain Injury Association of America (BIAA)⁷ in the US, and the Hjärnskadeförbundet Hjärnkraft⁸ in Sweden. Several studies have also been published on the burden of traumatic brain injury on the caregivers.⁴ To the best of our knowledge, there are no studies involving a large number of people with higher brain dysfunction. The present study was designed to evaluate the burden on Japanese families caring for persons with higher brain dysfunction using a modified questionnaire.⁹

METHODS

The study subjects were families caring for 964 patients aged 19 years or older with higher brain dysfunction. The participating families were members of the Brain Injury Association of Japan and the Tokyo Metropolitan Council for Higher brain Dysfunction, who agreed in writing to participate in this study. The questionnaire-based survey was conducted between February and September 2018. Families were excluded from the study if (i) the person with higher brain

dysfunction was younger than 18 years of age at the time of the study, (ii) none of the family members provided support for the person with higher brain dysfunction, regardless of whether the person lived with the family or not, and (iii) the family refused consent to the questionnaire.

Based on the results of previous studies⁹, the estimated effect size (d) was 0.25, required total sample size was 874, with a power of test (1- β) of 0.95 and significance level (α) at 0.05. With an estimated loss to follow-up of 10%, 971 participants were considered the required study population.

Questionnaire and analysis

The survey questionnaire included the cause, severity, characteristics, living conditions of people with higher brain dysfunction, nursing care burden, response of medical, health, welfare and administrative professionals from the acute stage to the daily life stage, and recommendations regarding Japan's support system for persons with higher brain dysfunction. The survey questions also sought information on the severity of the disease, current living conditions, working conditions, cognitive behavioral disorders, activities of daily living (ADL), and caregiving burden. The ADL were evaluated using the Barthel Index (rating on a scale of 0 to 100, high scores reflected independence).^{10,11}

Even for persons with higher brain dysfunction who lived alone, the family members watching over him/her had a nursing care burden. Therefore, in this study, the caregiver burden was examined even in families where the affected person lived alone. The caregiver burden was evaluated using the short version of the Zarit Caregiver Burden (0 to 32 points; with high points reflecting heavier caregiver burden).¹²⁻¹⁴

For the individuals with higher brain dysfunction, we examined 7 items for the assessment of cognitive-behavioral disorders: 1) forgetfulness, 2) impatience/anger, 3) loss of concentration/distraction, 4) difficulty in achieving planned behavior, 5) loss of spontaneity and motivation, 6) interpersonal problems, and 7) lack of awareness of one's disability. These were evaluated in four grades using a 4-point Likert scale (0 point: no problems, to 3 points: severe problems in ADL).

The correlation of Zarit caregiver burden with cognitive behavioral disorder (4-point Likert scale) and ability to perform ADL (Barthel index) was examined statistically.

For the employment group, sheltered employment group, and non-employment group, statistical analysis was undertaken on the Zarit Caregiver Burden. We defined employment as community-based work without external support, sheltered employment as community-based work with temporary or permanent support (e.g., job coach), or work in a sheltered workshop if the person was unable to find work in the general business sector, and non-employment as unemployed. Furthermore, the nursing care burden was examined statistically by dividing it into a high-frequency outing group, which included care supporters who went out 4 days or more a week, and a low-frequency outing group who went out 3 days or less a week.

Statistical analysis

The G*Power 3.1.9.7 was used to determine the sample size. Spearman's rank correlation coefficient was used to correlate cognitive behavioral disorders (4-point Likert scale) with Zarit caregiver burden; Spearman's rank correlation coefficient was used to correlate Barthel index with Zarit caregiver burden. The Kruskal-Wallis test was used to compare the Zarit Caregiver Burden Scale among the three employment groups. The unpaired T test was used to compare the Zarit Caregiver Burden between the high and low frequency groups in terms of frequency of outings. The χ^2 test was used to compare the percentage of cohabitation between the two outing groups. All data are expressed as mean \pm SD. A *p* value <0.05 denoted the presence of a statistically significant difference. All analyses were performed using the SPSS statistics software (ver. 26, IBM Japan, Tokyo, Japan).

RESULTS

Subjects characteristics

All 964 family members (776 men and 188 women) caring for persons with higher brain dysfunction returned the questionnaires (100% response rate). The high response rate was probably related to the fact that the questionnaires were distributed only to families who were certain to respond. Table 1 summarizes the demographics of the patients. The mean age at onset was 34.5 \pm 17.4 (range: 0-85) years, the current mean age was 47.1 \pm 14.1 (range: 19-89) years, and the mean time from onset/injury was 12.6 \pm 9.2 (range: 0-60) years.

Higher brain dysfunction was caused by cerebrovascular accidents (n=292), brain trauma

(n=511), hypoxic encephalopathy (n=69), brain tumors (n=44), encephalopathy/encephalitis (n=36) or others (n=12).

The severity of the disease was judged by disturbance of consciousness at the time of onset. At the time of onset, patients who presented in coma or did not open their eyes in response to verbal stimuli included 139 of 292 cases (47.6%) with cerebrovascular disorders, 445 of 511 cases (87.1%) with brain trauma, 68 of 69 cases (98.6%) with hypoxic encephalopathy, and 20 of 36 cases (55.6%) with encephalopathy or encephalitis.

Of the total cases, 866 (89.8%) lived with another person, including 377 cases (43.5%) lived with their spouse. At the time of writing this report, 849 cases (88.1%) regularly visit medical institutions, including 37.3% to neurosurgery, 23.7% to psychiatry, and 38.7% to rehabilitation.

Caregiver burden

The Barthel Index (BI) was 86.9, and 727 (75.4%) had a BI of 85 points or high (i.e., independent living). The mean nursing care burden scale value was 12.3 points, with a scale of \geq 13 points in 424 cases (44.0%), which is considered to reflect tendency for depression.¹⁵

Table 2 summarizes the correlation coefficients between cognitive behavioral disorders (4-point Likert scale) and the Zarit Caregiver Burden. All items correlated with the caregiver burden. In other words, the more severe the cognitive behavioral disorder, the greater the caregiver burden among the supporting family members.

On the other hand, there was a significant but weak negative correlation ($r=-0.283$, $p<0.001$) between the BI and the Zarit Caregiver Burden. In other words, the greater the need for assistance with ADL, the greater the caregiver burden among the supporting family members.

With regard to employment, 223 cases were currently employed among the employment group, 254 cases among the sheltered employment group, and 455 cases among the non-employment group. Comparison of the Zarit Caregiver Burden scale according to employment showed a significant difference in the caregiver burden between the three groups ($p<0.001$, Table 3). Multiple comparisons identified significant differences in caregiver burden among the groups: between the employment and sheltered employment groups ($p=0.002$), the sheltered and non-employment groups ($p=0.009$), and the employment and non-employment groups ($p<0.001$).

With regard to the caregiver burden according

Table 1: Demographics of the participants

Gender	
male	776 (80.5%)
female	188 (19.5%)
Age at onset (years)	34.5±17.4 (0-85)
Age at time of questionnaire (years)	47.1±14.1 (19-89)
Time since onset/injury (years)	12.6±9.2 (0-60)
Causative condition/found in coma at onset or did not open eyes to verbal calls	
cerebrovascular disease	292/139 (47.6%)
cerebral infarction	89
cerebral hemorrhage	77
subarachnoid hemorrhage	89
cerebral arteriovenous malformation	28
moyamoya disease	8
uncertain	1
brain trauma	511/445 (87.1%)
hypoxic encephalopathy	69/68 (98.6%)
brain tumor	44
encephalopathy / encephalitis	36/20 (55.6%)
others	12
Individuals living with someone else	866 (89.8%)
individuals living with spouse	377 (43.5%)
individuals living with mother	505 (58.3%)
Individuals living alone	91 (9.4%)
uncertain	7 (0.7%)
Individuals visiting medical institutions	849 (88.1%)
Neurosurgery	37.3%
Neurology	12.0%
Psychiatry	23.7%
Internal Medicine	10.3%
Rehabilitation Medicine	38.7%
Barthel index (BI)	86.9±21.9 (0-100)
BI ≥85 points	727 (75.4%)
Zarit Caregiver Burden	12.3±8.2
Zarit Caregiver Burden >13 points	424 (44.0%)
Employment status	
competitive employment	223 (23.1%)
sheltered employment	254 (26.3%)
non-employment	455 (47.2%)
on leave/others	32 (3.3%)
Frequency of going out	
high-frequency outing group	745 (77.3%)
low-frequency outing group	215 (22.3%)
uncertain	4 (0.4%)
Consciousness disturbance	
consciousness disturbance for >4 days	649 (67.3%)
consciousness disturbance for <3 days	307 (31.8%)
uncertain	8 (0.8%)

Data are mean±SD, number of subjects (%) or range

to the frequency of outings, the mean Zarit Caregiver Burden was 11.5±8.0 for the high-frequency outing group (n=745) who went out ≥4 days/week, which was significantly less than that for the low-frequency outing group (n=215), who

went out ≤3 days/week (15.3±8.1, $p<0.001$). On the other hand, the cohabitation rate showed no significant difference ($p=0.944$; 90.6% vs 90.4%) between the groups.

Table 2: Correlation between cognitive behavioral disorders and the Zarit Caregiver Burden

		Correlation coefficient	p
1	Forgetfulness	0.371	<0.001
2	Impatience, anger	0.481	<0.001
3	Loss of concentration, distraction*	0.476	<0.001
4	Difficulty to achieve planned action	0.489	<0.001
5	Decreased spontaneity and motivation	0.474	<0.001
6	Interpersonal problems*	0.495	<0.001
7	Lack of awareness of own disability*	0.538	<0.001
	All items	0.621	<0.001

DISCUSSION

The majority of patients with higher brain dysfunction are males.¹⁶ In this survey, males accounted for 80%. Therefore, if the affected person is married, the wife is the primary caregiver. In comparison to cerebrovascular disorders, the most common age of patients with brain trauma ranged from 16 to 20 years. For such patients, the parents, especially mothers, were the main caregivers. In fact, the answers to this questionnaire survey were provided overwhelmingly by the mothers especially those of individuals with brain trauma. Of the 964 cases, 866 (89.8%) lived with the caregiver, and 377 (43.5%) lived with their spouses. In other words, 90% of patients with higher brain dysfunction lived with the caregiver, and about 60% of the caregivers were mothers while 40% were wives.

The BI is a standardized measure of ADL and is widely used globally.^{10,11} A BI score of 0-100 points is used, with high scores indicating greater independence in ADL. In general, BI score ≥ 85 is defined as a good index of functional ability in ADL.¹⁷ In this study, the BI score was ≥ 85 in 75% of the subjects, though in general, individuals with higher brain dysfunction can perform ADL independently.

The family caregiver burden was evaluated using the short version of the Zarit Caregiver Burden scale. The shortened version of the

Japanese Zarit Caregiver Burden scale (J-ZBI_8), which was used in this study, is reliable and has been validated¹²⁻¹⁴, and had been created to further simplify the Japanese version (J-ZBI)¹⁸ of the Zarit Caregiver Burden scale¹⁹, which is the most widely used nursing care burden scale in Europe and the United States. Our results, which were analyzed according to a previous study¹⁵ that highlighted the tendency of caregivers to depression when the score is ≥ 13 (out of 32 points), showed a J-ZBI_8 score of ≥ 13 points in 424 (44.0%) caregivers. These results suggest that not only the caregiver's mental, but also physical health could be affected. Our results also showed a positive correlation between the caregiver burden felt by parents and other family members, and cognitive behavioral disorders. In this regard, psychiatric symptoms, such as irritability, interpersonal problems, decreased spontaneity, and decreased awareness of one's disability seen in patients with higher brain dysfunction are the result of damage to the frontal and temporal lobes. The patient-related factors that are often identified as burdensome by the caregivers of brain trauma patients are (1) violent disposition, (2) selfishness, (3) aggression, (4) anxiety, (5) lack of leisure, (6) easy fatigue, (7) slow movement, and (8) forgetfulness.²⁰ Other studies also included behavioral disorders and emotional/personality disorders^{21,22}, and personality changes (disinhibition, withdrawal,

Table 3: Zarit Caregiver Burden by employment status

	n (%)	Zarit Caregiver Burden (points)
Employment group	223 (23.1)	9.6 \pm 7.5
Sheltered employment group	254 (26.3)	12.1 \pm 8.1
Non-employment group	455 (47.2)	14.0 \pm 8.2

lack of spontaneity).²³ It can be said that from the viewpoint of being a burden on the caregivers, these emotional problems are serious brain trauma-related complications. The fact that 34.0% of the subjects in our survey visited a psychiatry clinic more than 10 years after the trauma suggests that their psychiatric symptoms are long-lasting.

Our study also showed that employment status affected the caregiver burden. The burden was lower for patients of the employment group than the non-employment group, whereas the burden for the sheltered employment group ranked high than the employment group but lower than the non-employment group. Similarly, the frequency of going out also affected the caregiver burden. The burden was significantly lower when patients could go out and mix with the society at large, compared with those who went out infrequently. In this regard, one study investigated the caregiver burden over time in 80 families of brain trauma patients and found 30% of families reported increased burden from one to two years after the trauma, and stated that social isolation had a significant effect on this increase in caregiver burden.²⁴ Brain trauma patients and their families are vulnerable to social isolation. In particular, severe cases suffer various problems for the rest of their lives, and thus the medical profession needs to build a relationship of trust with the patients and their families, and provide long-term support. In this context, Sander²⁵ described the best approach to the family, which included: (1) medical education on traumatic injury by professionals, (2) mental support: a. Peer support (support by other brain trauma patients and official support by organizations for persons with disabilities) b. Support by professionals, and (3) psychotherapy (e.g., individual therapy, group therapy, cognitive behavior therapy). In addition, Moriarty *et al.*²⁶ divided 63 brain trauma patients at random into a group that received a home-based program (6 home visits by occupational therapists and 2 telephone consultations over 3-4 months), and a group that did not. Their results showed significantly smaller scales of depression and caregiver burden in the former group. The positive effects of medical education and mental support by professionals on caregiver burden were also confirmed in other studies.^{27,28}

The present study has several limitations. The study was limited to families registered with two family associations for persons with higher brain dysfunction and who support persons with disabilities who attended medical institutions. The study did not include people with higher brain

dysfunction who did not attend hospitals and received no medical care. In addition, because the study was based on a questionnaire survey directed at family members who provided support to their relatives, it is not possible to completely eliminate the subjectivity of the respondents from the content of their answers. In addition, the reliability of the respondents' answers about the condition of the disabled person at the time of the onset of the disorder may be diminished because they relied on their past memories. Nevertheless, our study has highlighted some factors associated with burden of caring for persons with higher brain dysfunction by family members. We believe that this study could provide background information for enhancement of social resources to support people with higher brain dysfunction, the establishment of further cooperation between clinical care and the community, and the creation of a social mechanism for this purpose.

In conclusion, our study showed that higher brain dysfunction (e.g., memory impairment, irritability, attention impairment, executive dysfunction, emotional control, decreased spontaneity, interpersonal relationship disorder, and decreased awareness of one's own disability) in patients with brain trauma and cerebrovascular accidents, rather than their physical disability, is the most important factor affecting the caregiver burden. In particular, irritability, emotional control, and interpersonal problems increase the mental burden of nursing care. Our study also identified social participation status of persons with higher brain dysfunction as a factor with an important impact on the caregiver burden. We stress the need to familiarize the patients and caregivers with the social resources of the area where they live and promote social interaction. It is necessary to increase social resources that provide support to individuals with higher brain dysfunction and build further cooperation between medical care and the community.

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