Epidemiological Survey of Vegetative State Patients in Tohoku District in Japan

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Summary

An epidemiological study of vegetative state patients (abbreviated as VSP) in the Tohoku district was carried out. The prevalence rate of VSP in this area is estimated to be 2 to 3 per 100,000 population. From this figure, a rough estimate of the total VSP population in Japan of some 2,000 to 3,000 may be reasonably obtained. The causative illness leading to vegetative state was most frequently cerebrovascular disorder (notably hypertensive intracerebral hemorrhage and cerebral infarction) which accounts for 58% of all VSP. Another 24% are accounted for by head injury. As to the age group, the largest proportion (25%) of entire VSP are in their sixties.

These VSP are in quite miserable condition economically as well as psychologically and they are badly in need of financial support from administrative authorities. Emphasis, therefore, must be placed on the necessity of providing for both medical expenses and very high nursing fees being charged by round-the-clock attendants, so that the patients' families can be aided from going into financial ruin.

Purpose of this Survey

VSP and their family members are mostly in the depth of misery, both materially and mentally,

and they are in dire need of financial help. However, before any effective economical support program can be translated into action, it seems to be necessary to grasp a correct picture of the actual state of such individuals. This

prompted the authors to make an epidemiological survey of VSP in the Tohoku district.

Methods

1) *Subjects of survey:* Among VSP, those who met six requirements promulgated by the Japan Neurosurgical Society, had been in this deplorable state for more than 3 months and who had been leading a useful life before falling into that state were taken as subjects for the study (Table 1).

2) *Survey areas and process of collecting case material:* This survey was carried out over the 6 prefectures in the Tohoku district (namely, Aomori, Akita, Iwate, Miyagi, Yamagata and Fukushima) and Niigata Prefecture. These 7 prefectures have a total population of 11,630,000 and 759 hospitals. The population and the number of hospitals in each prefecture are listed in Table 2.

Currently, in all of the 6 prefectures in the Tohoku region, VSP are receiving financial aid from prefectural authorities. In Aomori, Akita,

Iwate and Fukushima Prefectures, VSP are given support for medicare expenses only, while in Miyagi and Yamagata Prefectures both medicare expenses and attendant nursing fees are compensated by prefectural authorities. VSP are requested to apply for official help and to be registered on the panel before they are able to receive financial support. In the present survey, registered VSP were contacted by a questionnaire in 4 prefectures, i.e. Aomori, Akita, Iwate and Miyagi. In Yamagata, Fukushima and Niigata Prefectures, a questionnaire was sent to all the hospitals, asking for responses. Valid responses were obtained from 87% of VSP in Yamagata Prefecture, 87% in Fukushima Prefecture, and 65% in Niigata Prefecture, or an average of 78%.

Items of investigation were patient's age and sex, the duration of vegetative state, the mechanism of brain damage (cerebrovascular disorder, head injury, brain tumor, intracranial inflammation, poisoning, and others), economical conditions of patient's family and the actual status of financial support in each prefecture.

Table 1 Definition of the vegetative state patient

The vegetative state patient is defined as one who has sustained brain damage while living a useful life and subsequently has fallen in a state characterized by the undermentioned 6 features and who has since been in that state for more than full 3 months without showing any substantial improvement in response to therapy.

1. Unable to move by himself.
2. Able to vocalize but unable to make any meaningful speech.
3. Can barely respond to such a simple order as "open your eyes", "squeeze my hand", etc. but no further communication is possible.
4. Eyes can follow an object but cannot recognize it.
5. Unable to take a meal by himself.
6. Be in a state of rectal and urinary incontinence.

Table 2 Survey area

Prefecture	Total population of each prefecture	No. of hospitals	No. of VSP	Prevalence rate per 100,000
Aomori	1,470,000	109	11	0.75
Akita	1,230,000	75	21	1.71
Iwate	1,390,000	93	14	1.01
Miyagi	1,960,000	141	50	2.55
Yamagata	1,220,000	60	29	2.38
Fukushima	1,970,000	137	51	2.59
Niigata	2,390,000	123	43	1.80
Total	11,630,000	759	219	1.88

Prevalence day: Dec. 31, 1975.

Results

1) *Prevalence rate* As shown in Table 2, the prevalence rate of vegetative state patients in a population of 100,000 was estimated to be 0.76 for Aomori Prefecture, 1.71 for Akita Prefecture, 1.01 for Iwate Prefecture, 2.55 for Miyagi Prefecture, 2.38 for Yamagata Prefecture, 2.59 for Fukushima Prefecture and 1.80 for Niigata Prefecture, or an overall prevalence rate of 1.88. To be noted is the fact that values for Miyagi Prefecture (wherein a thoroughgoing survey had been made) and 3 other prefectures, i.e. Yamagata, Fukushima and Niigata Prefectures (where responses to questionnaire were received from all the hospitals), were in good agreement with each other (being around 2.5) except for 1.80 for Niigata Prefecture. The reason for low prevalence rates reported in Aomori, Akita and Iwate Prefectures could be due to the fact that in these prefectures only medicare expenses are compensated and, accordingly, among patients who are exempt from medicare expense (patients aged over 70, those admitted as handicapped and those covered by various health insurance programs), there might be some dropout cases since they do not receive any further benefit by registration.

From the foregoing it seems justifiable to assume that the prevalence rate for the entire Tohoku region might be approximately 2 to 3, meaning that there are 2 to 3 VSP in every 100,000 persons in this area. When estimated from these figures (although such an inference

is of questionable validity), there are roughly 2,000 to 3,000 VSP among Japan's total population of some 100 million.

2) *Causative illnesses* Table 3 lists causative illnesses for the entire VSP investigated. As can be seen, cerebrovascular disorders accounted for 128 (58%) of the entire 219 cases; head injury accounted for 53 cases (24%) and brain tumor 12 (6%). Hypertensive intracerebral hemorrhage and cerebral infarction were relatively more frequent among cerebrovascular disorders. Of 53 cases of head injury, 41 (77%) were due to traffic accidents.

3) *Age distribution* Table 4 gives age distributions in the entire series as well as in individual disease categories. Of the entire cases, the largest proportion of 62 cases (28%) were in their 60's, 37 cases (17%) were in their 70's, and 36 others (16%) were in their 50's. Of cases of cerebrovascular disorder, 70% were above 60 years, while 66% of those of head injury were in the age ranging from 20 to 60 years.

4) *Duration of vegetative state* The duration of vegetative state in this series was less than one year in 30% of cases, 1 to 3 years in 50%, and more than 4 years in 19% (Table 5).

5) *Economical condition of VSP families* Those replied as being financially secure were 19% of the entire series and 67% replied as in very poor state and 11% replied that they are on the verge of being financially bankrupt.

6) *Actual status of financial aid in each prefecture (Table 6)* In Aomori, Iwate and Fukushima Prefectures, so-called "self-bearing" medicare expenses excluding those covered by various

Table 3 Causative illness

	No. of cases	%
Cerebrovascular disorders	128	58
Subarachnoid hemorrhage	(8)	
Aneurysm	(23)	
Hypertensive intracerebral hemorrhage	(46)	
Cerebral infarction	(47)	
AVM and others	(4)	
Head injury	53	24
Traffic accident	(41)	
Other accident	(12)	
Brain tumor	12	6
Intracranial inflammation	8	4
Intoxication	2	1
Others	16	7

Table 4 Age distribution by causative illness (head injury and CVD)

Age group	Head injury	CVD	Total
0-9	2		2
10-19	7	1	8
20-29	11		11
30-39	9	4	13
40-49	7	11	18
50-59	8	22	30
60-69	5	50	55
70-79	3	34	37
80<	1	6	7
	53	128	181

CVD: Cerebrovascular disorders.

Table 5 Duration of VSP

Duration	3-6M	7-11M	1Y~	2Y~	3Y~	4Y~	5Y~	Unknown	Total
Number of cases	40	24	53	31	27	18	25	1	219
Percent	18%	12%	24%	14%	12%	8%	11%		
	30%		50%			19%			
	54%								

Table 6 Actual status of financial aid to VSP in each prefecture (1975)

	Medicare expenses	Attendant's nursing fees	Diaper costs
Aomori	+	—	—
Akita	+	—	¥4,000/month
Iwate	+	—	—
Miyagi	+	¥2,300/day	¥350/day
Yamagata	+	¥3,500/day	¥350/day
Fukushima	+	—	—
Niigata	—	—	—

health insurance programs are compensated by prefectural authorities. In Akita Prefecture, in addition to the above arrangement, a monthly payment of ¥4,000 as diaper costs is made. In Yamagata and Miyagi Prefectures, in addition to giving support for medicare expenses, prefectural authorities are making a daily payment for attendant's fees (¥3,500 in Yamagata and ¥2,300 in Miyagi) as well as ¥350/day as diaper costs. In Niigata Prefecture, no such support is given as of today.

Discussion

The incidence of VSP in Tohoku districts is

estimated to be 2 to 3 in every 100,000 population. This regional estimate cannot, of course, be used in the estimation of prevalence rate of VSP throughout Japan since cerebrovascular disorder is known to be more frequent in the Tohoku region than in the other districts and also since there are differences between the Tohoku area and the rest of Japan in terms of traffic and industrial situations as well as in the density of medical institutions. When, nevertheless, roughly estimated from the above figure, there are 2,000 to 3,000 VSP in Japan, assuming that the nation's total population is 100 million. Higashi *et al.*^{1,2)} reported in their survey that there were 2.8 VSP in every 100,000 population

in Yamaguchi Prefecture in 1973. Suzuki and Kodama^{5,6)} obtained a figure of 2.25 per population of 100,000, while a similar value was reported by Kitamura et al.³⁾ (1975) in their survey of the Kyushu district. Higashi et al.^{1,2)} (1973) and Suzuki and Kodama^{4,5)} (1972) found VSP to occur most frequently from head injury. In contrast, the results of our survey (1975) and Kitamura's (1975) indicate that more than half of VSP are accounted for by cerebrovascular disorder, which is by far the most likely cause of vegetative state. This might be explained by the fact that there has been a marked decrease in the number of cases of head injury due to traffic accidents in the most recent years and also that intensive surgical treatment has recently been undertaken for cerebrovascular disorders, permitting otherwise mortal patients to keep alive, including some in a vegetative state.

Age distribution of VSP showed a peak frequency at ages in the 60's. This is apparently related to the high incidence of cerebrovascular disorder in this age group. It is to be noted, however, that VSP caused by head injury ranged widely in age but mostly were in the working age group of 20 to 50 years.

According to our survey, the duration of a vegetative state was most frequently less than 2 years (54%). Clinical experience tells that many of VSP die within 2 years of onset but those who have survived this critical period tend to live long. The results of our survey might be in keeping with these experiences.

Speaking of how financial aid should be given to VSP, we must realize that VSP's families are in an extremely miserable state, economically and materially, and administrative financial help is very much desired. However, economic assistance alone is not good enough and we feel it is an absolute must to provide for support of attendant's nursing fees. This is due to the fact that by our country's medicare system, complete attendance of such serious patients by nurses only is very difficult if not impossible, so round-

the-clock attendants will be necessary. Fees charged by such attendants are rather expensive and, when families cannot afford this fee, they must take turns to replace attendants. Being away from home to attend to VSP result in family collapse in many instances. To cope with this situation it is considered necessary to compensate even partially costs for hiring professional attendants.

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ERRATUM

"Proceedings of the XXXIV Annual Meeting" in p. 107, Vol. 17, Part I, No. 1 should read "Proceedings of the XXXV Annual Meeting." The editors express their sincere apologies for the oversight.