

Survey on the Medical Care and Daily Life of Patients 'Intractable Diseases' in Shimane Prefecture

(intractable diseases/medical care/daily life)

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An interview survey on the medical care and daily life of 128 patients of 'intractable diseases' in Shimane Prefecture was carried out in 1977. Seventy-one (55.4%) of the patients regarded the medical care in various institutions as quite satisfactory. Ninety-three patients (72.7%) went to hospital as out-patients. Concerning the difficulties of their daily life, 42.7% could lead an ordinary life, but more than half had some hindrance. Of the latter group only 15.6% were in-patients, and 84.4% were out-patients. Long-term medical care and more attentive guidance by expert physicians and public health nurses is urgently required for these out-patients.

In recent years an increasing social attention has been given to various intractable diseases. Since 1972 government began to take measures for the diseases, e. g. assistance at public cost to the extra-expenses of medical fees on the health insurance list for a number of the diseases specially defined and promotion of fundamental as well as clinical research. Each patient, to say nothing of his economic burden, is living with an inexpressible pain and difficulty.

Thanks to the progress of medical science, it is now possible to prolong the lives of even very ill patients, and the number of those facing a long-term struggle is on the increase. In addition to medical care nursing and individual attention, the psychological care of patients is also important. In Japan, there are few studies related to health guidance and considerations of the daily life of the patient and family.

The present conditions and problems related to medical care in cases of intractable diseases have been reported by Murase *et al.* (1, 2), and there is a detailed report (3) on everyday life of the patients.

We report the results of survey on the diseases in Shimane Prefecture and discuss herein the medical care and actual condition of the daily life of these patients.

MATERIALS AND METHODS

This survey was conducted on 128 patients with Becht's Disease, Systemic

Abbreviations used : BD, Bechet's Disease ; SLE, Systemic Lupus Erythematoses ; SMON, Subacute Myelo-Optico-Neuropathy ; AA, Aplastic Anemia ; UC, Ulcerative Colitis ; PSS, Progressive Systemic Sclerosis ; DM, Dermatomyositis ; PMM, Primary Multiple Myositis.

Lupus Erythematoses, Subacute Myelo-Optico-Neuropathy, Aplastic Anemia, Ulcerative Colitis, Progressive Systemic Sclerosis, Dermatomyositis, and Primary Multiple Myositis, and their families in Shimane Prefecture. The symptoms and situations at the initiation of the disease, history of treatment, course of the disease, and the present status of medical care were the main subjects of investigation.

The Survey was done by interview with the prefixed questionnaire and the interview was conducted by public health nurses at each health center from the beginning of February to the end of March, 1977.

RESULTS

As regards the locality of the cases, Ohda Health Center showed the highest rate, while Masuda Health Center, the lowest (Table I). Numbers of males and females were much the same in cases of Aplastic Anemia, but in other diseases, the number of women was double (Table II). The period of time from the first visit until a definite diagnosis was less than 6 months in 70 % of cases, except for 53.3 % in SLE (Table III). There were a few cases where over ten years elapsed before the final diagnosis. Ninety-three (72.7 %) of the patients were out-patients of their respective medical institution (Table IV). For patients, the doctors made house calls. Twenty per cent of the out-patients walked to the hospital, or came by bus or car. Seventy-one (55.4 %) of the patients stated that the present medical service was satisfactory (Table V).

Eighty-two of the 128 patients had some difficulty in their daily life. The difficulty varied according to the kind of the disease, the state of medical treatment, and the degree of progress (Table VI-1). Several items of their daily lives are shown in Table VI-2 to VI-6. The hindrances at meal-time

TABLE I. *The Number of Patients in Each Health Center* in Shimane Prefecture*

	BD	SLE	SMON	AA	UC	PSS, DM, PMM	Total
Matsue	3	11	8	3	3	6	34
Nogi	3	5				1	9
Mitoya	2	5		6	4	1	18
Izumo	2	11	2	1	2	5	23
Ohda	2	4	2	4	3		15
Kawamoto	2		1		1		4
Hamada		4	7	1			12
Masuda		2	2	3	1		8
Saigo		3					3
Kuroki		2					2
Total	14	47	22	18	14	13	128

* Population of district covered by each health center (1976).

Matsue 183,824 Nogi 48,586 Mitoya 79,376 Izumo 158,807
 Ohda 48,791 Kawamoto 37,416 Hamada 71,976 Masuda 80,699
 Saigo 19,680 Kuroki 9,460

TABLE II. *Sex and Ages of Patients in Shimane Prefecture*

Age (yr)	BD		SLE		SMON		AA		UC		PSS, DM, PMM		Total	
	m*	f**	m	f	m	f	m	f	m	f	m	f	m	f
0-5									1				1	1
6-10			1				1	1					1	2
11-15			1	2			3			1			4	3
16-20				3			1	1		1			1	5
21-25	1		2					1	1				1	4
26-30	1	2	6				1		2		1		3	10
31-35	2	1	9						1		3		3	13
36-40	1	1	2		1					1			1	5
41-45		2	3		1									6
46-50		2	1	5	2	3		1			1		3	12
51-55		1	4		3		3		3		3			17
56-60	1		1	3	1		1		1		2		4	7
61-65			2	1	3	1	1				1	2	3	8
66-70	1				6		1		1				1	8
71-					1		1							2
Total	5	9	5	42	3	19	8	10	4	10	1	12	26	102

* male ** female

TABLE III. *Period from the First Visit of Patients to a Definite Diagnosis*

Period (yr)	BD	SLE	SMON	AA	UC	PSS, DM, PMM	Total (%)
-1	9	30	17	15	12	8	91 (71.1)
1-	2	4	1		1	1	9 (7.0)
2-		3	1	2			6 (4.6)
3-	1	4			1		6 (4.6)
4-			1			1	2 (1.6)
5-		2	1			2	5 (3.9)
6-	1						1 (0.8)
7-		1		1			2 (1.6)
8-		1					1 (0.8)
9-	1	1				1	3 (2.3)
10-		1	1				2 (1.6)
Total	14	47	22	18	14	13	128 (100)

were characteristically few. The commonest actions in daily life, such as standing-up, standing from sitting and squatting, the duration of squatting, turning over in bed, wringing out a towel, tying of a shoe lace, picking and clutching, putting on one's stockings were classified in to three grades as 'easy', 'not easy', and 'impossible'. As a result, extreme difficulty was seen in cases of SLE, SMON and PMM. Personal care was required in 32% of all these patients (Table VII).

TABLE IV. *State of Medical Care Afforded to Patients at Institutions*

	BD	SLE	SMON	AA	UC	PSS, DM, PMM	Total
In-patients	2	8	3	3	2	2	20
Out-patients	11	34	14	14	10	10	93
Doctors' visits			2		1		3
Suspension of medical care	1	2				1	4
Unknown cases		3	3	1	1		8
Total	14	47	22	18	14	13	128

TABLE V. *Reasons for Dissatisfaction with Present Medical Care**

	BD	SLE	SMON	AA	UC	PSS, DM, PMM	Total
No medical expert available	1	3	1		2		7
Medical institution too far from home	2	6	1	4	3		16
Poor facilities		2	1				3
No improvement in health	2	2	5	2	1	1	13
Other reasons		3		1		1	5
Total	5	16	8	7	6	2	44

* Seventy-one patients expressed no dissatisfaction.

TABLE VI-1. *Hindrances in Daily Life**

	BD	SLE	SMON	AA	UC	PSS, DM, PMM	Total
Can enjoy ordinary home life	2	9	9	7	2	6	35
Needs a certain period of rest cure	4	6	5	4	2	4	25
Can lead home life with some help	2	1	3			1	7
Almost always confined to bed	1	3	5	2	2	2	15
Total	9	19	22	13	6	13	82

* Forty-six patients felt no hindrance.

TABLE VI-2. *Hindrances in Walking**

	BD	SLE	SMON	AA	UC	PSS, DM, PMM	Total
With the help of a cane			8	1	1	1	11
With the help of handrail		4	3	1		1	9
Cannot walk	1	1	4	1	1		8
Other cases	2	5	5	1		7	20
Unknown cases		1		1		1	3
Total	3	11	20	5	2	10	51

* Seventy-six patients felt no hindrance.

TABLE VI-3. *Use of Toilet Facilities**

	BD	SLE	SMON	AA	UC	PSS, DM, PMM	Total
Difficulty with evacuation	1	7	10		2	7	27
Feasible with assistance		1	1	1			3
Incapable of using toilet facilities	1	1	3	1	2		8
Unknown cases					1		1
Total	2	9	14	2	5	7	39

* Eighty-six patients felt no hindrance.

TABLE VI-4. *Use of Bath Facilities**

	BD	SLE	SMON	AA	UC	PSS, DM, PMM	Total
Impossible alone	1	1	1	2	1		6
Feasible with help		4	5	1		4	14
Other cases	1		4	1	2	5	13
Unknown cases		3	1				4
Total	2	8	11	4	3	9	37

* Eighty-eight patients felt no hindrance.

TABLE VI-5. *Dressing and Undressing**

	BD	SLE	SMON	AA	UC	PSS, DM, PMM	Total
Impossible	1	1	1	1	1		5
Feasible with help	1	2	3			6	12
Other cases		4	4	1	1	1	11
Unknown cases		1				2	3
Total	2	8	8	2	2	9	31

* Ninety-five patients felt no inconvenience.

TABLE VI-6. *At Mealtime*

	BD	SLE	SMON	AA	UC	PSS, DM, PMM	Total
No great hindrance	13	44	19	17	13	9	115
Can feed self fairly well		2	3			4	9
Impossible	1	1			1		3
Total	14	47	22	17	14	13	127

TABLE VII. *Need of Personal Care**

	BD	SLE	SMON	AA	UC	PSS, DM, PMM	Total
Total care	1	2	3	2	1	1	10
Some care	2	7	6	1	2	8	26
Unknown cases			2	1	1	1	5
Total	3	9	11	4	4	10	41

* Eighty-six patients needed no personal attention.

TABLE VIII. *Sectors of Health Guidance*

	BD	SLE	SMON	AA	UC	PSS, DM, PMM	Total
Physician	7	36	15	13	10	9	90
Public health nurse		4		1		1	6
Nurse	1	11	1	2			15
Other cases		2	1		1	2	6
Total	8	53	17	16	11	12	117

Forty-four of 128 patients asked for financial help. One hundred and seventeen patients (91.4 %) had access to some kind of health guidance (Table VIII), and the advisors were medical doctors in almost all cases. Eighty-seven (68.1 %) of the patients thought their housing condition was adequate.

DISCUSSION

Medical care and the actual state of the patients' daily life were clarified to some extent. Many patients with intractable diseases are left alone in their homes with no hope of rehabilitation. Direct and adequate governmental aid is insufficient. The family worries about the bleak prognosis, economic factors, all the while being burdened with the care of nursing those people. Murase *et al.* point out the defects in the present system as concerned with general practitioners in the field of 'intractable diseases': emergency medical aid, guidance and aid for home nursing and the health care of each member of the family, systematization of the local accommodation, and the appeal to the authorities in order to solidify the health and welfare system. Our findings also testify to the enforced number of out-patients due to the lack and capacity of special medical institutions and to the lack of adequate financial assistance. Some patients have lost faith in the benefits of medical treatment, as treatment has been ineffective.

On the basis of these investigations, the proper distribution and improvement of medical institutions and betterment of medical must be hastened. A large majority (84.4 %) of the intractable cases in the survey were out-patients, thus indicating the need of health guidance in the home. The present system of guidance is inadequate and the co-operation of welfare officials and public health nurses should be elicited. It is not yet established as their customary duty for public health nurses to make rounds of their 'intractable' patients' homes, and therefore the improvement of their medical knowledge and nursing skill ought to be promoted. This survey also reveals a large number (57.3 %) of personal hindrances, therefore, visiting and health guidance by public health nurses is one of the important measures to be taken.

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