＜報　告＞

A Governmental Attitude toward Releasing Information to the Public on Providing Prostheses — A Pilot Study to Survey the Nation Wide Status on Supplying Prostheses —

Shigeru TANAKA*

Key Words : Local government attitude, Domenstic survey, Prosthesis

1. Introduction

From the view point of a research and development of the prostheses, it is a must to get information of the reality in provision of the prosthesis. A Special Interest Committee on Surveying Amputees and Prostheses (SICSAP) organized in Japanese Society of Prosthetics and Orthotics (JSPO) has had a focus on this object. The author has been in charge of the committee as a chairman.

In the first step of this project we discussed what is the best way to get the related information. After several SICSAP meetings we conducted a survey of all local governments regarding available information for a future study. In this article I will demonstrate the obtained data from the survey. The result may give some idea on Japanese governmental attitude toward releasing information to the public, specifically on providing prostheses.

2. Information currently available

From the year 1951, nationwide surveys of physically disabled people aged 18 years and over have been conducted every 5 years except 1975 in Japan[1]. The most recent survey was conducted in 1992.

We can find the data obtained from those surveys in some official publications which is titled "Physically Disabled Persons in Japan (written only in Japanese language)[2]". In the book, however, only glossary data are available. Even on the most precise data, the number of handicapped persons in terms of sex, age, and whether amputated extremity is upper or lower limb can be available. According to the November 1991 survey, it is estimated that there are 1,553,000 persons of 18 year of age or over who are physically disabled in trunk and extremity. In Table-1 the most recent data of the survey performed in 1992 is presented.

Table 1　The total number of persons with the impairment in trunks and extremities

Sort of impairment	Numbers
Upper-extremity amputee	111,000
Upper-extremity malfunction	395,000
Lower-extremity amputee	57,000
Lower-extremity malfunction	525,000
Trunk malfunction	182,000

(obtained from the 1991 survey)

The other possible sources to get information is from some researches submitted in the related jounals. There are international and domestic jounals. In the researches TECHO is usually used as a source of data[3]. TECHO literally means a small note book or it is Physically Disabled Person's Certificate (here, TECHO will be used.). The persons with amputation usually get TECHO. Therefore, if we can survey registered contents of TECHO, we are able to know detailed information such as the precise loction of the amputation, sort of prosthesis or orthosis, cause of amputation, etc..

3. Methods

Based on the SICSAP discussions and informa-

Department : *Department of Occupational Therapy, School of Health Science, International University of Health and Welfare.

Received : March 30, 1996.

tion source currently available, we decided to survey whether TECHO data is accessible for us. TECHO is regulated by local (prefectural and special ward) governments. There are total of 58 local governments including 47 prefectural and 11 special ward governments (at the time of following questionnaire was sent). We prepared a set of questionnaires and sent to the all local governments mentioned above. In order to make the questionnaires easy to ask, whole questions were put in an A 4 type paper. The questionnaires were sent by mail on June 20, 1994 and had collected by August 15, 1994.

3.1 Questionnaire

The questionnaire had 6 sorts of questions. The main questions contained following lines ;

Q 1 : Does your office have computerized data storage system.

Q 2 : What media does your office use to keep handicapped persons' records ?

Q 3 : Can your office accept a future survey to get any information about amputees ?

Q 4 : What kind of conditions does your office need if you can accept a future survey ?

4. Results

4.1 The rate of valid answers

We could obtain 51 answers out of 58 sites which are 44 prefectural and 7 special ward governments. Therefore, the rate of valid answers was 87.9%. This rate was higher than we had expected.

4.2 The answers

(1) Q 1 About computerization (Computerization)

1) Yes (already computerized) : 28 (one is under inputting data)

2) No (not yet computerized) : 23

(2) Q 2 What media is used to record the registered data (Type of media)

1) The forms registered (on paper) : 17 (one is under inputting data)

2) The forms requirement : 8

3) The magnet tape : 1

4) The micro-film : 3

5) The magnet-optic disc : 1

6) Miscellaneous : 1

Table 2 Type of media to record data and condition of using computer

Type of media	Usage of computer		Total
	Yes	No	
Register	7	9	16
Original form	2	6	8
Magnet tape	1	0	1
Micro-film	2	1	3
Magnet-optic disc	1	0	1
Misc.	1	0	1
No answer	13	7	20
Total	27	23	50

(excluding an answer from the site under inputting data)

Table 3 Condition of acceptance for a future survey

Condition necessary or Reason of unacceptance	Condition of acceptance		Total
	Conditionally acceptable	Unacceptable	
Not to violate privacy	7	19	26
Only statistic data available	12	0	12
Impossible to access amputee data	0	4	4
No statistic data available	0	3	3
Misc.	2	1	3
No answer	1	0	1
Total	22	27	49

(excluding no answers in terms of "Condition of acceptanse")

(3) Cross tabulation of Q 1 and Q 2 (Table 2)

(4) Q 3 About accepting a future survey (Acceptance)

1) Acceptable unconditionally : 0

2) Acceptable under some conditions : 22

3) Not acceptable : 27

(5) Reason for unacceptance or conditions necessary for a future survey (Table 3)

(6) Cross tabulation of Q 1 and Q 3 (Table 4)

(7) The number of prostheses provided per year

1) Upper extremities (the number of answers : 40 sites)

Total of the provided prostheses : 1862, average : 47

2) Lower extremities (the number of answers :

Table 4 Condition of acceptance for a future survey and computerization

Acceptance	Usage of computer		Total
	Yes	Not yet	
Conditionally acceptable	16	6	22
Unacceptable	11	15	26
Total	27	21	48

(excluding no answers in terms of "Condition of acceptance" and an answer from the site under inputting data)

40 sites)

Total of the provided prostheses : 5397, average : 724

3) Total number of upper and lower extremity prostheses available (the number of answers : 2 sites) : 213

5. Discussion

Our main purpose was to find the most feasible way to get information on the reality in provision of the prostheses. On the way that, we have to survey getting what the attitude of the government toward opening information to the public.

The rather high rate of valid answers may indicate that local governments are interested in this kind of surveys. Even though more than half answers (27) insisted that it is impossible to answer the future survey, approximately the same numbers of answers (22) showed acceptable to some extent. This rate is higher than we have expected.

From Table-4, it can be said that the attitude can be affected by the situation of computerization. After this survey more and more local governments have put computerization forward. There might be more possibility to get the information now.

Not only about this kind of information but generally, "opening information public" is required. But at the same time, there has been strong resistance against such surveys both on the part of the disabled persons themselves and their families, who assert that these surveys can constitute a violation of human rights and privacy.

In Denmark the Danish Amputation Register and the nationwide National Patient Register are now practically working[4]. In the register, very precise information about amputation and prosthesis/orthosis is sent to the office whenever an amputation performed and/or a prosthesis provided on a person. Knowing the reality in provision of the prosthesis is feasible not only on developing new technology for prosthesis or orthosis, but also on political decision making.

Based on this survey, we have already performed a new survey for TECHO data from the few local governments. We also performed another similar survey on makers of prosthesis and orthosis. We are looking forward to getting feasible information to find real needs on prostheses from these new surveys.

Acknowledgments

This work have been done by the members of SICSAP listed below. I appreciate these SICSAP members and the board members of JSPO.

Gyouiti OOISI : College of Prosthetics and Orthotics, National Rehabilitation Center for the Disabled

Isao OJIMA : Center Hospital, Hyogo Rehabilitation Center

Yoshiaki KAMEDA : Kameda Prosthesis and Orthosis Ltd.

Takashi KINOSE : Devision of Occupational Therapy, Tokyo Metropolitan College of Allied Medical Science

Harumi TAKADA : JR Tokyo General Hospital

Tokuhide DOI : Tokyo Metropolitan Institute of Prosthetics and Orthotics

Hiroaki NAGASHIMA : Central Rehabilitation Service, Okayama University Medical School

Hideko HAYAKAWA : Division of Occupational Therapy, Kyoto University College of Allied Medical Science

Masahiro MIKAMI : Department of Rehabilitation, Teikyo University School of Medicine

Reference

1) Rehabilitation in Japan, edited by The Japanese Society for Rehabilitation of Disabled Persons, 3rd ed., (1995).

2) Physically handicapped persons in Japan－Report on the 1991 survey－, edited by Ministery of Health and Welfare, Daiichi-hoki Publishing Company, March 1995 (in Japanese language)

3）Nagashima, H., Inoue, H. and Takeuchi, H. Incidence and prognosis of dysvascular amputations in Okayama Prefecture (Japan), Prosthetics and Orthotics International, 17, 9-13 (1993).
4）Ebskov, L.B. Level of lower limb amputation in elation to etiology : an epidemiological study, Prosthetics and Orthotics International, 16, 163-167 (1992).