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

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Key Words: Local government attitude, Domestic 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. 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)". In the book, however, only glossy 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.

The other possible sources to get information is from some researches submitted in the related journals. There are international and domestic journals. In the researches TECHO is usually used as a source of data. 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 location of the amputation, sort of prosthesis or orthosis, cause of amputation, etc..

3. Methods

Based on the SICSAP discussions and informa-

<table>
<thead>
<tr>
<th>Table 1</th>
<th>The total number of persons with the impairment in trunks and extremities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sort of impairment</td>
<td>Numbers</td>
</tr>
<tr>
<td>Upper-extremity amputee</td>
<td>111,000</td>
</tr>
<tr>
<td>Upper-extremity malfunction</td>
<td>395,000</td>
</tr>
<tr>
<td>Lower-extremity amputee</td>
<td>57,000</td>
</tr>
<tr>
<td>Lower-extremity malfunction</td>
<td>525,000</td>
</tr>
<tr>
<td>Trunk malfunction</td>
<td>182,000</td>
</tr>
</tbody>
</table>

(Obtained from the 1991 survey)}
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 all local governments mentioned above. In order to make the questionnaires easy to ask, whole questions were put in an A4 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:
Q1: Does your office have computerized data storage system.
Q2: What media does your office use to keep handicapped persons’ records?
Q3: Can your office accept a future survey to get any information about amputees?
Q4: 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) Q1 About computerization (Computerization)
   1) Yes (already computerized)
      : 28 (one is under inputting data)
   2) No (not yet computerized) : 23

(2) Q2 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

<table>
<thead>
<tr>
<th>Type of media</th>
<th>Usage of computer</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Register</td>
<td>Yes</td>
<td>7</td>
</tr>
<tr>
<td>Original form</td>
<td>Yes</td>
<td>2</td>
</tr>
<tr>
<td>Magnet tape</td>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>Micro-film</td>
<td>Yes</td>
<td>2</td>
</tr>
<tr>
<td>Magnet-optic disc</td>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>Misc.</td>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No answer</td>
<td>Yes</td>
<td>13</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>27</td>
</tr>
</tbody>
</table>
(excluding an answer from the site under inputting data)

<table>
<thead>
<tr>
<th>Condition necessary or Reason of unacceptance</th>
<th>Condition of acceptance</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not to violate privacy</td>
<td>7</td>
<td>19</td>
</tr>
<tr>
<td>Only statistic data available</td>
<td>12</td>
<td>0</td>
</tr>
<tr>
<td>Impossible to access amputee data</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>No statistic data available</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Misc.</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>No answer</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>22</td>
<td>27</td>
</tr>
</tbody>
</table>
(excluding no answers in terms of “Condition of acceptance”)

6) Miscellaneous : 1

3) Cross tabulation of Q1 and Q2 (Table 2)

4) Q3 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 Q1 and Q3 (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

<table>
<thead>
<tr>
<th>Acceptance</th>
<th>Usage of computer</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>Not yet</td>
</tr>
<tr>
<td>Conditionally acceptable</td>
<td>16</td>
<td>6</td>
</tr>
<tr>
<td>Unacceptable</td>
<td>11</td>
<td>15</td>
</tr>
<tr>
<td>Total</td>
<td>27</td>
<td>21</td>
</tr>
</tbody>
</table>

(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. 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.

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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
