

# 24-Hour Records of Daily Activity for Persons with Severe Physical Disabilities and Demands of Assistive Devices

Toshinori MARUOKA<sup>a</sup>, Takenobu INOUE<sup>a,1</sup> and Koichi MORI<sup>a</sup>

<sup>a</sup>*Research Institute of National Rehabilitation Center for Persons with Disabilities*

**Abstract.** In order to develop and make widely available assistive devices for persons with severe physical disabilities, understanding their needs is crucial. However previous surveys limited to interviews and questionnaires might not reflect their needs properly or fully. Here we report the results of 24-hour monitoring of daily activities and assisted activities for 3 persons with severe physical disabilities to better understand their actual needs of assistive technology objectively. The results showed that two of the participants with severer disabilities spent more time to keep their health levels than persons without disabilities and needed more assists to gather information and to communicate. Gathering information and communicating with telephones, televisions and computers were most of these two participants' social activities. One of them desired for assistive technology to help them more than others keep privacy in these activities. The other participant used a communication aid and mostly satisfied with the *status quo*, even with the severest handicap of the three. The results suggests that, in spite of the use of public support and availability of certain assistive devices, the demands for developing and distributing new assistive devices still exists in terms of better support, of ADL, of easier maintenance of health, and of more independence in gathering information and communication, for persons with severe physical disabilities.

**Keywords.** persons with severe physical disabilities, daily activity, assisting activity, quality of life

## Introduction

Advanced assistive technology such as brain computer/machine interface is now actively developed and tried in the clinical setting for enhancing the quality of life for those who are not benefited very well from the conventional assistive technologies, especially for those with the severest physical disabilities like the near-final stages of neurodegenerative diseases and cervical spinal cord injuries [1], [2]. In order to properly guide the efforts and resources to develop and make assistive devices widely available for persons with severe physical disabilities, it is crucial not only to develop new technology but also to understand their needs and priorities from their life structure. However previous surveys have been limited to interviews and questionnaires, which may not reflect their actual needs properly [3]. Here we report

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<sup>1</sup> Corresponding Author: Takenobu Inoue, Research Institute of National Rehabilitation Center for Persons with Disabilities, 4-1 Namiki Tokorozawa Saitama; E-mail: inoue-takenobu@rehab.go.jp

the results of 24-hour monitoring of daily activities for 3 persons with severe physical disabilities, in order to better understand their actual needs of assistive technology objectively.

## 1. Methods

### 1.1. Participants and procedures

Three persons with severe physical disabilities (Table 1) participated in the study after informed consent was obtained. The research was approved by the ethical committee of National Rehabilitation Center for Persons with Disabilities.

Table 1. Profiles of Participants

| Participant | Age | Sex | Impairment                          | Movable parts  | Use of visiting assistants    | Person lived with |
|-------------|-----|-----|-------------------------------------|--|-------------------------------|-------------------|
| A           | 44  | M   | Cervical injury (C3, C4 incomplete) | Left arm, abdominal muscles, muscles of the back, Right arm, left foot (limited) | 1 day a week, 8 hours a day   | Parent            |
| B           | 59  | M   | Cerebral palsy, Cervical injury     | Neck, head, left shoulder with athetosis   | 7 days a week, 24 hours a day | Alone             |
| C           | 67  | M   | Amyotrophic lateral sclerosis       | Eyes, eyebrows, mouth, cheeks, right first finger, left hand (limited)           | 6 day a week, 7 hours a day   | Wife              |

### 1.2. 24-hour monitoring of daily activities and assisting activities

The activities of the participants and their assistants were recorded with start and stop times to the minute for twenty four hours. The researcher recorded the activities of the participants A and C and their assistants from the hour of rising to the bedtime. The rest of the 24 hours (from the bedtime to the hour of rising) was recorded either by the participant himself (the participant A) or by the participant's family (the participant C). For participant B the researcher recorded his activities from nine to nineteen o'clock at the first visit and from nineteen to nine o'clock of the next morning at the second visit.

We classified daily activities into 4 categories according to the type of the assistance or assistive technology, as shown in Table 2.

### 1.3. Questionnaires Survey

The three participants were interviewed about the assistive devices they regularly used and their wishes for future assistive technology that would allow them more independence.

**Table 2.** Classification of assistive activities

| Category                                | Activity   |
|---|--|
| Activities of Daily Living              | Changing clothes, taking a bath, transfer, cleaning and washing face and body, eating, going out                         |
| Maintaining health                      | Changing posture, health care  |
| Gathering information and communication | Writing and reading, operation of electric appliances (TV, video player, radio), operation of telephone, operation of PC |
| Others                                  | Others   |

## 2. Results

### 2.1. 24-hour monitoring of daily activities and assisting activities

#### 2.1.1. Daily activities

On the day of the survey, the weather kept participant A from outing. A nurse visited the participant B's home for regular health care and assisting him taking a bath. The participant C had a cold, which somewhat limited his usual daily activities and responsiveness to the questionnaires. Some of the activities by the participant C could not be investigated because his family recorded only activities of assistance.

Figure 1 shows the kinds and times of the three participants' activities, either assisted or unassisted. To maintain health, the participant A spent 9 minutes while the participant B spent 62 minutes and the participant C 185 minutes. The participants B and C needed much more time for these activities than the other participant, due to their more complicated medical status. Their social activities comprised mainly shopping, household chores, telephone, watching television, and operating a personal computer. Most hours of social activities were spent for "gathering information and communicating" through telephones, televisions and computers by all of the three participants.

#### 2.1.2. Assisted activities

Figure 2 shows the number of times the three participants were assisted. ADL was assisted 30 times for the participant A, while the participant B needed 58 times of assist in ADL, the participant C requiring 41 times. As with the assisted activities related to health maintenance, the participant A required the least help, while the difference from that of the other two was smaller than for the health maintenance activities.

Figure 3 shows the number of hour-bins of assisted activities, which would show the degree of distribution of assisted activities across the 24 hours, and would indicate how long helpers should attend. The participant A needed 11 hour-bins while the participant B needed 18 hour-bins and the participant C 16 hour-bins for ADL assistance. The three participants needed long hours of assistive attendance for supporting ADL with a smaller variance between the participants than that for the count of assistive activities.

For assistance in maintaining health, the participant A needed 5 times and 4 hour-bins, while the participant B needed 18 times and 11 hour-bins, and the participant C 57 times and 16 hour-bins, the differences of which are comparative to the difference in the cumulative times (minutes) of assistance shown in Figure 1. The largest differences were observed among the subjects for assistance in gathering information and communication: the participant A did not need any assistance, while the participant B needed 90 times and 18 hour-bins and the participant C needed 18 times and 12 hour-bins.

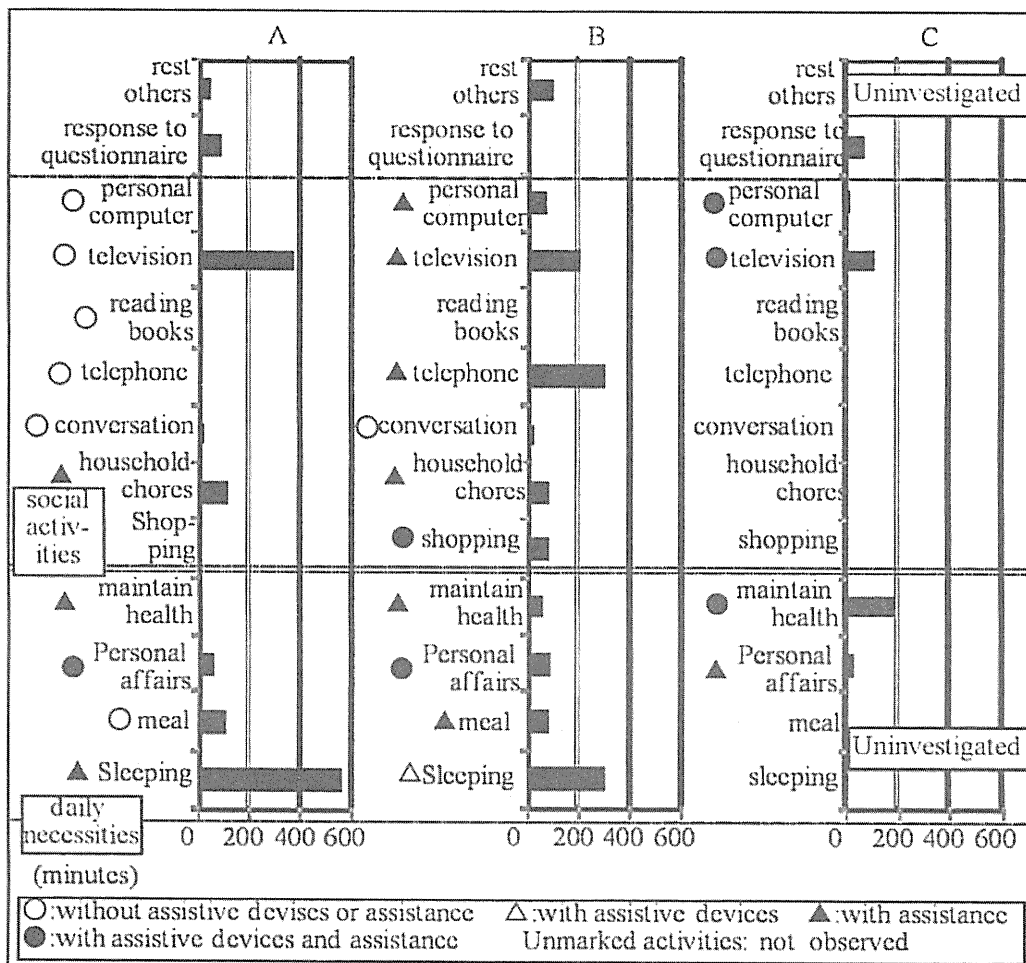


Figure 1. The number of daily activities.

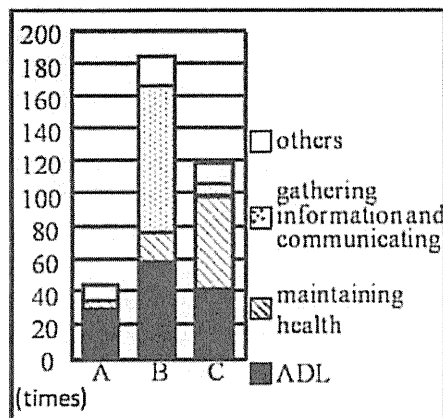


Figure 2. The number of assistive activities

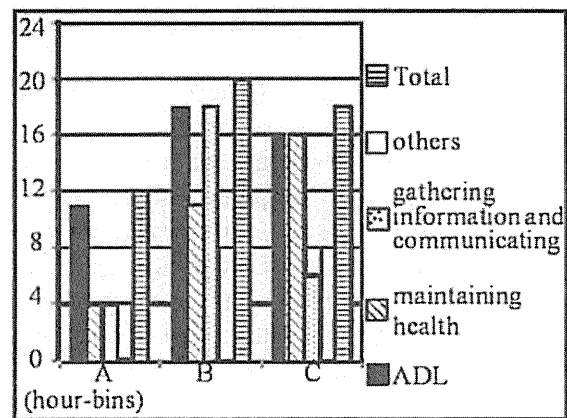


Figure 3. The number of hour-bins of assistive activities

## 2.2. Questionnaires Survey

### 2.2.1. The Use of Assistive devices

Table 3 shows the assistive devices that the three participants used. The participant B slept without assist to change his posture with because he used an air mattress that distributes body weight evenly. The participant C was able to converse with others and to operate TV and a personal computer with a communication aid (Dennoshin) which he controlled with a finger-operated switch. He also used a hearing aid.

Table 3. Use of Assistive Devices

| Participant | Assistive Devices   |
|-------------|---|
| A           | Powered wheelchair, hoist, powered bed, shower chair, mouth stick   |
| B           | Manually driven wheelchair, hoist, air mattress, shower chair, belt for seating   |
| C           | Manually driven wheelchair, hoist, powered bed, handy aspirator, respirator, hearing aid, communication aid (Dennoshin) |

### 2.2.2. Desire for new assistive technology

Participant A desired for assistive technology development to help him change clothes, to take a bath, discharge feces, and read books by himself, which would allow him more independence and enhanced self-esteem. Participant B desired for development of technology to help him operate a TV remote control and telephone, and send and receive e-mail. He wished for privacy in telephone and email. Participant C desired nothing for the development of assistive technology.

## 3. Discussion

According to "NHK's National Time Use Survey" [4], daily activities were classified into three categories; daily necessities for existence, obligatory social activities to make

living or to go to school, and free, spare time activities. However, because only one of the participants in the present study worked regularly to make living (the others are on the disability pension) and because we monitored activities at home, we did not use the second category of the above report, and adopted a different classification system, with the kinds of relevant assisting activities in mind (Table 2). Two of the present participants (participants B and C) spent much more time for the activities to keep their health levels than persons without disabilities as reported in the NHK's national survey [4], and also more than the participant A. The longer time necessary to keep their health levels limited their social activities and put heavy burdens on their assistants. Two of the participants with severer disabilities (participants B and C) needed more assistance to maintain health and to gather information and to communicate than the participant A, although the need for ADL assistance was more or less similar among the participants in terms of the number of assistive events and hour-bins to be attended.

On the day of survey, gathering information and communication through telephones, televisions and computers were most common social activities for all of the three participants. However, two of the present participants (participants B and C) always needed assist in these activities. The necessity of assist to gather information and communicate made it difficult for them to keep their privacy, although the participant C could communicate semi-privately with a PC once a finger-operated switch was properly set up. The participant B therefore desired for assistive technology to help him in these activities more than others.

Since some activities (outing, nurse visits, etc) are scheduled weekly rather than daily, and with other conditions implicated the participants on the particular day of the survey as described in the results, the results of our survey are not unbiased. However, the heavy necessity for assistive activities of daily living, health maintenance, and communicating is well above the ordinary people.

#### 4. Conclusions

The results of 24-hour monitoring of daily activities and assisting activities shows that gathering information and communicating through telephones, televisions and computers constitutes the major part of the social activities of the three participants, but with varying degrees of assistance, while the three participants needed similarly many times of assistance in ADL over extended hour-bins in the 24-hour observation. They also suggest that severer disabilities require more time in maintaining health, which limit their time for social activities, and also make it difficult for them to keep their privacy, and put heavy burdens on their assistants.

The findings may imply that, in spite of the use of public support and availability of certain assistive devices, the demands for developing and distributing new, more effective assistive devices still exist in terms of better support of ADL, of easier maintenance of health, and of more independence in gathering information and communicating, for persons with severe physical disabilities.

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