Assessment of Care by Time For Daily Life

On Time for Daily Life and Degree of Freedom from Caring

October 13, 2002
Third International Conference on Family Care in Washington DC

Ms. Atsuko Ikeda, the Representative, and Mr. Masami Yamada, Researcher

This report describes an outline of the result from the 4^{th} survey conducted in May 2001 in "the basic research from 1999 through 2003 on the nursing care insurance system" for 500 senior cared citizens living in 43 cities and towns in the Tokyo area.

Surveying Team;

Tokyo Conference of Seikatsu Club Groups on Welfare Policy
NPO Hitomachi-sha

Assessment of Care by Time for Daily Life

The survey, conducted from April to May in 2001, is the fourth part of ten of a periodic tracking poll on the elderly, which started in 1999 over five years for the basic research on the nursing care insurance system.

1 Outline of the survey

- 1) purpose: To record elderly persons'(respondents) and care takers'(including secondary caregivers and care insurance services) time spent on their daily activities in order to get basic data, which is necessary when we consider how care services can support elderly people and how nursing care will have to be accepted more and promoted in society.
- 2) **respondents**: 138 persons (out of 163 at care levels 3 to 5 in the third survey), who consented to participate in the survey.
- 3) **period**: One month from April 25 to May 24, 2001.
- 4) **items:** To record how respondents and their care takers spend a day / a week, as well as time spent on care by secondary caregivers including care services. To evaluate their daily life by themselves in terms of time and the sense of achievement. Opinions by survey staff members.
- 5) **method:** Respondents had been informed about the questions beforehand, then visited by a pair of staff members; one asked questions, the other recorded answers. After a face-to-face talk, the interviewers wrote a summary and comments on them.

2 Outline of the survey results

1) Questionnaire

The questionnaire form originates with Professor Ryoji Kobayashi from the Tokyo Metropolitan University, which care managers and social workers use as a tool when evaluating care management.

The previous survey showed that changes in the lifestyles of care takers caused burden on them physically and psychologically even if they could use care services, while persons requiring care were affected in a slightly different way.

To study the background it has been very useful for us to adopt the form by courtesy of Kobayashi, who also gave us valuable advice on the survey.

2) Respondents

Tables 1 to 4 show the composition of the 100 respondents with valid answers. Twenty-nine persons of them had been diagnosed their illness as dementia at the time

of the second survey conducted in October 2000.

Table 1

| | | Tubic 1 | | |
|-------------|--------------|---------|--|--|
| Respondents | Number of | Valid | | |
| Respondents | collection | answers | | |
| 138 | 108 | 100 | | |
| 100.0% | <i>78.3%</i> | 72.5% | | |

Table 2

| | Number of |
|--------|-----------|
| Sex | person |
| Male | 17 |
| Female | 83 |
| Total | 100 |

Table 3

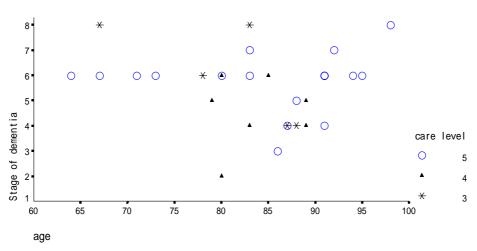
| | Number of |
|-------|-----------|
| Age | person |
| 40-64 | 5 |
| 65-69 | 10 |
| 70-74 | 11 |
| 75-79 | 10 |
| 80-84 | 18 |
| 85-89 | 20 |
| 90-94 | 22 |
| 95- | 4 |
| Total | 100 |

Table 4

| | Number of |
|--------------|-----------|
| Care level | persons |
| Care level 3 | 22 |
| Care level 4 | 31 |
| Care level 5 | 47 |
| Total | 100 |

Figure 5

Age and dementia by care level



deterioration quotient: 1=1,2=11a,3=11b,4=111a,5=111b,6=1V,7=M,8=unknown

3) Percentages of primary and secondary care takers

According to Figure 6, most of the primary caregivers are sons' wives, followed by daughters; that is, female care takers are 74 per cent, including wives; with 24 per cent male (husbands and sons). Figure 7 shows the composition of secondary caregivers

who substitute for primary ones. The percentage of care insurance services and home help is more than half by 51 per cent, with daughters and sons the second most.

Primary care takers Figure 6 Home help Husband 2% Son's Wife wife 36% 8% Son 7% Daughter 30%

Secondary care takers Wife Husband Son 1% 1% 16% Son's wife Nusing 2% care insurance Daughter services 49% 18% Daughter Daughter's husBand husb Grand Home child help 4% 3%

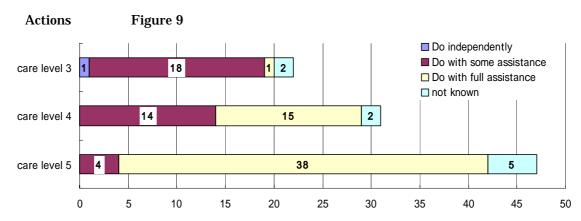
Figure 7

As for family backgrounds, most respondents live with their children under 64, with 28 per cent living with spouse or other family member(s) over 65, and 4 per cent live alone.

Table 8 Number of House hold persons Live alone 4 16 With spouse With member(s) over 65 12 With member(s) under 64 68 **Total** 100

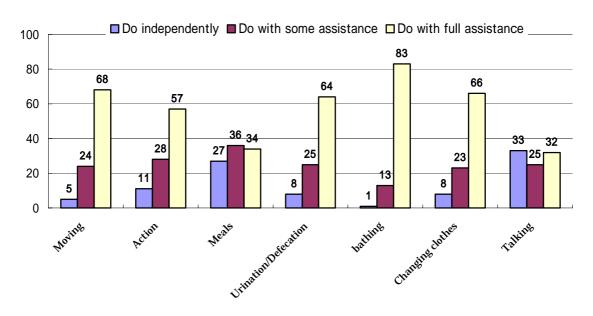
4) Persons requiring care and their activities in daily life

Their basic actions and movements in life can be grouped into three stages according to care; persons in need of care (1)do it by themselves,(2) need some assistance and (3)unable to do it unassisted. From Figure 9 it is obvious that the most are at stage(3). As for specific actions, however, many of them have meals themselves and can talk with other people; while they require assistance, to some extent or fully, when moving around, urinating/defecating, changing clothes, especially bathing.



Housework, as shown in Figures 11 and 12, requires continuous movements and eighty per cent of the respondents depend on full assistance to do it. One to three percent persons are able to do paper work for home management, go shopping, cook and do the laundry by themselves or with some assistance.

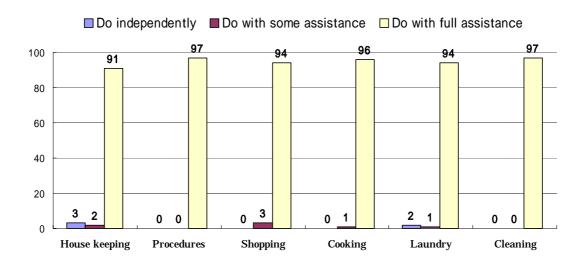
Actions in daily life Figure 10



Daily routine Figure 11 ■ Do with some assistance ■ Do with full assistance care level 3 15 3 not known 3 care level 4 care level 5 41 5 10 0 20 30 40 50

Daily routine

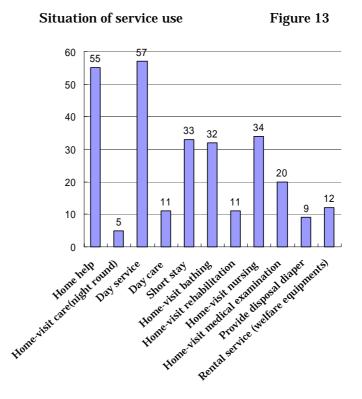
Figure 12



5) Situation of service use

Of in-home care services there is a great demand for three main services, which are home-visit care (Home help service), commuting for care (Day service) and short-term stay at a care facility (Short stay).

Five persons use a night round service. Some persons need home help to get up and dress before going out for Day service. Many care recipients have a bath twice a week



during their stay at facilities for Day service. Home-visit bathing is provided in thirty-two cases mainly for those high at care level or in need of home-visit medical care. Rehabilitation workout is absolutely essential for those with weakened physical functions to regain a desirable condition to live independently as possible. Nevertheless,

home-visit rehabilitation service is seen in only eleven cases. Another eleven persons use commuting rehabilitation service.

Despite a high demand for rehabilitation service, the amount of it is in short supply at the moment due to the delay of establishing infrastructure.

6) Time for service use

Time for service use

Table 14

| Time for service use | | | | | | | Tubic 14 |
|----------------------|-----------|----------|-----------------------|---------|----------|-------------|-------------|
| | | | The most | Average | Maximum | Average | Maximum |
| | Number of | Average | times per amount of | | time par | time at one | time at one |
| Service | users | per week | week | time | week | time | time |
| Home help | | | | | | | |
| | 55 | 5.0 | 21 | 10.1 | 44.0 | 2.3 | 11.0 |
| Day service | | | | | | | |
| | 57 | 2.8 | 6 | 17.5 | 54.0 | 6.2 | 12.0 |
| Day care | | | | | | | |
| | 11 | 1.9 | 4 | 12.7 | 28.0 | 6.7 | 7.5 |
| Home-visit | | | | | | | |
| bathing | 32 | 1.2 | 2 | | | | |
| Home-visit | | | | | | | |
| rehabilitation | 11 | 1.5 | 5 | | | | |
| Home-visit | | | | | | | |
| nursing | 34 | 1.6 | 3 | | | | |

7) Time spent on daily routine life and care

As for persons requiring care, naturally their daily activities take place almost at the same time as care does. On the other hand, the fact is that the more time caregivers spend time on care, the less they can spend on their own life.

When divided into the following seven activities, care takers' typical day and time spent on them are:

1. Care

Sixty-two per cent of the caregivers take less than 5 hours to do it. The maximum amount of time is 14 hours, with the minimum 1 hour in four cases, and the average 5.0 hours.

2. Housework

In household chores, part of care-related work is included such as, preparing meals for the care recipients, doing the laundry, doing the cleaning, and so on. Most of the caregivers take 2 to 3 hours to do it. The maximum is 10 hours, with the average 4.3.

3. Work

Twenty-four per cent of the care takers have jobs, excluding those unknown and with no job. Eleven persons work full time over 8 hours. Other persons with jobs seem to give priority to care taking. One caregiver keeps shop while looking after the person in need of care. The longest working hours are 13, the shortest is less than 1. The average time is 2.2 hours.

4. Going out

Sixty-eight per cent of the care takers spend up to 3 hours. Fifteen persons reply that they do not go out at all. The maximum amount of time reaches almost 5 hours. When Day service is provided or secondary caregivers are available, they have time to go out to do things such as, shopping, paper work and procedure for things, to go to the bank, to see the doctor for their own treatment. The average time is 1.4 hours.

5. Rest

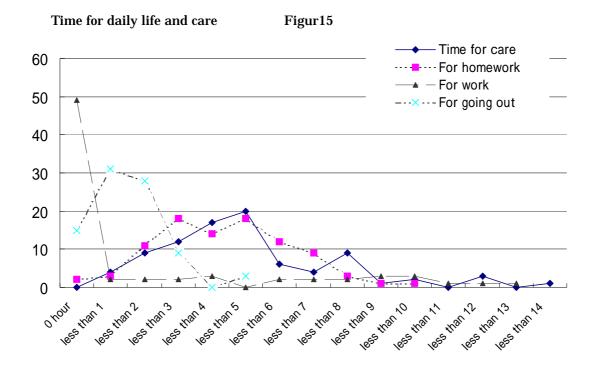
About 55 per cent of the caregivers have 1 to 3 hours' relaxation time, during which they tend to watch TV or look over magazines and newspapers. Seven persons say they have no rest, which strongly suggests that a short break doesn't make them feel really relaxed. There is an elderly care taker who has a 9 hour rest, which is the maximum amount of time. The average is 2.8 hours.

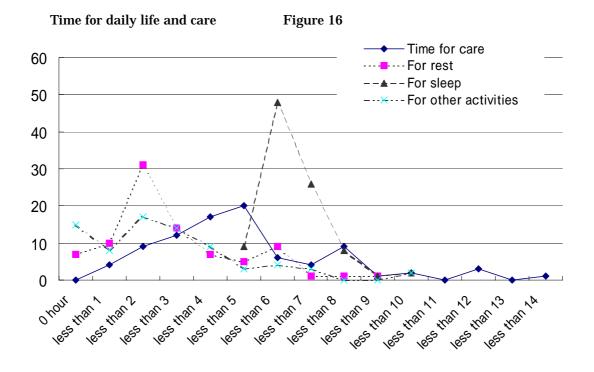
6. Sleeping

The survey shows that about 70 per cent of the care takers sleep from 6 to 7 hours. Some feel chronic lack of sleep because of the care in the night— assistance to going to the toilet, changing diapers, and so on. Time is from less than 5 to 10 hours, with the average of 6.4. Fifteen caregivers who have a job and work over 6 hours, sleep 6.1 hours.

7. Other activities

Many caregivers spend the time to call their own on miscellaneous activities other than specific ones mentioned above; such as, time for going out (on personal business), hobbies, taking a bath, watching TV, reading, going to church, gardening, taking/giving lessons, taking care of children, commuting. Four persons do housework, keep shop or rest while tending the persons in need of care, and they put the time into this category. One person, who shares a room with the person he cares, replies that it is impossible to draw a clear distinction between time for life and that for care. The minimum is 0 hour, with the average 2.6, and with 25 persons giving no answer.





8) Assistance: meals and urination/defecation

According to the survey, part of caregivers' everyday routine is as follows:

1. Meals

Seventy to eighty per cent of the care recipients take 30 to 60 minutes to have a meal, with some persons taking about 90 to 120 minutes. This shows that caregivers tend to think it important for the persons they care to take food through their mouth even though they have difficulty in swallowing it. As a result, it is likely that the persons assisted get tired.

Almost 50 per cent of the primary care takers give assistance to the care recipients with breakfast and supper, with secondary or Day service substituting for them at lunch. Many primary caregivers have their own meal while giving assistance to the recipients with theirs. In such a situation meals cannot be satisfying and enjoyable for some caregivers, whether they spend enough time or not. Twenty-seven persons can eat unassisted.

2. Urination/Defecation

Care recipients fall into two groups: those who go to the toilet by themselves or with assistance, and those who use diapers. The number of the former is larger than that of the latter. Eleven persons make use of both the toilet and diapers.

Table 17
The toilet 45
Diapers 33
Both 11
Not known 11
Total 100

More than half of them go to the toilet helped by primary care takers, next there are many persons unassisted, and only a few persons use Care service. In some other cases, primary caregivers need help by secondary ones or Care service staff when taking the care recipients to the toilet. In any case, giving toilet assistance is care takers' demanding hard work.

9) Spare time of care takers

In the questionnaire there were not any questions about caregivers' spare time to be answered by the hour, but it is referred to in their comments written in Section[V](Other activities) and evaluation of their daily routine life in Section[IV]. Sections [I] and[II] also show how they spend their spare time in everyday life.

They have their free time mostly while the care recipients are out for Day service, Short stay, and in

Spare time of care takers

Table 18

| Spare time of care takers | | | | |
|---------------------------|------|--|--|--|
| Monday | 3:30 | | | |
| Tuesday | 3:22 | | | |
| Wednesday | 3:15 | | | |
| Thursday | 3:48 | | | |
| Friday | 3:23 | | | |
| Saturday | 4:01 | | | |
| Sunday | 4:09 | | | |
| Average | 3:38 | | | |
| | | | | |

some cases while secondary caregivers—husbands, relatives, brothers and sisters—substitute for them. A few care takers manage to find the time while looking after a bedridden person high at the care level. The average time is 3.38 hours, with

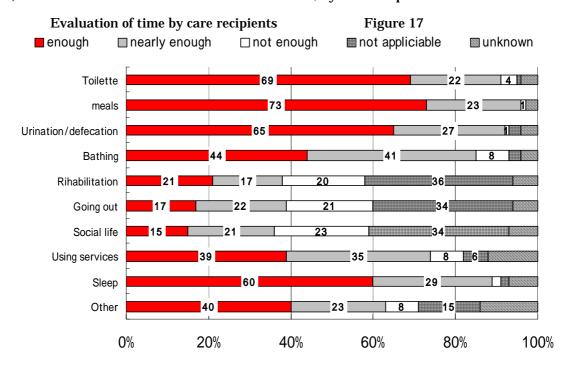
slightly over 4.0 hours on Saturdays and Sundays.

There are three ways of their spending the time:

- 1. on hobbies that earn some money— giving piano lessons, instructing in swimming/ flower arrangement, keeping shop, working at home, and so on.
- 2. on social life and hobbies—going out on their business, taking the dog for a walk, playing sports, singing in a chorus, volunteer work, sauna, and so on.
- 3. on relaxation and rest at home—using computers, watching TV, reading books and newspapers, and so on.

10) Evaluation of time for daily life

1) Evaluation of life and care in terms of time, by care recipients



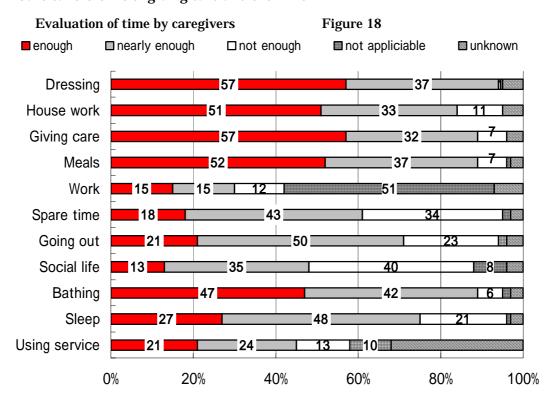
According to Figure 17, more than 50 per cent of the care recipients think they have "enough" time for meals(73 persons), toilette(69), urination/defecation(65) and sleep(60); the second group finds the time "nearly enough", and the figures are: meals(23 persons), toilette(22), urination/defecation(27) and sleep(29). Therefore about 89 to 96 per cent of the care recipients think the situation good. Their routine activities are done mostly with assistance by primary care takers, who work hard and probably feel it to be worth doing.

On the other hand, many care recipients put "not enough" to rehabilitation(20 persons), going out(21) and social life(23). Other persons, some care givers too, put "not applicable" to rehabilitation(36), going out(34) and social life(34). Nine persons want

more time to go out, and 6 persons to social life.

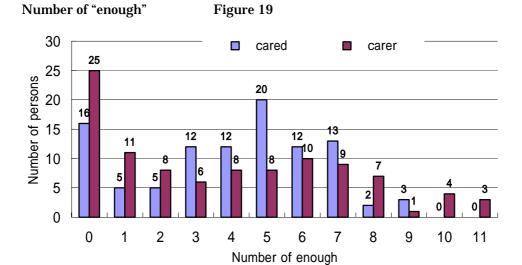
These items are not problems that can be solved by caregivers' harder efforts, but they need to be discussed further. It should be examined what prevents them from doing these activities or why they are dissatisfied. The shortage of service supply makes it difficult for care recipients to do rehabilitation workout, which is caused by the delay of the infrastructure.

2) Care takers' time of giving care and their life



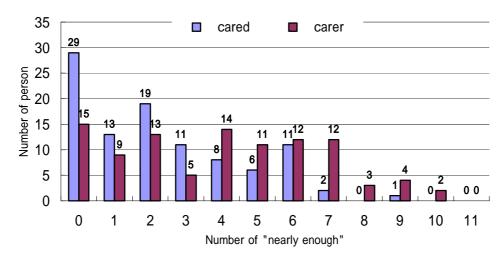
Most caregivers think they have "enough" and "nearly enough" time in the activities of dressing(94 persons), housework(84), giving care(89), meals(89) and bathing(89). In fact, housework includes cooking, doing the laundry and cleaning for the persons they care to live comfortably. Some caregivers have meals looking after or giving assistance to the care recipients at the same time, which could make their own meal unsatisfying. Spare time and social life are what care takers have "not enough", and they want much more time for it. Even those who put "nearly enough" in these columns are in dire need of time. Caregivers also desire to go out on their business and to sleep. Care, especially assisting recipients with urination/defecation in the night and taking care of these with dementia 24 hours a day, keeps caregivers in worries, which often causes their suffering from chronic lack of sleep. Care takers bear the burden in the present situations.

11) Different evaluations



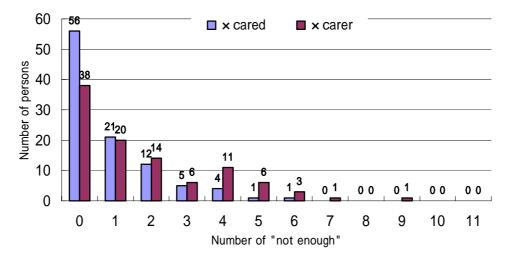
Number of "nearly enough"

Figure 20



Number of "not enough"

Figure 21



Figures 19, 20 and 21 simply show that care recipients and givers have different opinions about their time in everyday life. More than half of the recipients seems to be content, while many care takers do not.

This clarifies an image of care takers, who, securing care time and housework first, apply the rest of the hours to going out and free time. Thus they wish to have more time for social and friendly activities as well as for sleep.

With the start of the nursing care insurance system, care time for the recipients has been secured, while care takers still cut their own daily-life time because of care just the same. Caregivers express their frank feeling: "We have never realized so much time was devoted to care giving."

If the aim of the insurance system lies in the society shouldering the care, where care takers can spend caring life without much burden on them physically and mentally, first of all they(care takers) need to have the will of entrusting the care to the society. Both recipients and their families also need to talk about it to reach an agreement. Then family members should secure their time so that they can manage to do what they want. It is clear that this system needs to become an incentive to the socialization of care services.

In this sense, key persons of the system are care managers, whose job is to set the aim of care, to adjust demands of recipients, caregivers and families, and to make proper care plans based on them.

3 Summary of the Poll Findings

1) Utilization of services and the life of the nursed

The situations of using the services under the nursing care insurance system are greatly improving in comparison with those at the beginning of the system. From the point of the rate of users, however, the average usage still stays at 69 per cent. The monthly average cost per person is 12,835 yen, meaning 55.7 per cent of the upper limit of benefits, which is about the same as at the start of the system.

In this fourth survey we have got at the number of hours used for the services by 100 cases of the care levels 3 to 5. The maximum time for home help service used by 55 persons is 11 hours a day, with the average time for one service is 2.3 hours and the average using hours a week is 10.1.

Fifty-seven persons use Day service; the maximum hours a day is 12, the average hours of the service at a time is 6.2, with an average of 17.5 hours a week. Besides, there are 32 cases of home-visit bathing and 34 home-visit nursing, both of which are

used quite often, and the time spent on these services is generally 1 hour. One person uses 2.9 different services in average.

From these data it seems to me the service use per person is: 10.1 hours' home help, 17.5 hours of Day service, weekly home-visit nursing/bathing, and one week's Short stay every one or two months.

Table 23

The amount of services is decided, taking account of the relation between the life of the care recipients and that of caregivers. Inferred from the caregiver's life(Table 24), time for daily activities is modeled like Figure 25, which indicates

| a) care time less than 5 hours | |
|-----------------------------------|-----|
| House work | 4.0 |
| Work | 3.7 |
| Going out | 1.3 |
| Rest | 2.6 |
| Sleep | 6.5 |
| Others | 3.5 |
| | |

b) care time over 5 hours

| House work | 4.8 |
|------------|-----|
| Work | 0.6 |
| Going out | 1.6 |
| Rest | 3.0 |
| Sleep | 6.2 |
| Others | 1.8 |

^{*}Excluding twelve persons with no answer

that the more divided the hours of nursing, the heavier becomes the burden on them. It is true that when caregivers can concentrate only 1 hour or two on whatever they do their irritation becomes almost unbearable and they long for free time and social life(Table 23a, b).

2) Nursing life and decision of service selection

In this way, time for care means living hours for care recipients, while it is the nursing hours for caregivers. In order to change it into living hours, they must depend upon other people's help. Local communities should prepare both quality and quantity of care as resources for use. It is a problem who will bring it out to the surface and how it should be solved, which is a clue to the decision of service selection.

Under the public nursing care insurance system, every person over 40 pays premiums and everyone in need of care nursing is supposed to receive care services. Since the start of this system, according to their answers, the biggest change in caregivers' life has been: "It is a relief that we can consult care managers." Care managers investigate the above problem, adjust and try to make opportunities for solving them. Whether to get great help by secondary care takers from family members, relatives, or to use social support depends upon the decision of each care recipient, caregiver and their family. It is necessary for care managers or the third person who can advise to support the process.

In the survey "Assessment of Care by Time for Daily Life", living hours of both

caregivers and care recipients are investigated by the staff, finding facts and problems to be solved, out of their checking on individual cases. This has led to the necessity and possibility of civilian advisers as a part of local welfare system which covers provision of information, consultation, and so on.

Table 24

| | Giving care | Work | House work | Going out | Rest | Sleep | Others | Total |
|------------------|-------------|------|---------------|-----------|------|-------|--------|-------|
| Average time for | | | | | | | | |
| daily activities | 5.0 | 2.2 | 4.3 | 1.4 | 2.8 | 6.4 | 2.6 | 24.7 |
| Allotment based | | | | | | | | |
| on average time | 5.1 | 2.5 | 4.5 | 1.4 | 2.0 | 6.5 | 2.0 | 24.0 |

Allotment time based on average time

Figure 25

