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博 士 論 文

Changing attitudes to care of disabled older people within a changing health care system in Japan.

(日本におけるヘルスケアシステムの変化に伴う障害高齢者のケアに関する意識変化)

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神戸大学大学院医学系研究科保健学専攻

備酒 伸彦

Changing attitudes to care of disabled older people within a changing health care system in Japan.

Nobuhiko Bishu

Physio therapist,
Tajima Choju Village in Hyogo, Japan,
Division of Health Sciences, Kobe University Graduate School of Medicine

Abstract

The implementation of a more flexible system of care for disabled older people in Japan is in some respects being hindered by the outdated perceptions of the general public and professional carers of the needs and desires of older people. This multifaceted study sought to quantify the disparity in order to provide guidance on a way forward .

Two sets of data were collected to provide a full picture: the levels of functional independence of a sample of disabled older people; and responses to a questionnaire about perceptions of older people and their care by a sample of 'average' people.

The results show that while functional independence in disabled older people does decrease with age, it can in many cases be improved by being cared for at home. The wider public is aware of this, but increasingly do not wish to participate in caring for their older relatives at home and are happy for relatives to be cared for in nursing homes. Younger people also have unrealistic views of older people's preferences and level in independence.

In order to encourage effective care for the disabled older population, care should be focused on understanding their needs and circumstances in order to facilitate improvement in their functional independence.

Key Words ; ADL, Older people, Aging society, Public awareness

Introduction

The population of Japan has aged rapidly since the mid-20th century. In 1950, the percentage of old people (over 65 years old) was 4.9%, in 1970 it reached 7.1%, and by the year 2000 it was supposed to be 17.2%. The rapid aging rate of the population has become especially prominent in the past 30 years. The aging of a society at such a rapid rate is also unprecedented among other nations¹⁾.

In response to this, the Japanese Ministry of Social Welfare and Labor named the 21st century as the "Century of the Aged", and expressed the importance of enriching and improving our social security provision for elderly people¹⁾.

Attitudes towards social security and care provision for old people have changed drastically. It could be described as a change from "an institution for the relief of poverty" to "a social security contract based on individual requirements", which are extremely different. For the handicapped older person, it could also be said that the need for care rather than cure has been recognized, which is also a big change²⁾. Accordingly, in the 1990s, different measures were initiated with their emphasis on nursing care³⁻⁵⁾.

If taking a broad view, provision for older people has changed in accordance with society's needs. However, actual care service provision is often dependent on the provider's experience, and services are still not able to fulfil the diverse needs of society.

Clinical evaluation of the older person, a necessity of effective care provision must include their mental, functional, social, and economical views and values⁶⁾.

In Japan, comprehensive evaluation has only come about because of the institution of a care insurance system that demands to approve the care given to each patient.

Although an increasingly individualized system of assessment is coming into being, there is still a paucity of research into older people's needs and wants and the application of the care system to providing for these. An typical example is the continued use of children's games in older people's day care services in spite of ongoing criticism. This practice highlights a gap between older people's perceptions of themselves and their carers' perceptions of them that, as the population continues to age and manifest its diversity, will grow.

Since the care-insurance system began, public perceptions of nursing care have been rapidly shifting from family centered nursing care to nursing care by social services⁷⁾. However, it is still common to encounter a situation where the providers of care services are still working with a family care mentality. While there is a disparity of awareness between service users, providers and citizens, it could be said that it is impossible for effective care to become a reality.

The study we discuss below gathered two very different sets of data to illustrate aspects of this discussion: the changes in functional independence in disabled older people and the attitudes of members of the public and caring professions towards older people and their care. These were annualized and drawn together to provide some suggestions for future development of care services in Japan.

Subjects and Methods

1. Transition in ADL degree of independence of the disabled elderly

We examined 343 persons (men 141, women 202, average age 76.5 13.3 years) who met our following (1-3) criteria. We evaluated the ADL at the first visit and at the last visit and examined the ADL changes in the first and last visit. We set no other limitations besides these when we chose individuals.

- (1) They had been visited twice by physical therapists and occupational therapists who belong to the department of regional nursing care of Tajima Choju Village in Hyogo, Japan between January 1999 and August 2001
- (2) They lived in their own homes
- (3) They were elderly persons who had some kind of disability
(Cerebrovascular accidents; CVA 207, Parkinson disease 25, Osteoarthritis 61, Fracture 28, Other 22)

They were classified into four ranks and eight levels, i.e. J1, J2, A1, A2, B1, B2, C1, C2 and 8 levels (Table 1).

Table 1
Classification of Independence in ADL for Disabled Elderly
(Ministry of Health, Labour and Welfare)

<p>Rank J A person with some disabilities who is independent in ADL and able to go out by himself or herself.</p> <ul style="list-style-type: none"> 1. I can go out, making use of public transportation. 2. I can only go out near where I live. <p>Rank A Quasi-bedridden A person who has a degree of independence but is not able to go out without assistance.</p> <ul style="list-style-type: none"> 1. With assistance, I can go out and do daily activities, without lying in bed during the daytime. 2. I can go out less frequently and lie in bed even during the daytime. <p>Rank B Bedridden A person who needs assistance with ADL at home, and spends most of their time in bed but can sit in a chair for extended periods.</p> <ul style="list-style-type: none"> 1. I can get into my wheelchair by myself and have meals and go to the bathroom by myself. 2. I can only get into my wheelchair with assistance. <p>Rank C Bedridden A person who needs assistance with ADL such as going to the bathroom, eating and dressing, and who spends all day in bed.</p> <ul style="list-style-type: none"> 1. I can roll over by myself. 2. I cannot roll over by myself.
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Regarding the analysis of the results, we processed age, the number of visits, and the evaluation period by using the unpaired t-test of average. Using the unpaired t-test of the statistically significant, we identified an improved group, a worsening group, and an unchanged group.

2. Consciousness Survey of Citizens about Nursing Care

Six hundred and forty eight subjects (233 men, 415 women) participated in this study and they were classified into 5 groups as follows: A group of the elderly: 134 individuals who are 65 years old and over (65 men, 72 women). A group of average citizens: 125 individuals who don't work in the nursing care field (25 men, 100 women). A group of care managers: 124 individuals aged less than 65 who work as a care manager (11 men, 113 women). A group of physical therapists: 177 individuals aged 65 and less who work as physical therapists (93 men, 84 women). A group of students: 88 individuals who are students at Physical Therapist School (42 men, 46 women). Table 2 shows the detailed classification of the subjects (Table 2).

A 28 items questionnaire was made (Table 3). Questions 17 to 22 concerning awareness of nursing care were quoted from research conducted by the General Administrative Agency of the Cabinet in 1995. The questions were used to make it easy compare the situation in 1995 to the one in 2002⁸⁾.

We used the questionnaire mentioned above and had a group interview with the elderly, average citizens, care managers and students and obtained the responses from them. We gave the questionnaire to the physical therapists and also obtained the answers from them. We compared the obtained answers between each group mentioned above and concerning one question about awareness of nursing care, we compared them with the results of the survey conducted by the General Administrative Agency of the Cabinet in 1995.

Table 2

Classification of Subjects Consciousness Survey of Citizens about Nursing Care

Group	Men	Women	Total	Average age
Elderly	62	72	134	76.3 ± 5.3
Average Citizens	25	100	125	40.9 ± 11.3
Care Manager	11	113	124	45.8 ± 8.2
Physical Therapist	93	84	177	27.1 ± 6.7
Students	42	46	88	22.8 ± 3.5
Total	233	415	648	42.9 ± 18.9

Table3
Consciousness Survey of Citizens about Nursing Care

1. Age
2. Sex 1. Male 2. Female
3. Status 1. Married 2. Single 3. Widowed
4. Family member residing in the same house 1. Single person 2. Couple 3. With another family member except spouse Family member () relationship.
5. Children 1. With 2. Without
6. Paralysis of some part of the body 1. Yes 2. No
7. Experience of nursing care 1. Yes 2. No 3. Belong to care agency () name of agency.
8. TV programs you like (Please mark three items in the categories below.)
 1. Samurai dramas 2. Popular song programs 3. Dramas 4. News 5. Sports programs 6. Information programs 7. Travel programs 8. Documentaries 9. Movies 10. Others 1() 11. Others 2()
9. TV programs you like best (Please mark one in the categories below.)
 1. Samurai dramas 2. Popular song programs 3. Dramas 4. News 5. Sports programs 6. Information programs 7. Travel programs 8. Documentaries 9. Movies 10. Others 1() 11. Others 2()
10. TV programs which you imagine the healthy elderly aged 75 and over like (Please mark three items in the categories below.)
 1. Samurai dramas 2. Popular song programs 3. Dramas 4. News 5. Sports programs 6. Information programs 7. Travel programs 8. Documentaries 9. Movies 10. Others 1() 11. Others 2()
11. TV program which you imagine the healthy elderly aged 75 and over like the best (Please mark one in the categories below.)
 1. Samurai dramas 2. Popular song programs 3. Dramas 4. News 5. Sports programs 6. Information programs 7. Travel programs 8. Documentaries 9. Movies 10. Others 1() 11. Others 2()
12. How do you think the healthy elderly aged 75 and over will spend the money? 1. Spend it on themselves 2. Spend it on their families 3. Other ()
 3. I didn't decide yet. 4. I don't know.
13. In the event that you need to be cared for, where do you want to be cared for? Which answer is nearest to how you feel?
 1. I want to be cared for at home. 2. Depending on the circumstances, I could stay at a special elderly nursing home or a health care facility for the elderly. 3. I didn't decide yet. 4. I don't know.
14. In the event that you need to be cared for and have nursing care at home, what kind of nursing care would you like?
 1. I want to be cared for by family members. 2. Mainly I want to be cared for by family members, but I don't mind being looked after by care-workers other than family members on occasion.
 3. Mainly I want to be cared for by care-workers alongside family members. 4. I want to be cared for only by care-workers, and not family members.
15. In the event that your spouse needs to be cared for, where would you like him/her to be cared for? Which answer is closest to your feelings?
 1. I want him/her to be cared for at home. 2. Depending on the circumstances, I want him/her to stay at special elderly nursing home or health care facility for the elderly. 3. I didn't decide yet. 4. I don't know.
16. In the event that your spouse needs to be cared for and has nursing care at home, what kind of nursing care do you want for him/her?
 1. I want him/her to be cared for by family members. 2. Mainly I want her to be cared for by family members, but I don't mind him/her being looked after by care-workers other than family members on occasion.
 3. Mainly I want him/her to be cared for by care-workers along with family members. 4. I want him/her to be cared for only by care-workers.
17. In the event that your parents need to be cared for, where do you want them to be cared for? Which answer is closest to your feelings?
 1. I want them to be cared for at home. 2. Depending on the circumstances, I want them to stay at a special elderly nursing home or health care facility for the elderly. 3. I didn't decide yet. 4. I don't know.
18. In the event that your parents need to be cared for, and have nursing care at home, what kind of nursing care do you want for them?
 1. I want them to be cared for by family members.
 2. Mainly I want them to be cared for by family members, but I don't mind them being looked after by care-workers other than family members on occasion.
 3. Mainly I want them to be cared for by care-workers along with family members. 4. I want them to be cared for only by care-workers other than family members. 5. Other 6. I don't know.
19. When do you think that you will again be able to do the ADL (getting dressed, bathing, taking care of your appearance, eating, transportation, communicating) that you cannot complete now because of sickness or injury?
 1. In hospital 2. Just before leaving hospital 3. After being back home 4. Other

Thank you for your cooperation.

Results

1. The transition in ADL degree of independence of the disabled elderly

We compared the persons whose degree of functional independence were rank A1, A2, rank B1, B2 and rank C1, C2 at the first visit, and if the classified level of the degree of independence at the last visit was higher than the one at the first visit, the subjects were placed into the improved group, and if the level of the degree of independence at the last visit was lower than the one at the first visit, the subjects were placed into the worsening group.

As a result, the improved group consisted of 88 persons (25.7%) and the worsening group consisted of 40 persons (11.7%). A significant difference between both groups was found ($p < 0.01$), but there was no significant difference between the groups as regards composition of males and females and evaluation period respectively (Table 4).

Table 4

The survey into the change of the degree of independence in ADL of the disabled elderly

At the conclusion of the survey, the improved group consisted of 88 persons (25.7%) and the worsening group consisted of 40 persons (11.7%). A significant difference between them was observed ($p < 0.01$), but there was no significant difference between the groups as regards composition of males and females and evaluation period.

	Improved	Worsening	No changed
Numbers of subject	88(25.7%)	40(11.7%)	215(62.7%)
Average age	76.2 ± 12.5	77.6 ± 12.4	76.5 ± 13.3
Average number of visit	3.1 ± 1.3	3.1 ± 1.4	3.1 ± 1.4
Average evaluation period	175.1 ± 140.1	229.9 ± 167.9	229.9 ± 167.9

(a: P < 0.01 b: NS)

2 .Awareness of Nursing care

1)Lifestyle preferences

After gathering some demographic information, the survey questionnaire opened with some casual questions regarding perceptions of a) what television programmes people over 75 like to watch and b) how they would spend ¥100000 (about \$800). These questions had no serious intent, but were an attempt to explore people's stereotypes of older people.

Fig. 1 shows that, even in the simple matter of television preferences, there was a significant difference between what older people preferred and what younger people thought they preferred(Fig 1).

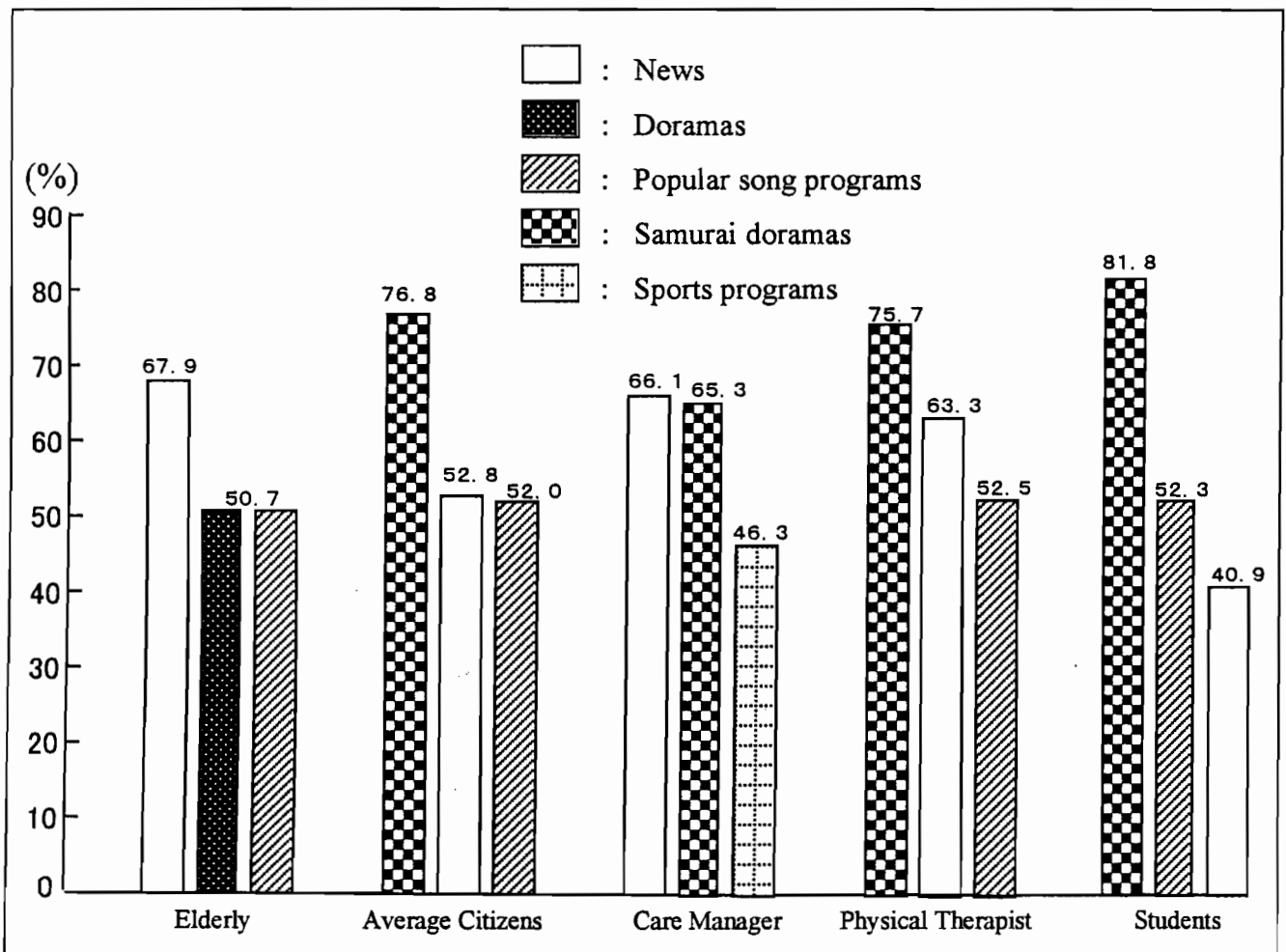


Fig1

Favorite TV programs

"Samurai dramas" didn't appear in the top 3 responses from a group of the elderly though in the answers from the other groups it appeared in the top 3. This shows that there is a difference between what the elderly think, and the image of the elderly that the others have, even over such a matter as TV preferences.

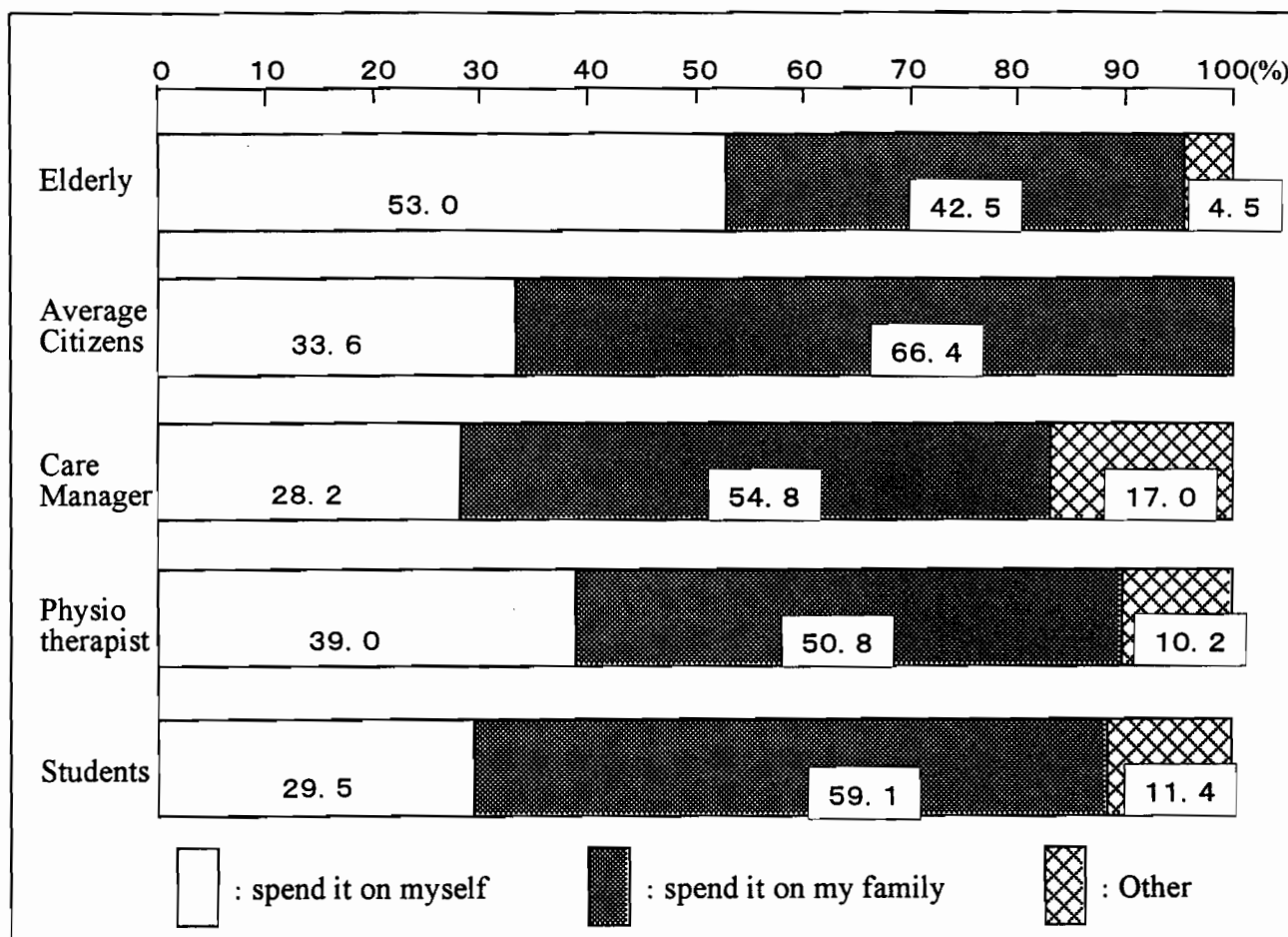


Fig2
 How do you think the healthy elderly aged 75 and over would spend an extra 100 thousand yen?
 A majority of the group of the elderly answered "spend it on myself, on the other hand the answers from the other groups stay around 25.0%. It is characteristic.

Fig.2 shows that there is also a significant discrepancy between older people's preferences and younger people's perceptions of their preferences in relation to the money question(Fig 2).

2) Perceptions of nursing care

Fig.3 shows the answer to the question "In the event that you need to be cared for, where would you like to be cared for?" 58.2% of the older group responded "I want to be cared for at home" This compared to 24.8% of the group of average citizens. 40.3% of the group of care managers. 32.8% of the group of physical therapists, and 27.3% of the group of students. These results show that the answer from the elderly is significantly higher than the other groups (P<0.01)(Fig 3).

Fig.4 shows the answer to the question "In the event that you need to be cared for and have nursing care at home, what kind of nursing care would you like?" Also, in Fig. 4 appear the results to the same question obtained from " The survey on the elderly" conducted by the General Administrative Agency of the Cabinet in 1995(Fig 4).

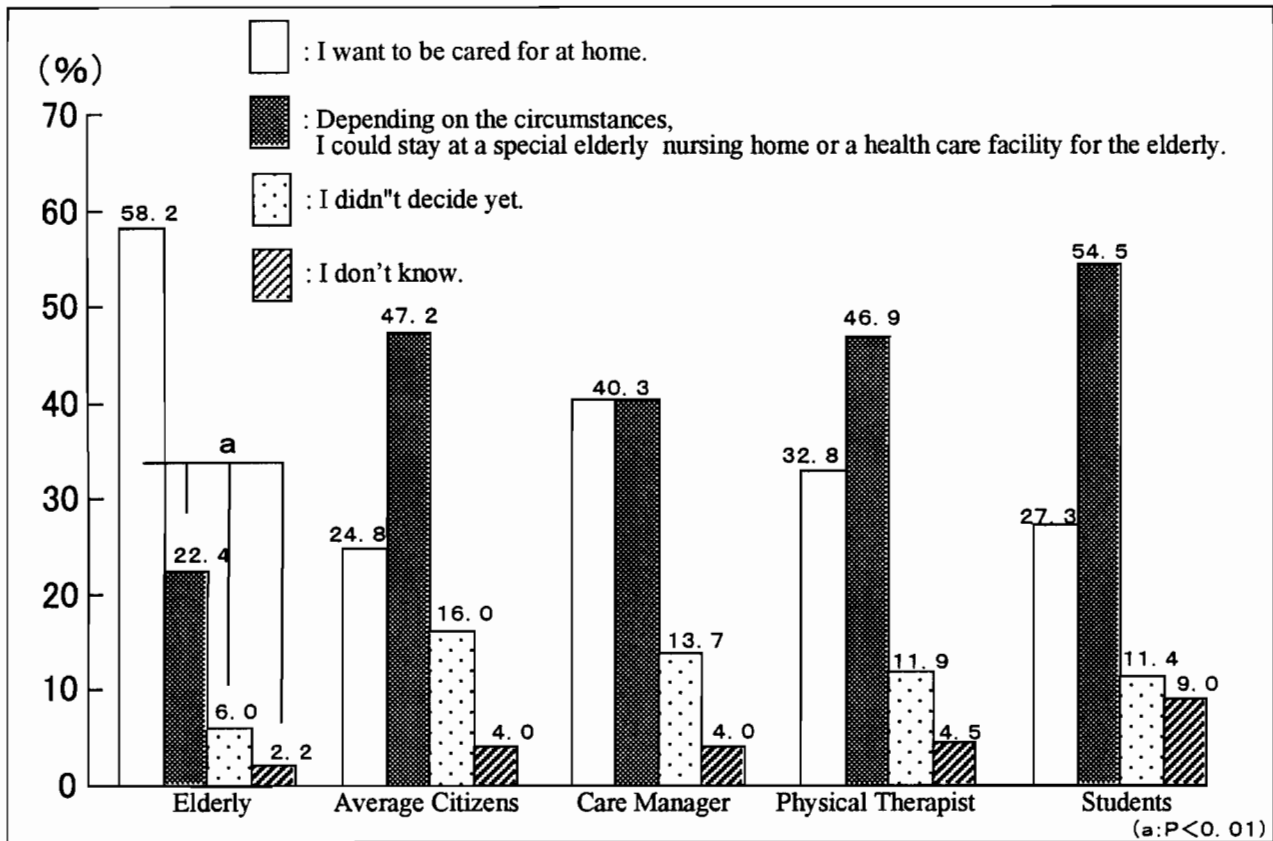


Fig3

In the event that you need to be cared for, where would you like to be cared for?

This result shows that the answer from the elderly is significantly higher than the other groups (p<0.01).

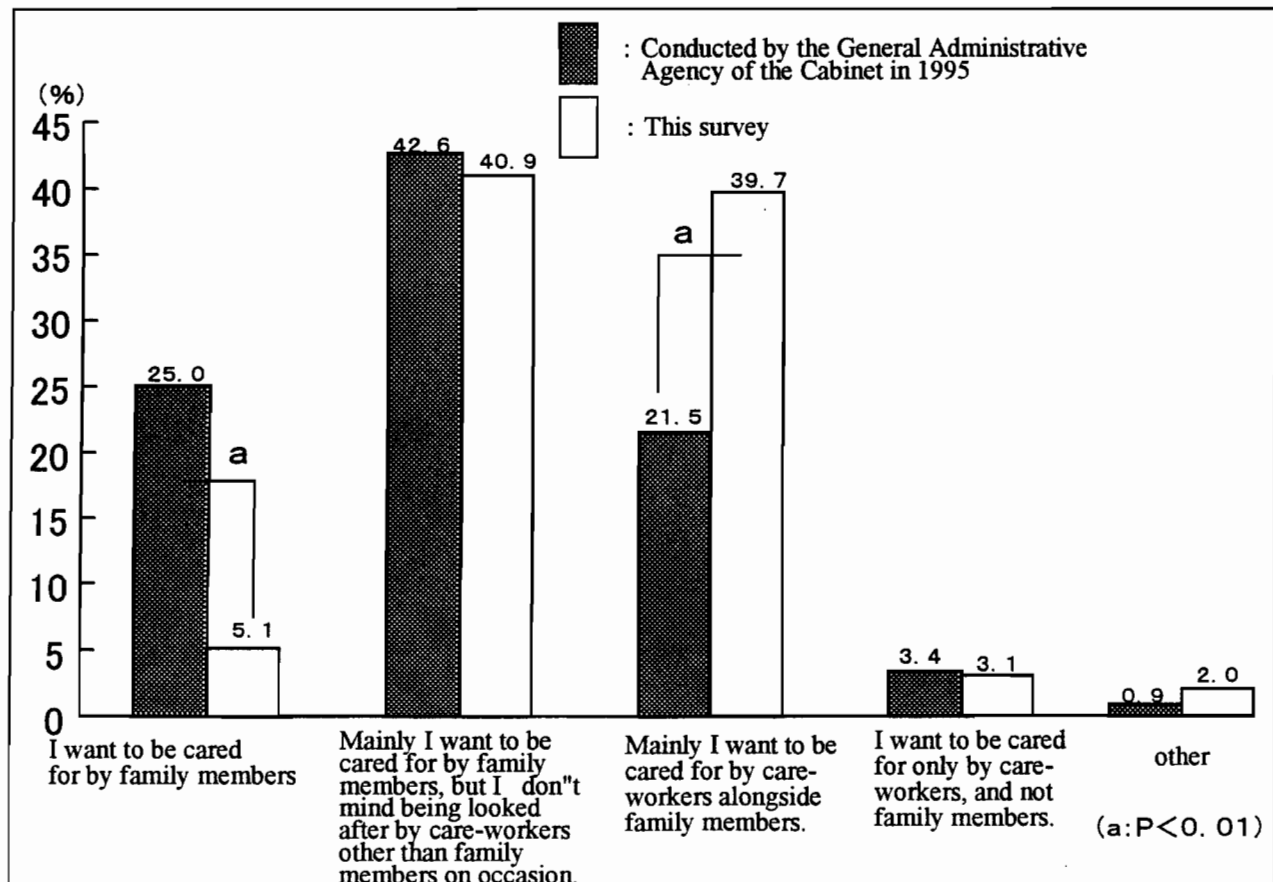


Fig4

In the event that you need to be cared for and have nursing care at home, what kind of nursing care would you like?

When both of the above were compared, regarding the response "I want to be cared for by family members.", this survey shows a significantly lower rate at 5.1% compared to the 25.0% response in 1995. On the contrary, regarding the response that "Mainly I want to be cared for by family members, but I don't mind being looked after by care-workers other than family members on occasion.", this survey shows a significantly higher rate at 39.7% compared to the 21.5% response in 1995 (p<0.01).

The results show two significant changes from the 1995 survey. Markedly fewer people wish to be cared for by family members alone, and far more would accept their family taking a lesser role with care workers doing most of the work ($P<0.01$).

There appears to have been a less dramatic change in preferences for care of older relatives (Fig. 5).

Nevertheless, there appears to have been a statistically significant decline in those wishing their relative to be cared for at home (41.6% vs 52.8%, $P<0.01$), while the percentage wishing them to be cared for in an institution has grown (35.1% vs 43.4%, $P<0.01$).

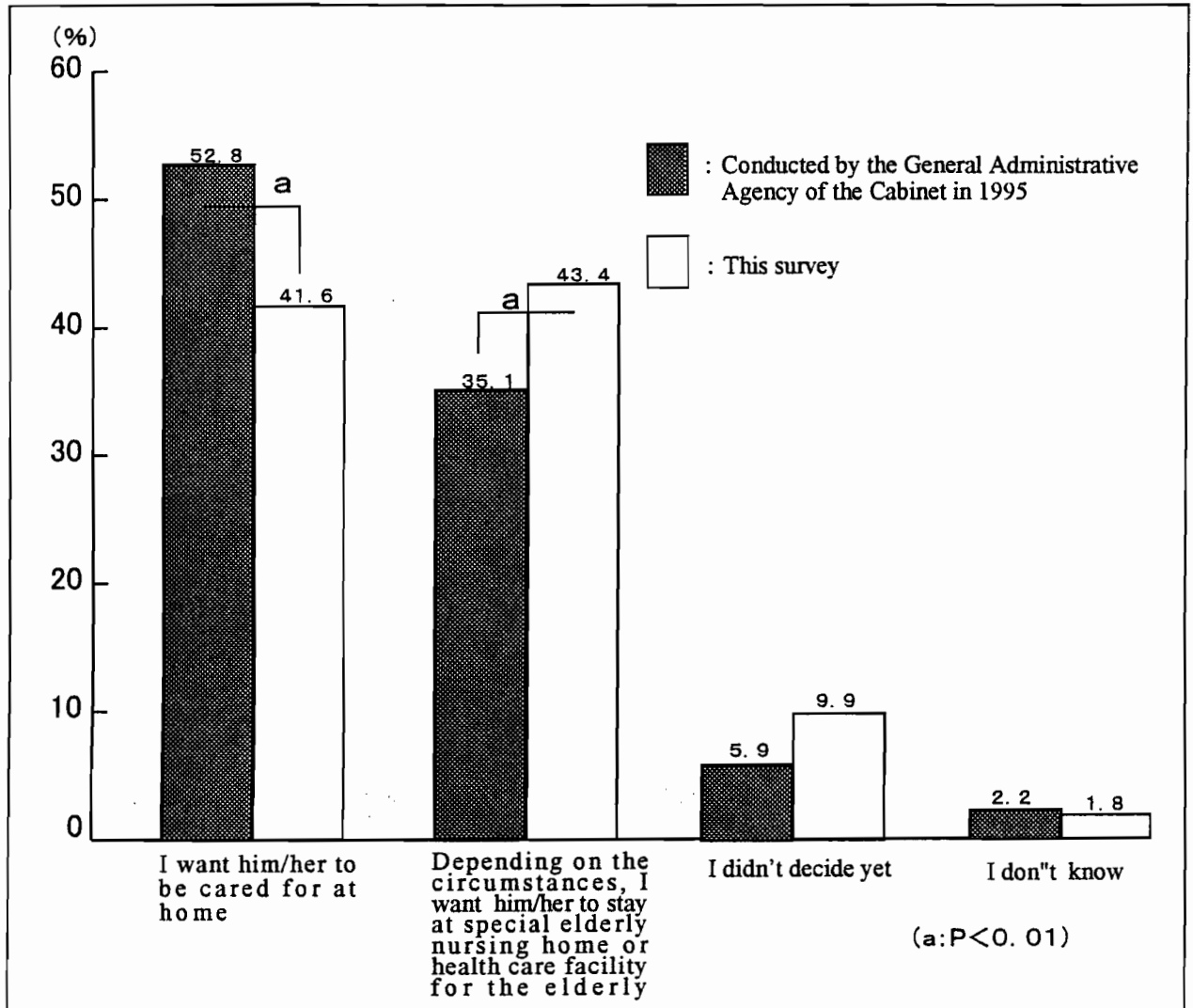


Fig5

In the event that your parents need to be cared for, and have nursing care at home, what kind of nursing care do you want for them?

When both of the above were compared, regarding the response that "I want them to be cared for by family members.", this survey shows a significantly lower rate at 41.6% compared to the 52.8% response in 1995 ($p<0.01$).

On the contrary, regarding the response that "Depending on the circumstances, I want them to stay at a special elderly nursing home or health care facility for the elderly.", this survey shows a significantly higher rate at 43.4% compared to the 35.1% response in 1995 ($p<0.01$).

Fig.6 shows the answer to the question "When do you think that you will be able to do the ADL again that you cannot complete now because of sickness or injury?"

The results show that the response rate of "Just before leaving hospital" from a group of average citizens is significantly higher than that of "After being back home". In the event that we regard the whole group as one group, 51.7% "After being back home" is significant higher than 30.3% "Just before leaving hospital" ($P < 0.01$) (Fig 6).

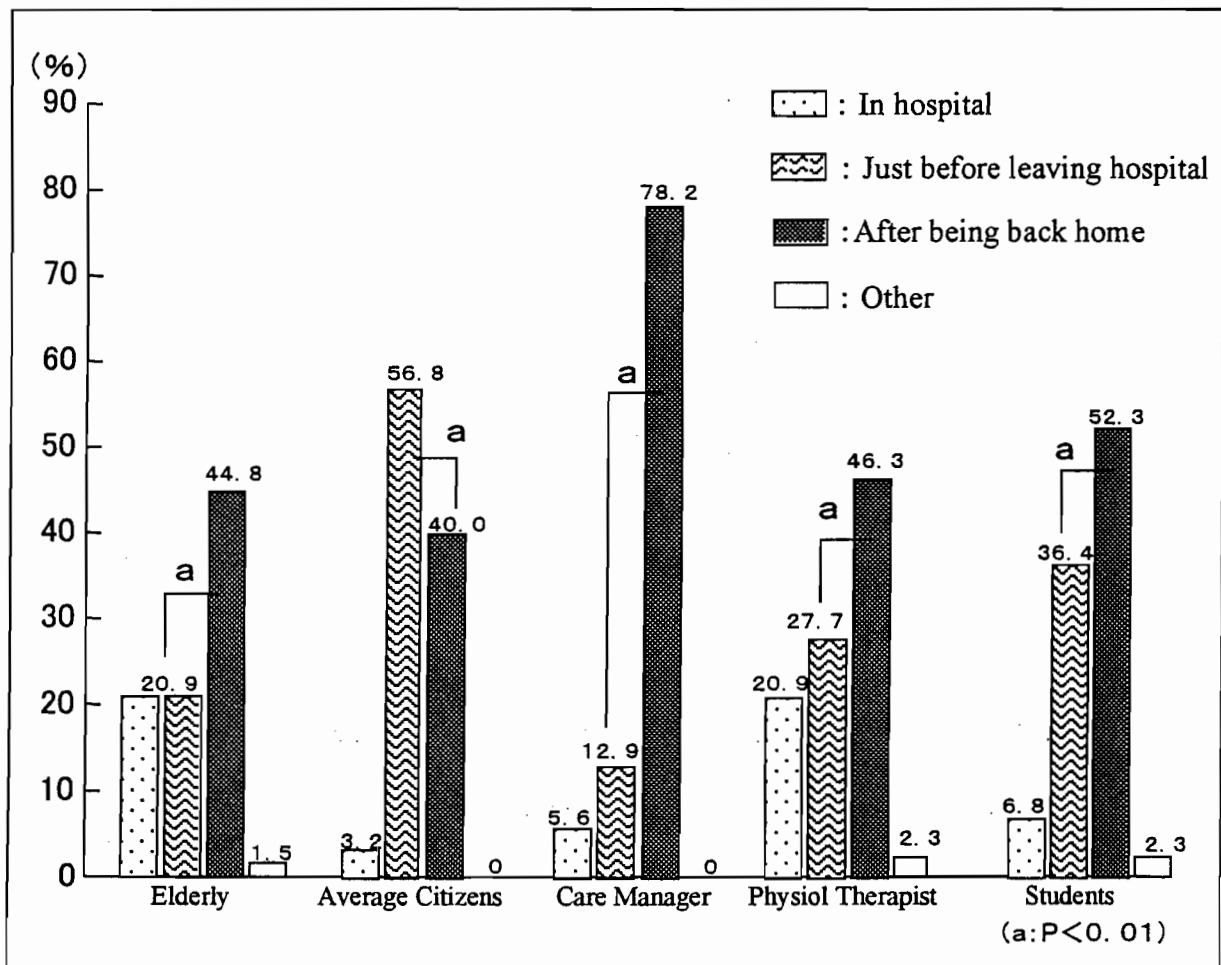


Fig6

When do you think that you will be able to do the daily activities again that you cannot complete now because of sickness or injury?

This result shows that the response rate of "Just before leaving hospital." from a group of average citizens is significantly higher than that of "After being back home." In the event that we regard the whole group as one group, 51.7% "After being back home" is significant higher than 30.3% "Just before leaving hospital" ($p < 0.01$).

Discussion

1. The transition in ADL degree of independence

In existing research, there are many reports that the degree of functional independence of the elderly with disabilities declines noticeably at home.

Arakawa conducted follow-up studies on 206 people who were hospitalized with cerebral strokes between 1989 and 1990 after discharge from hospital and reported that in the three years after discharge from hospital, the ADL independence Level of persons aged 70 and over worsened, even using the evaluation scale of the Barthel index⁹⁾.

Sajiki mentions that the functional conditions of the elderly who have suffered cerebral strokes needs to be responded to as a chronic progressive condition on a long-term basis¹⁰⁾.

Against preceding research which has shown functional attrition after discharge from hospital like this, Kelly-Hayes reported that the Barthel index of the patients who suffered a cerebral stroke decreased slightly one year after the onset but statistically there was no significant difference¹¹⁾.

On the other hand, McGinnis examined patients with cerebral strokes between 2 and 5 years after rehabilitation treatment in hospital using the Barthel index, and consequently reported that the functional level had lowered. In this advanced research that the ADL independence level of the elderly with disabilities lowers as time goes on, seems to be a commonly held belief¹²⁾.

It is obvious that the ADL degree of independence lowers with age if it is monitored for years. But the result of our research showed that if it was measured for 2 years or so, the rate of improvement of the ADL independence level is higher than the rate of attrition, due to age, of the ADL independence level.

In addition, it was also shown that citizens had awareness that the ADL independence level improved at home in this research.

Rimmer considered that tackling basic health enhancement for persons with disabilities is good prevention from secondary disablements. We can see a part of the effect from the results of our research as well. It is necessary to go forward and approach positively the future of nursing care for the elderly, more from the point of view of preventing the need for nursing care¹³⁾.

2. Lifestyle Preferences

Casual questions such as, what is your favorite TV program, or how would you spend an extra 100,000 yen, have revealed the gap between the image of elderly people that young and middle-aged people hold and the real picture of them.

For example, the results of the present study illustrate the picture of elderly people who prefer watching news programs and act on their own initiative economically, while young and middle-aged people's image of the elderly is "people that like watching samurai dramas and are dependent economically".

The Annual Report on Health and Welfare for the fiscal year 2000 closely annualized the real economic picture of elderly people, and concluded that the elderly are economically active. In addition, Masuda has shown that the elderly people's expenses are on the rise, actively spending, in particular for their own enjoyment such as on education and recreation fees, concluding that in economic aspects, the elderly today have intense consciousness of acting to enjoy their life¹⁴⁾.

However, at the actual site of nursing care, the elderly are seen as economically weak and quite often they are not given the opportunity to make economic judgments about the installation of nursing care services, welfare equipment and so on.

Faced with the results of this study and the objective facts stated in this paper, one can understand that images such as "elderly people like samurai dramas" or "elderly people are subordinate economically" have no foundation.

In order to accomplish the appropriate nursing care services, we have to keep close to the real picture of an individual or group of people, without getting caught up in groundless wrong images¹⁵⁻¹⁸⁾.

3. Awareness of Citizens about Nursing Care

Taking into account the above points, the result of this study shows that elderly people strongly wish to receive nursing care at home. This result is understandable for the elderly group, for whom nursing care is a serious issue. However, it would be shortsighted to think only about in-home care services for older people. Currently in Japan, only two choices, either in-home care or a special elderly nursing home, are generally available. We have to consider not only the whole concept of special elderly nursing homes, but also in-home services such as group homes, collective housing, or assisted-living condominiums in the wider perspective.

Public consciousness about tenant facilities has been changing from "facilities that one is admitted into" into "facilities where one decides to move in" since nursing care insurance started⁵⁾. In this survey, more of the respondents answered the question "when your parents need nursing care, where do you want them to be taken care of?" with a place other than their home, compared to the 1995 survey. This result reflects the change in public consciousness. However, the sample size was small in this survey and was only conducted in the northern part of Hyogo Prefecture, compared to the 1995 survey, which was conducted throughout Japan. We hope to survey a larger area of Japan in the near future.

Also, to the question of "when you need nursing care and you are taken care of at home, what kind of nursing care do you want to receive?" answers saying "mainly an outside service such as in-home nursing care worker, but I want to receive family member's care too" significantly increased, also indicating the change in citizen's attitude toward nursing care.

Likewise, with the application of nursing care insurance as a turning point, a paradigm shift concerning elderly social security has occurred both in "system" and "civil consciousness." In order to meet this kind of change and provide appropriate care services, it is important for us, who provide the care service, to try innovating value all the time and to keep the attitude of watching the society in the real world without prejudging

Conclusion

The results obtained in the present study suggest that to encourage effective measures for the care of the elderly required by the coming ageing society, the support provided to them by social care on the basis of improvement in ADL and understanding their diverse circumstances and flexible service expansion to respond to their needs are required. Finally to carry out such things as stated above, it is meaningful to examine such services provided by average citizens, not only for some experts to discuss measures of nursing care. As another point, we, who provide care services, should always be sensitive to society.

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