Characteristics of Support Cases for Single Elderly People in Daily Life, Medical Care, Long-term Care, and Death Situations

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Abstract
In Japan, the number of older persons who cannot be supported by family members in decision-making is increasing. Difficulties in making medical decisions due to dementia or deteriorated physical conditions are apparent. Considering the aging process, difficulties in maintaining the quality of daily living must exist beforehand, and support is required from earlier stages. We collected real cases from local government staff, care managers, social welfare personnel, and private support companies, according to five scenarios of supported decision making: (1) Difficulty with daily activities, (2) Receiving serious medical treatment, (3) Being discharged and rebuilding life, (4) Rearranging care services and residence according to functional decline, and (5) Dealing with death. Of the 134 collected cases, most were in Scenario 4 (n = 52) and involved men aged 75 to 84 years (n = 45). Even if it becomes difficult for a person to recognize problems and carry out solutions, expressing intentions, which is the basis of decision-making, plays an important role for the person and the most sustainable one. What is lost by the absence of family members is the "point of contact" between the individual and the outside world, which is related to the fact that issues cannot be discovered until Scenario 4 and that support at each stage is not continuous. In light of the decrease in the number of supporters and the increase in the number of people who need support, contact should be established in a way that requires less human involvement, such as through the use of information technology.

Keywords: Decision Making, Activities of Daily Living, Legal Guardians, Quality of Dying and Death

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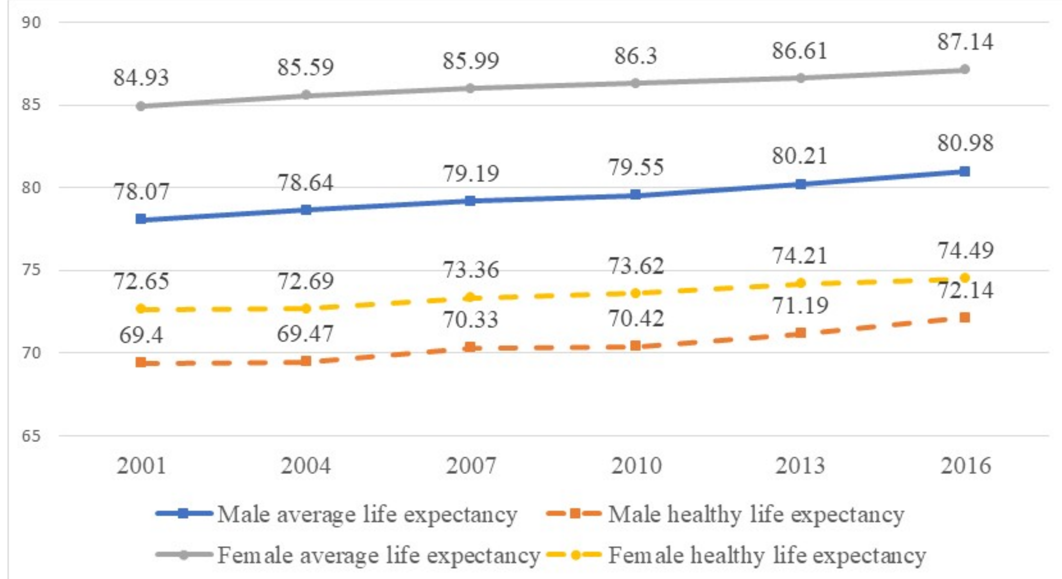
Background

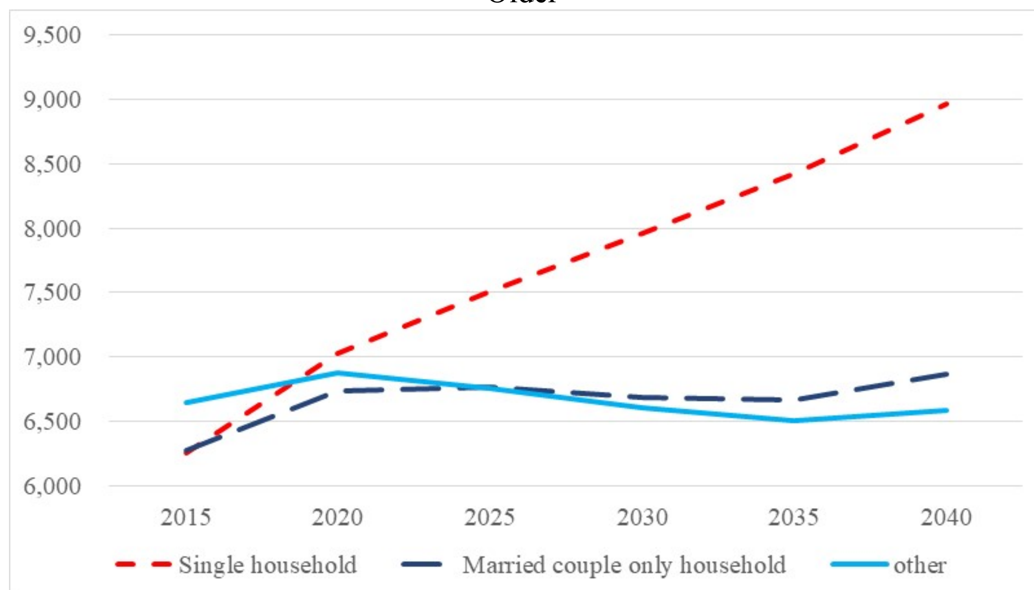
Despite the fact that longevity is increasing in Japan, the final approximately 10 years of life are characterized by some form of functional impairment (see Figure 1).

Figure 1: Difference between Healthy Life Expectancy and Average Life Expectancy[1]



At the same time, families are becoming smaller. As the birthrate declines and the unmarried rate increases, the number of people without child support is expected to increase (Figure 2).

Figure 2: Number of Households in Which the Head of the Household Is 65 Years Old or Older[2]



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[1] Annual Report on the Ageing Society: 2018 (Summary)., Cabinet Office, Government of Japan

[2] For the period from1990 to 2015, the data are from the National Census conducted by the Statistics Bureau of the Ministry of Internal Affairs and Communications. For the year 2040, the data are from the National Institute of Population and Social Security Research, “Future Projections of the Number of Households in Japan (Estimates for 2008).”

Under these conditions, we believe that the biggest challenge facing older people is the increased burden of decision-making in the final stages of life. The reasons for this are as follows.

First, as their physical and mental functions decline with advancing age, older persons have to make more important and novel decisions than before, for example:
What kind of daily assisted living support services do they need?

- What kind of housing for older adults will they move into?
- Should they undergo a major surgery or not?

Such decisions may need to be made.

In addition, from a policy perspective, the goal is to optimize one's own life by purchasing services from the market (exercising choice). The basic concept emphasized by Japan's public Long-term Care Insurance System is the opportunity to receive services from a variety of entities based on choice (Figure 3). While it is desirable to have a variety of options and to be able to make choices, it is also a heavy burden, considering the decline in physical and mental functions that is the reason for needing such services.

Figure 3: Basic concept of the Japanese public Long-term Care Insurance System[3]

Introduction of the Long-Term Care Insurance System
(a mechanism to enable society to provide long-term care to the elderly)

【Basic Concepts】

○ **Support for independence:** **The idea of Long-Term Care Insurance System is to support the independence of elderly people, rather than simply providing personal care.**

○ **User oriented:** **A system in which users can receive integrated services of health, medicine, and welfare from diverse agents based on their own choice.**

○ **Social insurance system:** **Adoption of a social insurance system where the relation between benefits and burdens is clear.**

Regarding this issue, the use of the adult guardianship system is now being promoted, and decision-making guidelines are being developed.

Along with the introduction of long-term care insurance, support measures for property management and personal care of people with impaired judgment are being developed, mainly through the adult guardianship system.

Guidelines for decision-making support have been developed for people receiving end of life care and for people with dementia. Figure 4 illustrates these guidelines.

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[3] https://www.mhlw.go.jp/english/policy/care-welfare/care-welfare-elderly/dl/ltcisj_e.pdf

Figure 4: Recently developed guidelines for decision making

Title	Year
Guidelines for Decision-Making Support for the Provision of Welfare Services for Persons with Disabilities, etc.	2017
Guidelines for Decision-Making Support in Daily Life and Social Life of People with Dementia	2018
Guidelines for the Decision-Making Process for Medical Care and Treatment in the Final Stage of Life, Revised 2019	2018
Guidelines on Support for People Without Relatives Who Have Difficulty in Making Decisions Regarding Hospitalization and Medical Care	2019
Guidelines for Guardianship Affairs Based on Decision-Making Support	2020

It is certain from population projections that the number of people who cannot receive support will increase and that resources for support will decrease.

We anticipate that there will be a need for methods that can support decision-making over the long term by broadening the range of targeted people beyond only for those with dementia or who are faced with end-of-life.

Purpose of the Study

The purpose of our study was to determine what activities are needed to maintain quality of life and quality of death in the later stages of life. To accomplish this purpose, we set up five scenarios for investigation and analysis.

In Scenario 1, the subject has a slight functional decline and has minor difficulties in daily life, such as housework.

In Scenario 2, the subject was hospitalized and has undergone serious medical treatment.

In Scenario 3, the subject was discharged from hospital and has rebuilt their life.

In Scenario 4, the subject has experienced further functional decline and has reassessed the services they use and where they live.

In Scenario 5, the subject has expressed their wishes regarding procedures to be followed after their death.

The results of this study are expected to provide suggestions regarding the kind of support that will be needed in the future and how to provide it in order to ensure quality of life and quality of death in old age.

Method

This survey was conducted via email between December 25, 2019, and February 10, 2020.

Study Sample

The survey was sent to professionals in six prefectures in Japan who had agreed to participate in the survey.

The participating institutions and professions are shown in Table 1. They included public institutions such as local government, social welfare councils, and community comprehensive support centers; welfare supporters closely associated with the lives of older persons, such as care managers and community members; professionals, such as medical institutions and legal professionals; and private stakeholders, such as elderly support providers.

Table 1: Participant institutions and professionals

Classification	Number of participants	Number of cases collected
Local government	3	46
Social welfare councils	9	31
Community comprehensive support center	3	4
In-home care support offices	2	8
Council of Civil Liberties Commissioners and Children's Commissioners	1	1
Medical institutions	2	18
Lawyers and judicial scriveners	2	6
Private companies	2	20

Criteria for Cases to Be Collected

Information about cases in which no supporters were available and decision-making difficulties had arisen was collected from participants via e-mail.

Questionnaire

The data collected were as follows:

- Basic characteristics of the support recipient (sex, age, economic status).
- Relatives and other supporters (family members living together, relatives, friends, acquaintances, neighbors).
- Health status, level of care required, cognitive function, and decision-making ability of the person to be supported.
- Reason for support, situations where support was difficult, contents of support, and collaborating organizations.
- Basic characteristics of respondents (occupation).

Analysis

We analyzed cases according to their decision-making process and clarified their characteristics.

The Stages of the Decision-making Process

1. Problem recognition/need clarification.
2. Designing solutions to problems.
3. Execution of the solution.
4. Evaluation.

In the analysis, we focused mainly on problem recognition/need clarification and on designing solutions to problems, both of which are central to decision-making.

Results

Basic Information

Number of Cases

A total of 134 cases were collected including both cases involving multiple scenarios and cases involving a single scenario. When categorized based on the most major support scenarios, Scenario 4 was the most common (Table 2).

Table 2: Collected cases (*N* = 134)

Scenario	n	%
1	30	22.4%
2	12	9.0%
3	6	4.5%
4	52	38.8%
5	27	20.1%
unrecognizable	7	5.2%

Basic Attributes of the Subjects

Basic attributes of the subjects of the cases are shown in Table 3.

Two-thirds of the subjects who received support were male, and the most common age group was 75 to 84 years old.

Many did not have a spouse now due to unmarried, bereaved, or separated; even if they had children, there were many situations where support could not be provided due to lack of contact, refusal to get involved, or the child's own disability.

Table 3: Basic Attributes of the Subjects

	Male		Female		Total	
	n	%	*n*	%	*n*	%
Age						
40 to 64 years old	10	11.1	2	4.5	12	9.0
65–74 years old	24	26.7	7	15.9	31	23.1
75–84 years old	45	50.0	18	40.9	63	47.0
85–94 years old	10	11.1	14	31.8	24	17.9
Over 95 years old	1	1.1	3	6.8	4	3.0
Marital status						
Married	6	6.7	2	4.5	8	6
Common-law marriage	1	1.1	1	2.3	2	1.5
Divorced	33	36.7	10	22.7	43	32.1
Bereaved	20	22.2	16	36.4	36	26.9
Unmarried	28	31.1	15	34.1	43	32.1
Unknown / No record	2	2.2			2	1.5
Total	90	100	44	100	134	100

Scenario 1 Cases

Typical cases related to Scenario 1 are as follows.

The person feels anxious about the future.

The subject had a bad relationship with relatives who supported them during their sudden hospitalization.

The subject has no one to ask for help when they are hospitalized in the future, and are worried about what to do.

The patient talked with the social welfare council and care manager, clarified the points of concern, and signed a voluntary guardianship contract and a power of attorney for posthumous affairs contract with a legal professional.

Signs of difficulty in continuing independent living.

Garbage is strewn around their apartment, and the landlord is concerned.

The local government person in charge of welfare talked with the subject and the subject started using the nursing care insurance service.

It becomes difficult for the subject to continue with independent living, as they cannot receive support from people close to them.

They live in an elderly care facility because of the aftereffects of stroke. The subject’s younger brother became ill, and there was no one to pay the bills or do the subject’s shopping.

A private support provider was contracted to provide services on behalf of their brother.

Characteristics of the Problem-Solving Process in Scenario 1

The characteristics of the problem-solving process in Scenario 1 are as follows.

Difficulties

Anticipation of future problems is often vague or limited to a specific area (e.g., worry about the grave), so designing solutions requires clarification of the problem and confirmation of the situation.

Since subjects’ judgment at this stage is not impaired enough to use the public system, they have to go through the process on their own.

Since the issues are extensive and long-term, it is necessary to formulate multiple solutions.

Advantages

The subject or their close supporters are often willing to solve the problem actively.

Scenario 2 Cases

Typical cases related to Stage 2 are as follows.

The subject's intentions were clear, but the medical institution refused treatment because there was no one else to sign the consent form.

The subject was transported to the emergency room with a broken bone. The subject consented to the surgery, but because of their advanced age, the medical institution demanded that another person sign the consent form; otherwise, the subject would be discharged. Since the subject's intentions were confirmed, a staff member of a public institution who knew the subject well negotiated with the hospital, and the medical institution decided to perform the surgery with only the subject's signature.

It is difficult to perform a medical procedure because the subject's intentions are unstable.

A subject is diagnosed with cancer after being transported to an emergency room and has to choose whether to undergo surgery. Since the patient's intentions were inconsistent, the ethical review committee of the medical institution and people who knew the patient had a meeting and decided to perform the surgery.

Characteristics of the Problem-Solving Process in Scenario 2

The characteristics of the problem-solving process in Stage 2 are as follows.

If the subject's intentions are clear, it is possible to negotiate for medical treatment based on those intentions.

If the subject's intentions are not clear, a collective review based on the subject's circumstance is conducted by the ethics review committee or conference.

Scenario 3 Cases

Typical cases related to Scenario 3 are as follows.

Unable to complete procedures and negotiate for services to be used at home after discharge from the hospital.

The landlord was trying to evict the subject at the time of hospitalization, but the social worker of the medical institution and the care manager from the Long-term Care Insurance System took care of the procedures for using the long-term care insurance services and negotiations with the landlord, and the subject was discharged with the cooperation of local residents.

Characteristics of the Problem-Solving Process in Scenario 3

The characteristics of the problem-solving process in Stage 3 are as follows.

Intensive support is provided through the involvement of multiple supporters, including discharge coordinators at medical institutions, care managers at in-home care support offices, officers at local governments tasked with seeing to older persons' welfare, social welfare councils, community comprehensive support centers, private support companies, and legal professionals.

The individual is often unable to be involved because of a decline in physical and mental functions.

Collaboration with informal resources (neighbors and acquaintances) can be attempted.

Stage 4 Cases

Typical cases related to Stage 4 are as follows.

It became difficult for the subject to live at home due to a decline in IADL（Instrumental Activities of Daily Living）, and since the subject did not fully understand the necessary services and public systems, the community comprehensive support center provided support and connected her to private services.

There were accidents involving fire and falls, and the subject needed some kind of support to continue living at home, but they did not understand the use of the adult guardianship system.

A local support organization helped the subject to sign a contract with a private life support provider.

Characteristics of the Problem-Solving Process in Scenario 4

The characteristics of the problem-solving process in Scenario 4 are as follows.

The subject has difficulty recognizing the problem and may have unrealistic intentions.

The problem-solving process needs to be led by an entity other than the subject.

A combination of institutional support, legal professionals, and other support resources is necessary.

Scenario 5 Cases

Typical cases related to Stage 5 are as follows.

The subject made the decision based on life expectancy and dealt with it by means of a contract.

The subject had not socialized privately since retirement. The subject became ill and was hospitalized, and it was found that they had approximately two weeks to live. After consultation with the social worker at the medical institution and the care manager, the patient signed a contract to entrust the post-death procedures, including their funeral and disposal of assets, to a lawyer.

There was no one to take care of the remaining procedures after death.

A subject who had been using a certain public service died suddenly and payment for their cremation and removal of their belongings from the residence was needed. In addition, the subject's bank book and other documents needed to be transferred to relatives, but the relatives refused to get involved, so the public service could not be reimbursed, and the bank book could not be returned.

Characteristics of the Problem-solving Process in Scenario 5

The characteristics of the problem-solving process in Stage 5 are as follows.

If information regarding the subject's will and heirs, and the power of attorney contract for dealing with posthumous affairs are known, the people close to the subject can provide support based on that information.

When a person dies without such information being available, the local government can take over the body, cremate and bury it, but the disposition of property and payments for services used before death may go unpaid.

Discussion

Among the five scenarios, Scenario 2, which involves the criterion of medical expertise, and Scenario 5, where a power of attorney for postmortem affairs possibly exists, can be addressed even though they are significant because the issues are limited and a specialized framework is in place.

In scenarios 3 and 4, where the subjects are living their individual daily lives, are more diverse and the burden of support is higher because the subjects' ability to solve problems has reduced.

Even if it becomes difficult for a person to recognize problems and carry out solutions, expressing intentions, which is the basis of decision-making, plays an important role for the subject and is the most sustainable one.

What is lost by the absence of family members is the "point of contact" between the subject and the outside world, which is related to the fact that issues cannot be discovered until Scenario 4 and that support at each stage is not continuous.

Conclusion

Receiving support after a subject's problem-solving ability has deteriorated to the point that they are unable to maintain the quality of daily life on their own is highly burdensome for both the support providers and the subject. Currently, the burden is increased by the discontinuous support provided at each stage.

Maintaining contact between older persons and the outside world prior to Scenario 1 will enable early identification of problems and reduce the difficulty of solving problems in subsequent stages.

In light of the decrease in the number of supporters and the increase in the number of people who need support, contact should be established in a way that requires less human involvement, such as through the use of information technology.

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