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Characteristics of Decision-Making by Family Members When Older Adults Are Hospitalized in Emergency Cases with Life-Threatening Conditions

Chiyoko Kimura¹, Ruriko Kidachi¹, Tetsuko Takaoka², Motoya Yamada³, Yosuke Kamata⁴

¹Department of Nursing, Faculty of Nursing, Aomori Chuo Gakuin University, Aomori, Japan

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Abstract

Aim: This study aims to elucidate decision-making characteristics based on interviews with family members with experience in having to select treatments for older adult patients who have been hospitalized following emergency transport to the hospital. Design: Semi-structured interviews were conducted with 10 individuals with experience in surrogate decision-making for an older adult family member. Methods: The recorded interview data were transcribed verbatim, divided into minimum semantic units, and coded. Next, categories and subcategories were abstracted. A comparison was made with the conceptual constructs of a previous study that examined decision-making by families in a life-threatening crisis. Results: Four categories were extracted from 489 antecedents, 370 attributes, and 388 consequences. One new category was abstracted for each of: 1) antecedents: observing abnormalities and responding, while being worried about death; 2) attributes: deliberating on the patient prognosis, the relationship with the patient, and what they believe the patient would want; and 3) consequences: continuing support during convalescence. It is desirable to provide support based on the characteristics of families of older adults, including considering the psychological burden on the families who make surrogate decisions, and also the burden of subsequent caregiving because it is not and in the present environment has not been common for patients to express their wishes beforehand.

Keywords

Older Adults, Surrogate Decision-Making, Life Crisis, Emergency Transport

²Department of Nursing, Faculty of Human Sciences, Hokkaido Bunkyo University, Eniwa, Japan

³Department of Nursing, Graduate School of Health Sciences, Hirosaki University, Hirosaki, Japan

⁴Department of Nursing, Faculty of Health and Welfare, Hirosaki Iryo Fukushi University, Hirosaki, Japan Email: chiyoko-kimura@aomoricgu.ac.jp

1. Introduction

Japan has one of the oldest populations in the world. The mean life expectancies among males and females are 81.64 and 87.74 years, respectively [1]. From an international perspective, Japan has the second highest life expectancy for males and the highest for females [2]. Japan has announced that its ratio of aged in the population in 2021 was projected to be 28.9% [3]. In 2021, Japan reported the highest rates of emergency transport among developed nations, with 62.3% of users being older adults [4], involving mostly older adults with severe or moderate levels of disease or injury which required hospitalization (severe, 10.2%; moderate, 51.5%) [5]. The diseases involved were mainly circulatory, including cerebral and cardiac diseases (19.9%) among these older adults (78.7%) [6], with underlying diseases frequently of a life-threatening nature [7]. Older adults often present non-typical symptoms, multiple diseases, and decreased organ reserve capacity, and easily become critically ill [8]. These characteristics of older adults make both treatment and the selection of treatments difficult, and patients are unable to evaluate the treatment choices due to the severity of the condition and poor cognitive functions [8]. To respond to these cases, the concept of advance care planning (ACP) has been gaining popularity in recent years in Japan, and surrogate decision-making is still mainly made by family members.

1.1. Background

Published findings in the field of emergency and critical care have shown that there are the following problems in surrogate decision-making: differences in thinking and emotion occur among family members [9] [10], and one in three among family members selecting surrogate treatments experience psychological after-effects, such as regrets which may linger for months after the death of a patient [11]. Medical staff also report concerns regarding surrogate decision-making involving emergency cases of the elderly, such as doubts regarding the treatment selection as really aligned with the patient intentions [12] and if the selection was made with an understanding of the consequences of treatments prolonging lives [13]. In some cases, patients were transported directly from a nursing facility to the hospital and were given treatments that did not agree with the intentions of the family or family doctor, even in cases where discussion (treatment decisions) had been made in advance [7]. These issues raise the possibility of conflicts in determining the intentions of elderly patients arriving at hospitals via ambulance and may hinder cooperation among family members, family doctors, and the hospital.

When it is difficult for a person to express intentions, it may be assumed that there is a potentially serious psychological burden on the family making decisions about the treatment at the end of life for a patient, unless the patient has expressed such intentions prior to the hospitalization. This study explores the kinds of care that could support the family in such cases to reduce the burden of surrogate deci-

sion-making. Since 1987, the Japanese Ministry of Health, Labour and Welfare has conducted repeated investigations of terminal-stage medical care—including the initiation, non-initiation, and discontinuation of treatments—focusing on terminal-stage cancer. However, since the 2007 release of the "Guidelines for decision-making procedures in terminal-stage medical care" [14], aging and the increasing number of older adults with dementia have been included as areas of concern. In 2015, the "terminal-stage medical care" term in the Guidelines was changed to "medical care in the final stages of life" [15], followed by a revision of the title to "Guidelines for decision-making procedures about medical and other care in the final stages of life" in 2018 [16]. The concept of advance care planning was also included in the Guidelines, and the term "life conference" was introduced to encourage the acceptance of advance care planning in Japan [17]. However, while a general recognition that people should make their own decisions about how to approach death is becoming increasingly accepted, efforts to achieve this have not been systematic.

While considerable time may be needed for acceptance of the need for advance care planning, surrogate decisions are often being made by family members. A literature review of surrogate decision-making for older adults reveals that, in addition to the decision-making related to gastrostomy, introduction of tube feeding [18] [19] [20], and transfer to at-home care, there have been studies about care environments [21] [22] and final stages of living and caregiving [23] [24] [25]. However, the only study that focused on surrogate decision-making for acute-phase older adults was one by Ishizuka and Inoue (2015) [26].

1.2. Research Question

This study aims to identify details of surrogate decision making based on narratives provided by family members with the experience of selecting the treatment for older adults after emergency transport and hospitalization, and identify the decision-making characteristics specific to older adult cases based on the differences in the concepts extracted in Study I, which was not specific to older adults.

2. Methods

2.1. Design

Interviews with people with experiences of treatment-related surrogate decision-making for older family members were used to create the conceptual constructs referenced in our research question. The comparative concepts were based on a previous study by the present authors—"A concept analysis of decision-making by families in critical life situations" (Study I) [27]. The concept of surrogate decision-making for older adults is in accordance with Rodgers' (2000) concept analysis approach, which is not specific to older adults [28].

The literature reviewed in Study I was the result of a search for all years (from 1975 to 2016) available in PubMed, an English-language medical database. Study I covered qualitative studies in the emergency and critical care fields that focused on families involved in treatment selection for family members, not specific to older adults (but excluding children), and analyzed 29 articles published in and outside Japan. Based on Rodgers' concept analysis approach, the extracted articles included attributes that constitute the concept, antecedents preceding the occurrences involved in the concept, and consequences subsequent to the concept investigated. The contents related to family decision-making were extracted, coded, and categorized by comparing their similarities and differences. Similarly, assuming that support of medical professionals may influence decision-making, the support of medical professionals was extracted as a complementary concept. As a result, five attributes, three antecedents, and three consequences were identified for the family decision-making in treatment selection in life-threatening situations. For the support of medical professionals, the number of attributes, antecedents, and consequences identified in each category was one. The "decision-making for treatment selection by families in a life-threatening crisis" is a process where families of the older adult patients make treatment decisions in the unusual environment of "life-saving", time constraints, and unstable psychological conditions, while seeking comfort from medical professionals and considering the feelings of other family members.

A qualitative, inductive analysis was employed using semi-structured interviews. The criteria for selecting the participants were that the individual:

- had decided on a treatment for a family member over 65 years of age in connection with a life-threatening crisis, such as emergency transport and hospitalization, within the last five years; and
- was evaluated to be capable of being interviewed and provide informed consent.

2.2. Basic Characteristics of the Study Participants and Adult Patients

Ten families of patients met the criteria and participated in the study (Table 1), and each participant (males, 2; females, 8) was interviewed once, for a mean duration of 42 minutes. The mean age of those interviewed was 57.2 years (SD \pm 9.3), and their relationship with the adult patient involved was as follows: three were wives, five sons or daughters, and two were grandchildren. Six lived with the older adult patients, while four did not. The mean age of the older adult patients in the study was 80.6 years (SD \pm 10.6) and their medical history included diseases such as hypertension, diabetes, myocardial infarction, and leg venous thrombosis. Two elderly patients suffered from a mild decrease in cognitive function. One of the older adults had no underlying diseases.

2.3. Data Collection

Data were collected from December 2017 to August 2020. The study covered the

Table 1. Details of the study participants (interviewees), patients, and their condition at hospitalization, and treatment.

Patient	Intervie- wee age	Relation with patient		Living alone/ with family	Disease history	Transport to hospital	Disease at admission	Treatment	Outcome (with time since death)
A	60s	Eldest daughter	80s	Alone	Leg venous thrombosis, mild dementia	Family car	Ileus	Surgery, repeated surgery (hemorrhage)	Death (1 year 7 months)
В	40s	Grandchild	90s	Alone	Cerebral infarction	Doctor helicopter	Consciousness disorder (seizures)	Life support: yes/no	Discharged
С	60s	Wife	60s	With family	Diabetes, dialysis	Doctor helicopter	Cardiopulmonary arrest	Life support: yes/no	Death (3 months)
D	50s	Eldest daughter	80s	Alone	Diabetes, cardiac infarction, mild dementia	Family car	Appetite loss (aspiration pneumonia)	Treatment continued	Death (2 years)
E	50s	Second daughter	70s	Alone	Tongue cancer, pancreatitis	Ambulance	Cardiopulmonary arrest (myocardial infarction)	Life support: yes/no	Death (5 years)
F	50s	Eldest daughter	70s	With family	Prostate hypertrophy	Family car, ambulance	Brain-stem infarction	Life support: yes/no	Discharged
G	70s	Wife	60s	With family	Transient cerebral ischemia, arterial aneurysm	Family car	Fever (infected arterial aneurysm)	Treatment continued, convalescence at home	Death (4 years)
н	70s	Wife	70s	With family	Hypertension, diabetes	Family car, ambulance	Myocardial infarction	Treatment continued Life support: yes/no	Death (3 years)
I	50s	Eldest son	90s	With family	Prostate hypertrophy, hypertension	Ambulance	Abdominal aortic dissecting aneurysm	Life support: yes/no	Changed hospital, convalescence continuing
J	50s	Grandchild	90s	Together	None	Family car, ambulance	Cerebral infarction	Life support: yes/no	Changed hospital, convalescence continuing

secondary healthcare areas under the jurisdiction of three locations out of the six in Prefecture X [29]. Explanations, orally and in writing about the study were made to people responsible for planning seminars and related activities for the general population, and written and/or oral consent as research collaborators was obtained. At a place where seminars, business meetings, etc., were held, the researchers described the objectives, summary, and ethical considerations of the study to prospective participants, family of older patients. Later, a date and time were agreed on with the family members who expressed a wish to participate, and the research was explained again. Thereafter, written consent was obtained, and the interview was conducted. The interview locations were the participant (interviewee) homes or other locations where privacy could be ensured. Each participant was interviewed once for approximately 60 minutes. Audio recordings of the interviews were made with the interviewee consent.

Basic information, such as the participant age, relationship with the older pa-

858

tient, and whether they lived with the older patient were ascertained. We created questions based on Rodgers' (2000) concept analysis approach of time processes, such as antecedents, attributes, and consequences. Questions relating to antecedents included events prior to the hospitalization including the condition at the time of the emergency leading to transporting the patient to and up to the examination at the hospital, the feelings and mental state at that time, the explanation by the physician at the time of the emergency admission to the hospital, and the support of medical professionals. Questions relating to attributes included the situation at the time of the explanation of selection of treatment, feelings of the participants at that time, other family member reactions, how participants thoughts about relevant matters at that time, who decided the treatment, and the support of medical professionals at that time. Questions relating to consequences included the feelings of the participants after making the decision, other family member reactions, and the support of medical professionals.

2.4. Analysis

Based on the content analysis approach [28], the recorded interview data were transcribed verbatim for the analysis, interpreted, and coded into the smallest semantically meaningful units. Codes were abstracted by comparing their similarities and differences, with the abstraction being at the same level as the concepts in Study I. To ensure the validity of the analysis, the assessment was repeated with two or more researchers, and every effort was made to ensure validity. As a result of analyzing the interviews, 28 codes, 9 subcategories, and 4 categories were extracted from 489 codes corresponding to the antecedent requirements from emergency transportation to treatment. Additionally, 31 codes, 12 subcategories, and 4 categories were extracted from 370 codes corresponding to the attributes indicating the comments of decision-making. Finally, 13 codes, 6 subcategories, and 4 categories were extracted from 388 codes corresponding to the consequences after the treatment decision for the older adult patients.

2.5. Ethics

All study participants were given written and oral explanations of the main points and objectives of the study; they were informed that they were free to withdraw from the study at any time during the participation, and that the data collected and the associated study results would be anonymized, would not be used other than for the study, and would be stored for 10 years after the completion of the study under rigorously managed conditions in a secure location. Each participant signed an informed consent form. The study was approved by the Ethics Committee of the institution the authors belong to.

3. Results

3.1. Overview of the Conditions and Treatment at Arrival to the Hospital

Table 1 presents details of the status and treatment for the older adult patients at

hospital arrival and admission, as well as occurrences during the transport to the hospital. The number of older adult patients arriving at the hospital by different routes was as follows: two (B and C) were transported to a tertiary emergency medical facility by a helicopter with a doctor attending; two (E and I) were transported to a general, regional hospital by ambulance; three (F, H, and J) were transported in the family car to the family physician or hospital, and then by ambulance to a tertiary emergency medical facility; two (A and D) were hospitalized at the family physician or hospital and then transported to a tertiary emergency medical facility via the family physician or hospital, and patient G to a secondary medical facility.

Of the families who make the surrogate decision, seven families were asked whether they would choose life-prolonging treatment. The patients of the families who were asked this were patients who were evaluated to be in critical conditions and in the 90s or older, and with underlying diseases, and those who were evaluated to be subject to potentially highly urgent and serious conditions, such as in cardiopulmonary arrest. Decision-making for life-prolonging treatments was requested at the time of the initial examination in three cases (B, C, and E), at the time of selecting the treatment for two patients (F and I), and during the course of treatment for two patients (H and J). Three family members were requested to select surgery (A, D, and G). The treatment outcomes were: death in six cases (A, C, D, E, G, and H), recovery and discharge from the hospital in two cases (B and F), and transfer to a different hospital for convalescence in two cases (I and J). Of the six persons who died, three died suddenly and without further warning signs (A, C, and E), and three died as their condition deteriorated during the treatment (D, G, and H). The length of time since death at the interview was 3 months for one participant (C), 1 to 2 years for one (A), and more than 2 years for four participants (D, E, G, and H).

3.2. Decision-Making by the Family Members of the Older Adult Patients

Details of the concepts abstracted in the authors' previous study and the categories abstracted in the present study are shown in **Tables 2-4**, respectively, for antecedents, attributes, and consequences. The subcategories that were the same as in Study I are underlined. Symbols and parenthesizing text have the following meanings: Categories are indicated with angular brackets (< >), subcategories with double angular brackets (<< >>), codes with single quotation marks (' '), narratives of participants as *Italic* with double quotation marks (" "), and new abstracted categories or subcategories in Study II with asterisks (*).

4. Discussion

The present study compares the categories abstracted from the narratives of family members who make surrogate decisions for the older adult patients who experienced a medical emergency (Study II) with the categories abstracted from

 Table 2. Details of concepts abstracted in Study I and categories in Study II: Antecedents.

Study I: Decision-making by family members of persons in life-crisis states	Study II: Decision-making by family members of older adults in life-crisis states			
	<observing abnormalities="" about="" and="" being="" death="" of="" patient="" responding,="" the="" while="" worried="">*</observing>			
	<< Feeling that there is an emergency because he/she seems different from the usual >>*			
	< <feeling a="" crisis="" death,="" due="" is="" life="" of="" risk="" sudden="" that="" there="" to="">>*</feeling>			
	< <while abnormal="" ascertain="" aware="" being="" condition,="" disease="" limits="" of="" physical="" state="" the="" to="" trying="">>*</while>			
	$<<\!\!\mathrm{Feeling}$ conflicted about calling an ambulance, and impatience with waiting>>*			
<bewildered best="" but="" by="" condition="" hopes="" of="" on="" pinning="" seriousness="" the="" their="" treatment=""></bewildered>	<bewildered best="" but="" by="" condition="" hopes="" of="" on="" pinning="" seriousness="" the="" their="" treatment=""></bewildered>			
	< <given about="" an="" explanation="" limits="" of="" the="" treatment="">></given>			
< <unable accept="" condition="" of="" seriousness="" the="" to="">></unable>	< <unable accept="" condition="" of="" seriousness="" the="" to="">></unable>			
< <pinning best="" hopes="" on="" the="" their="" treatment="">></pinning>	< <pinning best="" hopes="" on="" the="" their="" treatment="">>*</pinning>			
<conflicted by="" condition="" confronting="" course="" feelings="" of="" the="" unacceptable="" while=""></conflicted>	<conflicted by="" condition="" confronting="" course="" feelings="" of="" the="" unacceptable="" while=""></conflicted>			
< <intently condition="" course="" monitoring="" of="" the="">></intently>	< <intently condition="" course="" monitoring="" of="" the="">></intently>			
< <wanting dignity="" life="" of="" respect="" the="" to="">></wanting>				
< <unable abandon="" hope="" of="" recovery="" the="" to="">></unable>				
<thinking family="" for="" frameworks="" members="" of="" support=""></thinking>	<thinking family="" for="" frameworks="" members="" of="" support=""></thinking>			
<< Thinking about the effect of hospitalization on family life and supporting each other >>	<< Thinking about the effect of hospitalization on family life and supporting each other >>			

Note. *New categories or subcategories abstracted in Study II. The same subcategories as in Study I are underlined.

Table 3. Details of concepts abstracted in Study I and categories in Study II: Attributes.

Study I: Decision-making by family members of persons in life-crisis states	Study II: Decision-making by family members of older adults in life-crisis states			
<decision-making a="" care="" critical="" do="" in="" little="" of="" setting="" so="" the="" time="" to="" unit="" unusual="" with=""></decision-making>				
< <lack because="" condition="" of="" seriousness="" the="" time,="">></lack>				
< <the care="" context="" critical="" of="" the="" unit="">></the>				
<decision-making an="" conscious="" in="" of="" own="" psychological="" responsibility="" state,="" their="" unstable="" while=""></decision-making>	<thinking an="" in="" psychological="" state="" unstable=""></thinking>			
< <mental agitation="">></mental>	< <mental agitation="">></mental>			
< <feelings and="" of="" regret="" responsibility="">></feelings>				
< <anxiety due="" future="" of="" the="" to="" uncertainty="">></anxiety>				
< >				

Continued

<deliberating and="" believe="" deeply="" on="" patient="" patient's="" patient,="" prognosis,="" relationship="" the="" their="" they="" want="" what="" with="" would=""></deliberating>	<deliberating deeply="" on="" patient's="" prognosis,="" relationship<br="" the="" their="">with the patient, and what they believe the patient would want></deliberating>
	< <undergoing disease="" for="" the="" treatment="" underlying="">>*</undergoing>
	< <thinking 80s="" about="" being="" in="" patient="" the="">>*</thinking>
	< <guessing attitudes="" beforehand="" from="" patient="" the="" their="" wishes="">>*</guessing>
< <not knowing="" patient's="" the="" wishes="">></not>	< <not knowing="" patient's="" the="" wishes="">></not>
<< Thinking from the viewpoint of the current status of family relationships>>	< <thinking current="" family="" from="" of="" relationships="" status="" the="" viewpoint="">></thinking>
< <thinking about="" basis="" medical="" of="" situation="" the="">></thinking>	
< <thinking about="" financial="" resources="" the="">></thinking>	
<seeking decision-making="" emotional="" from="" in="" medical="" staff="" support="" the=""></seeking>	<seeking decision-making="" emotional="" from="" in="" medical="" staff="" support="" the=""></seeking>
< <wanting an="" explanation="" understandable="">></wanting>	< <wanting an="" explanation="" understandable="">></wanting>
<< Feeling reassured when medical staff are close at hand >>	<< Feeling reassured when medical staff are close at hand>>
< <empathy feelings="" their="" with="">></empathy>	
<taking account="" decision-making="" family="" in="" into="" members'="" other="" views=""></taking>	<taking account="" decision-making="" family="" in="" into="" members'="" other="" views=""></taking>
< <conjecturing patient's="" the="" wishes="">></conjecturing>	< <conjecturing patient's="" the="" wishes="">></conjecturing>
<< Making decisions by agreement after discussions within the family>>	$\leq <$ Decision-making based on discussion and agreement within the $\underline{family>>}$
< <deciding as="" family="" for="" person="" responsible="" the="">></deciding>	< <deciding as="" family="" for="" person="" responsible="" the="">></deciding>
< <trusting and="" everything="" leaving="" medical="" staff="" them="" to="">></trusting>	<< Trusting medical staff and leaving everything to them>>
< <making decisions="" discussion="" in="" medical="" team="" the="" with="">></making>	
< <checking a="" decision-maker="" existence="" for="" legal="" of="" the="">></checking>	

Note. *New categories or subcategories abstracted in Study II. The same subcategories as in Study I are underlined.

 Table 4. Details of concepts abstracted in Study I and categories in Study II: Consequences.

Study I: Decision-making by family members of persons in life-crisis states	Study II: Decision-making by family members of older adults in life-crisis states
<while end="" grieving,="" patient="" staying="" the="" until="" with=""></while>	<while end="" grieving,="" patient="" staying="" the="" until="" with=""></while>
< <while end="" grieving,="" patient="" staying="" the="" until="" with="">></while>	< <while end="" grieving,="" patient="" staying="" the="" until="" with="">></while>
< <feeling gratitude="" medical="" of="" staff="" toward="">></feeling>	< <feeling gratitude="" medical="" of="" staff="" toward="">></feeling>
< <looking back="" life="" on="" patient's="" the="">></looking>	
<feeling a="" after="" and="" decision="" distressed="" even="" making="" uncertain=""></feeling>	<feeling a="" after="" and="" decision="" distressed="" even="" making="" uncertain=""></feeling>
< <wanting about="" affirmation="" decision}<="" td="" their=""><td><<wanting about="" affirmation="" decision="" their="">></wanting></td></wanting>	< <wanting about="" affirmation="" decision="" their="">></wanting>
< <continuing correct="" decision="" made="" question="" the="" they="" to="" whether="">></continuing>	
<reaffirming among="" connections="" family="" members="" remaining="" the=""></reaffirming>	<reaffirming among="" connections="" family="" members="" remaining="" the=""></reaffirming>

Continued

< <rebuilding th="" the<=""><th>remaining</th><th>family,</th><th>despite</th><th>confusion>></th></rebuilding>	remaining	family,	despite	confusion>>

- << Reestablishing the roles of remaining family members, in the context of their dealing with feelings of loss>>
- <Continuing support for life as a convalescent>*
- <<Gratitude for still being alive and rapidity of response>> *
- <<Support for life as a convalescent in the hospital to which transferred>> *

Note. *New categories or subcategories abstracted in Study II. The same subcategories as in Study I are underlined.

Study I that excluded pediatric patients, and discuss new abstracted categories or subcategories in Study II as characteristics of the family members.

4.1. Antecedents: Factors in Family Member Decisions about Transport for the Older Adult Patients

<Observing abnormalities and responding while being worried about death of the patient> is a new category among the antecedents. The abnormalities observed in the older adults were "sudden", "different from the usual", and showed "no improvement". Among these, "sudden" and "different from the usual" are abnormalities that can be clearly observed and understood by the family members, while "no improvement" is something where the family members are unsure and may wonder about what it is, and which requires continued observation. These conditions indicate an irreversible state in which the pain threshold has increased due to decreased sensitivity [30] [31] and are consistent with the characteristics of extremely acute diseases in older adults. Put differently, it seems that symptoms appear suddenly due to the increased pain threshold and decreased sensitivity, and may only be interpreted as different from the usual because the symptoms are not typical and the older adults are not sensitive and unaware of the symptoms. The characteristic of an irreversible state leads to no improvement.

The next issue relates to hesitations on the part of family members about the transport of the older adults to medical facilities. The subcategory <<Feeling conflicted about calling an ambulance and impatience with waiting>> relates to the inconsistency between waiting for some time before deciding that the person should be transferred to the hospital, and the impatience with waiting. Hesitation to call an ambulance in urban areas may result from not knowing which hospital to go to and not having a way of transport, which can prevent people from calling for an ambulance when they could use a taxi [32] [33]. In an opinion poll about emergencies in 2017, 28.5% of respondents reported hesitation to call an ambulance [34]. In addition, in a survey of ambulance use by the inhabitants of farming and mountain villages, 44.2% were hesitant about calling an ambulance. The most common reason for this was to avoid the noise of the siren (73.3%) and so not cause problems for their neighbors (42.6%) [35]. These explanations can be considered equivalent to "concern about neighbors" in the

present study.

In addition, after making an emergency telephone call, despite having taken time to decide to make the call, family members of the patients feel impatient. Time also seems to pass particularly slowly if they wait outside the emergency room with no information and nothing to do, making it necessary to provide support for family members waiting in a different room.

If <<Given an explanation about the limits of treatment>> is interpreted together with the components of the narratives such as "I was really surprised" and "I appreciated the severity of the disease for the first time", this could mean that the family member did not recognize the severity of the disease until they heard the explanation. In addition, most laypersons find it difficult to understand that improvement may not be achieved with medical treatment. For these reasons, informed consent is also important to facilitate surrogate decision-making about treatments.

4.2. Attributes: Factors in the Decisions of Treatment Selection by Patient Family Members

The following new subcategories were abstracted as decision factors for the treatment selection by patient family members: << Undergoing treatment for the underlying disease>>, << Thinking about the patient being in the 80s>>, and << Guessing the patient wishes beforehand from their attitudes>>.

<<Undergoing treatment for the underlying disease>> relates to the fact that the patients in the present study had multiple diseases, including hypertension, diabetes, heart disease, and cerebral infarction, which are among the most important diseases in terms of both cause of death (2021) [36] and cases of emergency transport [4]. These underlying diseases require continued control by the patients themselves, along with help from family members; further, the condition gradually worsens with age. This can be considered an item in decision-supporting information that is required when family members select treatment.

A further newly added subcategory among reasons for treatment selection, <<Thinking about the patient being in the 80s>> can be considered as the decision-supporting information for treatment selection. The mean age of the older adult patients in the present study was 80.6 years (SD \pm 10.6), and in a study on the trends in people who had been treated in an intensive care unit within the previous nine years, it was found that those over 80 years old tended not to want invasive treatment such as artificial respiration and preferred a do-not-resuscitate order [37]. In addition, among the family members of nursing home residents, the factor that had the greatest effect on the decision to request transport to a medical institution in end-of-life care was age; in particular, the proportion of people wanting such transport was found to be lower for those who had passed the mean life expectancy of 87 [38]. In the present study, judging from elements of the narratives, "I don't want the patient to suffer at that age" and "I feel the person lived a full life", whether someone has reached the age at which it can be objectively said that they have lived long enough probably influences the deci-

sion-making. When someone has passed the mean life expectancy, if their family members do not want the treatment to be continued, they can expect an approving sentiment, such as "I feel the person lived a full life", to be expressed by friends and neighbors, which may enable acceptance. Therefore, the age of the older adults transported to the hospital is a major factor influencing family member selection of treatment.

Text heads organize the topics on a relational, hierarchical basis. For example, the paper title is the primary text head because all subsequent material relates and elaborates on this one topic. If there are two or more sub-topics, the next level head should be used and, conversely, if there are not at least two sub-topics, then no subheads should be introduced. Styles named "Heading 1", "Heading 2", "Heading 3", and "Heading 4" are prescribed.

Further, <<Guessing the patient wishes beforehand from their attitudes>> refers to searching for some reason to make the selection from previously expressed/perceived patient wishes. These include, for example, the older adult having casually said something like "I don't want to be all tied up with tubes" or "I'd like to remain active, and then die quickly and painlessly which could be expressed by 'Pin Pin Korori' in Japanese".

The present study suggests that when family members are requested to be surrogate decision-makers, they search for clues to get hold of the thoughts of the older adults. In this context, Katayama (2020) has reported that when the patients themselves have not clearly stated their thoughts, things that may have been said casually during ordinary life are taken to be their serious, thought-out opinions, and such comments are gathered as fragments representing the wishes of the patients [39]. This highlights the need for advance care planning (ACP). In the present study, it is possible that some family members made conjectures based on casual comments during daily life, and used these as clues to try to understand the wishes of the patient.

However, there were cases of not knowing what the wishes of the patients were. The reasons for this included not recognizing that it was necessary to ask: "The patient was healthy, so I didn't ask", "I've never asked about what was wished", or "The patient had dementia, so I was unable to discuss this issue". It can be understood that it is difficult to talk to someone about this if the situation is already such that one cannot evaluate whether something someone says is their genuine opinion. It has been pointed out that, in the case of Japanese where the people involved share a home, it is unusual for them to talk about death among family members, and they may therefore not know what the thinking is [26]. This suggests the necessity for family members to talk to the older adult about death in a timely manner.

These also suggest that when families were asked to make treatment decisions, they felt it a burden to make decisions that directly affected life and death. They may not have anticipated to be in such situations as illustrated by statements showing that they were not familiar with the term, life-prolonging treatment, not knowing what it meant. A survey on public awareness in March, 2018 [40]

reports that 55.1% of the public had never discussed the final stages of life with family members or others, and 75.5% had never heard of Advance Care Planning (ACP). In another survey of hospital staff [41], it is reported that the recognition of the terms "death with dignity" and "activities toward the end of life" as seen in newspapers and magazines for the general public was high at 75% to 80% for both medical and clerical staff, while the recognition of "End-of-Life Discussion at Home" was low at 4.0% for both medical clerical staff, and "ACP" at 23.2% for medical staff and 17.4% for clerical staff. The term "life-prolonging" is a term that is not likely to be used in everyday life. Medical, healthcare, and social welfare service professionals may understand that older patients cannot be excluded from the decision to provide life-prolonging treatment when patients are in a life-threatening crisis. However, this may not be the case for the general public.

Further, a category <Seeking emotional support from medical staff in the decision-making> was extracted, and this would suggest that the concept of selfdetermination of medical care has become common through involving informed consent and second opinions. However, if families of older adults are in a situation where they have to make a decision, they tend to rely on medical professionals. This holds more often in situations related to a life-or-death decision, and families feel <<Not confident enough to make a decision>> or <<Encouraged if they have advice from medical professionals>>. It is reported that the influence of medical professionals is significant especially in emergency situations, where families leave decisions to physicians or accept the decisions proposed by physicians with no time to spare [42]. This stresses that there may be differences in the awareness of life-prolonging treatment, emergency care, and self-determination between medical professionals and non-medical participants. In Japan informed consent that bridges this difference in awareness is not fully practiced as illustrated by the category < Taking other family members' views into account in decision-making>.

In this study, the final decision makers were the wife in three cases (C, G, and H), the eldest son or grandson living with the older adult patient, or a daughter living nearby in the case where the older adult patient lived alone. All of the decision makers other than the wife were blood relatives. There are differences in family structure, but still the category <Taking other family members' views into account in decision-making> was extracted. For the Japanese traditional family system, Nakane [43] reported that the concept of *uchi* (inside home) and *soto* (outside home) had a clear line drawn between family members, who are *uchi* people and the others, and families tried to resolve family problems among the *uchi* family members, including relatives, without accepting intervention from *soto* family members. For this reason, it was implicitly agreed that the eldest son, daughter, or other heirs would make the decisions. Even if the spouse of the eldest son, a daughter-in-law, continued to take care of the older family members, the heir was given priority as a decision maker, even when there were differences

in opinion among family members. Especially in the era when firstborn inheritance was the rule, the head of the family or the heir was acceded to as the authority to make decisions.

However, family bonds became looser after the Second World War, a period when the birthrate has been declining and the trend toward nuclear families has been rapidly advancing. In 1980, 50% of households were comprised of three generations living together, but by 2019, households living alone (28.8%) and those of married couples only (32.3%) accounted for 60% [44]. This change in family structure resulted in an absence of decision makers within the family and the dispersal of responsibilities. Further, even though decisions are now made in consideration of the interests of each family member, unlike decisions based on prewar family norms, there may be cases where family members have different ideas and feelings when there are conflicts of interest among families [9] [10]. What is best for the individual should be the top priority, and for this reason, it is important to provide support by taking into account the characteristics of the families of older adults when "expressing wishes beforehand" is not yet common.

4.3. Consequences: Factors Enabling the Family Members of Older Patients Who Have Recovered to Decide upon a Place for Convalescence

<Continuing support for life as a convalescent> was a new category in this study, based on the narratives of the family members of the older patients who had recovered and were convalescent at home, or convalescent after transfer from an acute-phase hospital to a convalescence hospital. From the point of view of being responsible for the results of the decision-making about continuation of treatment, this is not limited to older adult patients. However, in the case of older adult patients, and taking into consideration issues such as the requirement for rehabilitation and nursing care after recovery [45], it is possible that the decision-making premises support for life as a convalescent.

<<Gratitude for still being alive and rapidity of response>> refers to older adult patients being at high risk of rapid changes and showing large individual differences in the response to treatment [31], which make it difficult for also medical professionals to predict recovery. In relation to family members who listen to the explanations of medical professionals, and then find themselves in the situation of not being able to do anything other than simply rely on fate, this subcategory explains feelings of gratitude about this older adult recovering, and the medical response.

<<Support for life as a convalescent in the hospital to which transferred>> was another category, and based on the narratives of the families of patients transferred from an acute-phase hospital to a secondary medical facility. Under the regulations of the national health insurance system, additional medical fees needed for medical services after 15 days in emergency medical centers in Japan are not

covered by the national health insurance [45]. For this reason, after 15-days of a hospital stay patients are transferred to secondary medical facilities after treatment at an acute-phase hospital [45]. While recognizing feelings of relief and gratitude about the older adult patients who have recovered from a life-threatening crisis, family members are now realizing that the practical burden of long-term nursing care is a reality. When starting nursing care for older adults, and nowadays when traditional intra-family norms related to care have weakened, there have been reports of family feuds about where (at home or in a nursing facility) nursing care is to take place, who is to provide the care, who is to cooperate, and other matters [46] [47] [48] [49].

The main goal of the nursing care insurance system of Japan is to alleviate the burden on family caregivers by thinking of such burden as an issue common to the all nations, but there is a shortage of residential facilities [50] [51]. While progress is being made with recommendations to shift to home care, there have been numerous reports that the system supporting family members is unsatisfactory [52]-[57]. This subcategory may be considered an expression of these wishes, focusing on post-recovery nursing care, of the family members who make decisions about the treatment at the time of the emergency transfer. However, whether such decision-making is based on preparation for the worst-case scenario cannot be ascertained from the narratives about attributes in the interviews conducted in the cases reported here. In terms of support for the families of older patients, the findings described above suggest the necessity of providing thoughtful support by taking it into consideration that some family members may not have had time to deliberate on the selection of treatment in emergency transfers, showing consideration of the feelings of the families from the time of emergency transport to the selection of treatment, and providing informed consent in easy-to-understand language focusing on the conditions after treatment. The findings also suggest the necessity of support to ensure a smooth transition to medical care, long-term and home care after the hospital change and discharge from the hospital.

4.4. Limitations

The number of study participants was only 10, and they were living in one geographic locality; this introduces limitations to the conceptualizations in this study of surrogate decision-making for the older adult patients who have been subject to emergency transport, and it is not yet possible to make any recommendations for the support involved in surrogate decision-making. However, based on the current status of emergency medicine for older adult patients in Japan, problems faced by family members who made decisions as surrogates were clearly demonstrated. In the future, changes are expected in the way of thinking about decision-making related to the final stages of life, and further research will therefore be necessary to be able to support family members involved in surrogate decision-making.

5. Conclusions

In terms of attributes, the following are decision-supporting factors when the families of older adult patients are asked to determine a treatment: the older adult 1) is undergoing treatment for an underlying disease; 2) is 80 - 90 years old; and 3) has indicated their wishes, including having casually indistinctly expressed such a wish. The consequences after selecting a treatment include continuing support for life as a convalescent and recognition of feelings of relief and gratitude about recovery from life crises. Later, the family members mentioned their realization about the practical problems involved with the burden of long-term nursing care.

In terms of support for the families of older patients, it is necessary to provide thoughtful support from the time of emergency transport till the selection of treatment. It is also necessary to provide support to ensure a smooth transition to medical care, long-term and home care after hospital changes and discharge from the hospital. Promoting advance care planning and providing decision-making support in the emergency setting are needed to alleviate the psychological burden on the families.

When providing support for families, it is necessary to take into account the characteristics of the families of older adults, including the psychological burden on the families who make surrogate decisions and will be exposed to the burden of subsequent caregiving. This is because ideas for patients to determine by themselves and express their wishes beforehand have not been commonly realized in Japan. It is important to promote advance care planning and provide decision making support in clinical settings to reduce the psychological burden on the families. The findings also suggest the need for transition support for the medical care, long-term care, and home care after discharge from the hospital, while everywhere maintaining an awareness of the situation after treatment.

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Conflicts of Interest

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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