

# The judgment grounds in surrogate decision-making in Japanese clinical practice: A qualitative survey

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## Research article

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## Abstract

**Background** Surrogate decision-making is expected to become more prevalent in Japanese clinical practice. In recent years, activities to promote advanced care planning (ACP) have gathered momentum, which may potentially affect the ways in which judgments are made in surrogate decision-making. The purpose of this study is to clarify the current judgment grounds on which surrogate decisions are made in Japan.

**Methods** We adopted a qualitative research method that was based on semi-structured interviews to reveal the judgment grounds in surrogate decision-making involving critical, life-sustaining treatment choices in acute hospitals.

**Results** We received a list of 228 participants who met the inclusion criteria. Of these, we interviewed 15 participants. We analyzed the content of the 14 transcribed texts, eliminating one text that did not meet the inclusion criteria. We extracted a total of four core categories, 17 categories, 35 subcategories,

and 55 codes for qualitative analysis of interviews regarding the judgement grounds in surrogate decision-making. The four core categories are as follows: Type 1 "Patient preference-oriented factor," Type 2 "Patient interest-oriented factor," Type 3 "Family preference-oriented factor," and Type 4 "Balanced patient/family preference-oriented factor." Type 4 was the reasoning related to an attempt to balance preferences of the patient and those of the surrogate decision-maker.

**Conclusions** This study revealed the current status of surrogate decision-making about important matters related to a patient's life in Japan. Surrogate decision-makers base their decisions not only on the preferences and best interests of the patient, but on their own preferences as well.

In the future, we believe that surrogate decisions-makers will be required to consider the judgment grounds from a more diverse perspective and that such attitudes should be ethically accepted.

## Background

Surrogate decision-making is expected to become more prevalent in Japanese clinical practice. In 2017, Japan reported 1.34 million deaths, 70% were deaths of elderly people aged 75 years and older. This figure is predicted to continue increasing. (1). According to one report, 42.5% of hospitalized elderly people are required to make decisions about end-of-life treatment; however, when such decision-making takes place, only 29.7% have the capacity to make such a decision (2). Thus, more and more patients are expected to have someone else make decisions on their behalf (surrogate decision-maker) in the future.

In the United States, surrogate decision-makers are expected to base their decisions on the substituted judgment standard; that is, by considering what the patient, if competent, would choose (3). Buchanan and Brock introduced "a hierarchy of standards" for surrogate decision-making, which include the following three standards: a patient's known wishes, substituted judgments, and the patient's best interests (4). These standards provide guidance for surrogate decision-makers in deriving judgments and have thus far been considered the 'orthodox' view of surrogate decision-making in the field of bioethics (5).

In practice, however, the judgment grounds in surrogate decision-making are not always considered in accordance with the hierarchy of standards. This has been pointed out in Japan as well as in other countries (6). For example, a study in Japan reported that surrogate decision-makers and physicians base their decisions on their own preferences (7). These reports suggest that patient preferences or best interests might not always form the grounds for judgment in surrogate decision-making. Notably, studies in Japan have been limited in terms of sample size as well as content pertaining to surrogate decision-making. In recent years, activities to promote advanced care planning (ACP), have gathered momentum in Japan. ACP is defined as "a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care." For many people, this process may include choosing and preparing another trusted person or persons to make medical decisions in the event the person can no longer make his or her own decisions (ref. *J Pain Symptom Manage.* 2017 May;53(5):821-832.). This may potentially affect the ways in which judgments are made in surrogate decision-making. In 2018, the Ministry of Health, Labour and Welfare (MHLW) revised the "Guidelines on the decision making process for end of life care." This revision reflects the reality that activities and research efforts relating to ACP (commonly practiced in the United States and European countries) have also increased in Japan. The revised guidelines highlight the importance of discussing on a regular and repeated basis what the patient's intentions are regarding medical and care strategies as well as their desired way of living, with the premise that such intentions can change as their physical and psychological conditions change. In other words, the importance of actions relating to ACP is emphasized in the revised guidelines. Another important point discussed in the guidelines is that the patients themselves should specify a surrogate decision-maker who would presume their intentions before they become incapable of communicating their wishes (8). The MHLW also organizes workshops for consultants across Japan as part of their jurisdictional project based on "Education For Implementing End-of-Life Discussion (E-FIELD)" for medical practitioners. The goal of these workshops is to develop a consultation system involving approximately 400 medical institutions nationwide to promote decision-making that respects patient preferences (9). The guidelines and workshops primarily advocate for the use of the standards proposed by Buchanan and Brock in eliciting grounds for judgments and recommend the use of ACP. Dissemination of these guidelines could potentially change the judgment grounds in surrogate decision-making in Japan.

There exist cultural differences regarding surrogate decision-making between Europe and the United States and Japan. For example, with respect to ACP, while it is considered a process that respects patient preferences and has been actively prompted in Europe and the United States, in Japan, it is culturally regarded as a taboo to disclose to patients that their condition might deteriorate in the future. Also, when it comes to selecting a surrogate decision-maker, Japan has a culture that values seniority (e.g., being the eldest and/or male is an important determinant) more than the criterion of being the one who knows the patient's preferences better than anyone else. Differences in religious beliefs also underlie differences in culture. The sacredness of death and life is deeply rooted in cultural and religious beliefs in Japan and has given rise to the unique idea that unnecessary suffering should be avoided (ref. (10) *BMC Med Ethics.* 2018;19(1):12. Published 2018 Feb 27. doi:10.1186/s12910-018-0251-z). From cultural perspectives related to surrogate decision-making in Japan, several relevant points can be presented that clearly separate Japan from Western countries, which can be interesting and insightful. However, the context of the

culture is not fixed, and as the introduction of ACP is being promoted in Japan, cultural transition and merging have often happened, which can be said to be a global phenomenon. Therefore, the present survey on the current status of surrogate decision-making and ACP in Japan will be of international significance.

The purpose of this study is to clarify the judgment grounds on which surrogate decisions are made in Japan, in the face of a rise in surrogate decision-making in this country. In particular, this study aims to reveal judgment grounds in surrogate decision-making involving critical, life-sustaining treatment choices in acute hospitals. Finally, based on our results, we consider how the expected dissemination of ACP might change the judgment grounds in surrogate decision-making. Until now, reports on surrogate decision-making in Japan have been limited to those published within the country. We think it is meaningful to report to the international audience the judgment grounds in surrogate decision-making currently used in Japan, where the aging of society is progressing further and activities relating to ACP are expected to intensify.

## Methods

### Study design

The objective of this study was to analyze the process of surrogate decision-making from the perspective of surrogate decision-makers in Japan, and to clarify the judgment grounds in surrogate decision-making in clinical practice. Given that each case is highly personal in nature, we predicted that only research methods that allow for careful analysis and examination of each decision-making process would clarify the reality of each situation. Accordingly, we adopted a qualitative research method that was based on semi-structured interviews, described below.

### Eligibility criteria

Participants of this study were individuals residing in the suburbs of Tokyo recruited through a recruitment company (11). Eligible participants were surrogate decision-makers of a patient who met all of the following five conditions: (a) hospitalized during the period spanning April 1, 2012 through March 31, 2017; (b) had no capacity to make decisions for themselves; (c) aged 65 years or older; (d) required decision-making regarding life-sustaining treatment (dialysis, artificial respirator, tube feeding, central venous hyperalimentation); and (e) meeting with the physician regarding treatment took place with individuals other than the patient. Exclusion criteria were as follows: (a) those who did not wish to participate in this study; (b) those with difficulty in Japanese oral communication; and (c) underage individuals. Based on the study protocol and informed consent form, the recruitment company created a list of participants selected from a database in accordance with the inclusion and exclusion criteria. Considering only the schedule of the interview venue, the interviewer, and the participants, the interviewer selected 15 participants from the list of 228 people and contacted the participants via the recruiting company. Whether to complete the interview process after interviewing 15 participants had not been specified in the protocol, and it was thus possible to conduct additional interviews; however, no additional interviews were necessary, as content saturation and theme development had already been achieved. These participants were provided with an informed consent form regarding the present study, and a list of contact information for those who expressed an intention to participate was submitted to the investigator of the present study.

### Interview procedure

Documents describing the contents of planned interviews were distributed to participants in advance. Interviews were conducted by researchers at the date and time specified by the interviewees in a conference room of the study center (Tokyo Medical Center), where participant privacy was ensured. The interviews were conducted in line with the questions listed in the interview guide (Table 1).

#### Table: Individual interview with surrogate decision-makers

1. What was the specific content(s) of decision-making in your surrogate decision-making?
2. In performing surrogate decision-making, were you aware of the fact that you were making decisions as the patient's "surrogate"?
3. Do you think making surrogate decisions was hard for you?
4. Do you think your surrogate decision-making went smoothly?
5. Do you think there was a disagreement between the surrogate decision-maker and medical personnel or among several surrogate decision makers?
6. Did you receive sufficient information from medical personnel when you made surrogate decisions? Do you think you were able to have discussions with medical personnel?
7. What were the bases for judgment in your surrogate decision-making?
8. After having performed surrogate decision-making, do you think you made a good surrogate decision for the patient?
9. Do you have any regrets over this surrogate decision-making?

### Ethical considerations

This study was approved by the Ethics Committee of Tohoku University School of Medicine (Approval No. 2017-1-856). At the time of the survey, participants were provided with explanations regarding the survey. Written consent was obtained from all participants regarding their participation, that the content of interview would be recorded, and that their statements would be reported anonymously. In this study, all participants were provided with 8,000 yen compensation (for paperwork of about 30 minutes and transportation expenses) during the interviews that lasted up to 2 hours.

### Analysis methods

We outsourced the creation of transcripts of recorded interviews to Kyoto Data Service, a private transcription company. One of the authors (MT) performed all fidelity checks for voice audio data and transcript reports. Analyses were performed using a qualitative analysis method by referencing the KJ method (12) and the “Ueno method”(13). The above equation method is a simplified version of the KJ method and was developed by Chizuko Ueno, Professor Emeritus, the University of Tokyo.

The specific method is as follows.

First, interviews were recorded using an IC recorder, and a verbatim report of the interview data was created. The interview data were analyzed by the following procedures.

All sentences in the raw data were subject to analysis; all researchers involved in the analysis individually read all sentences carefully. Sentences or portions of sentences relating to the same content were coded. At the time of coding, no attempt was made to simplify expressions. Codes with similar content were grouped into a subcategory and given a name that represented the shared content. When creating subcategories, consideration was given to make the meaning easily understandable (i.e., just by reading the subcategory). Similar subcategories were grouped into categories and then into core categories, with increasing levels of abstraction. The researchers verified the content validity by repeating discussions until a consensus was reached regarding classification as well as coding, in order to ensure the reliability and validity of the analyses. Analyses were performed by a multidisciplinary group of researchers including 2 physicians, 1 nurse, 2 philosophers, and 1 pharmacist.

Since the codes (sentences) derived using the present analysis method were long, it was not feasible to present them all in this report. Accordingly, we excerpted important parts within each code as appropriate, omitting some parts without changing the meaning. Data were analyzed by MAXQDA Plus12 (Release 12.2.1) software.

## Results

### Overview of study participants

We received a list of 228 participants who met the inclusion criteria. Of these, 15 participants were selected from among those who were available for interviews at a date and time that was convenient for both researchers and participants (i.e., interviewees). It should be noted that the number of individuals pooled by the web survey company, to whom survey requests could be sent, was not disclosed. Interviews with the 15 participants were carried out over the course of 6 non-consecutive days (up to 3 interviewees per day) in November and December 2017. Of the interviewed participants, 14 were subject to analysis after excluding one who was a family member of a patient, who supported the surrogate decision-maker but did not actually make decisions on the patient’s behalf. Details on participant attributes and other background characteristics are summarized in Table 2. All surrogate decision-makers who participated in this study were family members of the respective patients.

Table 2

Sex (surrogate decision maker)	Age (surrogate decision maker)	Relationship with patient	Interview time [minutes]	Sex(patient)	Age(patient)	living together [patient and surrogate decision maker]	Inpatient department	Content of su	
								Life prolonged treatment	Ventilator
Female	30s	daughter in law	48	Male	70s	NO	Cardiology	●	●
Female	40s	the eldest daughter	50	Male	70s	NO	Neurology		
Female	40s	daughter in law	40	Male	70s	NO	Respiratory	●	●
Male	60s	the second son	50	Male	80s	NO	Neurology	●	
Male	60s	the eldest son	26	Female	90s	NO	Internal medicine	●	●
Female	40s	the eldest daughter	40	Male	80s	NO	Neurology		
Male	40s	the eldest son	25	Male	60s	NO	Cardiology		●
Female	50s	daughter in law	45	Female	70s	NO	Internal medicine	●	
Female	50s	the second daughter	37	Male	80s	NO	Internal medicine		
Female	40s	the second daughter	34	Male	70s	NO	Neurosurgery		
Female	50s	daughter in law	48	Female	70s	YES	Neurosurgery	●	
Female	60s	the second daughter	37	Female	70s	YES	Internal medicine	●	●
Male	60s	the eldest son	37	Female	80s	YES	Internal medicine		
Male	50s	the eldest son	54	Female	80s	NO	Internal medicine	●	●

### Qualitative results

Qualitative results of interviews regarding the judgment grounds in surrogate decision-making are summarized in Table 3. A total of 4 “core categories”, 17 [categories], 35 <subcategories>, and 55 (codes) were extracted.

Table 3

core category	category	subcategory
1. Patient preference-oriented factor	I respected the preference of the patient	I told them that I had been instructed by the patient to decide against life support
		Since the patient's preferences were clear, my decisions were never swayed
		I made the decision by respecting the patient's intention regarding life-prolonging treatment
	I respected the presumed intention of the patient	I made the decision, thinking what the patient would do
		My daily communication helped (patient-family)
		I thought the family would be able to guess the patient's intentions
		I think I made the decision believing it was in line with the patient's intentions
		I guessed the patient's intention by observing his/her condition
2. Patient interest-oriented factor	I tried to make the decision by considering the patient's best interest	I valued patient safety
		I thought that what would be good for the patient would be to receive medical treatment and recover
		I did not know what was good for the patient
	I did not want to do anything cruel to the patient	I decided against life-prolonging treatment out of pity
		The patient appeared to be suffering so I thought he/she would be better off with gastrostomy
		I decided against life-prolonging treatment out of pity
	I made the decision based on the patient's ADL and communication capacity	I agreed not to undergo life-prolonging treatment because I sympathized with the patient when I saw him/her being bedridden
		I did not choose gastrostomy as the patient was not able to communicate
		I thought that it was my ego that wanted to choose life-prolonging treatment when the patient's condition was such that no communication was possible
	I expected the patient to recover	If the patient can recover, I want him/her to be treated
		I continued to have hopes for recovery
		I chose artificial alimentation in hopes of recovery
	3. Family preference-oriented factor	I wanted to protect my family's life and interests
I judged it realistically impossible to provide home care		
I made the decision that family members would not regret		
I thought that patient safety would lead to my own self-protection as the surrogate decision-maker		
I made the decision based on the thoughts of family members and people close to the patient		I ignored my discussions we had in advance
		The feelings of the (closest) family member were important
I wanted the patient to live		I was aware of the position of the patient who refused life support, but I wanted him/her to live
		When death suddenly became a real possibility, I as a family member wanted to prolong the patient's life
I wanted to do everything I could		I had the patient have gastrostomy for my family
		I thought nobody would want to die
		Because the patient's life was limited, I thought I wanted to keep him/her alive even for one more day
I accepted death		I had no regrets so I didn't choose life support
		I thought that death was inevitable
4. Balanced patient/family preference-oriented factor	I balanced the patient's intention and the lives of family members	I made the decision considering the balance between the patient's life and lives of family members
		I balanced the intention of the patient and thoughts of family members

Type 1: Core category "Patient preference-oriented factor"

The judgment grounds rooted in patient preferences were classified as the Type 1 core category. This core category comprised 2 categories, 8 subcategories, and 13 codes. Representative categories/subcategories/codes are described below.

[I respected the preference of the patient]

One of the subcategories of this category was <Since the patient's preferences were clear, my decisions never swayed>, which included the following code: (*I had conversations with the patient in advance. We often talked about when the patient was going to die, half-jokingly. The patient also mentioned specific matters, such as not wanting to live with the help of various machines connected to the body*). In this case, the patient mentioned specific treatment choices in prior discussions, and the surrogate decision-maker respected those as the judgment grounds in surrogate decision-making.

[I respected the presumed intention of the patient]

One of the subcategories of this category was <I made the decision, thinking what the patient would do >, which included the following code: (*We as family members tried to put ourselves in the patient's place. We wondered which one of the choices my father would pick after hearing what the doctor had said, had he been able to make his own decision*). This code reflected the attitudes of the surrogate decision-maker who tried to figure out what the patient's preferences might be, from the patient's perspective. ☐

Type 2: Core category "Patient interest-oriented factor"

The judgment grounds rooted in patient interests were classified as the Type 2 core category. This core category comprised 4 categories, 12 subcategories, and 20 codes. Representative categories/subcategories/codes of this core category are described below.

[I tried to make the decision by considering the patient's best interests]

This category included the subcategory <I thought that what would be good for the patient would be to receive medical treatment and recover>, which contained the following code: (*What I thought would be good for the patient was, for example, to be able to lead a normal life as before, even if it is somewhat inconvenient. I thought any decision that would allow for this would be in the best interest of the patient and was a good decision*). This surrogate decision-maker thought that a treatment option that allowed for the patient to live as usual would be in line with the patient's best interests and used this as the basis for judgment in surrogate decision-making.

[I did not want to do anything cruel to the patient]

This category included the subcategory <I decided against life-prolonging treatment out of pity>, which contained the following code: (*To be honest, we as family members just felt sorry for the patient, whom we couldn't even recognize anymore, and since we were no longer able to have a conversation, we did not know how much the patient was understanding what we were saying – so we did not choose life-prolonging treatment. We clearly communicated these thoughts with the doctor and made the decision*). As the patient became increasingly ill, the surrogate decision-maker judged that the patient's dignity was not being preserved; this formed the basis for the judgment to tell the physician that life support was not desired.

[I made the decision based on the patient's ADL (Activities of Daily Living) and my communications with the patient]

This category included the subcategory <I thought the patient would find it painful to live in a vegetative state>, which contained the following code: (*I might come off as an ungrateful child if I say this, but my feeling was that, rather than living in a vegetative state at age 87, the patient would be better off just dying. ... Living in pain connected to numerous tubes, just lying in bed and sleeping for 1 year, or 2 years – how pitiful, I thought, if that's what it comes to*). The surrogate decision-maker felt sorry for the patient living with significantly reduced ADL, given the patient's age. Such a thought could potentially lead to a decision that shortens the time to death of the patient. This code also reflected a sense of guilt associated with making a surrogate decision based on the family's preferences.

Type 3: Core category "Family preference-oriented factor"

The judgment grounds rooted in the preferences of the surrogate decision-maker, who is a family member of the patient, were classified as Type 3 core category. This core category comprised 5 categories, 13 subcategories, and 17 codes. Surrogate decision-makers made decisions on behalf of the patient based on their (family's) own preferences, rather than considering the patient's preferences. In some cases, the surrogate decision-maker was unaware of the patient's preferences originally, while in other cases, the surrogate decision maker was aware of the patient's preferences but chose not to consider them, prioritizing their own preferences.

[I wanted to protect my family's life and interests]

This category included the subcategory <I realistically considered the lives of family members and decided to forgo gastrostomy>, which contained the following code: (*I thought 'I must look to the best interests of my father,' but realistically speaking, my younger sister, the second daughter, had small children and was running her own business. Her life would have been affected if she did not work. As the eldest daughter, I myself was also unable to leave the house for a long period of time because I was raising my children. Therefore, it was not at all realistic for me to provide home care. I shut my eyes to his pain and wishes and decided not to have him receive gastrostomy in consideration of continuing medical treatment at the hospital*). While this surrogate decision-maker wished to prioritize the patient's preferences, she had to make the decision that did not go along with the patient's preferences in light of the realistic circumstances surrounding herself as well as other family members.

[I made the decision based on the thoughts of family members and people close to the patient]

This category included the subcategory <The feelings of the closest family member were important>, which contained the following code: (*I needed to convince my mother-in-law, who was closest to the patient. I thought that, rather than us (the son and his wife) making decisions against her will, she should make decisions that she is satisfied with, after she has organized her own thoughts. For this reason, it took a lot more time to come to a decision, and I'm*

*afraid my father-in-law suffered for a prolonged period*). This code describes a surrogate decision-making process in which the surrogate decision-maker secured the time necessary for the family to agree with the decision. However, this in turn increased the time that the patient was in pain.

[I wanted the patient to live]

This category included the subcategory <When the death suddenly became a real possibility, I as a family member wanted to prolong the patient's life>, which contained the following code: *(The shock was tremendous when the doctor told us that death was inevitable, as the patient's condition worsened. At that time, I honestly just thought, 'I want the patient to live, even a day longer,' and it didn't matter if gastrostomy, or anything, had to be done. It was hard for the family to have to say goodbye all of a sudden, so I wanted the patient to get better, even just a little. I was always prepared, to no small extent. But when a doctor talks about life-or-death, you can't help but think "please just help the patient")*. When the death of the patient became a real possibility with worsening of the patient's health, the hope of the surrogate decision-maker to prolong the patient's life by even one day formed the basis for judgment in surrogate decision-making.

Type 4: Core category "Balanced patient/family preference-oriented factor"

The core category classified as Type 4 was the reasoning related to an attempt to balance preferences of the patient and those of the surrogate decision-maker (i.e., family). This core category comprised 1 category, 2 subcategories, and 5 codes.

[I balanced the patient's intention and the lives of family members]

This category included the subcategory <I made the decision by considering the balance between the patient's life and lives of family members>, which contained the following code: *(I had mixed feelings when I had to decide about the patient's nutrition. Considering the burden on my brother and his wife who actually provided care, I wondered how my decision might affect their lives. On the other hand, I also had to think about the feelings of my father who wanted to recuperate at home. It was hard at the time of decision-making. I was particularly worried about the burden on my sister-in-law)*. As suggested by this code, the surrogate decision-maker made decisions while considering the patient's wish to receive home care, as well as the burden on the lives of family members who provide the care. On these grounds, the surrogate decision-maker ultimately decided on gastrostomy as a means of nutrition support, which was not in line with the patient's wish to receive home care. This decision was also made in order to reduce the burden of care.

## Discussion

In this study, we identified four judgment grounds that lead to decision-making by surrogate decision-makers in Japan. With respect to Type 1-3 factors, in view of the standards proposed by Buchanan and Brock for guiding surrogate choices, the Type 3 (family-preference oriented) factor represents one that must be disregarded to the extent possible in the reasoning process leading to surrogate decisions. However, the results of the present study revealed just how difficult it is to eliminate this factor. In the following sections, we analyze this factor, which reflects the difficulty of making surrogate decisions based on the patient's preferences and/or best interests, while considering the background of Japanese society. We also comment on the influence of ACP that is expected to become more widely used in the future.

<Culture in which conversations about EOL rarely occur>

One of the subcategories extracted from the results of the present analysis was <I did not know what was good for the patient>. This indicated a struggle that, no matter how hard the surrogate decision-maker tries to guess the patient's preferences, there is no way of knowing what the patient would actually choose, or how (i.e., based on what values). During the interviews, surrogate decision-makers described difficulties presuming the patient's preferences. In other words, it is difficult for surrogate decision-makers to see things from the patient's point of view.

One factor contributing to this difficulty is a culture in Japan that does not encourage having specific conversations about EOL (end of life). Such talk is generally considered bad luck and even taboo in some families. According to actual data, only 5.5% of Japanese citizens reportedly talk about medical treatment in EOL situations with their family or medical care personnel, and only roughly 8% put their intentions in writing beforehand (14). Thus, it is likely that the number of surrogate decision-makers who clearly recognize the patient's preferences is low.

<Changes in social circumstances>

In 1980, almost 70% of elderly people aged  $\geq 65$  years lived with their children. By 2015, this rate had significantly decreased to 39.0%. Also, the rate of double-income families, which was 49.3% in 1980, has been rising year by year, and reached 64.4% in 2015. (15) These data suggest an increase in the number of adults (i.e., offspring of elderly individuals) who are not at home all day. With respect to the degree of communication between parents and children who do not live in the same house, Japan reportedly has the lowest frequency of older individuals meeting or contacting (e.g., by phone) their non-cohabiting children, relative to the United States, Germany, and Sweden (16). Although these international comparisons are based on a small number of countries, in Japan, the frequency of communication between elderly individuals and their non-cohabiting children or other family members may be low, according to international averages.

Based on these reports, we predict that in recent decades, it has become less common for children (i.e., potential surrogate decision-makers) to share time and space with their parents (i.e., patients) on a daily basis. This suggests that children in this generation may not be able to easily understand or imagine how their parents live, or what they value in their daily living. This may become an obstacle when they need to figure out what the patient preferences are as a surrogate decision-maker. It is also possible that this situation underlies the practice of surrogate decision-making for which factors other than the patient's preferences or best interests form the judgment grounds. All 14 of the surrogate decision-makers included in this study were children of patients or the

children's spouses. Although their working statuses are unclear, the rate of cohabitation was 20%. Thus, their circumstances might have made it difficult to imagine the life and values of the patient.

<Time restriction in surrogate decision-making >

When considering the judgment grounds in surrogate decision-making, it is likely that time restrictions have some influence. According to a report from the United States, 48% of surrogate decision-makers had to make critical decisions about life-sustaining treatment for patients aged  $\geq 65$  years within 48 hours after hospitalization in acute hospitals (17). Thus, in acute hospital settings, surrogate decision-makers may be forced to make these decisions in a short period of time. If a surrogate decision-maker was to make decisions in such a short time frame on behalf of an elderly patient who developed a serious life-threatening disease, to what extent would the surrogate decision-maker weigh the patient's preferences? There were some cases in the present study in which the family did not choose life-prolonging treatment (e.g., <I judged it realistically impossible to provide home care>). We presume that, in a setting that requires judgment regarding treatment options related to life support, it can readily be envisioned that the life of the surrogate decision-maker (family) would be affected somewhat depending on outcomes after treatment, especially when the patient's condition is unfavorable. In such situations, the surrogate decision-maker might make a hasty decision about which treatment to choose, thinking it realistically impossible to bear the burden of care, given their own life circumstances.

<Novelty of Type 4 factor>

The Type 4 factor reflects the reasoning of surrogate decision-makers who consider not only preferences of the patient but also those of family members in an effort to balance the two. Many previous reports examining the judgment grounds in surrogate decision-making only introduced one basis for judgment per case of surrogate decision-making, i.e., one that serves as the core of decision-making. On the other hand, the present study identified 3 types of factors that are not necessarily mutually exclusive; in fact, our findings suggested the possibility that in actual decision-making, multiple types of elements might be considered in reasoning and deriving surrogate decisions. The present study analyzed data obtained from an interview survey pertaining to the entire process of surrogate decision-making up to the judgment stage. For this reason, multiple judgment grounds were identified for each case of surrogate decision-making. From 14 cases of surrogate decision-making subjected to analysis, 55 codes relating to the judgement grounds were extracted. We presume these codes were considered in combination in actual settings of surrogate decision-making, and perhaps in a comparative manner. Those included in the Type 4 factor were categorized separately from others intentionally, since Type 1 - 3 factors reflected single judgement ground, whereas Type 4 reflected the outcome of comparative weighing of multiple grounds. In the United States, where patient autonomy is valued in most cases, there have been reports that, in actuality, surrogate decision-makers derive decisions based on their own values and circumstances in some cases (18-19). In Japan, the present report is the first to address this issue.

<Concerns about the potential psychological difficulties in surrogate decision-making as the consequence of wide use of ACP in Japan>

ACP, which is expected to become more prevalent in the future, has been suggested to activate communication between physicians and surrogate decision-makers (20). While the widespread use of ACP is desirable, there are concerns that the increased use of ACP might complicate the process of considering judgment grounds in surrogate decision-making and also increase the psychological burden on surrogate decision-makers. In other words, by clearly recognizing patient preferences (more than they already do), the surrogate decision-maker may end up with more conflicts in surrogate decision-making. This is because, as demonstrated by the present study, there are actual situations in which surrogate decision-making is practiced based on preferences of the surrogate decision-maker, which differ from those of the patient.

In Japan, patients rarely talk about their own preferences and values. Having advance discussions more often would allow the surrogate decision-maker to be more aware of patient preferences than they have in the past. This may help identify judgment grounds in surrogate decision-making that are rooted in patient preferences and best interests. However, this may also lead to a clearer awareness among surrogate decision-makers of the fact that their preferences may differ from those of the patient. As a result, we worry that surrogate decision-makers might become more conflicted as they struggle to decide whether to prioritize patient preferences or those of their own. This is a situation that can be inferred from the current state of surrogate decision-making as revealed in the present study, i.e., decisions are made on bases rooted in the preferences of the surrogate decision-maker. We surmise that clarifying patient preferences does not necessarily result in a situation in which those preferences are smoothly prioritized, but rather causes a struggle in surrogate decision-makers who must consider the preferences of both patients and their own families. Whether such struggles are good or bad is beyond the scope of this discussion. Nonetheless, it should be noted that this struggle may complicate the process of surrogate decision-making. Rather than focusing solely on the principles of respect for patient autonomy and standards of decision-making, the judgment grounds in surrogate decision-making should be discussed while considering multiple factors including culture, social situation, and circumstances of surrogate decision-makers. Such approaches in decision making should be allowed for future surrogate decision-makers and medical practitioners in Japan. Given that some patients think it is permissible that, in addition to their own preferences, preferences of the surrogate decision-maker may be prioritized in the surrogate decision-making process, as revealed by previous studies (21-22).

Some patients may want to be aware of possible conflicts before choosing their surrogate decision-makers. Surrogates decision-makers may experience increased conflict when they learn more about patient preferences; however, ACP discussions could lead the patient to choose a different surrogate decision-maker who may not have such conflicts, or who may be more willing to enact the patient's wishes. We believe that the results and discussions described so far can be useful for health care professionals in Japan as well as in other countries where surrogate decisions are made with a culture and background similar to Japan. For example, it is the case in the region that does not prioritize patient self-determination as much as the United States, but also the case in the society that considers the interests of people surrounding the patient, including family members. Moreover, it has been reported that ACP is not always performed in all patients, even in Europe and the United States, and not all patients want their autonomy to be respected ((23)Br J Gen Pract. 2013;63:e657-68.). As long as there is a possibility that healthcare professionals encounter cases similar to Japanese culture, this study could

contribute to more practical and complicated deliberation concerning surrogate decision-making involving international audiences as well as healthcare professionals worldwide.

### **Strengths and limitations**

The present study analyses were performed by a multidisciplinary group of 6 professionals including non-medical practitioners (physician, nurse, pharmacist, philosopher). Discussions were carried out among these analysts from various perspectives, making this system more favorable compared to those adopted by previous studies. In addition, in devising the analysis method, we referenced the “Ueno method” which is based on the KJ method. This allowed us to analyze the entire process of surrogate decision-making and clarify the judgment grounds. The “Ueno method” is superior to other methods in that it allows for the analysis of entire interview contents without omission.

This study also has limitations worth noting. First, since the recruitment process was outsourced to a web research company, interview respondents were limited to Internet users. In addition, participants were restricted to those living in the suburbs of Tokyo due to the location of the interview site. Potential bias also exists as the detailed characteristics of surrogate decision-makers, such as the number of years of care experience, educational background, economic status, religion, and family composition of the patient other than the surrogate decision-maker, were not available. However, as we analyzed data from the 14 participants, we achieved theoretical saturation of concepts extracted as judgment grounds in surrogate decision-making. Thus, we did not increase the sample size any further.

The second limitation is recall bias related to the timing of the interviews. The interview survey was performed within 6 months to 3 years after surrogate decision-making. Due to the time lag, interview contents might have differed from actual events. However, given that experiences of surrogate decision-making might be connected to grief, ethical consideration was given such that interviews were performed after a certain amount of time had passed.

Finally, there was also a limitation regarding the “Ueno method.” Although this method has the analytical advantage discussed above, it has not been validated internationally. No English description is available, and no studies using this method have been reported internationally.

Despite these limitations, the present study provides novel insights into the judgment grounds in surrogate decision-making. A large-scale cross-sectional study on this topic based on the present results would help clarify the actual diversity and its frequency of grounds used for judgment in surrogate decision-making in Japan.

## **Conclusions**

This study revealed the current status of surrogate decision-making in Japan: when making decisions about important matters related to a patient’s life, surrogate decision-makers base their decisions not only on the preferences and best interests of the patient, but on their and their family’s preferences as well. Included in the preferences of surrogate decision-makers were their own views of life and death, their values, and care burden.

In Japan, ACP is likely to become more prevalent in the future. ACP will provide a valuable source of information and is beneficial in terms of respecting patient autonomy. However, given the cultural and social backgrounds in Japan, it remains unclear whether this information can be properly reflected in judgment grounds in surrogate decision-making. It would be undesirable to base judgments solely on the principle of respect for autonomy or the principles of surrogate decision-making originating from the United States. In the future, we believe that surrogate decisions-makers will be required to consider the judgment grounds from a more diverse perspective and that such attitudes should be ethically accepted.

## **Declarations**

### **Ethics approval and consent to participate**

This study was approved by the Ethics Committee of Tohoku University Graduate School of Medicine(2017-856).

### **Consent for publication**

Not applicable

### **Availability of data and material**

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

### **Competing interests**

The authors declare that they have no competing interests.

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### **Authors' contributions**

All authors (MT,KO,AE,TO,AA) contribute to the analysis and thesis writing, and they have read and approved the final manuscript.

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