Research Square

Preprints are preliminary reports that have not undergone peer review. They should not be considered conclusive, used to inform clinical practice, or referenced by the media as validated information.

Judgment grounds in surrogate decision-making in Japanese clinical practice: A qualitative survey

Masashi Tanaka (tanakamasashino@gmail.com)
Tohoku Daigaku https://orcid.org/0000-0002-5710-5116

Kayoko Ohnishi
Konan Joshi Daigaku

Aya Enzo
Tohoku Daigaku

Taketoshi Okita
Tohoku Daigaku

Atsushi Asai
Tohoku Daigaku

Research article

Keywords: surrogate decision-making, clinical practice, advanced care planning, ACP, Japan

Posted Date: December 18th, 2020

DOI: https://doi.org/10.21203/rs.3.rs-24105/v3

License: This work is licensed under a Creative Commons Attribution 4.0 International License. Read Full License

Version of Record: A version of this preprint was published on January 13th, 2021. See the published version at https://doi.org/10.1186/s12910-020-00573-4.

Abstract

Background

Surrogate decision-making is expected to become more prevalent in Japanese clinical practice. Recent years have seen an increase in activities to promote advance care planning (ACP), potentially affecting the manner in which judgments are made in surrogate decision-making. This study aimed to clarify judgment grounds on which surrogate decisions are made in Japan.

Methods

This qualitative study was based on semi-structured interviews regarding judgment grounds in surrogate decision-making for critical life-sustaining treatment choices in acute hospitals.

Results

A total of 228 participants met the inclusion criteria, and 15 were selected for interviews. We qualitatively analyzed the content of 14 interview transcripts, excluding one which did not meet the inclusion criteria. Based on this analysis, four core categories, 17 categories, 35 subcategories, and 55 codes regarding judgement grounds in surrogate decision-making were extracted. The four core categories were as follows: Patient preference-oriented factor (Type 1); Patient interest-oriented factor (Type 2); Family preference-oriented factor (Type 3); and Balanced patient/family preference-oriented factor (Type 4). The Type 4 core category represented attempts to balance preferences of the patient with those of the surrogate decision-maker.

Conclusions

Surrogate decision-makers based their decisions on important matters related to a patient's life not only on the preferences and best interests of the patient, but also on their own preferences. As the need for surrogate decisions increase in the future, decision-makers will need to consider judgment grounds from a more diverse perspective.

Background

Surrogate decision-making is expected to become more prevalent in Japanese clinical practice. In 2017, Japan reported 1.34 million deaths, of which 70% corresponded to those aged ≥75 years. This number 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, only 29.7% have the capacity to make such decisions (2). Thus, an increasing number of patients are expected to rely on others to make decisions on their behalf (surrogate decision-maker).

In the United States, surrogate decision-makers are in principle expected to base their decisions on the substituted judgment standard, i.e., 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 bioethics (5).

In practice, however, judgment grounds in surrogate decision-making are not always based on the hierarchical standards. This has been pointed out in Japan and other countries (6). For instance, according to a study in Japan, some surrogate decision-makers and physicians base their decisions on their own preferences (7), suggesting that patient preferences or best interests might not always form the grounds for judgment in surrogate decision-making. Notably, studies on this topic in Japan have been limited in terms of sample size and content relating to surrogate decision-making.

In recent years, activities to promote advance care planning (ACP) have gained 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, this process may include entrusting medical decisions to another person or persons if they cannot make them on their own (8). This may impact the manner 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” to reflect the increased activities and research efforts relating to ACP 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 may 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 patients themselves should specify a surrogate decision-maker who would presume their intentions before they become incapable of communicating their wishes (8.9). 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 (10). 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.

Cultural differences exist in surrogate decision-making. For example, while ACP is considered a process that respects patient preferences and has been actively prompted in Europe and the United States, it is culturally taboo in Japan for physicians to disclose to patients the fact that their condition will deteriorate in the future. Moreover, with regard to selecting a surrogate decision-maker, Japanese culture values seniority (e.g., being the eldest and/or male) over normative standards (e.g., being the one who knows the patient’s preferences better than anyone else). Differences in religious beliefs also underlie these cultural differences. The sacredness of life and death is deeply rooted in cultural and religious beliefs in Japan

and has given rise to the notion that unnecessary suffering should be avoided (11). When considering these cultural perspectives in surrogate decision-making, several aspects clearly differ between Japan and Western countries. However, culture is not fixed, and as the introduction of ACP continues to be promoted in Japan, cultural transitions and merging have occurred. Importantly, this type of transition is not unique to Japan, but likely observed in other countries as well. Therefore, the present survey on the current status of surrogate decision-making and ACP in Japan is of international relevance.

The purpose of this study is to clarify the judgment grounds on which surrogate decisions are made in Japan, in view of the aging population which has intensified activities surrounding surrogate decision-making. In particular, this study aims to reveal judgment grounds in surrogate decision-making involving critical, life-sustaining treatment choices in acute hospitals. Finally, we consider how the spread of ACP practice might alter the judgment grounds in surrogate decision-making. To date, reports on surrogate decision-making in Japan have been limited to those published domestically. Thus, we believe it meaningful to report on judgment grounds in surrogate decision-making currently being used in Japan to an international audience.

Methods

Study design

This study aimed to analyze the process of surrogate decision-making from the viewpoint of surrogate decision-makers in Japan, and to clarify judgment grounds in surrogate decision-making in clinical practice. Given the highly unique nature of each case, we considered the need for research methods that allow for a careful analysis and examination of each decision-making process in order to understand the reality of each case. Accordingly, we adopted a qualitative research design based on semi-structured interviews, as described in further detail below.

Eligibility criteria

Participants were individuals residing in the suburbs of Tokyo who were recruited through a recruitment company (12). Eligible participants were surrogate decision-makers of patients who met all of the following 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; (d) required decision-making regarding life-sustaining treatment (dialysis, artificial respirator, tube feeding, central venous hyperalimentation); and (e) held discussions regarding treatment with physicians in the presence of another individual. Exclusion criteria were as follows: (a) those who did not wish to participate in the study; (b) those with difficulty communicating in Japanese; 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. The interviewer selected 15 participants from the list of 228 people and contacted them through the recruiting company. The protocol did not specify a limit to the number of individuals to interview, allowing for the possibility of additional interviews. However, no additional interviews were necessary, as content saturation and theme

development was achieved with the 15 participants. The recruitment company provided to the investigator a list of contact information for those who expressed an intention to participate in the study.

Interview procedure

Contents of planned interviews were explained to participants in written form 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).

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 informed consent was obtained from all participants, and they were explained that the contents of the interview would be recorded and that their statements would be reported anonymously. All participants were compensated 8,000 yen (to cover about 30 minutes of paperwork and transportation expenses) for the interviews which lasted up to 2 hours.

Analysis methods

Interview transcript preparation was outsourced 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 (13) and the Ueno method (14), which is a simplified version of the KJ method developed by Chizuko Ueno (Professor Emeritus, the University of Tokyo).

Interviews were recorded using an IC recorder, and verbatim transcripts were created. All sentences in the raw data were subjected to analysis, and all researchers involved in the analysis read each sentence 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, efforts were made to simplify the title so that the meaning of the subcategory could be readily understood from the title alone. Similar subcategories were grouped into categories and then into core categories, with increasing levels of abstraction. Content validity was verified 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 all of them in this report. Accordingly, important parts within each code were excerpted as appropriate, omitting some parts without changing the overall meaning. Data were analyzed using MAXQDA Plus12 (Release 12.2.1) software.

Results

Overview of study participants

A total of 228 participants met the inclusion criteria. Of these, 15 participants were selected from among those who were available for interviews at a convenient date and time for both researchers and participants (i.e., interviewees). The number of individuals pooled by the web survey company, to whom survey requests could be sent, was not disclosed by the company. 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, data from 14 were subjected to analysis after excluding one who was a family member of a patient but did not make decisions on the patient's behalf. Details regarding participant characteristics are summarized in Table 2. All surrogate decision-makers who participated in this study were family members of the respective patients.

Qualitative analysis

Results of the qualitative analysis of 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.

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

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 patient's preferences]

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 various machines connected to the body*). In this case, the patient mentioned specific treatment choices in prior discussions, and the surrogate decision-maker respected them.

[I respected the patient's presumed intentions]

One of the subcategories of this category was <I made the decision based on what I thought 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*). In this case, the surrogate decision-maker attempted to figure out what the patient's preferences might be, from the patient's perspective.

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

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 making the decision by considering the patient's best interests]

This category included the subcategory <I thought it would be good for the patient 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*). The surrogate decision-maker considered 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 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 to 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 activities of daily living (ADL) and communication capacity]

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 thoughts could lead to a decision that shortens the patient's time to death. 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"

Judgment grounds rooted in the preferences of the surrogate decision-maker, who is a family member of the patient, were classified as the 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 young 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 us 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 made a 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 members 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 the patient was in pain.

[I wanted the patient to live]

This category included the subcategory <When 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 health, the desperate hope of the surrogate decision-maker to prolong the patient's life formed the basis for judgment in surrogate decision-making.

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

Judgment grounds rooted in balancing preferences of the patient and those of the surrogate decision-maker (i.e., family) were classified as the Type 4 core category. This core category comprised 1 category, 2 subcategories, and 5 codes.

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

This category included the subcategory <I made the decision 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 make a decision 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 a hard decision to make. 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 provided 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 to reduce the burden of care on family members.

Discussion

In this study, we identified four types of judgment grounds for decision-making by surrogate decision-makers in Japan. In view of the standards proposed by Buchanan and Brock for guiding surrogate choices, the Type 3 (family-preference oriented) factor must be avoided to the extent possible in the reasoning process leading to surrogate decisions. However, our present findings highlight just how difficult it is to eliminate this factor. In the sections that follow, we include an analysis of this factor from a cultural perspective, and also discuss the influence of ACP which is expected to become more widespread in Japan in the future.

Culture in which conversations about EOL rarely occur

One of the subcategories extracted in this study was <I did not know what was good for the patient>. This reflects the 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. During the interviews, surrogate decision-makers described difficulties presuming the patient's preferences, suggesting that it was difficult for surrogate decision-makers to see things from the patient's point of view.

One factor contributing to this difficulty is the culture in which specific conversations about the end of life (EOL) are avoided. Such talk is generally considered bad luck and even taboo for some families. 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 (15). Thus, the number of surrogate decision-makers who clearly recognize the patient's preferences is likely to be low.

Changes in social circumstances

In 1980, almost 70% of elderly people aged ≥65 years lived with their children. By 2015, this rate had significantly declined to 39.0%. The rate of double-income families, which was 49.3% in 1980, has increased year by year, reaching 64.4% in 2015 (16). These data suggest an increase in the number of adults (i.e., offspring of elderly individuals) who are not at home all day. In terms of communication between parents and children who do not live in the same house, Japan reportedly has a lower frequency of older individuals meeting or calling their non-cohabiting children compared to the United States, Germany, and Sweden (17). Although these comparisons are based on a small number of countries, international averages confirm the low frequency of communication between elderly individuals and their non-cohabiting children or other family members in Japan.

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. Thus, children in this generation likely have difficulty understanding or imagining how their parents live, or what they value in their daily living. This may present an obstacle when making a surrogate decision, and may also underlie the basis for judgements in surrogate decision-making which involve factors other than the patient's preferences or best interests. All 14 of the surrogate decision-makers in this study were children of patients or the children's spouses. Although information regarding their work status was unavailable, the rate of cohabitation with patients was low (20%), which may have made it difficult to envisage and understand the patients' life and values.

Time restrictions in surrogate decision-making

Time restrictions likely had an impact on judgment grounds in surrogate decision-making. 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 ≥65 years within 48 hours after hospitalization in acute hospitals (18). Thus, surrogate decision-makers may be forced to make these decisions quickly, particularly in acute care settings. In such a scenario, to what extent would the patient's preferences factor into the surrogate decision-maker's judgements? Some families in the present study chose to forego life-prolonging treatment for the patient (e.g., <I judged it realistically impossible to provide home care>). In settings that require judgments regarding treatment options related to life support, the life of the surrogate decision-maker (family) would likely be affected to some degree depending on the outcome of treatment, especially when the patient's condition is unfavorable. In such situations, a hasty decision might be made about treatment choices which reflects the inability of the surrogate decision-maker 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 the preferences of the patient, but also those of family members in an effort to balance the two. Previous studies on 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. In contrast, the present study identified 3 factors that are not necessarily mutually exclusive, suggesting the possibility that in actual decision-making, multiple elements might be involved in reasoning and deriving surrogate decisions. We analyzed interview contents which spanned the entire process of surrogate decision-making up to the judgment stage, which yielded numerous judgment grounds for each case of surrogate decision-making. From the 14 cases we analyzed, 55 codes were extracted. We speculate that these codes were considered in combination in surrogate decision-making settings, and perhaps even in a comparative manner. Codes related to the Type 4 factor were categorized separately from Type 1-3 factors, since the latter reflect a single judgement ground, whereas the former reflects the outcome of comparative weighing of multiple grounds. In the United States, where patient autonomy is valued, surrogate decision-makers have been reported to derive decisions based on their own values and circumstances in some cases (19-20). The present study is the first to address this issue in Japan.

Concerns about potential psychological difficulties in surrogate decision-making as ACP use becomes widespread in Japan

ACP has been suggested to activate communication between physicians and surrogate decision-makers (21). While the widespread use of ACP is desirable, there are concerns that the increased use of ACP might complicate the process of surrogate decision-making and increase the psychological burden on surrogate decision-makers. That is, by placing more weight on patient preferences (more than they already do), the surrogate decision-maker may be faced with more conflicts because there are situations in which surrogate decision-making is based on preferences of the surrogate decision-maker, which may 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 and may help them identify judgment grounds that are rooted in patient preferences and best interests. However, this may also lead to a clearer awareness that their preferences differ from those of the patient. Thus, surrogate decision-makers may become more conflicted in their struggle to decide whether to prioritize patient preferences or their own. Clarifying patient preferences through ACP might not necessarily result in the prioritization of those preferences, but instead place a psychological burden on surrogate decision-makers who must struggle to balance the preferences of both patients and their own families. Whether this struggle is good or bad is beyond the scope of this discussion. Nonetheless, it could complicate the process of surrogate decision-making. Rather than focusing solely on the principle of respect for patient autonomy and standards of decision-making, judgment grounds in surrogate decision-making should be discussed while considering multiple factors including culture, social context, and circumstances of the surrogate decision-makers. Along these lines, previous studies have reported that some patients consider it permissible to have their preferences balanced with those of surrogate decision-makers (22-23).

Some patients may prefer to be aware of potential conflicts before choosing their surrogate decision-makers. ACP discussions could help the patient choose a different surrogate decision-maker who may not have conflicts, or who may be more willing to abide by the patient's wishes. We believe our results are not only helpful to healthcare professionals in Japan, but also widely apply to countries with similar cultural values, for instance, countries which do not prioritize patient self-determination to the degree seen in the United States, and countries which also consider the interests of individuals surrounding the patient, such as family members. Even within Western countries, ACP is not always performed by all patients, and not all patients want their autonomy to be respected above all else (24). If a healthcare professional is likely to encounter cases similar to those discussed here, the findings of this study could provide meaningful information that would contribute to surrogate decision-making.

Strengths and limitations

Analyses in this study were performed by a multidisciplinary group of 6 professionals, which included non-medical practitioners (2 physicians, 1 nurse, 2 philosophers, and 1 pharmacist). This allowed for discussions from various perspectives, contributing to a well-rounded analysis as compared to the narrower strategies adopted in previous studies. When developing the analysis method, we looked to the "Ueno method," which is based on the KJ method. This made it possible to analyze the entire process of surrogate decision-making and identify judgment grounds. The "Ueno method" is superior to other methods in that it allows for the analysis of entire interview contents without omitting any information.

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 living in the suburbs of Tokyo due to the location of the interview site. Potential bias also exists since detailed information on the 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, was not available. Notably, however, since data from 14 participants were sufficient to achieve theoretical saturation of concepts extracted as judgment grounds in surrogate decision-making, the sample size was not increased.

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

Finally, although the "Ueno 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 judgment grounds in surrogate decision-making. A large-scale cross-sectional study on this topic could further clarify the diversity and

frequency of judgment grounds in surrogate decision-making in Japan.

Conclusions

This study revealed the current state of surrogate decision-making in Japan. When making decisions about important matters related to a patient's life, surrogate decision-makers based their decisions not only on the preferences and best interests of the patient, but also on their own preferences and their family's preferences. The underlying basis for preferences of surrogate decision-makers included their own views of life and death, values, and care burden.

ACP is likely to become more prevalent in Japan in the future. It will provide a valuable source of information and is beneficial in terms of respecting patient autonomy. However, given the cultural and social backgrounds of Japan, it is unclear whether this practice can be properly reflected in judgment grounds in surrogate decision-making. As discussed, basing judgments solely on the principle of respect for autonomy or the principles of surrogate decision-making originating from the United States would be undesirable in the Japanese context. Rather, surrogate decisions-making based on judgment grounds from diverse perspectives appears to be more appropriate.

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.

Funding：This research was funded by Grant-in-Aid for Scientific Research of Atsushi Asai, a representative of the research project / area number：18K09963 ：. The fund carried out research activities at all stages. For example, interview awards, making transcription, English proofreading / translation, travel fee to have research meeting, research-related literature / book purchase fees, etc.

Authors' contributions：All authors：Masashi Tanaka, Kayoko Ohnishi, Aya Enzo, Taketoshi Okita, Atsushi Asai： contribute to the analysis and thesis writing, and they have read and approved the final manuscript.

Acknowledgments：We are grateful to Dr. Seiji Bito for helpful discussions and Ms.Yui Otokozawa for analyzing the data.

References

1:https://www.mhlw.go.jp/toukei/saikin/hw/jinkou/geppo/nengai17/dl/kekka.pdf

2: Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death.N Engl J Med. 2010;362(13):1211-1218.

3:JAMA. 1992;267(15):2067.

4:Buchanan AE, Brock DW. *Deciding for others: the ethics of surrogate decision making*: Cambridge University Press, 1989.

5:Cunningham TV, *et al*. *J Med Ethics* 2017;0:1–6.

6:Ann Intern Med. 2008 Jul 1;149(1):48-53.

7: Bioethics. 2004;18(2):87–103.

8: J Pain Symptom Manage. 2017 May;53(5):821-832

9:https://www.mhlw.go.jp/file/04-Houdouhappyou-10802000-Iseikyoku-Shidouka/0000079906.pdf

10:https://square.umin.ac.jp/endoflife/2019/general.html

10: BMC Med Ethics. 2018;19(1):12. Published 2018 Feb 27. doi:10.1186/s12910-018-0251-z

11: BMC Med Ethics. 2018;19(1):12. Published 2018 Feb 27. doi:10.1186/s12910-018-0251-z

12:http://www.marsh-research.co.jp

13: Kawakita J. KJ-method - let chaos tell [in Japanese]. Tokyo: Chuoukouronsha; 1986.

14:https://www.ritsumei-arsvi.org/publication/center_report/publication-center27/publication-414/

15: https://www.mhlw.go.jp/toukei/list/dl/saisyuiryo_a_h29.pdf

16:https://www8.cao.go.jp/kourei/whitepaper/w-2017/html/zenbun/s1_2_1.html

17:https://www8.cao.go.jp/kourei/ishiki/h27/zentai/index.html

18:JAMA Intern Med. 2014 Mar;174(3):370-7.

19:Am J Geriatr Psychiatry. 2006 Aug;14(8):659-67.: Why doesn't a family member of a person with advanced dementia use a substituted judgmentwhen making a decision for that person?

20:J Am Geriatr Soc. 2006 Nov;54(11):1688-93.: Beyond substituted judgment:How surrogates navigate end-of-life decision-making.

21:J Am Geriatr Soc. 2007 Feb;55(2):189-94.

22:Ann Intern Med. 2008 Jul 1;149(1):48-53.

23:J Gen Intern Med. 2008 Sep;23(9):1514-7.

24:Br J Gen Pract. 2013;63:e657–68.

Tables

Table 1 Guide for interviews with surrogate decision-makers

1. What was the specific content(s) of your surrogate decision-making?
2. In 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 difficult 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 meaningful 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 regarding surrogate decision-making?

Table 2 Sex of surrogate decision-maker

Sex of surrogate decision-maker	Age of surrogate decision-maker	Relationship with patient	Interview duration (minutes)	Sex of patient	Age of patient	Cohabiting (patient and surrogate decision-maker)	Inpatient department	Content of surrogate decision-making				
								Life-prolonging treatment	Ventilator	Artificial nutrition	Place of treatment	Dialysis
Female	30s	daughter-in-law	48	Male	70s	NO	Cardiology	○	○	○	○	○
Female	40s	eldest daughter	50	Male	70s	NO	Neurology			○		
Female	40s	daughter-in-law	40	Male	70s	NO	Respiratory	○	○			
Male	60s	second son	50	Male	80s	NO	Neurology	○		○	○	
Male	60s	eldest son	26	Female	90s	NO	Internal medicine	○	○			
Female	40s	eldest daughter	40	Male	80s	NO	Neurology			○	○	
Male	40s	eldest son	25	Male	60s	NO	Cardiology		○	○		
Female	50s	daughter-in-law	45	Female	70s	NO	Internal medicine	○			○	
Female	50s	second daughter	37	Male	80s	NO	Internal medicine			○		
Female	40s	second daughter	34	Male	70s	NO	Neurosurgery			○	○	
Female	50s	daughter in law	48	Female	70s	YES	Neurosurgery	○		○	○	
Female	60s	second daughter	37	Female	70s	YES	Internal medicine	○	○	○	○	
Male	60s	eldest son	37	Female	80s	YES	Internal medicine			○		
Male	50s	eldest son	54	Female	80s	NO	Internal medicine	○	○	○		○

Table 3

Core category	Category	Subcategory
1. Patient preference-oriented factor	I respected the patient's preference	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 never swayed
		I made the decision by respecting the patient's intention regarding life-prolonging treatment
	I respected the patient's presumed intentions	I made the decision based on what I thought 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 intentions by observing his/her condition
2. Patient interest-oriented factor	I tried making the decision by considering the patient's best interest	I valued patient safety
		I thought it would be good for the patient 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 s/he would be better off with gastrostomy
	I made the decision based on the patient's ADL and communication capacity	I agreed to forego life-prolonging treatment because I sympathized with the patient when I saw him/her being bedridden
		I did not choose gastrostomy since the patient was not able to communicate
		I thought the patient would find it painful to live in a vegetative state
		I thought 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 had a chance at recovery, 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 wanted to bring him/her home, so I chose the procedure (gastrectomy)
		I judged it realistically impossible to provide home care
		I made the decision that family members would not regret
		I realistically considered the lives of family members and decided to forgo gastrostomy
		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 the discussions we had in advance
		The feelings of the (closest) family members were important
	I wanted the patient to live	I was aware of the stance 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 undergo gastrostomy for my family
		I thought nobody would want to die
		Because the patient's life was limited, 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 intentions and 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