

# Advance Care Planning for Intensive Care Patients During the Perioperative Period: A Qualitative Study

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Kanako Yamamoto, RN, MSN<sup>1,4</sup> , Yuki Yonekura, PhD<sup>1</sup>,  
Junko Hayama, RN, MSN<sup>1</sup>, Taketo Matsubara, MD<sup>2</sup>,  
Hiroyasu Misumi, MD, PhD<sup>3</sup> and Kazuhiro Nakayama, PhD<sup>1</sup>

## Abstract

**Introduction:** Patients in intensive care units (ICUs) may transition into an end-of-life phase during treatment. Advance care planning (ACP) for this population has not been studied comprehensively, and support for its implementation is insufficient.

**Objective:** This study aims to clarify the ACP support needs among critical perioperative patients.

**Methods:** In this qualitative descriptive study, semistructured interviews were conducted with patients previously admitted to the ICU. The survey was conducted from September to November 2019. Participants comprised 13 individuals, who were admitted to the ICU for a period of 3 months to 2 years after surgery.

**Results:** The average age of the participants was 63.8 years. The average mechanical ventilation duration following surgery was 24.5 h. The interviews focused on the ACP needs from the preoperative period to discharge. About 90% of the patients thought about the possibility of death before surgery and considered giving advance orders (e.g., “I don’t want life-sustaining treatment”). The participants discussed inheritance, work-related matters, and household issues with their families but rarely spoke about treatment and care. Although they examined the content of the advance directives, the medical staff was not informed about them. Patients revealed that they wanted to understand the distinction between life-prolonging and life-saving treatments and discuss it with the medical staff, apart from being educated on ACP. Many patients previously admitted to the ICU are unclear about the difference between life-prolonging and life-saving treatments; this is also true for medical staff.

**Conclusion:** Patients who had been admitted to the ICU after high-risk surgery thought they needed help with ACP before surgery. Therefore, patients have the right to know about treatment risks; however, medical staff believes that this is difficult to communicate. Thus, medical staff should consider ways to communicate clearly with patients, including discussing the risks associated with surgery.

## Keywords

intensive care unit, advance care planning, perioperative period, patient

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## Background

Patients undergoing high-risk surgery are typically severely ill and are subsequently admitted to a postoperative intensive care unit (ICU; Gillies et al., 2017; Nepogodiev et al., 2019). These patients are likely to have low resilience to excessive invasive treatment procedures, and ICU admission after high-risk surgery tends to cause postoperative complications, leading to a loss of consciousness and even death in some cases (Beggs et al., 2014; Nepogodiev et al., 2019). The proportion of complications associated with death is 2.4%, and complications in patients after a high-risk surgery is 50.4% (The International Surgical Outcomes

<sup>1</sup>Graduate School of Nursing Science, St. Luke’s International University, Tokyo, Japan

<sup>2</sup>Department of Gastroenterological Surgery, St. Luke’s International Hospital, Tokyo, Japan

<sup>3</sup>Department of Cardiovascular Surgery, St. Luke’s International Hospital, Tokyo, Japan

<sup>4</sup>Department of Critical Care, Graduate School of Nursing Science, St. Luke’s International University, Tokyo, Japan

### Corresponding Author:

Kanako Yamamoto, Graduate School of Nursing Science, St. Luke’s International University, Tokyo, Japan.  
Email: ykanako@slcn.ac.jp



Study Group, 2016). Additionally, patients' quality of life at the time of discharge is poorer than before the operation (Azoulay et al., 2017), and readmission is typically recurrent among patients who have undergone high-risk surgeries (Bagshaw et al., 2014). These issues may provide important insights for ICU patients and their families. However, the special nature of the perioperative period presupposes recovery and thus provides few opportunities to obtain adequate explanations, especially regarding pre- and postdischarge life. Moreover, in acute care hospitals, the preoperative hospitalization period for patients is brief, and the opportunities for medical personnel to support patients in decision-making related to treatment and care are extremely limited. For these reasons, providing decision support for ICU patients is challenging.

Advance care planning (ACP) is a process that enables patients to think about and plan their future and provides them with an opportunity to discuss their desired medical care and support with medical professionals. Presumably, ACP enhances patients' self-efficacy (Morrison et al., 2005) and support varies from country to country. Despite the geographical variation in the definition of ACP, it is jointly performed by the patient and the care provider, such as a health care provider or a family member, across various countries (American Medical Association, 2017; Ministry of Health, Labour and Welfare, 2018a; National Health Service, 2017). ACP provides medical care in accordance with the patient's values and requests in case the patient's decision-making ability declines in the future. Therefore, ACP is an ethical practice that promotes decision-making based on respect for patient autonomy.

Moreover, ACP implementation should not be limited to terminally ill patients, and it should be applied to all patients, depending on their health status and disease severity (Sudore et al., 2018). However, perioperative and ICU patients have a precondition for recovery, but the medical staff is disposed to think of it as support that is not too suitable.

Given this, the support of ACP is challenging, and its effectiveness has not been established. This challenge is attributed to the compromised judgment of ICU patients due to impaired consciousness and the use of sedatives, which hinders communication regarding patient values and intentions, an integral part of the ACP process. Furthermore, patients who are at risk of dying typically do not support ACP (Heyland et al., 2013) and tend to live in denial by avoiding any discussions (Evangelista et al., 2012). Therefore, it is almost impossible to introduce ACP to patients while they are admitted to the ICU.

Therefore, the integration of patients' values is lowered during the decision-making regarding the transition to end-of-life care, and the focus is directed toward the decision to not attempt resuscitation—a part of the ACP process.

During this period, family members and surrogates make decisions on behalf of the patient. However, these decisions tend to cause enormous conflicts and substantial physical and

mental burden. Therefore, these decision-makers often experience clashes with medical teams (Breen et al., 2001). Previous studies have reported that 50%–70% of surrogate decision-makers in families do not understand patient care (Azoulay et al., 2017; Lilley et al., 2017). However, no existing studies have examined the current decision-making status or the need for ACP among patients admitted to the ICU during the perioperative period and their families.

Examining these issues can lead to timely information provision as per the patients' requirements and can facilitate decision-making based not only on the patients' and the family's wishes but also using the necessary information. Thus, it is essential to clarify the decision-making process of patients undergoing invasive surgery to provide evidence to support ICU patients' decision-making. This study also provided an opportunity to explore strategies for information provision about ACP to patients and their families. Therefore, this study identified the need for introducing ACP among patients admitted to the ICU during the perioperative period and their families and considered the corresponding effective support methods.

In summary, this study aimed to clarify the perception of ACP among patients undergoing high-risk surgery and receiving critical care.

## Methods

### *Design and Participants*

Qualitative research examines participants' subjective experiences (Gray et al., 2016). This study used exploratory-descriptive qualitative research, as this approach can help patients and groups consider the impact of subjective experiences on their understanding and practice (Sandelowski, 2010). Thus, analyzing the experience of ACP among patients undergoing high-risk surgery using this approach may lead to the development and modification of the hypotheses regarding the need for ACP support and clinical practices for perioperative patients. Therefore, a qualitative approach is suitable for this study to evaluate the narrative of the participants. Subsequently, interviews were considered the most appropriate data collection method to evaluate the aims of the study, considering the sensitive subject of facing death. However, existing research on perioperative patients' and their families' perception and utility regarding ACP support is limited. Thus, it was necessary to conduct a qualitative study to determine the opinions about ACP among patients undergoing high-risk surgery.

The participants were patients admitted to the ICU during the perioperative period at a General Hospital in Japan. The inclusion criteria were as follows: (1) patients aged >20 years, mentally stable, and able to communicate and their family members; (2) patients undergoing gastrointestinal surgery, neurosurgery, or cardiovascular surgery (including stent surgery), whether elective or emergency; and (3) those who

underwent surgery within the last 2 years. The exclusion criteria were as follows: (1) having a history of dementia, (2) having a new disease that was caught within the last three months, and (3) having had surgery with serious complications and still undergoing medical treatment. Based on these criteria, some of the coauthors (who were physicians) screened potential participants for this study in advance. The interviews were conducted in October and November 2019.

### *Data Collection and Content of the Survey*

The research director randomly selected participants from the screened candidate pool. Subsequently, the purpose of the research was explained to the candidates, and those who provided consent to participate were recruited. The researchers prepared semistructured interview questionnaires using interview guides (Supplement 1) about the patients' experience and decision-making processes from the perioperative period to hospitalization and discharge. The first author conducted all interviews on a one-to-one basis, for ~30 min each, in private rooms or at places designated by the participants. The interviews were recorded using digital voice recorders with the consent of the participants.

The interview questions inquired as to whether treatments for life-threatening conditions were considered during the perioperative period, what these treatments were, if any, and if there was a need for the preoperative introduction of ACP. Participants were forewarned regarding the unpleasant and painful memories of hospitalization and mental strain that might be evoked due to the interview questions. Therefore, participants were carefully observed during the interviews, and they were informed in advance that they could withdraw their participation from the study at any point if they began to experience any mental burden or discomfort.

Medical records were also reviewed with the consent of the participants to obtain data regarding gender, age, presence or absence of family, complications, medical history, type of surgery, name of illness leading to surgery, hospital length of stay, ICU length of stay, sequential organ failure assessment score (SOFA score), Acute Physiologic Assessment and Chronic Health Evaluation II (APACHE II) score, informed consent from the physician, and the presence or absence of prior instructions, if any.

### *Analytical Method*

The data obtained from the interviews were recorded, transcribed verbatim, and analyzed qualitatively. The data were interpreted within the context of the perioperative patients' current decision-making status—which was the theme of the analysis—and their need to consider ACP before surgery. Further, the data were codified, and each code was compared; codes with the same meaning were grouped to form subcategories and increase the degree of abstraction. Finally, similar subcategories were grouped and further abstracted and

categorized. The researchers replaced the participants' names with ID numbers, and the data were transcribed by an external company. The analysis results were confirmed by researchers who were unaware of the participants' identities, and the analysis was examined for any potential bias. In addition, the validity and reliability of the results were confirmed and discussed among the researchers until a consensus was reached. This manuscript adheres to the standards for reporting qualitative research guidelines for reporting qualitative studies (O'Brien et al., 2014).

### *Ethical Considerations*

This study was conducted with the approval of the Research Ethics Committee of the first author's affiliated institution (approval number: 19-A041). Participants were provided written and oral explanations regarding the purpose of the study, the method of investigation, participation in and withdrawal from the study, protection of personal information and data management, access to medical records, publication of the results, and withdrawal after the consent, and then their written consent was obtained by signing the documents. The acquired data were managed separately, with an ID number and a correspondence table created so that the individual participants could not be identified.

## **Findings**

### *Target Audience Summary*

A total of 13 patients who were treated in the ICU during the perioperative period were recruited in this study. Of these, nine were men and four were women. The participants' mean age was 63.8 years (range: early 30s to late 70s). The mean duration of ICU stay was 3.9 days, with an average SOFA and APACHE II score of 3.5 and 11.8 points, respectively. Six patients underwent mechanical ventilation in the ICU; the mean duration of this was 24.5 h. The mean length of hospital stay was 20.2 days. Nine patients underwent elective surgery, and four patients underwent semiemergency or emergency surgery. The most common types of surgeries were gastrointestinal surgeries ( $N=7$ ), followed by cardiovascular surgeries ( $N=5$ ), and neurosurgery ( $N=1$ ). The mean interval between discharge and interview was 8.7 months (range: 3 months to 1 year and 8 months). The average interview duration was 34.3 min, and the total interview duration was 446 min. A summary of the participants' characteristics is given in Table 1.

### *Current Decision-Making Status From Disease Notification to Discharge among Perioperative Patients*

During the period from disease notification to hospitalization, 11 patients (91.7%) reported that they had considered the possibility of dying, excluding one patient who was unconscious

**Table 1.** Characteristics of Study Participants, *n* = 13.

Characteristics	
Age, year, mean (range)	63.8 (31–78)
Female, gender, <i>n</i> (%)	4 (30.1)
ICU admission type, <i>n</i> (%)	
Surgical elective	9 (69.2)
Surgical (semi-)emergency	4 (30.1)
Surgical type, <i>n</i> (%)	
Cardiovascular	5 (38.5)
Gastroenterological	7 (53.8)
Neurosurgical	1 (7.7)
Acuity	
SOFA score, mean	3.5
APACHE II score, mean	11.8
Mean ICU length of stay, mean	3.9
Mean hospital length of stay, mean	20.2

ICU = intensive care unit; SOFA = sequential organ failure assessment; APACHE II = Acute Physiologic Assessment and Chronic Health Evaluation II.

prior to emergency surgery. One respondent, who did not consider the possibility of death, was a patient with nonmalignant diseases who underwent gastrointestinal surgery. The decision-making process from disease notification to discharge was examined at four time points (Table 2). These four time points are (1) perioperative (notification of disease approximately until surgery is decided), (2) preoperative (from decision-making to hospitalization), (3) during the hospital stay, and (4) after hospital discharge.

The following is an example of a participant's narrative at each time point:

I wrote a farewell note thinking about what to do after my death, but I didn't tell my doctor or the hospital about it. It's hard to say such a thing before surgery. (omission) I thought it would be better to go ahead and have an operation, and the doctor thought it would be comfortable, so I did.

I started crying suddenly just upon telling my wife the name of my disease. I thought it was a problem (omission). What I think about this time is that my family is much more mentally strained than me. After I decided to undergo surgery, I told my daughter and wife, and they opposed it. In my case, the possibility of hemiparesis by surgery was about 50%. That is why my family did not think that I needed the surgery. However, rather than dying without doing anything, I thought it would be better if I could recover enough to live in a wheelchair, even if I was still paralyzed. If you can survive, you can live the rest of your life. I thought I could read at home and do what I wanted to do.

My family and friends came to see me in the ICU after the surgery, but I don't remember anything about it. I still have a video of that time, but I don't remember it. The video shows me talking to my daughter and friends in a normal

way, but it's kind of weird. This was about three months ago, and I have no memory of it.

Life after discharge was much harder than the surgery itself. There is a slightly big traffic light from home to work. Until now, it was working fine. But even if it's blue as much as possible, if the signal is likely to change, try not to cross forcibly. If you walk fast, you'll definitely have difficulty breathing. (omission) I don't know how long this will last, and I don't know if it's going to be okay. But no one told me that. It's important.

### Patients' Views on Preoperative ACP

In this study, all the participants expressed a need to be briefed about ACP before their surgery. Twelve patients (92.3%) responded that they did not desire life-prolonging treatment, while the one remaining patient preferred treatment that would not burden their family. Preoperative ACP support needs were classified into 55 codes and further grouped into six categories and 16 subcategories. The extracted categories and subcategories are listed in Table 3.

The categories included making decisions about treatment in life-threatening situations before surgery, wanting accurate information including the worst risks, expressing one's discretion in end-of-life care, wanting to know about ACP, the condition of one's intentions being respected till the very end, and not worrying about surrogate decision-makers, including family members.

The patients expected that the experience of having surgery and being admitted to the ICU would hinder their ability to make decisions during pressing hours. Thus, they wanted to know not only about the benefits of the treatment they were undergoing but also about the risks. Moreover, they wanted to know the differences between life-prolonging and life-saving treatments. For those who did not opt for life-prolonging treatment, life-saving treatment included the following: (1) attaching a permanent or long-term ventilator or being kept alive by a machine, (2) being unconscious and unable to make their own judgments, (3) receiving food through a tube down their throat, and (4) being unable to eat or defecate independently. They also mentioned that it was difficult to determine the point at which life-saving treatment would be replaced by life-prolonging treatment. Furthermore, a patient expressed their need to be informed by the physician about their current survival rate to facilitate decision-making regarding wanting to stop life-prolonging treatment. In addition, the patient desired compliance with the condition of their intentions being respected to the end by wanting to consider the type of treatment that they would undergo at each time, depending on the situation. However, the patient was unsure if they could make their own end-of-life decisions.

Participants also wanted to ensure the selection and discretion of surrogate decision-makers in advance. This procedure was performed to avoid any quarrels among their family members if their decision-making ability declined. However,

**Table 2.** Current Status of the Decision-Making Process Before and After Discharge Among Patients Admitted to an Intensive Care Unit (ICU) During the Perioperative Period.

Category	Subcategory
Preoperative (notification of disease approximately until surgery is decided)	
Patients begin to confront the view of life and death and consider undergoing surgery	<ul style="list-style-type: none"> <li>Consider the risks of one's future surgery</li> <li>Listening to patterns of complications and treatment outcomes after surgery can make patients hesitant to reach decisions</li> <li>Confront death by disease notification</li> <li>Respond to the situation calmly</li> <li>Accept the fact that surgery is necessary without ruminating even after being informed</li> </ul>
Gather information and use resources required to make decisions	<ul style="list-style-type: none"> <li>Patients have few options (have no option of one's choice)</li> <li>Use the experience of a family member or loved one's surgery or treatment as a basis for one's treatment decisions</li> <li>Obtain information only from a physician</li> <li>Gather one's own information and use it as a basis for decisions</li> <li>Determine one's survival rate</li> <li>Enhance one's understanding of one's physical condition by viewing one's test images</li> </ul>
Patients look back on their own treatment trajectories	<ul style="list-style-type: none"> <li>Have family members collect information about one's surgery</li> <li>Consider surgery based on one's history and surgery</li> </ul>
Consider both the success and failure of surgery and explore one's own way of life	<ul style="list-style-type: none"> <li>Understand possible surgical complications and the need for surgery</li> <li>Reflect on one's life so far and confront one's view of life and death</li> <li>Image of life after discharge if surgery or treatment is unsuccessful</li> <li>Avoid thinking about the consequences of surgery</li> <li>Want as much treatment as possible</li> </ul>
Make decisions based on the patient's preference for decision-making	<ul style="list-style-type: none"> <li>Make decisions based on the trust of hospitals, doctors, and nurses</li> <li>Make a decision based on what one can do now</li> <li>It is hard to make a decision on your own, so leave it to your doctor</li> <li>Make a decision without having time to reflect on the urgency of the condition</li> </ul>
Make a decision in the presence of one's best and hope	<ul style="list-style-type: none"> <li>Choose treatment based on the recognition that it is a high-risk treatment</li> <li>Make a decision to live with uncertainty and a half-resigned feeling about treatment</li> </ul>
Do not tell your health care provider what you are thinking about doing	<ul style="list-style-type: none"> <li>Do not share your thoughts about your treatment so that you will not be misunderstood as giving up on your care and treatment</li> <li>I do not understand the meaning of the living will documents that I submitted to the hospital</li> </ul>
Preoperative (from decision-making to hospitalization)	
Consider who to communicate with and how to communicate decisions about treatment in a life crisis	<ul style="list-style-type: none"> <li>Share all information and decisions about the illness with family members</li> <li>Restrict information about illness and share decisions with family members</li> <li>Concerned about family concerns and anxiety about one's illness</li> <li>Realize that one's family is more stressed and worried than one is</li> <li>Dispel one's own fears through encouragement from family members and others</li> </ul>
Since there are only a few things that can be prepared before the operation, the necessary matters should be arranged	<ul style="list-style-type: none"> <li>Withholding details of illness or surgery from family</li> <li>Think about how long you will be in hospital for and what you need to organize and prepare at work and at home</li> <li>Perceive a lack of time to prepare and organize for one's hospitalization</li> <li>Increase anxiety because of the delay between decision-making and surgery</li> </ul>
Face one's view of life and death	<ul style="list-style-type: none"> <li>Use the bereavement experience of one's relatives and close associates as a basis for making one's decision</li> <li>Realize that one's values change in the course of one's life</li> <li>Construe one's own view of life and death as one's strength and feel it supports treatment</li> </ul>

(continued)

**Table 2.** Continued.

Category	Subcategory
Select an agent and consider discretion in treating life-threatening situations	Select a substitute decision-maker by yourself, but do not inform the person Select a surrogate decision-maker and communicate it to the person or family Stick to one's will even if it differs from the will of one's family
Consider and share with family members treatment intentions during life-threatening situations	For the first time in this surgery, I will think about the contents of advance orders and tell them to my family As I have already told my family (preclinical) in my life my intentions, I will not share them with them again Consider treatment you absolutely do not want and leave a will Prepare and organize oneself for a life-threatening situation
During hospital stay	
Decision-making of treatment during ICU admission is difficult	I do not remember being in the ICU Inability to participate in decision-making while in ICU Be treated without considering the details or reason of treatment due to the complexity of the condition
Current status of information provision and treatment decision-making after ICU exit	I was convinced by the explanation provided by the medical staff about the treatment progress during hospitalization and my body information Absolute reliance on health care providers and hospitals for the treatment they currently need
The end of the operation converts anxiety into a sense of security	Worry more about one's family than about oneself Think only about recovering and not about negative things I think we do not have to worry about unnecessary things by thinking about the instructions beforehand
After hospital discharge	
Plan one's own reintegration process	Realize that physical and mental recovery takes time Plan a new way of life after one leaves the hospital Resolve problems while seeking necessary information and support in the outpatient clinic
Need continuous and continuous decision-making after recovery	Intention before surgery remains unchanged after treatment Rethink one's treatment while continuing treatment The treatment you want depends on your condition and age Realize the benefit of making one's own decision and leaving it in writing
Do not remember prior instructions after treatment	There is no need to reconsider the advance directive plan after discharge I do not remember the prehospital instructions

patients were concerned that despite informing their families of their intentions regarding their preferred treatment in advance, their families might decide that they would undergo life-prolonging treatment against their wishes during an emergency.

## Discussion

### *Patients' own ACP Processes and Their Implications*

Although all participants of this study reported that they had never heard of ACP, they had equipped themselves with various methods and content in accordance with their life-threatening situations before being hospitalized. Notably, some participants discussed their treatment preferences (ACP) with their families, while others did not. In addition, the medical staff was not informed of what was discussed

between the patient and their family and of the patient's wishes, such as transitioning to end-of-life care.

However, family members may not necessarily understand all the aspects of a patient's medical condition as well as the decision-making process and content. This can act as a barrier to surrogate decision-making when patients are admitted to the ICU after surgery with declined decision-making capacity. A study reported that 512 (51.3%) of the 998 patients admitted to the ICU were reported to have prepared an advance directive or a power of attorney, and only 22% of the hospitals recorded this information correctly (de Heer et al., 2017); it is crucial for medical personnel to accurately understand the patients' intentions for treatment. However, in our study, even the participants who had thought about their end-of-life treatment preferences and their discretion in advance did not share these thoughts with their physicians. A possible

**Table 3.** ACP Support Needs of Patients Admitted to ICU.

Category	Subcategory
Decide on treatment options for life-critical situations before surgery	Predict that it will be difficult to make an urgent decision in a short time
I want accurate information including the risks.	Be unsure of one's own decisions at the end of life I want you to tell me all the possible risks. Determining the risks and benefits of treatment
I decide to whom and how much I will delegate surrogate decision-making for end-of-life	I want to know the difference between life-prolonging treatment and treatment. If there is a life crisis, I want to leave it to my family. I want to leave it to my doctor in case my life is in danger. I want you to respect my intentions until I die.
I want to know about ACP	I want to understand the ACP procedure I want the medical staff to tell me what I need to think about in advance.
I want my treatment hope to be respected until I die	I want support from medical personnel My intentions may change, so I would like to consider these each time Worried that my intentions may be incorrectly communicated to the proxy decision-makers Worried about my family making a decision different than I intended at the end of life
Do not want to be a problem for proxy decision-makers, including family members	I do not want my family to conflict with the intrafamily. I do not want my family to be in financial trouble.

ACP = advance care planning; ICU = intensive care unit.

reason for this is that patients behave modestly when discussing their concerns with their physicians.

In fact, the patient's narrative says, "I don't want the surgeon to think I'm giving up treatment." There seems to be an invisible power relationship between the patient and the surgeon before the operation. This is due to the fact that the patient puts their life in the hands of the surgeon.

All participants agreed to consider ACP before surgery and subsequently specified the timing of receiving support from the medical staff. Existing literature suggests that preoperative ACP support carries a risk of increasing patient anxiety (Gigon et al., 2017); however, the current study participants reported that preoperative ACP discussions did not increase their anxiety about the surgery. This contradiction may be due to the fact that the patients had already decided to undergo surgery, despite the risks, based on the physician's explanation of the treatment. Many patients want to know the worst risks before deciding to undergo surgery, and therefore, the physician's description of the treatment procedure is important for decision-making (Mulsow et al., 2012). A previous study reported that 249 (25.7%) of the 969 patients had not discussed their end-of-life preferences with anyone before surgery (Ankuda et al., 2014). Sufficient informed consent with physicians regarding surgery suggests that changes may occur in the content of patients' preoperative decision-making. This suggests that it is possible to support ACP in patients before surgery. Another possible reason is the lack of knowledge about ACP. Most previous ACP studies examined patients with a

prognosis of one year or less or at the end-of-life phase (Gilissen et al., 2017), suggesting that health care providers are more likely to view ACP as a process to gradually prepare for death. Moreover, patients also want to participate in the decision-making process but are unaware of how to do so (Couët et al., 2015). In Japan, public awareness regarding ACP was found to be low (MHLW, 2018b), and accordingly, none of the participants in this study were aware of it. Therefore, it might have been easier for them to consider their treatment preferences and end-of-life care as a necessary preoperative measure.

In addition, participants who reported that they did not consider specific measures for life-threatening situations before the operation contemplated the possibility of death after being informed about the name of the disease and the surgery type. As a result, they made some preparations, such as personal arrangements and measures, should such an event occur. However, one participant did not remember the answers they provided to the questions in the living will that they submitted while being admitted to the hospital. Except for those who underwent emergency surgery, most respondents reported that they submitted their living will response to the hospital without thinking carefully. These findings suggest that the support tools for ACPs do not reflect patients' original treatment values and wishes and are not credible unless they are provided with sufficient information.

Studies on informed consent obtained from patients before surgery have noted that consent forms are not actionable in themselves, and they do not capture real patient

understanding (Larobina et al., 2007). Furthermore, they suggested that written advance directives do not necessarily reflect patients' preferences for their end-of-life care (Bradley et al., 2010; Luce & White, 2009). In contrast, some patients who had previously considered their preferred type of end-of-life treatment changed their preferences during their treatment. Another study on code-status changes in hospitalized patients found that, regardless of ICU admission, as many as 10% of the patients had additional or no treatment restrictions due to their code-status on admission throughout their hospitalization (Kim et al., 2016). These findings emphasize the need to reconfirm patients' intentions to continue treatment, even if they have confirmed the same in advance.

In addition, patients scheduled to be admitted to the ICU after surgery are at high risk for the rapid deterioration of their condition, with the urgency necessitating treatment decisions be made in a short amount of time. Four of the patients in the current study had undergone emergency or semi-emergency surgery. In fact, they stated that "the decision was made with impending illness and no time to think deeply" and that "there was a lack of time before hospitalization or surgery."

In addition, the participants who decided to undergo surgery for prolonging life without considering their views on life and death before surgery recognized the merits of reconsidering their course of treatment and determining and documenting their treatment intentions throughout the treatment process. These results indicate the necessity to communicate information about ACP, not only before surgery but also periodically to assess patients' feelings, especially toward treatment after surgery.

### *Elements for Preoperative ACP Support*

There was a need for the participants to understand and examine ACP before their operation. However, the problem was that they lacked relevant knowledge and did not know what to consider. The results also indicated that the importance of ACP is better understood and recognized after the actual treatment. The patients' needs included receiving information from a medical practitioner about the distinction between usual care and survival. However, it is difficult to predict the prognosis of patients admitted to the ICU, and even medical personnel struggle in making such judgments (Hilton et al., 2013). This highlights the need for information sharing and close communication between health care providers, patients, and their families. Furthermore, because each patient regards life-prolonging treatment differently, it is necessary to inform patients of the treatments that would be useless for them to respect their autonomy. The principles of bioethics (Beauchamp & Childress, 2019) state that autonomy is based on individual autonomy, including informed consent. Therefore, for patients who have undergone high-

risk surgery and are known to have received critical care before surgery, it is important to discuss the risks with health care practitioners and family members elaborately and consider treatment preferences when patients can make their own decisions. For such patients, the preoperative period is the critical time to consider ACP and understand the risk of complications by communicating with health care providers.

While most of the patients reported they did not want life-prolonging treatment, only a few had been able to explain the details of its contents. This was because the merits and demerits of life-prolonging treatments, such as ventilators, cardiopulmonary resuscitation, assisted circulation, and dialysis, are unknown. In addition, the decision to receive life-prolonging treatment was focused on how likely it was to return to the previous life. When asked about the criteria for receiving life-prolonging treatment, it was also characteristic that many of the patients wanted to know the life-saving rate.

The ethical principles of nonmaleficence and beneficence in medical treatment are differently implemented in adherence to respect for patient autonomy. Moreover, if a patient is unable to decide their preferred course of end-of-life treatment before surgery, their goals for treatment and recovery are considered to facilitate a medical decision that emphasizes patient autonomy, even in the event of a life-threatening situation.

Furthermore, the main reason for participants' refusal to receive life-prolonging treatment was that they did not want to contradict the intentions of those around them, including their families. However, several people said that they wanted to live their own lives. Thus, it is important for patients to share their wishes with medical professionals to ensure that they are reflected in their treatment. This may provide an opportunity to increase the treatment satisfaction of patients and their families.

Preoperative ACP needs to include those who should be informed of patients' intentions—including end-of-life care preferences—and the extent of information shared with family members. However, there was no need to inform health care providers of their end-of-life care intentions before surgery. Patients who do not desire life-prolonging treatment have a clear image of the condition they want to avoid; however, they struggle to determine whether the preferred course of treatment will relieve them of that undesired situation. This dilemma reflects patients' diminished capacity to understand what might ensue from the complexity of the received treatment and disease state in the ICU. However, the accurate prognosis is still difficult for ICU patients (White et al., 2016), and there are situations where physicians provide the best treatment, even for patients struggling with uncertainty. Thus, improved information dissemination among patients regarding the various possible treatment patterns will help them choose the desired treatment based on their wishes and values.



## Strengths and Limitations

We obtained the consent of a wide range of participants across various age groups and were able to examine their viewpoints. In addition, we were able to investigate their current decision-making status and their perceptions of ACP at various time points—from diagnosis to the time of admission and postdischarge. These details can be important for providing ACP support to patients and their families. Furthermore, it is essential to help all patients make decisions while considering the recovery process after surgery, as these circumstances may change with time. ACP is based on informed consent. Thus, these study findings note worthily suggested that ACP may be useful for all perioperative patients.

However, the interviews did not collect data from patients who underwent surgery and developed major complications to minimize the burden on the study participants. In addition, this study was conducted among patients from a single center and might therefore be biased. Nonetheless, we attempted to eliminate biases as much as possible, and accordingly, all data were analyzed clearly and impartially through reappraisals and repeated reviews.

## Conclusion

This study aimed to clarify the decision-making process from diagnosis to postdischarge and evaluate the ACP needs among perioperative ICU patients. There was a need to consider ACP before surgery in patients who had been admitted to the ICU during the perioperative period and wanted to gain an understanding of ACP first. Patients required various kinds of information—including details about the worst-case scenarios and the positive outcomes of treatment—to facilitate informed decision-making. The main kind of information that patients needed when considering ACP was the survival rate associated with a particular type of treatment to determine whether it would be useless for them and minimize the burden on their families caused by their treatment.

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## ORCID iD

Kanako Yamamoto  <https://orcid.org/0000-0001-5809-9996>

## Supplemental material

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