

Definition and Recommended Cultural Considerations for Advance Care Planning in Japan: A Systematic Review

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ABSTRACT

Although Delphi studies in Western countries have provided a consensus for practices pertaining to advance care planning (ACP), their findings may not be applicable to Asian countries with distinct, family-oriented cultures. This systematic review aimed to synthesize the definitions of and evidence for ACP and analyze recommended practices in Japan. We conducted a systematic review using narrative synthesis in December 2018. Key words were searched from Ichushi-Web by NPO Japan Medical Abstracts Society, Citation Information by the National Institute of Informatics, and Japanese Institutional Repositories Online databases. In addition, in August 2019, we conducted hand searching using Google Scholar and Google. We included original Japanese articles that addressed factors regarding ACP (e.g. definitions, elements, roles and tasks, and timing of ACP). Data were synthesized using thematic analysis. The study protocol was registered prospectively (PROSPERO:

CRD42020152391). Of the 3,512 studies screened, 27 were included: 22 quantitative and 5 qualitative. Five-position statements/guidelines were added by hand searching. Definitions and several distinct practice patterns of ACP and the importance of families' roles were identified. Unique recommendations addressed the importance of properly eliciting patients' preferences that are the best for both patients and families, engaging the public to raise awareness of ACP, and developing policies and guidelines for ACP. We identified the definition of and unique recommendations for ACP based on Japanese cultural values and norms. Further research is needed to evaluate the recommendations provided in this systematic review.

Key words: Advance care planning, advance directives, culturally competent care, end-of-life care, systematic review

Introduction

Advance care planning (ACP) enables individuals to define goals and preferences for future medical treatment and care, discuss these goals and preferences with family and healthcare providers (HCPs), and record and review them, if appropriate.^[1] Several international Delphi studies

in western countries have recently provided a consensus regarding the definition and practice of ACP.^[1,2] Further, the national framework regarding ACP has been provided in Canada,^[3] the UK,^[4] and Australia.^[5]

In Japan, the concept of ACP has gradually become better known. The Guidelines for the Decision-Making

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Process in End-of-Life Care were developed by the Japanese government in 2007,^[6] after a case at Imizu City Hospital in Toyama prefecture, in which a ventilator was removed by physicians from an unconscious patient at the end of life (EOL), without the patient's wishes being made clear previously.^[7] These guidelines have incorporated the concept of ACP, such as the importance of providing and explaining appropriate information for patients and families and decision-making by patients themselves based on discussions with patients, families, and HCPs.^[6]

Owing to the recent progression of an aging society in Japan, demand for community-based treatment and care has increased, and the construction of community-based integrated care systems has been promoted. Thus, in March 2018, the guidelines were revised to place greater emphasis on the concepts of ACP, such as the importance of repetitive discussion and advance directives (AD), including designating a healthcare proxy.^[8]

However, in Japan, it remains unclear how ACP should be defined and implemented in actual clinical practice.^[9] Therefore, HCPs struggle to determine the most suitable way to practice ACP.^[10] Although the number of ACP studies in Japan has increased dramatically since 2010, it has been pointed out that many of them are commentaries that only highlight the importance of ACP, without concrete implications.^[11]

Unlike in western countries where ACP is developed with an emphasis on an individual's right to self-determination, Japan has unique values and family relationships which emphasize harmony for patients and families.^[7,9] Furthermore, Japan has its own cultural background, healthcare system, legal system, and social issues related to having the largest rapidly aging population worldwide.^[7] Therefore, it is necessary to consider Japanese cultural and social aspects when introducing ACP to Japan.^[9]

Sumita^[11] conducted a literature review on Japanese-language articles published between 1983 and 2014 to assess the content of studies published in Japan on ACP and to identify the elements that constitute ACP. However, specific clinical implications still need to be addressed. Additionally, Tanimoto, Akuta, and Shigeta^[9] conducted an integrative literature review of ACP research in Japan limited to 2011-2017 and reported a lack of detailed information regarding the definition of and strategies for ACP in a Japanese context. In these two review studies, "advance care planning" was used as a keyword in the searches, and no search terms strongly associated with ACP were used, such as "advance directive," "end of life discussion," and "do not attempt resuscitation (DNAR)." Therefore, it remains unclear whether the concept of ACP was comprehensively searched. Furthermore, the above

two studies were limited to literature reviews rather than systematic reviews.

Thus, the main purpose of this systematic review was to synthesize definitions of and evidence for ACP regarding elements of ACP, roles and tasks, the timing of ACP, elements of policy and regulation, and evaluations of ACP, and analyze recommended practices for Japan. The secondary purpose was to obtain insight into Japanese cultural aspects related to ACP.

Methods

This study's protocol has been registered in the International Prospective Register of Systematic Reviews (PROSPERO: CRD42020152391). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement was used for reporting.^[12]

Study design

Regardless of the study design, all original articles exploring perspectives on ACP definitions and recommendations reported in Japanese were included in this study. A systematic review of the English-language articles on ACP in Asia including Japan, available on Embase, MEDLINE, Web of Science, and Google Scholar, has been reported.^[13] The findings were integrated using a narrative synthesis because it has the distinction of being able to adopt a textual approach to the process of integration to "tell the story" of the findings from the studies it contains, as well as being able to involve the manipulation of statistical data.^[14]

Search strategy

The selected search strategy was developed in cooperation with a healthcare librarian. The search was conducted in December 2018 using the three most major bibliographic databases in Japan: Ichushi-Web by NPO Japan Medical Abstracts Society, Citation Information by National Institute of Informatics (CiNii), and Japanese Institutional Repositories Online (JAIRO, known as Institutional Repositories DataBase [IRDB] since April 2019). The databases were searched using keywords and MeSH headings, translated from each database's associated thesaurus. Additionally, in August 2019, we conducted hand searching using Google Scholar and Google. The keywords were "advance care planning," "living will," "advance directive," "do-not-resuscitate order," and "end-of-life discussions."

Inclusion criteria

Studies

We included original articles written in Japanese on ACP from peer-reviewed journals that addressed definitions,

elements of ACP, roles and tasks, timing of ACP, elements of policy and regulation, and evaluations of ACP. Each domain used was from the Delphi study of the European Association for Palliative Care.^[1]

Participants

Studies that included patients with decision-making capacity, families, and HCPs were included in our review.

Exclusion criteria

Studies

Based on the discussion and agreement by the research team, articles referring to decisions involving only family members were excluded in addition to case reports, reviews, systematic reviews, proceedings, quantitative studies with fewer than 100 participants, and qualitative studies involving fewer with 10 participants.

Participants

Studies conducted with trainee (unqualified) HCPs, children/adolescents (<18 years old), individuals with psychiatric illnesses, and general populations were excluded.

Study selection

After integrating the search results from each database, duplicate articles were excluded. Two reviewers (AC and ST) excluded literature from nonmedical fields, journal features, reviews, case reports, and nonJapanese studies. Two reviewers (AC and MM) independently screened titles and abstracts against eligibility criteria. Then, all potentially relevant articles were retrieved, followed by an independent assessment/screening of full-text articles before data extraction and synthesis. Any disputes were resolved through discussion with all three reviewers (AC, MM, and ST).

Data extraction

An extraction form was developed, and data were extracted using this form of study characteristics judged to be important for addressing this review's aims. Characteristics included source, eligibility, context (e.g., research setting), methods, results (e.g., the total number of participants, definitions, elements of ACP, roles and tasks, timing of ACP, elements of policy and regulation, evaluations of ACP, and conclusions), and quality assurance for each study. In addition, Japanese cultural characteristics affecting ACP were identified. Data were extracted and reviewed for accuracy by three authors (AC, ST, and MM) through discussion.

Risk of bias (quality) assessment

We assessed the quality of each study using an appraisal tool for systematic reviews^[15] and each reviewer assessed

the accepted empirical studies independently with clear criteria of “good,” “fair,” “poor,” and “very poor.” Studies were not excluded depending on methodological quality.

Strategy for data synthesis

We used narrative synthesis for the data, utilizing several tools suggested by Popay *et al.*^[14] The steps were as follows:

1. Textual description: Summarize the findings by focusing on discoveries that are unusual or related to a novel theme
2. Tabulation: Provide details of the study design, results of the study quality assessment, outcome measures, and other results visually on the extraction form
3. Thematic analysis: Based on the review question, systematically identify the main, frequent, and/or most important themes and/or concepts across multiple studies and explore similarities and differences between studies.^[16] More specifically, the extracted data were repeatedly read, and characteristic descriptions related to elements, roles and tasks, timing, elements of policy and regulations, and evaluation of ACP, and Japanese characteristics regarding ACP (decision-making process) were coded. Second, codes were classified based on similarities and differences; similar codes were integrated, and subcategories representing characteristics of the meaning of the group were extracted. Third, by comparing and examining the relationships between subcategories, the level of abstraction was further raised, and categories representing the characteristics of the meaning of the collection of subcategories were extracted. Finally, we explored relationships between the extracted categories
4. Assessing the robustness of the synthesized product: we reflected critically on the synthesis process.

Results

Out of 3,512 studies screened, 32 were included, with 22 quantitative studies, five qualitative studies, and five-position statements/guidelines added by hand searching [Figure 1]. Characteristics of included studies are shown in Supplementary Table 1.

Definition of advance care planning

We summarized definitions of ACP from previous studies [Table 1]. Seven out of 32 studies included definitions for ACP.^[8,17-22] Two studies directly referenced definitions from studies published in Western countries, two studies used operational definitions, and three guidelines used original definitions.^[8,21,22] The elements of the definitions were extracted as 14 codes from the descriptions and definitions of ACP in those studies. As a result, two themes were identified: “specific definition of ACP (i.e. meaning, purpose, and method of ACP)” and “goals for ACP.” The integrated definition's key

Table 1: Definition of advance care planning

2 sub-themes	2 themes
ACP is a process in which adult patients (individuals) repeatedly discuss future medical care with family and/or other closely related people and their healthcare team, so they can identify future medical care based on their values and preferences, should they, at some point, be unable to make their own decisions ^[8,17-20,22]	Specific definition of ACP (i.e., meaning, purpose, and method of ACP)
ACP helps make decisions that ensure patients' dignity at the end of life. ^[17,21,22]	Goals for ACP
ACP: Advance care planning	

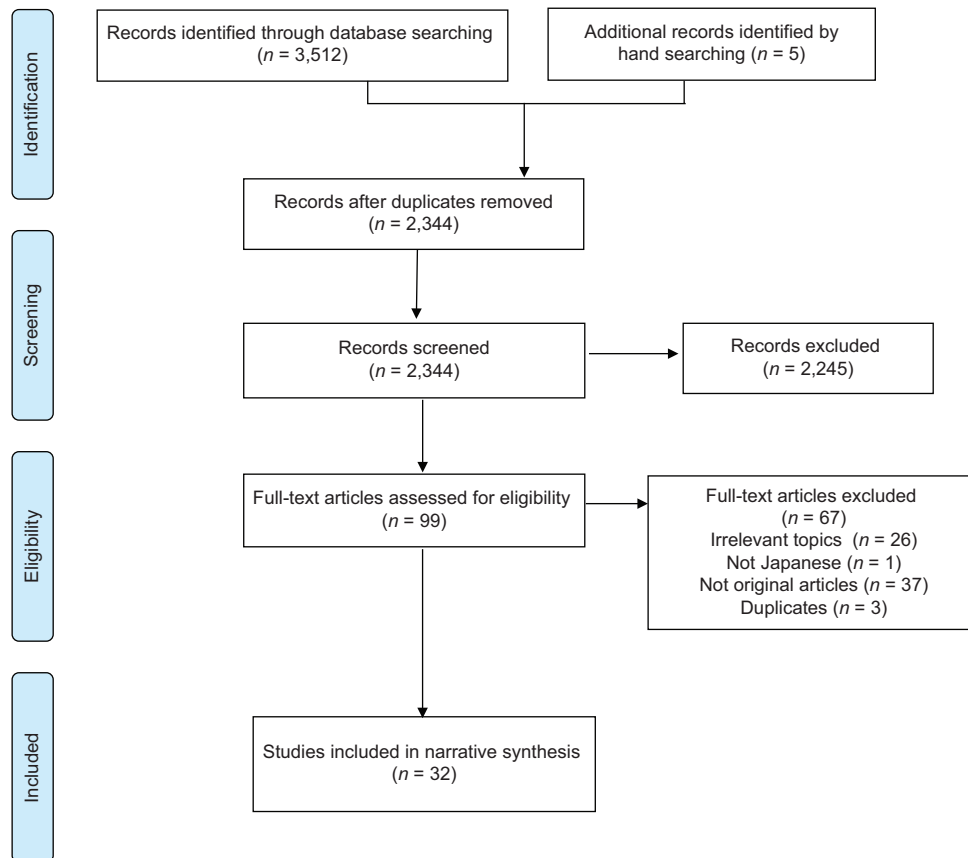


Figure 1: Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram

point is that ACP is a process of continuous discussions regarding future medical care based on the patient's values and preferences. The definition also includes realizing the patient's wishes and preferences regarding treatment to safeguard the dignity of a patient with a serious illness.

ACP is a process in which adult patients (individuals) repeatedly discuss future medical care with family and/or other closely related people and their healthcare team, so they can identify future medical care based on their values and preferences, should they, at some point, be unable to make their own decisions. ACP helps make decisions that ensure patients' dignity at the end of life.

Recommendations

Recommended elements of advance care planning

This domain included 15 sub-themes and six themes extracted from 233 codes [Table 2]. Recommendations

regarding the elements of ACP included ensuring patients understand their current medical conditions and prospects by providing sufficient information and explanations.^[8,18,19,21-28] ACP should also include clarification of patients' preferences for EOL medical treatment and care.^[8,20,21-24,26,28,31-35] In addition, it is recommended that coordination between patients and their families be repeated, and the best EOL plan for both the patients and their families be explored as elements of ACP.^[8,21,22-25,26,29,30,32,33,37,38] ACP involves having repeated conversations that aim to build a consensus through shared decision-making using a patient-centered approach that includes families.^[8,21-24,26,35,38,41-43] Where appropriate, ACP includes encouraging patients to provide their families and HCPs with a copy of their AD.^[8,17,21-24,26,29,31,35,37,38] Finally, ACP aims to help

Table 2: Recommended elements of advance care planning

15 sub-themes	6 themes
ACP ensures patient understanding by providing sufficient information and explanation from HCPs (e.g., diagnosis, prognosis, future trajectory of physical and psychological status, benefits and risks of all treatment/care options available) ^[6,18,19,21-26]	ACP ensures patients' understanding by providing sufficient information and explanation by HCPs ^[8,18,19,21-24,26-29] (<i>n</i> = 12)
ACP should evaluate patients' decision-making capacity ^[21,23,25,27,30]	
ACP should include clarification of patients' preferences for medical treatment and EOL care in case they become unable to make their own decisions ^[8,17,18,20-23,26-28,31-36]	ACP includes assessing patients' willingness to participate in ACP, clarification of patients' preferences for EOL care, and their selection of a representative ^[8,17,18,20-24,26,28,31-36] (<i>n</i> = 16)
ACP should be tailored to the patients' willingness to engage in the ACP process ^[17,20]	
ACP includes selecting a personal representative ^[8,22,23,33,35]	ACP includes an exploration of the best life plans for both patients and families ^[8,21,22,24-26,29,30,32,35,37,38] (<i>n</i> = 12)
ACP includes sufficiently eliciting information regarding patients' values and preferences ^[8,21,23,25,33]	
ACP should prompt patients to make their decisions autonomously ^[8,21-23,25,33,34,38,39]	
ACP should aim to ensure patients' decision-making process enables families to make the best decisions for both patients and families ^[21-23,28-30,33,35,37]	
ACP includes repeatedly having discussions among patients, families, and HCPs ^[8,21,22]	ACP involves having repetitive conversations and aim to build consensus through shared decision-making using patient-centered approach that includes families ^[8,21-24,26,35,40-43] (<i>n</i> = 11)
ACP includes collaboration for patients' decision-making within an interdisciplinary team ^[8,21-24,26,35,40-43]	
ACP includes consensus building by shared decision-making in the patient-centered approach, including families ^[8,21-23]	ACP includes encouraging patients to provide their families and HCPs with a copy of AD ^[20-22,26,31,34,37,38,41,42,44] (<i>n</i> = 12)
ACP includes recommendation that patients provide AD at appropriate times and ensuring patients' preferences will be respected by utilizing documents such as AD, LW, and POLST ^[20-22,26,30,31,34,37,38,41,42,44]	
ACP should include understanding of explanation that patients have a right to provide AD that reflects their preferences ^[23]	
ACP aims to help patients achieve a "good death" by providing medical care at the EOL that is consistent with patients' preferences ^[8,17,21-24,26,29,31,35,37,38]	ACP includes aims of achieving a good death by providing medical care at the EOL that is consistent with patients' preferences ^[8,17,21-24,26,29,31,35,37,38] (<i>n</i> = 12)
ACP should include the determination of patients' preferred EOL care based on medical validity and appropriateness by the interdisciplinary team ^[8,17,23,30]	
ACP: Advance care planning, HCPs: Health care providers, EOL: End of life, AD: Advance directive, LW: Living will, POLST: Physician orders for life-sustaining treatment	

Table 3: Recommended roles and tasks

13 sub-themes	6 themes
HCPs should develop rapport to discuss patients' preferences ^[17,25,27]	HCPs support patients to engage in the ACP process by developing rapport with patients and ensuring their basic needs are met and addressing symptoms ^[8,17,25,27,33] (<i>n</i> = 5)
HCPs help patients make decisions by ensuring their basic needs are met and addressing symptoms ^[8,17,27,33]	
HCP teams should provide sufficient information and explanations (e.g., diagnosis, prognosis, trajectory of physical and psychological status, benefits and risks of all treatment/care options available) so that it can be understood ^[8,17,18,21-23,25,27]	HCPs should provide information and explanations to patients and their families that consider their feelings and assess their understanding ^[8,17,18,21-23,25,27,30,39] (<i>n</i> = 10)
HCPs should assess patients' and families' understanding of such information and support their understanding ^[23,27,39]	
HCPs should care for families' feelings and positions, so that families can make the best decisions for patients ^[23,25,30]	
HCP teams should obtain information regarding patients' life histories and values through everyday conversations, and appropriately understand the reasons behind their expressed preferences ^[8,17,21,23,25,27,40,41]	HCPs should elicit patients' values and preferences through daily care ^[8,17,21,23,27,25,40,41] (<i>n</i> = 8)
HCPs should obtain communication skills and improve their sense of ethics to support ACP ^[8,17,18,21,30,34]	HCPs should acquire educational training to implement ACP ^[8,17,18,21,30,34] (<i>n</i> = 6)
HCPs should facilitate and coordinate conversations and resolve any differences between patients and families, so that patients' preferences are respected ^[8,17,23,25,27,30,33,41,45]	HCPs should facilitate and coordinate conversations, and resolve any differences between patients and families, so that patients' preferences are respected ^[8,17,18,21,23,25,27,33,45] (<i>n</i> = 9)
Nurses should coordinate with those involved, so that patients' preferences are shared ^[17,27,33]	
If no agreement is reached, HCP teams should consult with an ethics committee ^[8,21,23]	
HCP team should document and share conversations, especially patients' values, preferences, and life goals ^[8,17,21,23,27,41]	HCPs should regularly update patients' preferences through conversations, as well as document and share those conversations ^[8,17,21,23,25,27,30,34,41,42] (<i>n</i> = 10)
HCPs should keep monitoring and discussing patients' changes in medical conditions and feelings, and keep a flexible attitude, considering that preferences can change according to the situation ^[8,17,21-23,25,27,42]	
HCPs should share the results of discussions with HCPs of other facilities upon transition of care ^[21,27,34]	
ACP: Advance care planning, HCPs: Health care providers	

patients achieve "a good death" by providing medical care at the EOL that is consistent with patients' preferences.^[20-22,26,30,31,34,37,38,41,42,44]

Recommended roles and tasks

This domain included 13 sub-themes and six themes extracted from 121 codes [Table 3]. HCPs are

recommended to support patient engagement in the ACP process by developing a rapport with them, ensuring their basic needs are met, and addressing symptoms.^[6,17,27,25,33] This can increase patients' willingness to participate in ACP. HCPs should provide patients and families with sufficient information (e.g. diagnosis, prospects for future mental and physical changes, and the benefits and risks of all available treatment and care options) and explanations while considering their feelings and assessing their understanding.^[8,17,18,21-23,25,27,30,39] In addition, HCPs should obtain information about patients' life histories and values through everyday conversations and aim to understand the reasons behind patients' expressed preferences.^[6,17,21,23,25,27,40,41] Interdisciplinary teams should also collaborate and make efforts to support patients' decision-making, which includes improvement of ethics and training designed to create a sense of responsibility to fulfill one's role as a team member involved in ACP.^[8,17,18,21,30,34] Furthermore, HCPs should facilitate and coordinate conversations and resolve any differences between patients and families so that patients' preferences are respected.^[8,17,21,23,25,27,30,33,45] Finally, HCPs should regularly update patients' preferences through conversations, as

well as documents, and share those conversations with the interdisciplinary team.^[8,17,21,23,25,27,30,34,41,42]

Recommended timing of advance care planning

This domain included six sub-themes and three themes, extracted from 26 codes [Table 4]. We identified the recommended timing for starting ACP discussions and for repeating the discussions. It is recommended that older patients receiving any medical care or patients with an incurable disease immediately engage in ACP, in case they lose their decision-making capacity.^[21,22,25,28,34,43,46] It is also recommended that discussions focusing on EOL care and preferred place of death should be initiated at the introduction of integrated community-based care or upon transition of care.^[18,20,34,41] In addition, ACP conversations should be repeated among patients, families, and HCPs,^[8,21,23,25] keeping in mind that individuals' feelings and preferences can change.

Recommended elements of policy and regulations

This domain included eight sub-themes and five themes extracted from 50 codes [Table 5]. Standardizing the documentation of the ACP process (AD) and integrating it into the municipality unit are recommended to make it easy to share and transfer within the communities the

Table 4: Recommended timing for advance care planning

6 sub-themes	2 themes
All patients receiving any medical care should initiate ACP at the medical institution considering EOL ^[21,43,46]	Older patients receiving any medical care and/or patients with chronic diseases should immediately engage in ACP, in case they lose decision-making capacity ^[21,22,25,28,34,43,46] (<i>n</i> = 7)
Patients who have recovered from acute illnesses, or whose conditions have recurred, tend to have heightened awareness of EOL care, and may be ready to engage in ACP ^[28,46]	
Older patients receiving any medical care should immediately engage in ACP, in case they lose decision-making capacity ^[21,22,25,34]	
Discussions focusing on EOL care and preferred place of death should be initiated on introduction of integrated community-based care or upon transition of care ^[18,34,41]	Discussions focusing on EOL care and preferred place of death should be initiated at the introduction of integrated community-based care or upon transition of care ^[18,20,34,41] (<i>n</i> = 4)
As preferred timing of discussions differs among patients, preferences regarding ACP should be explored after changes in health condition ^[20]	
As preferences could change and decisional capacity could be lost, ACP conversations should be repeated among patients, families, and HCPs ^[8,21-23,25]	ACP conversations should be repeated among patients, families, and HCPs ^[8,21-23,25] (<i>n</i> = 5)
ACP: Advance care planning, HCPs: Health care providers, EOL: End of life	

Table 5: Recommended elements of policy and regulations

7 sub-themes	5 themes
AD should be standardized and disseminated, while how to use AD should be systematized by the municipality unit ^[19,21,23,36,42]	Standardize the format of AD, with municipal updates ^[19,21,23,36,42] (<i>n</i> = 5)
A system for selecting a personal representative should be developed by the government ^[22,23]	Government should develop a healthcare proxy system ^[22,23] (<i>n</i> = 2)
Laws and guidance should be launched regarding medical care and decision-making at EOL ^[21-23,32,34,37,44]	Government should establish laws and systems regarding medical care and decision-making at EOL ^[21-23,32,34,37,44] (<i>n</i> = 7)
A health insurance system should be developed to facilitate support for decision-making at EOL ^[22,37]	
Interdisciplinary collaborative systems by the municipality unit should be established to achieve patients' EOL preferences ^[8,19,21,22,33,34,47]	A collaborative support system for decision-making should be developed by interdisciplinary HCPs ^[8,19,21,22,33,34,43,47] (<i>n</i> = 8)
Healthcare organizations should develop a collaborative system to support decision-making and training opportunities for interdisciplinary HCPs ^[19,33,43]	
Awareness of EOL care, ACP, and AD should be raised among the public as well as HCPs ^[19,22,23,34,38,42]	Public awareness of EOL care, ACP, and AD should be raised ^[19,22,23,34,38,42] (<i>n</i> = 6)
ACP: Advance care planning, HCPs: Health care providers, EOL: End of life, AD: Advance directive	

Table 6: Recommended evaluation of advance care planning

4 sub-themes	2 themes
Whether place of death is consistent with the patient's preferences ^[18,25]	Quality of medical treatment and care at EOL ^[8,18,25,46] (<i>n</i> = 4)
Quality of medical treatment and care at EOL ^[8,46]	
Patients' and families' knowledge of medical treatment and care at EOL ^[28]	Opportunity to consider medical treatment and care at EOL ^[28] (<i>n</i> = 1)
Frequency of communication with family about goals and preferences ^[28]	
EOL: End of life	

Table 7: Japanese characteristics affecting advance care planning process

5 sub-themes	4 themes
Japanese people share a culture background in which they are understood without explicitly expressing their own preferences; their expressed preferences may not necessarily be their actual ones ^[17,21]	Japanese people tend to avoid explicit expression of their own preferences owing to the high-context nature of Japanese culture ^[17,21] (<i>n</i> = 2)
Many Japanese people are not comfortable thinking about death and tend to defer decision-making ^[22,23]	Japanese people are not comfortable thinking about death and tend to defer decision-making ^[22,23] (<i>n</i> = 2)
Japan has a family-centered culture, and families' preferences tend to be valued over patients' own ^[22,32,33,39,44]	Families' preferences tend to be valued over patients' own owing to the family-centered culture ^[22,31,32,39,44] (<i>n</i> = 5)
Patients' expressed preferences are based on consideration to their families rather than clarification of their own preferences ^[21,35,38]	Japanese people tend to refrain from explicit decision-making and place more value on harmony with families ^[21,35,38,39] (<i>n</i> = 4)
Japanese people tend to refrain from explicit decision-making, and place more value on harmony with others ^[21,35,39]	

patients live in.^[19,21,23,36,42] Further, it is recommended that the government enact a healthcare proxy law, as the current adult guardianship system in Japan does not authorize such guardians to make medical decisions, and there is no legally approved process for selecting a medical representative to make these decisions.^[22,23] The government should also develop laws and systems regarding medical care and decision-making at EOL, as there are currently no laws in Japan regarding AD, including death with dignity or the designation of medical representatives, making the related legal implications unclear.^[21-23,30,32,37,44] Furthermore, it is recommended that a collaborative support system should be developed^[8,19,21,22,33,34,43,47] in which opportunities for interdisciplinary HCP training are enhanced so that interdisciplinary team members can deepen their understanding of each occupation through training.^[19,33,43] Finally, the government should make efforts to raise public awareness of EOL care, ACP, and AD.^[19,22,23,34,38,42]

Recommended evaluation of advance care planning

This domain included three sub-themes and two themes, extracted from seven codes [Table 6]. Regarding the quality of medical treatment and care at EOL, it was suggested that the ACP conversation should reach a consensus among patients, families, and HCPs regarding medical treatment,^[21,24] with early initiation of the phase of disease trajectory^[45] creating a higher quality of EOL care. It was further suggested that a place of death consistent with the patients' preference^[18,25] is an outcome related to the quality of EOL care. Opportunities to consider EOL treatment and care could also be recommended as an endpoint.^[28]

Japanese cultural characteristics affecting the advance care planning process

This domain included five sub-themes and four themes extracted from 21 codes [Table 7]. The first characteristic was that Japanese people tend to avoid the explicit expression of their own preferences and expect "heart to heart communication" (i.e. nonverbal communication) owing to the high-context nature of Japanese culture.^[17,21] Second, although many Japanese people consider AD and EOL care to be necessary, they are not comfortable thinking about death and tend to defer decision-making.^[22,23] Third, families' preferences tend to be valued over patients' own owing to Japan's family-centered culture.^[22,32,33,44] Finally, Japanese people tend to refrain from assertive decision-making and view harmony with others as more important than the wish of individuals.^[21,35,38,39]

Discussion

To our knowledge, this study is the first to summarize culturally sensitive recommendations for ACP, by systematically dividing them into multiple domains used in a large international Delphi study^[1] and clarifying Japanese cultural characteristics. Definitions of ACP were also summarized based on literature extracted from the systematic review. Our findings provide insight on ACP in the context of Eastern culture, which respects the harmony between patients and families in patient-centered decision-making support.

Both our study and the Western Delphi study^[1] emphasized the process of conversing with patients, family members, and HCPs. However, our results suggest that the

ACP process should include building trust with patients before the conversation itself. Moreover, the ACP process in Japan should elicit patients' true feelings through daily care and by focusing on frequent communication, which can clarify the patients' goals and preferences, as well as the families'. Furthermore, although the Western Delphi study reported that laws should respect the results of an ACP process,^[1] Japan emphasized that the government should improve public awareness about the importance of ACP to develop laws regarding ACP and AD. Our overall findings indicate the importance of family involvement in and public awareness of ACP. Therefore, our systematic review offers two proposals for the implementation of the recommendations for ACP practices in Japan.

The first proposal is to include families in a patient-centered approach to ACP. Many studies mentioned the relationship between patients and families. For example, one element of ACP is having repetitive conversations using a patient-centered approach, including families, with the aim of creating a consensus through shared decision-making.^[8,17,18,21-26,29,32,35,37,38,40,42,43,45] Thus, in Japan, families are treated as full participants in medical consultations from the very start. We observed, however, differences between Japan and some western countries. In some western countries, HCPs adopt a person-centered approach when engaging in ACP conversations with patients and if the patient wishes, their family.^[1,2] ACP may include choosing and preparing trusted person (s),^[2] and whether or not families are included depends largely on the patient's wishes. Such a framework in western countries places emphasis on a patient-centered approach. In Japan, emphasis is placed on creating the best goals for both patients and families. A cultural anthropological perspective shows that in many Asian cultures, emphasis is placed on attending to others, fitting in, and achieving harmonious interdependence with team members.^[48] According to findings regarding how Japanese cultural characteristics affect the ACP process, Japanese patients expressed preferences that consider their families rather than their own preferences alone. Patient autonomy is reported to be subordinate to family values, while physician authority in most East Asian countries is influenced by Confucianism.^[49] In the West, where individualism is emphasized, patient autonomy is respected. While in East Asia, including Japan, relational autonomy, which is a concept of autonomy that places the individual in a socially embedded network of others,^[50] is favored.^[49] Thus, families may either be a facilitator or a barrier to ACP,^[51] especially in a family-oriented culture like Japan. Given that Japanese patients tend to care about their families' opinions and potential burdens in decision-making, family

engagement in ACP is imperative. Therefore, while HCPs should value the patient-centered approach, they should likewise ensure that family harmony is maintained. To implement ACP in clinical practice, HCPs need to be educated with the necessary communication skills to facilitate ACP discussions among patients and families. Several communication training programs have recently been developed and introduced in Japan, which include SHARE (<http://www.share-cst.jp/>), Education For Implementing End of Life Discussion (E-FIELD) (<https://square.umin.ac.jp/endoflife/2019/general.html>), VitalTalk Japan (<https://www.facebook.com/vitaltalk.jp/>), and Serious Illness Care Program (<https://portal.ariadnelabs.org/>).

The second proposal is to raise public awareness by disseminating and implementing existing guidelines to support ACP.^[8,21-23,30] Several studies pointed out the lack of laws and concrete guidelines and consequently recommended creating new models for implementing ACP conversations, as well as raising public awareness regarding the lack of laws, systems, and knowledge with respect to the ACP process and AD.^[22,23,31,32,37,38,42,44] Additionally, Japanese people tend to defer decision-making and also value their families' preferences over their own. Our results are consistent in that Japanese physicians and patients relied more on family and physician authority and placed less emphasis on patient autonomy, unlike in the US.^[52] Therefore, AD has no weight in Japan, as it does not always guarantee that patients' preferences will be respected. The United States and many European countries have laws regulating ACP and AD, as do some Asian countries, such as the Act on decisions on Life-Sustaining Treatment for patients in hospice and palliative care or at the end of life, in Korea, and The Mental Capacity Act, in Singapore. It was reported that public awareness and prevalence of ACP have improved after legislation in Taiwan^[53] and South Korea.^[54] Umezawa *et al.*^[55] found that Japanese patients with advanced cancer prefer that their HCPs not give sole preference or priority to their families and that patients want to participate in the decision-making process, even in situations of disease progression. Thus, public awareness of ACP should be increased, including its aims and content, legal policy, and its accessibility by approaching governments and municipalities to undertake promotional activities and to develop laws. Promotional activities using brochures, posters, websites, and educational curriculum may be effective. Further, we should continue to present the evidence regarding the ACP process and deliver the voice of clinical settings.

Of note, none of the reviewed literature examined the influence of religious beliefs and practices on ACP.

These literatures, including those in the field of sociology, cultural anthropology, and philosophy, may not have been found because they were excluded pursuant to the exclusion criteria. This may have contributed to the lack of literature focusing on religiosity. In the West, religiousness often influences EOL decisions.^[56] Previous studies that explored the difference in the physician-perceived importance of religion for a patient's "good death" in three East Asian countries, including Japan, reported that Japanese physicians had significantly lower awareness of the importance of religion for a patient's good death, as compared to Taiwan and Korea.^[57] There was also a correlation with the physician's own religiosity.^[57] It is possible that religious beliefs are not only the waning importance of religion in modern Japanese culture^[57] but also relatively not important for HCPs in clinical settings in Japan. In addition, understanding the characteristics of the cultural background presented in the results makes it easier to understand the values of individuals. However, HCPs must be aware that the four Japanese cultural characteristics may not necessarily reflect the value of all individuals and families in Japanese culture. Thus, it is important to respect individual values rather than taking a stereotypical approach.

Our study had strengths and several limitations. One of the strengths is that this study conducted a systematic review of ACP in Japan, whereas previous studies were limited to literature reviews. In addition, while "advance care planning" was the only keyword used in these previous studies, this study involved a comprehensive search that included keywords such as "advance directive," "end of life discussion," and "do not attempt resuscitation." Furthermore, our framework was based on the international Delphi study. Our study carefully examined the recommendations for ACP in Japan by integrating results from both quantitative and qualitative studies.

Regarding limitations, first, most studies were published before 2018, but the Ministry of Health, Labour and Welfare in Japan only first mentioned ACP in 2018. Thus, recommendations may change with future research, although aspects relating to Japanese culture remain. Second, the number of articles was limited and some lacked methodological rigor, with only a few having undertaken interventional studies. Further studies are needed to develop ACP intervention programs based on cultural norms in Japan. Third, since the extracted studies were written in Japanese, results from studies in other languages were not reflected. Finally, according to the agreement of the research team, we excluded quantitative studies with fewer than 100 participants and qualitative studies with fewer than 10 participants. The inclusion of this criterion

may have resulted in the exclusion of a small number of high-quality studies.

In conclusion, this systematic review provided a definition of and recommendations for ACP based on cultural norms in Japan, integrating published literature with currently available evidence by including both quantitative and qualitative studies. The recommendations in this study reflect an ACP process in Japan that is focused on the exploration of the best decision for patients and their families. Future research should evaluate the implementation of these recommendations in clinical practice.

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Conflicts of interest

There are no conflicts of interest.

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Supplementary Table 1: Characteristics of included studies

Authors	Publication year	Study aim	Methods	Participants and setting	Quality of method and data	Quality of sampling
Arita <i>et al.</i> ^[29]	2015	Investigate the views of patients with nonmalignant respiratory disease and lung cancer regarding AD for EOL care	Quantitative study (observational)	At four hospitals in Hiroshima prefecture; 121 outpatients with nonmalignant respiratory disease, including those who have experienced respiratory failure once and received mechanical ventilation, noninvasive positive pressure breathing, or high-flow oxygen therapy for over a week; 108 outpatients with lung cancer who were receiving or had received at least 2 courses of chemotherapy with anti-cancer drugs other than molecularly targeted drugs	Fair	Fair
Arita and Ikegami ^[43]	2012	Ascertain clinicians' opinions on obtaining AD regarding the EOL treatment of patients at the terminal disease stage	Quantitative study (observational)	282 physicians who were members of the Shikoku and Chugoku branch of the Japanese Respiratory Society	Fair	Good
Fukaura <i>et al.</i> ^[31]	1994	Investigate the practical conditions of the resuscitation and DNAR orders of patients with terminal lung cancers	Quantitative study (observational)	Physicians working at 127 facilities that treat many lung cancer patients in Japan	Poor	Fair
Fukuda ^[37]	2012	Determine the current situation and problems related to DNAR orders in out of hospital cardiopulmonary arrest patients	Quantitative study (retrospective)	304 hospitalized cardiopulmonary arrest patients who were transported to St. Luke's International Hospital's emergency and critical care center	Good	Good
Ikegami <i>et al.</i> ^[46]	2016	Evaluate the impact of the timing of EOLD on the quality of EOL care in patients with gynecologic cancer	Quantitative study (retrospective)	112 patients who died of gynecologic cancer from Yamanashi Prefectural Central Hospital, including at home or other facilities	Fair	Fair
Ishikawa <i>et al.</i> ^[18]	2017	Examine the association between ACP facilitated by a home health nurse and achieving one's desired place of death for patients with end-stage cancer	Quantitative study (observational)	Home health nurses at 1000 randomly selected home care agencies in Japan	Good	Fair
Iwabuchi <i>et al.</i> ^[45]	2016	Determine the factors that influence the decision maker regarding EOL care	Quantitative study (observational)	409 bereaved family members (cause of death including cancer, stroke, heart disease, and pneumonia) who are registered as monitors in a research company	Good	Fair
Japan geriatrics society ethics committee "sub-committee on end of life," geriatrics society of Japan ^[21]	2019	N/A (proposal for promoting ACP in geriatric medicine)	N/A	N/A	N/A	N/A
Japan medical association XV bioethics roundtable ^[22]	2018	N/A (proposal regarding medical treatment and care at EOL in a super-aging society)	N/A	N/A	N/A	N/A
Kajiyama and Yoshioka ^[27]	2018	Clarify the status of and factors related to nurses' decision-making support for the transition to home care settings for end-stage cancer patients	Quantitative study (observational)	1019 general ward nurses at 43 hospitals with more than 100 beds in the capital area	Good	Fair
Kawamoto <i>et al.</i> ^[42]	2014	Clarify the different intentions for EOL care in patients with and without cancer	Quantitative study (retrospective)	746 deceased patients with registered AD in their electronic health records at the National Hospital Organization Kure medical center	Good	Poor
Kobayashi <i>et al.</i> ^[26]	2008	Increase understanding of the present circumstances of death with dignity and issues of EOL care in geriatric intermediate care facilities	Quantitative study (observational)	Facility directors of 500 geriatric intermediate care facilities in Japan	Poor	Poor

Contd...

Supplementary Table 1: Contd...

Authors	Publication year	Study aim	Methods	Participants and setting	Quality of method and data	Quality of sampling
Komatsu and Shimatani ^[19]	2017	Investigate general ward nurses' knowledge about ACP for cancer patients to clarify what enhances ACP	Quantitative study (observational)	800 general ward nurses from a nationally designated cancer medical center and collaborating hospital in Hiroshima prefecture	Fair	Fair
Koshiishi <i>et al.</i> ^[41]	2018	Clarify nurses and care managers' awareness of changes in decision-making support after using the ACP sheet	Quantitative study (single arm trial)	8 nurses in a long-term care hospital and 4 care managers in a home healthcare support office or community comprehensive care center	Fair	Poor
Kuriaki and Kamimura ^[29]	2014	Evaluate decision-making regarding EOL care near death for terminally ill cancer patients	Quantitative study (retrospective study) and qualitative study (semi-structured interview)	52 patients who died of cancer who participated in EOLs and their 15 physicians in Harasanshin hospital	Poor	Poor
Matsushita <i>et al.</i> ^[24]	1999	Clarify elderly outpatients' attitudes toward care during the terminal disease stage	Qualitative study (observational)	562 elderly outpatients at the Tokyo Metropolitan Geriatric Hospital	Poor	Poor
Mayumi <i>et al.</i> ^[34]	2017	Clarify the present conditions of transportation of cardiac arrest patients	Quantitative study (retrospective study)	334 CPA patients transported to the emergency department of Ichinomiya Municipal Hospital	Fair	Fair
Ministry of health, labour and welfare in Japan. ^[8]	2018	N/A (guidelines for decision-making process in medical treatment and care at the EOL phase)	N/A	N/A	N/A	N/A
Naito Shirao <i>et al.</i> ^[20]	2016	Explore the ACP preferences of patients with advanced cancer	Qualitative study (semi-structured interview)	10 palliative care patients who were hospitalized at Seirei Mikatahara General Hospital	Fair	Poor
Ohira <i>et al.</i> ^[32]	2006	Clarify physicians' knowledge of EOL care for dialysis patients	Qualitative study (observational)	1215 physicians who were members of the Japanese Society for Dialysis Therapy	Poor	Fair
Okada <i>et al.</i> ^[44]	2003	Clarify nephrologists' knowledge regarding withdrawing from hemodialysis treatment for patients with terminal stage malignancy	Qualitative study (observational)	552 nephrologists working at dialysis facilities in each prefecture	Fair	Fair
Omomo and Tsuruwaka ^[17]	2018	Consider the process and specific support of ACP by analyzing assistance "between elderly people living alone and home care nurses"	Qualitative study (observational)	26 nurses with at least 3 years' experience in-home nursing care facilities (no location described)	Fair	Poor
Sato ^[33]	2014	Clarify how nurses currently recognize and support self-determination in cancer patients at EOL	Qualitative study (observational)	Nurses with more than 5 years' experience working in a general hospital or cancer hospital with more than 300 beds in the Kanto area, and those who had provided nursing care to adult terminal cancer patients (those who could express their intentions) within the past 3 years	Good	Good
Sato and Makigami ^[28]	2008	Examine the effectiveness of terminal care education provided by a physician to patients and their families	Quantitative study (non-RCT)	338 patients in a geriatric rehabilitation unit and long-term care unit in Health coop Watari hospital	Poor	Very poor
Sato <i>et al.</i> ^[40]	2011	Clarify the status of confirmation of patients' preferences by signature	Quantitative study (observational)	263 patients with a history of hospitalization at a hospital in the Tohoku region	Fair	Fair

Contd...

Supplementary Table 1: Contd...

Authors	Publication year	Study aim	Methods	Participants and setting	Quality of method and data	Quality of sampling
Shimada <i>et al.</i> ^[35]	2015	Explore individual factors that make it likely for older Japanese adults to engage in communication with important others regarding their preferences for EOL care	Quantitative study (observational)	968 outpatients at the Tokyo Metropolitan Geriatric Hospital	Fair	Fair
Soga <i>et al.</i> ^[36]	2017	Survey the present situation and problems with DNAR requests	Quantitative study (semi-structured interview)	Five emergency stations in the Nan-yo area of Ehime prefecture	Poor	Fair
Suzuki ^[47]	2015	Determine the reasons why terminal cancer patients with DNAR decisions require emergency ambulance transportation	Qualitative study (semi-structured interview)	19 paramedics who had more than 5 years of experience on an emergency crew, had passed their paramedic qualification more than 3 years ago and had experience in receiving emergency requests from terminal cancer patients with DNAR decisions in a certain prefecture	Fair	Poor
Takahashi and Fuse ^[39]	2014	Identify core information that helped visiting nurses understand Japanese homebound seniors' EOL care preferences	Quantitative study (observational)	756 home health nurses at 252 home health nursing stations which providing home healthcare until patients died in the Tohoku region after the earthquake	Good	Poor
The Japanese society of intensive care medicine <i>et al.</i> ^[30]	2014	N/A (Guidelines for EOL care in emergency and intensive care)	N/A	N/A	N/A	N/A
Watanabe <i>et al.</i> ^[25]	2010	Determine differences taking care ratio of death in nursing homes between nursing homes' difficulties and terminal care practices for residents with dementia	Quantitative study (observational)	Head nurses of 5249 special nursing homes for the elderly in Japan whose facility names and addresses could be confirmed on the welfare and medical service network system	Fair	Good
Watanabe <i>et al.</i> ^[23]	2015	N/A (proposal for a shared decision-making process regarding initiation and continuation of maintenance hemodialysis)	N/A	N/A	N/A	N/A

AD: Advance directive, EOL: End of life, EOLD: End-of-life discussion, CPA: Cardiopulmonary arrest, ACP: Advance care planning, DNAR: Do not attempt resuscitation, N/A: Not available, RCT: Randomized controlled trial