Advance care planning in Asia and Indonesia: Cultural perspectives

Diah Martina

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Advance care planning in Asia and Indonesia: Cultural perspectives

Proactieve zorgplanning in Azië en Indonesië: Culturele perspectieven

Thesis

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	prof. dr. J.L. Abrahm

In the loving memory of my mother

Elvi Nahdia Naumy

21 March 1954 – 10 October 2010

CONTENTS

Chapter 1

General Introduction

Providing care that aligns with patients' values, wishes, and preferences, also during periods of incapacity, is the foundation of patient-centered care.[1] However, patients' values, wishes, and preferences are not always known by healthcare professionals and their family members.[2, 3] Additionally, the advancement of medical technologies often enables care options that may not be in accordance with patients' values, wishes, and preferences.[4] Advance care planning is a process that was initially focused on asking patients to decide whether they would want to receive certain care or medical procedures should they lose their capacity in decision-making and indicate these preferences in writing ahead of time.[4] However, evidence showed that such a documentation approach frequently fails to affect the quality of care received at the end of life or improve clinicians' and surrogates' understanding of patients' preferences.[5]

Over the past two decades, an evolution of the concept of advance care planning arose from a process that focuses on creating a document of patients' preferences for future care and treatment towards aw communication approach that more strongly acknowledges an ongoing, holistic, and flexible shared communication process.[4, 6] In 2017, a panel of experts from eight Western countries developed an international consensus on the definition and recommended elements of advance care planning.[7] In this consensus, advance care planning was defined as a process that "enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate." This process emphasizes personal reflection on people's current health condition, what the future may look like, what it means to them, what values would be important, and what care they would prefer. Sharing these values and preferences with family members and healthcare professionals can help patients, family members, and healthcare professionals to better prepare for the patient's declining capacity.[7] This concept of advance care planning, based on evidence from mainly Western studies, improves patient and surrogate satisfaction with communication and care and decreases distress among surrogates and clinicians.[6, 8] Therefore, advance care planning has been considered an essential element of quality palliative care.[9] Particularly among patients with a life-limiting illness, advance care planning supports eliciting and sharing values, goals, and preferences for future medical care and treatment.

ADVANCE CARE PLANNING AND ASIAN CULTURE

Asian countries are primarily collectivist-oriented, where one's health and illness are a collective matter and care for an individual is viewed mainly as a family responsibility.[10] Therefore, medical decision-making is often family-centered, and social harmony is often valued over individual autonomy. Additionally, due to the prevailing paternalistic communication style between doctors and their patients in Asia, the latter often have little involvement in decision-making.[11] Nevertheless, studies have shown that Asian people's preferences are changing over the past decades and that more Asian patients wish for active involvement in decision-making.[10]

These changes may also affect preferences for advance care planning in Asia, i.e., Asian patients may be increasingly willing to have an active role in planning their care and treatment at the end of life.[12] Further studies are needed to better understand Asians' perspectives on advance care planning, including cultural barriers and potential facilitators.

INDONESIA, ITS CULTURE, AND ADVANCE CARE PLANNING

Indonesia is a lower-middle-income country and the fourth most populated nation in the world, where palliative care is still underdeveloped.[13] Since palliative care was introduced in Indonesia in 1989, its provision has been limited, unevenly distributed, and not well supported. Most palliative care services are predominantly funded by charity.[14]

A comparative study showed a relatively high level of unmet palliative care needs across all domains (physical, psychological, spiritual, and social) among patients with cancer in Indonesia.[15] Up to 70% of Indonesian patients with cancer were already in their advanced stage upon admission to healthcare facilities,[16] when rapid deterioration and unexpected deaths frequently occur.[17] Consequently, timely communication of wishes and preferences about (future) care and treatment is vital to ensure it will be delivered according to the patient's wishes and preferences.

Indonesia has a collectivist culture, like many other Asian countries.[18, 19] Being the largest Islamic population in the world, over 87% of its population is Muslim.[20] Additionally, a global survey showed that Indonesia is one of the most religious

countries in the world, where faith drives many aspects of life, including healthcare decision-making.[21, 22] Religiosity – or self-perceived religious importance – has been considered an essential factor that substantially influences decision-making about end-of-life care, particularly among religiously devout individuals.[23] The association between religious beliefs and engagement in advance care planning remains unclear and might vary depending on the cultural setting.[24-26] Indonesian culture, including the religious devoutness of its people, may influence advance care planning engagement in Indonesia.

AIMS, OVERVIEW OF STUDIES, AND OUTLINE OF THIS THESIS

Overall aim: This thesis aims to provide insights into the perspectives of Asians, in general, and Indonesians, in particular, on advance care planning.

Part I of this thesis aims to better understand Asian perspectives on advance care planning, including perceived barriers and facilitators to engaging in it. We focus on Asian experts in advance care planning, healthcare professionals, seriously-ill patients living in Asia, and Chinese immigrants living in Western countries.

Part II of this thesis aims to better understand Indonesian perspectives on advance care planning. We focus on professionals working in oncology, patients with cancer, family caregivers, and cancer survivors in Indonesia.

Research questions

The research questions of part I are:

1. What recommendations do Asian experts have with regard to research priorities for advance care planning in Asia? (Chapter 2)
2. What are Asian healthcare professionals' knowledge of, attitudes towards, and experiences with advance care planning, and perceived barriers and facilitators related to their engagement in advance care planning? (Chapter 3)
3. What are Asian patients' perspectives on advance care planning? (Chapter 4)
4. What is the role of acculturation in the engagement in advance care planning among Chinese immigrants in Western countries? (Chapter 5)

The research questions of part II are:

5. What are Indonesian cancer care professionals' perspectives on and experiences with advance care planning? (Chapter 6)

6. What are the perspectives of Indonesian patients with cancer and family caregivers on advance care planning? (Chapter 7)
7. What are Indonesian cancer survivors' perspectives on and experiences with information provision and advance care planning? (Chapter 8)

To answer research question (1), a team of multidisciplinary experts in advance care planning from six different sectors in Asia participated in several offline and online meetings to formulate recommendations regarding advance care planning research priorities, including tasks and roles of different stakeholders in advance care planning. In order to answer research questions (2) and (3), we performed a systematic review of scientific literature published in English from Southern, Eastern, and Southeastern Asia. To answer research question (2), a narrative synthesis was conducted of quantitative, qualitative, and mixed-methods studies followed by thematic analysis. To answer research question (3), we performed a multi-step, mixed-method synthesis and analysis to integrate the findings from quantitative and qualitative studies. Finally, to answer research question (4), we performed a systematic review of published articles published in English on advance care planning among Chinese immigrants in Western countries. We synthesized the quantitative data narratively and performed a thematic content analysis.

To answer research question (5), we performed focus group interviews with Indonesian healthcare professionals. To answer research question (6), we performed in-depth qualitative interviews with patients with cancer and family caregivers in two major hospitals in Indonesia. To answer research question (7), we performed an open online survey among nine cancer support groups in Indonesia.

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Part I

Advance Care Planning in Asia

Chapter 2

2019 Taipei Declaration on Advance Care Planning: A Cultural Adaptation of End of Life Care Discussion

Cheng-Pei Lin, Shao-Yi Cheng, Masanori Mori, Sang-Yeon Suh, Helen Yue-Lai Chan, Diah Martina, Weng-Sun Pang, Hsien-Liang Huang, Jen-Kuei Peng, Chien-An Yao, Jaw-Shiun Tsai, Wen-Yu Hu, Ying-Wei Wang, Chih-Yuan Shih, Su-Hsuan Hsu, Chien-Yi Wu, Ping-Jen Chen, Hsueh-Lin Ho, Grace Su-Yin Pang, Sumytra Menon, Raymond Ng-Han Lip, Kwok-Keung Yuen, Annie Oi-Ling Kwok, Sun-Hyun Kim, Jung-Young Kim, Sayaka Takenouchi, Yoshiyuki Kizawa, Tatsuya Morita, Futoshi Iwata, Shimon Tashiro, Tai-Yuan Chiu

Journal of Palliative Medicine, Volume 22, Issue 10, 2019, Pages 1175-1177

Dear Editor:

Every person has the right to attain a high-quality, humane healthcare from birth to death. To assist a patient achieve high quality of life towards the end of life and ensure high quality of dying and death (e.g., a "good death"), it is imperative to honor patient's rights of autonomy and respect their preferences regarding care decisions in healthcare circumstances. Advance care planning is an initiative to respect patient's values and ensure quality care in accordance with his or her preferences, usually followed by the completion of advance directives, serving as a significant means to preserve patient's dignity at the end of life. It is widely recognized as an indicator for high quality palliative care[1] and endorsed by many professional bodies (e.g., American, British and Australian medical associations) around the world.[2]

Advance care planning is a process that enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and/or other closely related people, and health-care providers.[3, 4] Advance care planning addresses individuals' concerns across physical, psychological, social, and spiritual domains. It may encourage individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account, should they, at some point, be unable to make their own decisions. Advance care planning is a tailored, culturally adapted development and implementation in a compassionate Asian society, emphasizing the importance of family involvement in an individual's decision-making in terms of future medical care. An influence of the cultural factor of filial piety should also be highlighted; nevertheless, advance care planning should be prospective and should not be jeopardized despite cultural difference.

In this declaration, various roles/stakeholders and tasks of advance care planning will be introduced in the hope for ethically sound implementation in the future (*See Table 1*).

Advance care planning honors patient autonomy in terms of healthcare decision-making and thus enhancing high quality of life towards the end of life, as well as ensuring high quality of dying and death of the terminally ill. The Asian Delphi Taskforce for Advance Care Planning is actively undertaken by six Asian countries and a more detailed, culturally-sensitive whitepaper for the Asian population will be published in the near future. It should be tailored to the Asian cultural context and local jurisdictions. We recommend that all National Medical Professional As-

Table 1. Recommendation of Tasks for Each Role in Advance Care Planning

Role	Tasks
Individuals	From an individual perspective, one should be informed of the right to decide for future medical care including the life-sustaining medical treatments (e.g. cardiopulmonary resuscitation, intubation, antibiotics, blood transfusion, renal dialysis, artificial nutrition and hydration etc.) when becoming terminally ill according to the laws and/or guidelines. Prior to such decision making, a patient should receive sufficient amount of relevant medical information including prognosis by clinicians. Advance care planning should be conducted when the person has decisional capacity. Patients are advised to appoint a certain family member(s) (including those important to the person) in advance as representatives to speak on behalf of the patient based on patients' preferences, should they, at some point, be unable to make their own decisions.
Family members	It is necessary to acknowledge the importance of the family members and the emotional environment of the patient especially in Asia. The needs of the family members and close caregivers throughout the course of the illness must be recognized and attended to. The family members are encouraged to participate in advance care planning discussions between the patient and clinicians, as the patient may lose decisional capacity in the future. Family members are expected to remind, help and/or accompany the patient to share his or her goals and preferences for future medical care, and consider advance directives, if appropriate, through the process of advance care planning when one of the family members is diagnosed with incurable disease.
Multidisciplinary Professionals	Palliative care is usually provided by multidisciplinary teams of healthcare and non-healthcare professions. Continuity of care is paramount. To ensure quality care and patient's informed decision making, clinicians should conduct discussions with patients and their family members if appropriate on the patient's medical conditions and future care based on patient's readiness. As patient's preferences can change over time, clinicians should assist the patient to share his or her preferences regarding care and conduct advance care planning discussions regularly as needed. Clinicians should document the contents of such discussion every time. The team should provide care consistent with the patient's preferences, such as facilitating a patient's wishes to die at home, if applicable and possible. The medical care team members must actively remind patients, especially those with terminal illness to consider advance directives through the process of advance care planning and choices of life-sustaining medical treatments (e.g. cardiopulmonary resuscitation, intubation, antibiotics, blood transfusion, renal dialysis, artificial nutrition and hydration etc.). Social workers should help arrange places of care and/or services based on patient's preferences and assist the patient and family to register and complete advance directives through available resources such as advance care planning clinic etc., as per local and legal jurisdiction.
Educators	From the cultural perspective, the Asians traditionally regard death as a taboo and are reluctant to face and discuss the topic. Therefore, it is crucial to provide clinicians and the general public with appropriate learning opportunities about dying and issues that arise during illnesses involving decisional capacity. Thanatology and ethics should also be included in all levels of education especially for medical professionals. The professional societies ought to take responsibility to better educate physicians, nurses and other health care professionals with the skills necessary to improve the quantity and quality of meaningful advance care planning discussions.
Researchers	More research and guidelines in the fields of advance care planning and palliative care are warranted to serve as references for various stakeholders such as the clinicians, educators and policymakers for future implementation in Asia. The strategies for conversation and culturally sensitive model of advance care planning delivery should be a research priority prior to the implementation in clinical settings.
Policymakers	Governments, health insurers and health-care organizations should secure appropriate funding and organizational support for advance care planning. In addition, patient autonomy related laws should be encouraged to recognize advance care planning process (such as surrogate decision making and advance directives) as a legally binding guide in medical decision making.

sociations develop a national policy of various roles and tasks on palliative care and advance care planning based on the recommendations in this declaration.

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Chapter 3

Advance Care Planning in Asia: A Systematic Narrative Review of Healthcare Professionals' Knowledge, Attitude and Experience

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ABSTRACT

Objective: The value of advance care planning (ACP) for patients with life-limiting illnesses is widely recognized but Asian healthcare professionals' (HCPs') perspectives on ACP have received little systematic attention. We aim to synthesize evidence regarding Asian HCPs' knowledge of, attitudes towards, and experiences with ACP.

Design: Systematic review with narrative synthesis and stepwise thematic analysis.

Setting and Participants: HCPs in southern, eastern and southeastern Asia.

Methods: Studies from inception to September 2019 were identified from English-language searches of EMBASE, MEDLINE, Web of Science, and Google Scholar with reference-chaining and hand-searching. Two investigators independently screened and assessed the risk of bias in all original studies reporting HCPs' knowledge of, attitudes towards, and experiences with ACP, including their perspectives towards barriers and facilitators of ACP.

Results: Fifty one studies were included, 42 were quantitative, 43 had been conducted in high-income countries, and 36 were of good quality. Twenty-six studies operationalized ACP as the completion of an advance directive rather than a value-exploration process. Thirteen studies reported knowledge, 44 attitudes, 29 experiences, and 36 barriers and facilitators of ACP. Asian HCPs addressed the essential role of families in ACP. They acknowledge the importance of ACP but rarely engage the patient in it. They considered ACP difficult to initiate, due partly to their lack of knowledge and skills in ACP, personal uneasiness to conduct ACP, fear of conflicts with family members and their legal consequences, and due to the lack of standard system for ACP. Most studies indicated HCPs' low engagement and late initiation of ACP.

Conclusions and Implications: Despite acknowledging its importance, Asian HCPs felt engaging in ACP is challenging. Capacity building for ACP in Asia should focus on culturally adapting ACP models concerning the essential role of the family in Asia, education for HCPs and public, and providing institutional support for ACP.

Keywords: advance care planning, health care professionals, knowledge, attitude, experience, Asia

INTRODUCTION

Complex decisions regarding medical care and treatment often need to be made during life-limiting disease trajectories. If healthcare professionals (HCPs) do not clearly understand patients' life goals and care preferences, patients may not always be treated in accordance with their preferences.[31] Advance care planning (ACP) is a process that enables individuals, family members, and HCPs to define, discuss, document, and review goals and preferences for future medical care and treatment.[32] Systematic reviews have shown that ACP has the potential to improve the quality of end-of-life care, the documentation of care preferences, the provision of goal-concordant care, and the use of palliative and hospice care, while potentially reducing the cost.[6, 9, 33-35]

The implementation of ACP in clinical practice is often affected by societal norms and values.[36, 37] While ACP was developed mainly in Western countries[6, 38] it is now gaining attention in Asia[39-41] – the largest and most populous continent in the world, and the home of various cultures. Examples of cultural values that may affect the uptake of ACP in Asia[37, 42-44] include family-centeredness in medical decision-making, paternalism on the part of HCPs,[45] and moderation or concealment of a poor prognosis.[46, 47] Central to these values is the great importance of social harmony and interdependence. Meanwhile, Asians require more support from their HCPs to voice their own wishes.[48]

Asian HCPs' perspectives on ACP have not been systematically analyzed. We therefore aimed to synthesize and appraise the evidence from Asia with regard to HCPs' knowledge of ACP, their attitudes towards it, and their experiences with it; and also to the barriers and facilitators related to their engagement in ACP.

METHODS

The study protocol has been registered in the International Prospective Register of Systematic Reviews (PROSPERO: CRD42018099980). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement was used for reporting (Appendix 1).[49]

Data Sources and Selection

With the aid of a biomedical information specialist (WMB), we developed a systematic search strategy based on the predetermined research question in the following

electronic databases: EMBASE.com (1971-), MEDLINE ALL Ovid (1946-), Web of Science Core Collection (1975-), and Google Scholar from inception to September 2019. We used the tailored search terms for each database, using thesaurus terms (Emtree and MeSH) where applicable. Appendix 2 shows the full searches for all databases. The searches contained not only words for advance care planning and advance directive (AD), but were also designed to retrieve articles on decision-making for the end of life. To ensure a comprehensive search, we scanned the reference lists from relevant existing literature reviews and from the included articles, and finally asked several experts in the field of ACP in Asia whether important studies that met our inclusion and exclusion criteria had been missed.

Study Selection

We did not limit the type of study designs for this review and included all original studies that studied "advance care planning", or studies that addressed one or both core elements of ACP as defined by the European Association for Palliative Care (EAPC):[32]

i. Discussing patients' goals and/or preferences for future medical care and/or treatment with family and/or HCPs and/or;
ii. Recording patients' preferences including the appointment of a personal representative and an advance directive (AD).

We defined AD as a document to record values, goals, and preferences to be considered when the individual is unable to express their preferences.[32] AD may include living wills,[50] durable power of attorneys,[51] and do-not-resuscitate (DNR) orders.[52-54] For the aim of this review, we included professionals that the authors had labeled as "healthcare professionals" or those who followed WHO definition as "professionals who maintain health in humans through the application of the principles and procedures of evidence based medicine and caring."[55] This may include, but is not limited to, physicians, nurses, social workers, and care managers. Due to the sheer size of the Asian continent, we limited our search to its southern, eastern and southeastern regions (Appendix 3), whose similarities in cultural background provided a reasonable representation of collectivism in Eastern cultures.[56] We included original articles on HCPs' knowledge of, attitudes towards, or experiences with ACP that had been published in English in peer-reviewed journals. We excluded studies in which the specific elements of ACP were not clearly described and studies on HCPs' perspectives towards ACP among patients under 18 years old or patients with psychiatric illnesses other than dementias.

Duplicates of the retrieved studies were removed and each title and abstract was screened by two out of three reviewers (DM, MSK and CPL) independently. This was followed by full-text reviewing for inclusion. Disagreements were discussed with JR and/or CR if necessary. Endnote bibliographic software version X9 was used to manage references.

Data Extraction and Quality Assessment

A tailored data-extraction form was developed and piloted by JR and CR and further used to extract data that included 1.) the study characteristics (study design, country or region, the element and term related to ACP studied, number of HCPs, type of HCPs, and setting); 2.) HCPs' knowledge of ACP; 3.) HCPs' attitudes towards and experiences with ACP; 4.) HCPs' perspectives on barriers and facilitators related to engagement in ACP. The extraction form was completed by DM and checked by MSK.

We used a nine-item tool developed by Hawker et al to assess the methodological quality of the included studies.[57] Per study, the risk of bias was evaluated for the following items: 1.) abstract and title, 2.) introduction and aims, 3.) methods and data, 4.) sampling, 5.) data analysis, 6.) ethics and bias, 7.) results, 8.) transferability, and 9.) implications. Each criterion was scored on a four-point Likert scale ranging from one (very poor) to four (good). In total, a summed score of 9–36 was calculated. Studies with scores between 30–36 were classified as having a low risk of bias, studies with scores between 24–29 were classified as having a moderate risk, and scores lower than 24 were classified as having a high risk.[58] Studies were not excluded on the basis of their methodological quality. DM assessed all studies, 50% of which were randomly selected and checked independently by CPL.

Data Synthesis and Analysis

Following the Guidance on the Conduct of Narrative Synthesis in Systematic Reviews, a narrative synthesis was conducted of the included quantitative, qualitative, and mixed-methods studies.[59] To summarize the findings of the included papers, we conducted textual description of the extracted data, tabulation, grouping, and clustering. This was followed by a stepwise thematic analysis. A critical interpretive synthesis approach was used to categorize knowledge, attitudes, experiences, barriers, and facilitators into domains.[60]

RESULTS

Study Selection and Characteristics

After deduplication, we identified 3,887 studies for titles and abstracts screening. Three studies were added following a manual search and input from experts in Asia and 244 studies were assessed for full-text review. Ultimately, 51 studies were included in the analysis (Figure 1).

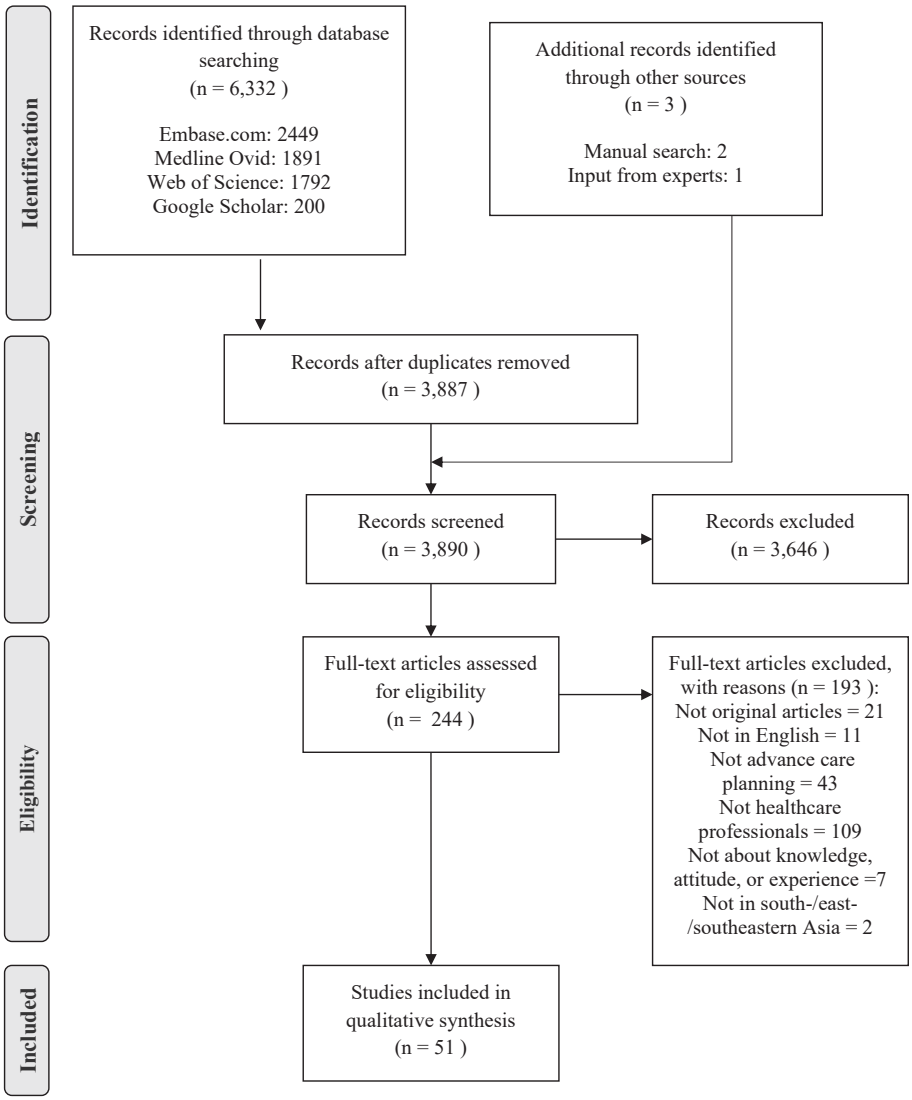

Figure 1. PRISMA flow diagram for study selection

Most of the studies included were quantitative among which 42 were surveys, 19 were conducted in hospital settings, and most included fewer than 500 HCPs (n=45), were performed among physicians (n = 42), and were from high-income countries (Table 1 and Appendix 4): Japan,[61-76] South Korea,[62, 77-88] Hong Kong,[89-94] Singapore,[95-100] and Taiwan.[101-104] Twenty-six studies operationalized ACP merely as the documentation process. The term ACP was used in 12 studies that had been published in the last decade (Table 1 and 2). Thirteen studies reported on HCPs' knowledge, 44 studies on attitudes, 29 on experiences, and 36 on barriers and facilitators of ACP. The risk of bias was low in 33 studies, moderate in 13, and high in two (Appendix 5).

Table 1. Characteristics of the included studies (n = 51)

Study characteristics		N (%)
Type of study	Quantitative study	42 (82)
	Qualitative study	7 (14)
	Mixed study	2 (4)
Country or region*	Japan	16
	South Korea	13
	Hong Kong	6
	Singapore	6
	Taiwan	4
	China	3
	Others†	5
Term related to ACP studied‡	Advance care planning	12
	Term related to ACP documents:	
	Advance (medical) directive	25
	DN(A)R order/form	13
	Living will	1
	Death-with-dignity request	1
	Term related to ACP conversation:	
	End-of-life discussion	2
	End-of-life (care or medical) decision-making	4
	DNR order discussion	3
	Code status discussion	2
	AD discussion	1
	CPR discussion	1
	DNR decision	1
	End-of-life care planning	1
The element of ACP studied	ACP as completion of documents	26
	ACP as process of a discussion on preferences	11
	Both	14

Table 1. Characteristics of the included studies (n = 51) *(continued)*

Study characteristics		N (%)
Number of HCPs in the study	0-100	18
	101-500	27
	501-1000	5
	>1000	1
Type of HCPs studied[§]	Physicians	42
	Nurses	20
	Social workers	10
	Case managers	1
Setting[‖]	Hospital (not further specified)	19
	Oncology	7
	Palliative care or hospice	4
	Intensive care	6
	Geriatric	4
	Dialysis	2
	Others, no restriction	15
Outcomes of the study	Knowledge	13
	Attitude	44
	Experience	29
	Barrier and facilitator	34

HCPs: healthcare professionals; ACP: advance care planning; AD: advance directive; DN(A)R: do-not-attempt-resuscitation
*Several studies were multi-country studies
[†]Others: India (2), Sri Lanka (1), Thailand (1), and Pakistan (1)
[‡]Several studies used more than one term related to ACP
[§]Several studies studied more than one type of healthcare professional
[‖]Several studies were done in more than one setting

Eleven of the 13 studies on HCPs' knowledge of ACP assessed their knowledge of the documents related to ACP, such as ADs or DNR orders (Appendix 6).[77, 78, 81, 83, 86, 90, 92, 97, 101, 105, 106]

In Hong Kong, 57% of the physicians[90] and 49% of the nurses[92] were familiar with ADs, as were 40-61% of the physicians and 56% of the nurses in South Korea.[77, 78] In Singapore, general practitioners answered 80-88% of the eight questions on ACP correctly.[97] Taiwanese nurses and intensivists provided correct answers to fewer than 5 of the 10 questions on their knowledge of ADs.[101] In Sri Lanka, while 67% of physicians had heard of DNR orders and 21% of ADs, only half of them (26% and 12%, respectively) understood the correct meanings of the terms.[105] In Singapore, physicians and social workers answered a mean of 8 out of 9 questions correctly, while nurses answered 6 questions correctly.[95] In a qualitative study,

Table 2. Categories of Asian HCPs attitudes towards and experiences with ACP

Asian HCPs' Attitude towards ACP		
No.	**Categories (References)**	**Number of studies**
1.	HCPs' perceptions of the usefulness/importance of ACP[63, 64, 68-71, 74, 75, 79, 81, 82, 93-95, 99]	15
2	Whether or not HCPs supported the use of AD[67, 76, 84, 85, 95, 97, 105-107]	9
3	HCPs' confidence about engaging in ACP[66, 69, 81, 91, 93]	5
4	The role HCPs perceived for themselves in ACP[87, 88, 95, 97, 101]	5
5	HCPs' willingness to engage in ACP[62, 78, 90, 103]	4
6	Who HCPs believed should participate in ACP[77, 87, 89, 98, 108-110]	7
7	HCPs' willingness to follow an AD[65, 70-72, 82, 89, 96, 109, 111]	9
8	Who HCPs believed should be the decision maker in ACP[70, 71, 82, 97-99, 105, 108]	8
9	Which factors HCPs believed influenced decision-making[70-72, 93]	4
10	HCPs' perceptions regarding the optimal timing to initiate ACP[61, 74, 77-79, 82, 84, 87, 88, 93, 94, 97, 98, 110]	14
11	HCPs' beliefs on the need for ACP training and education[74, 77, 93, 95, 104];	5
12	HCPs' beliefs on the need for legislation and standardization of ACP[70, 71, 77, 82, 90, 97, 103, 106]	8
Asian HCPs' Experience with ACP		
No.	**Categories (References)**	**Number of studies**
1	HCPs who had received an AD[65, 68, 72, 84, 92, 95, 106]	7
2	HCPs who had engaged in ACP[63, 64, 66, 70, 71, 81, 84, 87, 89, 90, 92, 93, 95, 102, 111]	17
3	Who (i.e., patients and families) had participated in ACP[62, 87, 89, 111]	4
4	Who had been the decision maker in ACP[75, 105]	2
5	HCPs who had followed an AD[63, 65, 68, 70, 71, 76, 84, 88, 89, 108]	10
6	When ACP had been initiated[87]	1
7	Whether HCPs had had ACP-related training and education[84, 95]	2
8	The presence of guideline or formal regulation for ACP[103]	1
9	HCPs who had experienced any negative or positive consequences of ACP[61, 70, 76]	3

HCPs: healthcare professionals; ACP: advance care planning; AD: advance directive

more physicians than nurses and medical social workers had heard of ACP, but few of them understood it as a series of conversations.[99]

Asian HCPs' Attitudes towards and Experiences with ACP

We synthesized the findings from 41 studies reporting Asian HCPs' attitudes towards ACP and 30 studies reporting Asian HCPs' experiences with ACP into 12 and nine categories based on the similar outcomes reported (See Table 3 and Appendix 7-8).

Table 3. HCPs- and system-related barriers and facilitators of ACP in Asia according to HCPs

HCPs-related barriers and facilitators	
HCPs-related barriers	**HCPs-related facilitators**
HCPs limited knowledge about and skills regarding ACP • HCPs' limited knowledge about and skills regarding end-of-life care (incl. prognostication) and ACP[61, 70, 71, 73, 74, 76, 78, 80, 82, 84, 87, 95, 99, 100, 104, 110] • HCPs' concerns that patients' preferences may change over time[76, 78, 85, 99]	**HCPs competence in ACP and EOL care** HCPs' knowledge and skills in end-of-life care (incl. prognostication) and ACP [61, 64, 78, 80, 87, 95, 97, 102]
HCPs' personal uneasiness with regard to conducting ACP • HCPs' uneasiness about discontinuing life-supporting treatments[75, 84, 95, 100, 103, 105] • HCPs being more inclined to the curative intent of medicine[70, 71, 73, 76, 80, 100, 104, 106, 107, 110] • HCPs' concern of patients receiving suboptimal care after signing ACP's document[76, 82, 98, 106, 110] • HCPs concern that engaging in ACP means advocating euthanasia[76, 84, 95, 106] • HCPs' uneasiness about engaging in end-of-life discussions[61, 73-75, 78, 80, 84, 87, 95, 99, 100, 103, 110] • HCPs' belief that discussing end-of-life with the patient challenges the local culture (e.g. filial piety and social hierarchy)[62, 73, 74, 76, 80, 99, 100, 111]	**HCPs' positive attitudes towards fostering patient's autonomy** • HCPs' positive attitudes towards fostering patients' autonomy[61, 68, 75, 81, 84, 85, 95, 104, 106] • HCPs' understanding of cultural relevance to EOL issues[80] • HCPs' feeling comfortable with engaging in end-of-life discussions[61, 81] • HCPs' positive attitudes towards hospice and palliative care[79, 81] • HCPs' beliefs on the benefits of ACP[61, 68, 70, 71, 75, 76, 82, 84, 85, 99, 105-107] • HCPs' positive attitudes towards legalization of ACP[102]

Table 3. HCPs- and system-related barriers and facilitators of ACP in Asia according to HCPs *(continued)*

System-related barriers and facilitators	
System-related barriers	**System-related facilitators**
Lack of standard system and institutional support for ACP • Lack of policy and formal regulation of ACP[70, 71, 77, 80, 82, 100, 106, 107, 110] • Lack of standard strategies to implement ACP[73, 74, 76, 80, 82, 100] • Lack of training and education related to ACP[74, 76, 78, 80, 93, 95, 104] • Time constraints on HCPs[75, 80, 84, 87, 95, 110, 111] • Trained staffs constraints[75, 110] • Insufficient leadership in the multidisciplinary care setting[73, 74, 100] • Lack of institutional support for application of AD[73, 80, 100, 110]	**The availability of legal and standard system for ACP** • Availability of policy and formal regulation of ACP[77, 80, 82, 88, 90, 97, 103, 106] • Availability of standard system for ACP[78, 80, 82, 88, 93, 100] • Training and education related to ACP[74, 78, 80, 88, 93, 95, 104] • Availability of palliative care team[87, 100] • Payment for conducting ACP discussions[78, 87] • Availability of data supporting the benefits of ACP for HCPs and public[100] **Cultural shift towards more open discussion** • Public promotion efforts for ACP[78, 80] • Fostering a culture that stimulates open conversations about death between patients with family members[78] • Paradigm shift in life and death, end-of-life care, and AD[80, 100]

HCPs: healthcare professionals; ACP: advance care planning; AD: advance directive

Here, we summarize our findings on Asian HCPs' attitudes and experiences into four overarching themes: 1.) HCPs' perceptions of the usefulness of ACP and their willingness to engage in it; 2.) the role HCPs perceive for themselves and their engagement in ACP; 3.) the role of patient and family in ACP as perceived by HCPs; and 4.) HCPs' perceptions on the optimal timing for initiation of ACP.

1.) HCPs' Perceptions of the Usefulness of ACP and Their Willingness to Engage in it

A majority of Asian HCPs perceived ADs as useful or important (e.g., 71-94% in Japan,[68-71, 75] 96-97% in South Korea[79, 82]). In Hong Kong, there were increases in the numbers of HCPs who perceived the completion of a DNR form to be useful, particularly for colleagues (from 48% in 2004 to 85% in 2008) and for patient management (from 32% in 2004 to 54% 2008).[93]

A study in Singapore (2011),[95] and more recent studies in Japan (2014, 2018, and 2019)[63, 64, 74] and Hong Kong (2019),[94] reported on HCPs agreement regarding the importance of ACP as a discussion process. Most Japanese HCPs who worked at palliative or geriatric facilities attached importance to discussing treatment goals (95-99%) and to recommending the completion of an AD (63-69%) or proxy designation (57-77%).[63, 64] Studies in Japan and Hong Kong (2019) showed that HCPs working at palliative or long-term care facilities believed that the main importance of ACP lay in achieving mutual understanding between patients and their families regarding their values.[74, 94]

As well as beliefs on the importance of ACP, studies also showed that half to a large majority of HCPs supported the use of AD (e.g., 51% in India,[107] 55% in Japan,[76] 68% in Sri Lanka,[105] 78-87% in South Korea,[84, 85] 84% in China,[106] and 83% in Singapore[97]) and were willing to engage in ACP particularly when involving the family (90% in China,[62] 95% in Japan,[62] 78% in Taiwan,[103] 94% in Hong Kong,[90] 64-97% in South Korea[62, 78]).

2.) The role HCPs Perceive for Themselves and Their Engagement in ACP

In general, oncologists (44% in Japan[68] and 69% in China[106]) more often had received an AD from a patient than physicians from other disciplines (1-22%),[65, 72, 84] nurses (22-24%),[92, 95] or social workers (23%).[95] Among Singaporean HCPs, 100% of social workers, 82% of physicians, and 37% of nurses considered themselves as having a role in ACP.[95] In actual practice, ACP had been initiated more often by social workers (90%) and physicians (82%) than by nurses (19%).[95] In Taiwan, 98% of physicians and 97% of nurses agreed that nurses should also participate in ACP.[101] The initiative to start an ACP conversation was more usually taken by physicians

(75%) than by nurses (22%).[101] In Hong Kong, nurses had less experience with ACP (13-28%),[89, 92] than physicians (49%),[90] intensivists (60%),[89] or HCPs working in palliative care units (63%).[94] In Japan, more physicians (62%) had ever participated in a DNR discussion than nurses (42%).[70, 71] In South Korea, 83% of oncologists believed they should initiate ACP, and 68% thought that the palliative care team should conduct the ongoing discussion thereafter.[87] Among the oncologists, 83-93% had engaged in the discussion of prognosis and 22% of proxy appointments.

3.) The Role of Patient and Family in ACP as Perceived by HCPs

All studies showed that involving family members – with or without the patient – was considered crucial in ACP. In Hong Kong (89%),[89] South Korea (63-85%),[77, 87] and Singapore (78%),[98] HCPs thought that, together with the patient, family members should be involved in ACP discussions. A higher number of HCPs would rather discuss DNR orders with the family than with the competent patient (India: 92% vs. 5%,[108] China: 90% vs. 13%,[62] Pakistan: 82% vs. 18%,[110] South Korea: 74% vs. 20%,[62] Japan: 95% vs. 67%[62]).

Studies of actual practice also showed that family members were often involved in ACP. Patients were less involved than families, particularly in discussions on life-sustaining treatment[75] and DNR orders (35% vs. 95% in Thailand;[111] 56% vs. 86% in Japan;[62] 5% vs. 80% in China;[62] 6% vs. 57% in South Korea;[62] and 52% vs. 89% in Hong Kong[89]).

Once a DNR order had been completed by the patient, it would be respected by 42% of HCPs in China,[109] 70-95% in Japan,[70, 71] 79% in Hong Kong,[89] and 91% in Thailand.[111] In the event of disagreement between a patient's AD and family's wishes, HCPs would defer to family's wishes (46-65% in Singapore,[96] 73% in South Korea,[82] 81% in Japan[65]). Studies of actual practice showed that more palliative care physicians had followed a DNR order when it was in accordance with the family's wishes (71%) than when it was in accordance only with the patient's wishes (33%).[63] In South Korea, although 67% of physicians reported they had followed an AD,[84] a qualitative study stated that noncompliance with patients' preferences often occurred.[88]

4.) HCPs' Perceptions on the Optimal Timing for Initiation of ACP

Forty-two percent of the general practitioners in Singapore believed that ACP should be initiated while the patient was still healthy.[97] This percentage was 15% for oncologists in South Korea.[79] More South Korean physicians would engage in ACP when the patient was terminally ill (97%) rather than when the patient was still

healthy (64%).[78] As the stage of a patient's disease advanced, the proportion of HCPs who would initiate ACP increased as follows: after diagnosis of life-limiting illness (12-13% in South Korea[77]); after diagnosis of incurable disease/metastasis (59-60% in South Korea[77] and 24-39% in Singapore[98]); and when life expectancy was less than 6 months (97% in South Korea[84]; 41-60% in Singapore[98]). In the last days of life, however, this proportion fell again, to 12-27% in South Korea[77] and 30% in Singapore[97] in the terminal stage, and to 0-5% in Singapore[98] in the dying phase.

Asian HCPs' Perspectives on Barriers to and Facilitators of ACP

We categorized the barriers and facilitators into four categories: 1.) HCPs-related 2.) system-related, 3.) patient-related, and 4.) family-related (Table 3 and 4).

We further grouped the barriers into six themes: HCPs' limited knowledge about and skills regarding ACP; HCPs' personal uneasiness with regard to conducting ACP; HCPs' fear of conflict with patient's family and its legal consequences; HCPs' concern about patients' readiness for and well-being after ACP; and lack of standard system and institutional support for ACP. We also categorized the facilitating factors for ACP into four overarching themes: HCPs' competence in ACP and end-of-life care; HCPs' positive attitudes towards ACP; the availability of legal and standard systems for ACP; and cultural shift towards more open conversation about death and dying.

Table 4. Patient- and family-related barriers of ACP in Asia according to HCPs

Patient-related barriers	Family-related barriers
HCPs' concern about patients' readiness for and wellbeing after ACP • HCP's concerns that ACP engagement might harm patients' wellbeing[74, 76, 84, 87, 95, 99, 110] • HCPs' concerns that patients' lacking the knowledge regarding their current condition[73, 74, 76] • HCPs concern that ACP is too complex for patients to engage[94] • HCPs concern that patients or society not being ready for ACP[84, 95, 99] • HCPs concern that patients were reluctant to express their preferences[74] • HCPs concern of patients' religious belief about death[74] • HCPs' concern of the lack of the rapport needed to discuss sensitive issues with patients[73, 74, 84]	**HCPs' fear of conflict with patient's family and its legal consequences** • HCPs fear of legal consequences of ACP[74, 75, 82, 84, 87, 93, 104, 106, 110] • HCPs' fear of conflict with family members[68, 74-76, 84, 87, 93, 95, 106, 110] • HCPs' fear of conflict among family members[75, 87, 110] • HCPs' concern of family members reluctance to include patients in ACP[84, 87, 104] HCPs' fear that ACP would upset or cause discomfort to family members[74, 95, 99] • HCPs' concerns that ACP had the potential to burden family members[70, 99]

HCPs: healthcare professionals; ACP: advance care planning; AD: advance directive

DISCUSSION

This systematic review explored Asian HCPs' knowledge of, attitudes toward and experiences with ACP. We found that despite most studies operationalization of ACP as the completion of an AD, some recent studies had focused on ACP as a value-exploration process. Most Asian HCPs considered family's role in ACP to be essential. The majority of them thought that ACP should be initiated when the patient's disease was no longer curable, and particularly when his or her life expectancy was less than 6 months. Despite a general willingness to engage in ACP, Asian HCPs found it challenging to initiate it. This led to relatively low engagement.

With regard to the role of family, our findings showed that Asian HCPs often engaged family in ACP without the patient. This finding is similar to studies from Western countries.[89, 112] However, in the contrary to our findings, HCPs in Western countries would provide patients greater voice in ACP.[113, 114] Meanwhile Asian HCPs tended to give families a greater voice. This was particularly prominent if a patient has lost capacity and has previously expressed a wish for future care and treatment that was different from wishes expressed by family members. In such situations, Asian HCPs tended to allow those of the family to prevail. This may result from Asian HCPs' attempt to maintain harmony with the family members – an important consideration in collectivist cultures such as those in Asia.[115, 116] Although Confucianism has long been viewed as the shared-values underpinning collusion and family-centeredness in Asia,[117] a similar spirit of collectivism is also found in studies from countries with little or no Confucian influence (India, Pakistan, and Sri Lanka), with various degrees of variance between them. Patient involvement in ACP is less valued by HCPs, particularly in China, India, Pakistan, and Thailand. A sensitive approach is required to ensure ACP promote meaningful conversation and facilitate mutual understanding between patients, families, and HCPs while maintaining family harmony.[74, 118]

Our study identified several barriers that were similar to those found in studies of Western countries: limited ACP formal education, legislations, institutional support, and cultural factors.[6] Asian HCPs viewed ACP as a discussion of forgoing life-sustaining treatments that may challenge medicine's life-prolonging intent norm. They reported uneasiness about discontinuing life-supporting treatments as barriers for initiating ACP. They also concerned that engaging in ACP may lead to patients receiving suboptimal care or to euthanasia. Education should therefore also target this common misconceptions among HCPs. However, education alone will not sustain without the support of the system. Our review highlighted Asian HCPs' fear of

the legal consequences of engaging in ACP. While this perspective may have shifted after the more recent enactment of ACP-related laws (e.g., South Korea, Taiwan) and guidelines (e.g. Japan, Hong Kong)[41], a recent study from Taiwan suggested that HCPs' were unsure if the law would protect them.[104] Lastly, our findings also suggested limited institutional support for ACP. South Korean HCPs, for instance, reported that financial incentives would encourage their engagement in ACP. All of these systemic characteristics may, in part, contribute to the late and limited ACP engagement in Asia.

STRENGTHS AND LIMITATIONS

A strength of this study is that it is the first systematic review to explore HCPs' knowledge of, attitudes towards, and experiences with ACP in Asia. A second strength is its comprehensive conceptualization of ACP, which enabled us to perform a sensitive search that included studies on specific elements of ACP (such as the process of discussing preferences and the completion of the documents) without these studies necessarily using the term ACP. Third, the risk of bias was high in only two of the 51 studies; neither did these studies not affect the overall results of the systematic review.

Several limitations need to be considered when interpreting this study. Firstly, limiting the search to studies published in English may have excluded important studies in other languages, potentially depriving our review of valuable contributions. However, due to our comprehensive search strategy, our wide inclusion criteria, and the similarities between findings in identified studies, we believe that we found sufficient studies to answer our research questions. Secondly, there may be selection bias in the studies that we included in the review: potentially, HCPs with an interest in ACP may have been more inclined to participate than those who did not participate. Thirdly, our study synthesized evidence on the barriers and facilitators of ACP based on Asian HCPs' perspectives which does not necessarily reflect all of the potential barriers and facilitators of ACP. Fourthly, the narrative approach of synthesizing evidence involved an interpretative process which may decrease the transparency. Finally, our results may lack generalizability to Asian low and middle-income countries, and to other regions of Asia (i.e. northern, western and central Asia).

CONCLUSIONS AND IMPLICATIONS

Our results show that the current Western-oriented ACP may not always easily be transferable to other cultures, including Asian ones. Its uptake in Asia may be improved by adapting the current ACP models to acknowledge the deep importance traditionally attached to the role of the family. If policy and standard system are established for ACP, HCPs may be empowered to deliver it. Similarly, its rate of delivery may be improved by training to HCPs and cultural shift.

Our findings may also be relevant to the practice of ACP in Western countries. HCPs who engage in ACP with patients of Asian origin should pay particular attention to the potentially essential role of family in ACP. Given that ACP is at an early stage of development in Asia, Asian patients and families living in another country may benefit from clear explanations of the legal and standard systems related to ACP specific to the country.

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Appendix 1: PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE: Advance care planning in Asia: A systematic review of healthcare professionals' knowledge, attitude and experience			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	1-2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	3
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	3
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	4
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	4-5
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	4
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Appendix 2
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	4-5 and Figure 1
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	5
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	5
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	6
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	5

Appendix 1: PRISMA 2009 Checklist *(continued)*

Section/topic	#	Checklist item	Reported on page #
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	6-7
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	6
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	NA
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	7 and Figure 1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Appendix 4
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Appendix 5
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	7-12, Appendices 6-8
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	NA
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	NA
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	NA
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	12,13, 14
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	14, 15
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	15
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	15

Appendix 2: Search strategies

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(exp Advance Directives/ OR Resuscitation Orders/ OR ((Decision Making/ OR Communication/ OR Physician-Patient Relations/ OR Patient Preference/ OR Personal Autonomy/ OR Knowledge/) AND (Terminal Care/ OR Palliative Care/ OR Terminally Ill/OR Resuscitation/ OR Life Support Care/ OR Euthanasia/ OR Hospice/)) OR (((Advance) ADJ3 (plan* OR directive*)) OR ((living-will*)) OR ((decision* OR decid* OR plan OR plans OR planning OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice* OR communication OR talking OR disclos* OR autonom* OR attitude* OR practice* OR perspective*) ADJ6 (terminal* OR end of life OR palliativ* OR serious*-ill* OR severe*-ill* OR death OR dying OR advanced*-cancer* OR euthanas* OR hospice*)) OR ((do-not OR refus*) ADJ3 resuscit*) OR ((decision* OR decid* OR plan OR plans OR planning OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice* OR communication OR talking OR disclos* OR autonom* OR attitude* OR practice* OR perspective*) ADJ6 life ADJ (saving OR saver* OR sustain* OR resuscit* OR threat* OR support*))).ab,ti.) AND (Asia/ OR exp Asia, Southeastern/ OR exp Far East/ OR Asia, Western/ OR Bangladesh/ OR Bhutan/ OR exp India/ OR Nepal/ OR Pakistan/ OR Sri Lanka/ OR Asian Continental Ancestry Group/ OR (Asia* OR Afghan* OR Bangla* OR Bhutan* OR Borne* OR Brunei* OR Cambod* OR China* OR Chinese* OR India OR Indonesia* OR Japan* OR Korea* OR Laos* OR Laotion* OR Malaysia* OR Mongolia* OR Myanmar* OR Birmese* OR Birma OR Nepal* OR Pakistan* OR Papua* OR Philippin* OR Singapore* OR Sri-Lank* OR Taiwan* OR Thailand* OR Thai OR Timor* OR Viet-Nam* OR VietNam* OR mekong OR (eastern NOT ((middle OR mediterr* OR europe) ADJ3 eastern)) OR far-east).ab,ti,jn,cp.) NOT (exp Emigration and Immigration/ OR exp Tissue Donors/ OR exp Transients and Migrants/ OR exp transplantation/ OR (immigr* OR migrant* OR emigra* OR refugee* OR donor* OR donation OR transplant* OR chinese american* OR japanese american* OR korean american* OR asian american*).ab,ti.) NOT (letter* OR news OR comment* OR editorial* OR congres* OR abstract* OR book* OR chapter* OR dissertation abstract*).pt. AND english.la. NOT (exp child/ NOT exp adult/

Web of science

TS=(((((("Advance") NEAR/2 (plan* OR directive*)) OR ((living-will*)) OR ((decision* OR decid* OR "plan" OR "plans" OR "planning" OR preference* OR "want" OR wish* OR dilemma* OR refus* OR choos* OR choice* OR "communication" OR "talking" OR disclos* OR autonom* OR attitude* OR pratice* OR perspective*) NEAR/5 (terminal* OR "end of life" OR palliativ* OR serious*-ill* OR severe*-ill* OR death OR dying OR advanced*-cancer* OR euthanas* OR hospice*)) OR (("do-not" OR refus*) NEAR/2 resuscit*) OR ((decision* OR decid* OR "plan" OR "plans" OR "planning" OR preference* OR "want" OR wish* OR dilemma* OR refus* OR choos* OR choice* OR "communication" OR "talking" OR disclos* OR autonom* OR attitude* OR pratice* OR perspective*) NEAR/5 life NEAR/1 (saving OR saver* OR sustain* OR resuscit* OR threat* OR support*)))) AND ((Asia* OR Afghan* OR Bangla* OR Bhutan* OR Borne* OR Brunei* OR Cambod* OR China* OR Chinese* OR India OR Indonesia* OR Japan* OR Korea* OR Laos* OR Laotion* OR Malaysia* OR Mongolia* OR Myanmar* OR Birmese* OR Birma OR Nepal* OR Pakistan* OR Papua* OR Philippin* OR Singapore* OR Sri-Lank* OR Taiwan* OR Thailand* OR Thai OR Timor* OR Viet-Nam* OR VietNam* OR mekong OR ("eastern" NOT (("middle" OR mediterr* OR "europe") NEAR/2 "eastern")) OR far-east)) NOT ((immigr* OR migrant* OR emigra* OR refugee* OR donor* OR donation OR transplant* OR "chinese american*" OR "japanese american*" OR "korean american*" OR "asian american*")) NOT (child* NOT adult*))

Appendix 2: Search strategies *(continued)*

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('living will'/exp OR (('patient decision making'/exp OR 'decision making'/de OR 'interpersonal communication'/exp OR 'doctor patient relation'/de OR 'patient information'/de OR 'patient preference'/de OR 'patient autonomy'/de OR 'personal autonomy'/de OR 'patient attitude'/de OR 'knowledge'/exp OR 'personal experience'/de) AND ('terminal care'/exp OR 'palliative therapy'/exp OR 'terminally ill patient'/exp OR 'terminal disease'/de OR 'life threat'/exp OR 'advanced cancer'/de OR resuscitation/de OR 'life sustaining treatment'/de OR euthanasia/de OR hospice/de)) OR (((Advance) NEAR/3 (plan* OR directive*)) OR ((living-will*)) OR ((decision* OR decid* OR plan OR plans OR planning OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice* OR communication OR talking OR disclos* OR autonom* OR attitude* OR pratice* OR perspective*) NEAR/6 (terminal* OR 'end of life' OR palliativ* OR serious*-ill* OR severe*-ill* OR death OR dying OR advanced*-cancer* OR euthanas* OR hospice*)) OR ((do-not OR refus*) NEAR/3 resuscit*) OR ((decision* OR decid* OR plan OR plans OR planning OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice* OR communication OR talking OR disclos* OR autonom* OR attitude* OR pratice* OR perspective*) NEAR/6 life NEXT/1 (saving OR saver* OR sustain* OR resuscit* OR threat* OR support*))):ab,ti) AND ('Asia'/de OR 'Asian'/de OR 'South Asian'/exp OR 'Southeast Asian'/exp OR 'Far East'/exp OR 'South Asia'/exp OR 'Japanese (people)'/exp OR 'Korean (people)'/exp OR 'Sino-Tibetan people'/exp OR (Asia* OR Afghan* OR Bangla* OR Bhutan* OR Borne* OR Brunei* OR Cambod* OR China* OR Chinese* OR India OR Indonesia* OR Japan* OR Korea* OR Laos* OR Laotion* OR Malaysia* OR Mongolia* OR Myanmar* OR Birmese* OR Birma OR Nepal* OR Pakistan* OR Papua* OR Philippin* OR Singapore* OR Sri-Lank* OR Taiwan* OR Thailand* OR Thai OR Timor* OR Viet-Nam* OR VietNam* OR mekong OR (eastern NOT ((middle OR mediterr* OR europe) NEAR/3 eastern)) OR far-east):ab,ti,ta,cy) NOT ('immigration'/exp OR 'donor'/exp OR 'migrant'/exp OR 'transplantation'/exp OR (immigr* OR migrant* OR emigra* OR refugee* OR donor* OR donation OR transplant* OR 'chinese american*' OR 'japanese american*' OR 'korean american*' OR 'asian american*'):ab,ti) NOT ([Conference Abstract]/lim OR [Letter]/lim OR [Note]/lim OR [Editorial]/lim) AND [english]/lim NOT (child/exp NOT adult/exp)

Google scholar (top 200 ranked)

"living will|wills"|"advance directive|directives"|"advance care planning|plans|plan" Asia|China|Chinese|India|Indonesia|Japan|Japanese|Korea -immigration -donor -migrant -transplantation -american

Appendix 3: List of Asian Countries Eligible for Inclusion

Regions of Asia	Countries or regions
Eastern Asia	China; Hong Kong; China Macao Special Administrative Region; Democratic People's Republic of Korea (North Korea); Japan; Mongolia; Republic of Korea (South Korea)
South-eastern Asia	Brunei Darussalam; Cambodia; Indonesia; Lao People's Democratic Republic; Malaysia; Myanmar; Philipines; Singapore; Thailand; Timor-Leste; Viet Nam
Southern Asia	Afghanistan; Bangladesh; Bhutan; India; Iran; Maldives; Nepal; Pakistan; Sri Lanka

Appendix 4. Characteristics of included studies

Author (Reference)	Year	Study Design	Country	Setting (N)	Type of HCPs	Asian HCPs' sample size	Elements of ACP	Term related to ACP studied
Kumar et al.[79]	1991	Cross-sectional survey	India	ICU of major hospitals in Delhi (not reported)	Physicians	102	Documentation	DNR order
Sehgal et al.[37]	1996	Cross-sectional survey	Japan, United States and Germany	Dialysis clinic in national academic hospitals (38)	Nephrologists	73 (out of 232 HCPs. Other participants: 72 Americans and 87 Germans)	Documentation	AD
Asai et al.[47]	1997	Focus group interview	Japan	Medical institution (6)	Internists	7	Documentation	AD
Tee et al.[69]	1997	Cross-sectional survey	Singapore	Private clinic (not reported)	General practitioners	174	Documentation	AD
Asai et al.[40]	1998	Cross-sectional survey	Japan	No restriction on the setting (N/A)	Internists (members of the Japan Society for Cancer Therapy)	339	Documentation	AD
Voltz et al.[41]*	1998	Cross-sectional survey	Japan, United States, and Germany	No restriction on the setting (N/A)	Physicians and nurses	38: 14 physicians, 24 nurses (out of 93 HCPs. Other participants: 26 Americans and 29 Germans)	Discussion, documentation	End-of-life decision, AD
Asai et al.[44]	1999	Cross-sectional survey	Japan	Academic hospital (not reported)	Physician members of the Japan Society of Apoplexy	190	Documentation	AD
Hosaka et al.[42]	1999	Cross-sectional survey	Japan	Academic hospital (1)	Physicians	150	Documentation	DNR order
Hosaka et al.[43]	1999	Cross-sectional survey	Japan	Academic hospital (1)	Nurses	706	Documentation	DNR order
Chao et al.[75]	2002	Cross-sectional survey	Taiwan	No restriction on the setting (N/A)	Internists and surgeons (members of national societies for internists or surgeons)	1,338	Documentation	DNR order

Appendix 4. Characteristics of included studies *(continued)*

Author (Reference)	Year	Study Design	Country	Setting (N)	Type of HCPs	Asian HCPs' sample size	Elements of ACP	Term related to ACP studied
Kim et al.[57]	2003	Cross-sectional survey	South Korea	Acute hospital in urban areas (3)	Nurses	185	Documentation	AD
Masuda et al.[48]	2003	Mixed method studies	Japan	No restriction on the setting (N/A)	Physicians (reported by relatives to have received a living will)	301 (survey); 120 (interview)	Documentation	Living will
Yap et al.[61]	2004	Cross-sectional survey	Hong Kong	ICU of public hospitals (11)	Intensivists	65	Discussion and documentation	DNR order, DNR order discussion
Yaguchi et al.[39]	2005	Cross-sectional survey	Japan and 20 other non-Asian countries	No restriction on the setting (N/A)	Intensivists attending international meeting on intensive care medicine	74 (out of 1,961. Other participants were non-Asian intensivists)	Documentation	DNR order
Barnett et al.[80]	2008	Cross-sectional survey	India	No restriction on the setting (N/A)	Pulmonary and critical care physicians	199	Discussion, documentation	End-of-life decision making, DNR order
Sittisombut et al.[82]	2009	Cross-sectional survey	Thailand	Medical department of academic hospital (1)	Physicians	55	Documentation	AD
Hu et al.[74]	2010	Cross-sectional survey	Taiwan	Nationwide, oncology care wards and palliative care units (N/A)	Physicians and nurses (members of hospice foundations and oncology organizations)	431	Discussion, documentation	ACP, AD
Lee et al.[49]*	2010	Cross-sectional survey	South Korea	General hospital in metropolitan areas (6)	Physicians, nurses	64: 30 physicians; 34 nurses	Documentation	AD
Park et al.[54]	2011	Cross-sectional survey	South Korea	ICU of general hospitals in metropolitan areas (not reported)	Nurses	252	Documentation	DNR order

Appendix 4. Characteristics of included studies *(continued)*

Author (Reference)	Year	Study Design	Country	Setting (N)	Type of HCPs	Asian HCPs' sample size	Elements of ACP	Term related to ACP studied
Weng et al.[83]	2011	Cross-sectional survey	China	ICU (not reported)	Intensivists	315	Documentation	DNR order
Yee et al.[67]	2011	Cross-sectional survey	Singapore	Nation-wide, dialysis center in public hospitals and private sectors (not reported)	Nephrologists, nurses, medical social workers	546: 51 physicians; 461 nurses; 13 medical social workers, 21 others	Discussion, documentation	ACP, AMD
Hong et al.[58]	2012	Cross-sectional survey	South Korea	Outpatient clinic and inpatient wards of acute hospital (3)	Nurses	293	Documentation	AD
Yang et al.[70]	2012	Cross-sectional survey	Singapore	Tertiary cancer center (1)	Oncology or palliative care physicians and nurses	146: 37 physicians, 109 nurses	Discussion, documentation	DNR discussion, DNR order
Foo et al.[68]	2013	Cross-sectional survey	Singapore	Cancer center hospital (1)	Oncology or palliative care physicians and nurses	147: 47 physicians; 110 nurses	Discussion	End-of-life care decision-making
Keam et al.[51]*	2013	Cross-sectional survey	South Korea	National cancer center (1) and general hospital (16)	Oncologists	303	Documentation	AD
Kim et al.[52]	2013	Cross-sectional Survey (part of a Delphi study)	South Korea	No restriction on the setting (N/A)	Experts panel members of Korean Society for Hospice and Palliative Care (physicians, nurses, social workers)	Round 1: 40 (14 physicians, 18 nurses, 8 others); round 2: 15 (7 physicians, 5 nurses, 3 others)	Documentation	AD
Pinto et al.[78]	2013	Cross-sectional survey	Sri Lanka	Academic hospital (3) in urban area	Physicians	232	Documentation	AD, DNR order
Nakazawa et al.[35]	2014	Cross-sectional survey	Japan	Nationwide, certified palliative care unit members of national palliative care association (203)	Palliative care physicians	99	Discussion, documentation	ACP, AD

Appendix 4. Characteristics of included studies *(continued)*

Author (Reference)	Year	Study Design	Country	Setting (N)	Type of HCPs	Asian HCPs' sample size	Elements of ACP	Term related to ACP studied
Lam et al.[65]	2015	Cross-sectional survey	Hong Kong	Medical department of tertiary referral hospital (1)	Physicians	106: 60 in 2004; 46 in 2008	Documentation	Do not attempt resuscitation form
Luk et al.[62]	2015	Cross-sectional survey	Hong Kong	Public teaching hospital (1)	Physicians (internists, surgeons, oncologists)	77 (40 internists, 31 surgeons, 6 oncologists)	Discussion, Documentation	AD discussion, AD
Mori et al.[33]	2015	Cross-sectional survey	Japan	Nation-wide, no restriction on the setting (N/A)	Medical oncologists	479	Discussion	End-of-life discussion
Chen et al.[77]	2016	Cross-sectional survey	China	Oncology department in academic (1), tertiary general (4), and urban general (5) hospitals	Oncologists	223	Documentation	Living will
Coffey et al.[64]	2016	Cross-sectional survey	Hong Kong, Ireland, Israel, Italy, and United States	Clinical and educational setting (not reported)	Nurses	157 (out of 1,089. Other participants were HCPs from Ireland, Israel, Italy, and United States)	Documentation	AD
Kwon et al.[53]	2016	Cross-sectional survey	South Korea	Registered geriatric social work institutions in metropolitan area	Social workers	246	Discussion, documentation	ACP, AD
Han et al.[55]	2016	Cross-sectional survey	South Korea	Long-term care facility (not reported)	Social workers	297	Discussion, documentation	End-of-life care decision, AMD
Hiraoka et al.[38]	2016	Cross-sectional survey	Japan	Acute care hospital (3)	Physicians	111	Discussion, documentation	Code status discussion, DNR order

Appendix 4. Characteristics of included studies *(continued)*

Author (Reference)	Year	Study Design	Country	Setting (N)	Type of HCPs	Asian HCPs' sample size	Elements of ACP	Term related to ACP studied
Koh et al.[60]	2016	Focus group interview	South Korea	Acute care hospital, palliative care ward, and hospice facility (not reported)	Physicians and nurses	13: 8 oncologists; 5 nurses	Discussion	End-of-life care planning
Lee et al.[63]	2017	Cross-sectional survey	Hong Kong	No restriction on the setting	Physicians, nurses, and social workers attending palliative care conference in Hong Kong	102	Discussion	ACP
Syed et al.[81]	2017	Cross-sectional survey	Pakistan	Department of medicine in academic hospital (1)	Physicians (who discussed at least 5 code statuses)	77	Discussion	Code-status discussion
Hirakawa et al.[46]	2018	Focus group interview	Japan	Long-term care facility (6) and psychogeriatric hospital (1)	Social workers and care managers	14: 3 social workers, 11 care managers	Discussion	ACP
Koh et al.[59]	2018	Cross-sectional survey	South Korea	No restriction on the setting	Oncologists attending annual meeting of oncology and residen physicians	376: 147 oncologists; 229 residents	Discussion	End-of-life discussion
Menon et al.[71]*	2018	Focus group and individual in-depth interview	Singapore	Acute public hospital, public specialist cancer center, private clinics (not reported)	Physicians (family physicians and junior doctors), nurses, medical social workers	33: 15 physicians; 13 nurses, 5 medical social workers	Discussion	ACP
Park et al.[34]	2018	Cross-sectional survey	China, South Korea, Japan	Nation-wide, ICU (not reported)	Physicians	605: China: 195; South Korea: 186; Japan: 224	Documentation	DNR order
Tsuruwaka et al.[45]	2018	In-depth interview	Japan	Hansen's disease sanatoria (13 national; 1 private)	Physicians, nurses, social workers, care workers	66: 10 physicians, 27 nurses, 6 social workers, 23 care workers	Discussion	ACP

Appendix 4. Characteristics of included studies *(continued)*

Author (Reference)	Year	Study Design	Country	Setting (N)	Type of HCPs	Asian HCPs' sample size	Elements of ACP	Term related to ACP studied
Yokoya et al.[36]	2018	Cross-sectional survey	Japan	Nationwide, geriatric health care facilities (844)	Head nurses	844	Discussion, documentation	ACP, AD
Chan et al.[66]*	2019	Mixed-method studies	Hong Kong	Regional hospital (2)	Physicians, social workers	24	Documentation	AD
Ke et al.[73]	2019	Cross-sectional survey	Taiwan	Medical and surgical ICU in medical center in northern Taiwan (7)	Physicians, nurses	176: 56 physicians; 120 nurses	Discussion, Documentation	End-of-life medical decision-making process, AD
Lee et al.[56]	2019	Cross-sectional survey	South Korea	No restriction on the setting (N/A)	Geriatricians attending national geriatric conference	181	Documentation	AD
Lin et al.[76]*	2019	Semi-structured interview	Taiwan	Inpatient oncology (1) and hospice (1) unit in northern Taiwan	Physicians, nurses, social workers, case managers, psychologist, chaplain, volunteer	12: 4 physicians; 4 nurses; 1 social worker; 3 case managers; 1 psychologist; 1 chaplain; 1 volunteer	Discussion	ACP
Park et al.[50]*	2019	Cross-sectional survey	South Korea	Nation-wide, large hospital (1 general and 1 cancer center) in capital, 5 major provinces and 3 metropolitan cities	Physicians	928	Discussion, documentation	ACP, AD
Tan et al.[72]	2019	Focus group interview	Singapore	Public hospitals and specialist center	Physicians, nurses, social workers who had completed national ACP training program	63: 12 physicians; 15 nurses; 24 medical social workers; 12 ACP coordinators	Discussion	ACP

N/A: not applicable; ACP: advance care planning; AD: advance directive; AMD: advance medical directive; ICU: intensive care unit; DNR: do-not-resuscitate
* Studies also studied non-HCPs

Appendix 5: Quality assessment scores for included studies

Author (Reference)	Year	Abstract and title	Introduction and aims	Method and data	Sampling	Data Analysis	Ethics and bias	Results	Transferability	Implications and usefulness	Total
Kumar et al.[79]	1991	2	1	2	2	1	2	2	2	4	18
Sehgal et al.[37]	1996	4	4	4	3	4	3	4	3	4	33
Asai et al.[47]	1997	4	4	3	3	1	4	4	2	4	29
Tee et al.[69]	1997	4	4	4	4	4	1	4	3	4	32
Asai et al.[40]	1998	4	4	3	3	4	1	4	3	3	29
Voltz et al.[41]	1998	4	4	3	3	4	1	4	3	3	29
Asai et al.[44]	1999	3	4	3	4	3	1	2	3	4	27
Hosaka et al.[42]	1999	4	4	3	3	1	1	4	3	3	26
Hosaka et al.[43]	1999	4	3	3	3	1	1	4	3	3	25
Chao et al.[75]	2002	4	4	4	4	3	1	3	3	3	29
Kim et al.[57]	2003	3	4	3	3	3	2	4	3	3	28
Masuda et al.[48]	2003	4	4	3	3	1	4	4	3	4	30
Yap et al.[61]	2004	4	4	4	4	4	4	3	3	3	33
Yaguchi et al.[39]	2005	4	4	3	3	4	1	4	3	4	30
Barnett et al.[80]	2008	2	2	2	2	1	2	1	2	3	17
Sittisombut et al.[82]	2009	4	3	4	3	4	4	4	3	4	33
Hu et al.[74]	2010	4	4	3	4	3	4	3	4	4	33
Lee et al.[49]	2010	4	4	4	4	4	4	4	3	3	34
Park et al.[54]	2011	3	4	3	3	3	4	4	3	4	31
Weng et al.[83]	2011	4	4	3	3	4	3	3	3	3	30
Yee et al.[67]	2011	4	4	4	4	4	4	4	3	4	35
Hong et al.[58]	2012	2	4	4	3	4	1	3	3	4	28
Yang et al.[70]	2012	4	4	3	3	1	2	4	3	4	28
Foo et al.[68]	2013	4	4	4	3	4	4	4	3	3	33
Keam et al.[51]	2013	4	4	3	3	4	3	4	3	3	31
Kim et al.[52]	2013	4	4	4	3	3	4	4	3	4	33
Pinto et al.[78]	2013	4	3	3	4	3	3	4	3	4	31
Nakazawa et al.[35]	2014	4	4	4	4	4	4	4	3	4	35
Lam et al.[65]	2015	4	4	3	3	4	1	4	3	3	29
Luk et al.[62]	2015	4	4	3	3	4	4	4	3	4	33
Mori et al.[33]	2015	4	4	4	4	4	4	4	4	4	36
Chen et al.[77]	2016	4	4	3	3	4	1	4	3	4	30
Coffey et al.[64]	2016	2	4	2	3	4	4	4	3	4	30
Kwon et al.[53]	2016	4	4	4	4	3	4	3	4	3	33

Appendix 5: Quality assessment scores for included studies *(continued)*

Author (Reference)	Year	Abstract and title	Introduction and aims	Method and data	Sampling	Data Analysis	Ethics and bias	Results	Transferability	Implications and usefulness	Total
Han et al.[55]	2016	4	4	3	3	4	4	3	3	4	32
Hiraoka et al.[38]	2016	3	4	4	1	4	4	4	3	4	31
Koh et al.[60]	2016	3	4	2	4	3	2	4	2	4	28
Lee et al.[63]	2017	4	4	4	3	4	4	4	3	3	33
Syed et al.[81]	2017	4	4	4	3	4	4	4	3	4	34
Hirakawa et al.[46]	2018	3	4	4	3	4	4	4	3	2	31
Koh et al.[59]	2018	3	4	3	3	3	2	4	3	3	28
Menon et al.[71]	2018	3	4	4	4	4	4	4	3	4	34
Park et al.[34]	2018	4	4	4	4	4	4	4	4	4	36
Tsuruwaka et al.[45]	2018	4	4	4	3	4	4	4	3	3	33
Yokoya et al.[36]	2018	4	4	4	4	4	4	4	4	4	36
Chan et al. [66]	2019	3	4	3	4	4	4	3	3	4	32
Ke et al.[73]	2019	4	4	4	3	4	4	4	3	4	34
Lee et al.[56]	2019	4	4	4	3	3	1	4	3	4	30
Lin et al.[76]	2019	4	4	4	4	4	4	4	3	4	35
Park et al.[50]	2019	4	3	4	3	4	4	4	4	4	34
Tan et al.[72]	2019	4	4	3	4	4	1	4	3	4	31

Appendix 6: Asian healthcare professionals' knowledge of advance care planning

No.	Author	Year	Country/ Region (Setting)	Subjects	Awareness of ACP (or its elements)	Main finding
1	Luk et al. [62]	2015	Hong Kong (Hospital)	Physicians (various specialties)	1. Familiarity with a standardized AD form 2. Familiarity with local guidelines for AD	1. 57% were familiar 2. 21% were very familiar; 68% knew the guidelines existed but were not very familiar; 10% not familiar
2	Chen et al. [77]	2016	China (Hospital)	Oncologists	1. Familiarity with DNR order 2. Knowing the difference between DNR order and euthanasia	1. 28% knew a lot; 51% knew something, 21% knew nothing 2. 74%
3	Coffey et al. [64]	2016	Hong Kong (Clinical and educational setting)	Nurses	Familiarity with AD	49%
4	Lee et al. [49]	2010	South Korea (Hospital)	Physicians, nurses	Having heard of AD	40% (physicians); 56% (nurses)
5	Pinto et al. [78]	2013	Sri Lanka (Hospital)	Physicians	1. Having heard of DNR orders 2. Knowing the correct meaning of DNR orders 3. Having heard of AD 4. Knowing the correct meaning of AD	1. 67% 2. 26% 3. 21% 4. 12%
6	Kwon et al. [53]	2016	South Korea (Geriatric institution)	Social workers	Having heard of AD	27%
7	Park et al. [50]	2019	South Korea (no restriction)	Physicians	Having heard of AD	61%
8	Menon et al. [71]	2019	Singapore (Geriatric or family medicine institution)	Physicians, nurses, medical social workers	Having heard of ACP [Qualitative data]	Physicians: most had heard of ACP and knew it involved making advance health care plans Some nurses and medical social workers had heard of ACP but were not aware of the details. Some knew nothing Nearly none knew that ACP is a series of conversations and that a trained facilitator may/can conduct it

Appendix 6: Asian healthcare professionals' knowledge of advance care planning *(continued)*

No.	Author	Year	Country (Setting)	Subjects	Knowledge of ACP (or its elements) measured by specific instrument[a]	Main finding
1	Tee et al. [69]	1997	Singapore (Private clinic)	General practitioners	Based on a questionnaire of knowledge about AD (8 questions): 1. AD knowledge score (Range = -9 to 9) 2. Correct answer rates to questions related to AD definition, possibility to be revoked, continuity of care after withdrawal of life-sustaining treatment, proxy appointment	1. Median = 7; min to max = -2 to 9 2. 80-88%
2	Yee et al. [67]	2011	Singapore (Dialysis center)	Nephrologists, nurses, medical social workers	Based on questionnaire of knowledge about ACP (9 questions): 1. ACP knowledge score (Range = 0 to 9) 2. Correct answer rate to questions referring to: a)Communication skills for ACP, the appropriate timing of ACP, and patient's values is taken into account in ACP b) Whether ACP can be proceeded without patient signing in an AD c)Whether ACP is a legal document rather than a process,	1. Mean = 8.0 (physicians); 6.3 (nurses); 8.3 (medical social workers) 2. a)88-97% b) 55% c)23%
3	Hong et al. [58]	2012	South Korea (Hospital)	Nurses	Based on a questionnaire of knowledge about AD made for public population (9 questions): 1. AD knowledge score (Range = 0 to 9)* 2. Correct answer rate	1. Mean ± SD = 7.6 ± 1.39 (min to max = 3 to 9) 2. 84%
4	Han et al. [55]	2016	South Korea (Long-term care facility)	Social workers	Based on a questionnaire of knowledge about AD (10 questions; 5-point Likert scale): 1. Medical knowledge of AD score (4 questions, range = 4-20) 2. General knowledge of AD score (6 questions, range = 6-30)	1. Mean ± SD = 2.3 ± 0.93 2. Mean ± SD = 2.3 ± 0.99
5	Ke et al. [73]	2019	Taiwan (ICU)	Physicians, nurses	Based on a questionnaire of knowledge about AD (10 questions): AD knowledge score (Range = 0 to 10)	Physicians: Mean ± SD = 4.39 ± 1.49 Nurses: Mean ± SD = 3.89 ± 1.3

[a]Higher score indicated better knowledge

Appendix 7: Asian healthcare professionals' attitudes towards advance care planning

No.	Author	Year	Country (Setting)	Type of HCPs	HCPs' perceptions of the usefulness/importance of ACP (or its elements)	Main finding
1	Asai et al. [40]	1998	Japan (no restriction)	Internists (members of cancer society)	HCPs who believed that AD is useful	89%
2	Voltz et al. [41]	1998	Japan (Hospice or palliative care unit)	Physicians, nurses	1. HCPs who believed that AD is useful 2. HCPs who believed that surrogate appointment is useful	1. 71% 2. 45%
3	Hosaka et al. [42]	1999	Japan (Hospital)	Physicians	HCPs who believed that DNR order is important	94%
4	Hosaka et al. [43]	1999	Japan (Hospital)	Nurses	HCPs who believed that DNR order is important	87%
5	Yee et al. [67]	2011	Singapore (Dialysis center)	Nephrologists, nurses, medical social workers	HCPs' perceptions of the usefulness of ACP in a 5-point Likert scale[a] [a](1=strongly disagree; 5=strongly agree)	Mean score: physicians: 4.2; nurses: 3.8; social workers: 4.3[a]
6	Park et al. [54]	2011	South Korea (ICU)	Nurses	HCPs who believed that DNR order is important	96%
7	Keam et al. [51]	2013	South Korea (Hospital)	Oncologists	HCPs who believed that AD is important	97%
8	Nakazawa et al. [35]	2014	Japan (Palliative care unit)	Palliative care physicians	1. HCPs who believed that ACP is useful for guidance 2. HCPs who believed that discussing patient's goals of care with the family is important 3. HCPs who believed that discussing patient's goals of care with the patient is important 4. HCPs who believed that confirming existing AD with the patient is important 5. HCPs who believed that recommending patient to complete an AD is important 6. HCPs who believed that asking the patient to designate a health care proxy is important 7. HCPs who believed that patients would worry less about unwanted treatment after making an AD	1. 87% 2. 99% 3. 98% 4. 69% 5. 63% 6. 57% 7. 85%

Appendix 7: Asian healthcare professionals' attitudes towards advance care planning *(continued)*

No.	Author	Year	Country (Setting)	Type of HCPs	HCPs' perceptions of the usefulness/importance of ACP (or its elements)	Main finding
9	Lam et al. [65]	2015	Hong Kong (Hospital)	Physicians	1. HCPs who believed that DNR order is useful for colleagues 2. HCPs who believed that DNR order is useful for terminal patient management	1. 48% (in 2004); 85% (in 2008) 2. 32% (in 2004); 54% (in 2008)
10	Kwon et al. [53]	2016	South Korea (Geriatric institution)	Social workers	HCPs who believed that self-determination is important	87%
11	Yokoya et al. [36]	2018	Japan (Geriatric health service facilities)	Head nurses	1. HCPs who believed that asking about existing AD is important 2. HCPs who believed that recommending completion of AD is important 3. HCPs who believed that asking for health care proxy designation is important 4. HCPs who believed that discussing patient's goals of care with the family is important 5. HCPs who believed that discussing patient's goals of care with the patient is important	1. 80% 2. 69% 3. 77% 4. 96% 5. 95%
12	Asai et al. [47]	1997	Japan (Medical institution)	Physicians	HCPs' perception of the usefulness of AD [Qualitative data]	Physicians found AD useful for setting the parameters for patient care at the end of life
13	Menon et al. [71]	2018	Singapore (Geriatric or family medicine institution)	Physicians, nurses, medical social workers	HCPs perception of the usefulness of ACP [Qualitative data]	HCPs believed that ACP would be useful if adequate information related to the disease was provided to the family members and the patient
14	Chan et al. [66]	2019	Hong Kong (Palliative care unit)	Physicians, social workers	HCPs perception of the importance of AD [Qualitative data]	HCPs believed that the main importance of AD discussion is to enhance mutual understanding between patients, families, and healthcare professionals
15	Hirakawa et al. [46]	2019	Japan (Long-term care facilities)	Social workers	HCPs perception of the usefulness of ACP [Qualitative data]	HCPs believed that ACP is useful to enhance mutual understanding between the patients and their families

Appendix 7: Asian healthcare professionals' attitudes towards advance care planning *(continued)*

No	Author	Year	Country (Setting)	Type of HCPs	Whether or not HCPs supported the use of AD	Main finding
1	Kumar et al. [79]	1991	India (ICU)	Physicians	HCPs willing to apply DNR orders on patients beyond salvage	51%
2	Tee et al. [69]	1997	Singapore (Private clinic)	General practitioners	HCPs supported the use of AD	83%
3	Kim et al. [57]	2003	South Korea (Hospital)	Nurses	HCPs supported the use of AD (after being educated on AD)	78%
4	Masuda et al. [48]	2003	Japan (no restriction)	Physicians (who had been presented with living will according to relatives)	HCPs supported the use of AD	55%
5	Yaguchi et al. [39]	2005	Japan (no restriction)	Intensivists	HCPs not willing to apply DNR orders (in persistent vegetative state patient with no close relatives nor AD)	33%
6	Yee et al. [67]	2011	Singapore (Dialysis center)	Nephrologists, nurses, medical social workers	Whether or not HCPs supported the use of ACP in a 5-point Likert scale[a] [a] (1=strongly disagree; 5=strongly agree)	Mean score: Physicians: 4.48; nurses: 4.0, social worker: 4.46[a]
7	Pinto et al. [78]	2013	Sri Lanka (Hospital)	Physicians	HCPs supported the use of DNR order	68%
8	Chen et al. [77]	2016	China (Hospital)	Physicians	HCPs supported the use of AD	84%
9	Lee et al. [56]	2019	South Korea (no restriction)	Physicians	HCPs supported the use of AD	87%

Appendix 7: Asian healthcare professionals' attitudes towards advance care planning *(continued)*

No	Author	Year	Country (Setting)	Type of HCPs	HCPs' confidence about engaging in ACP	Main finding
1	Voltz et al. [41]	1998	Japan (Hospice or palliative care unit)	Nurses, physicians	1. HCPs who felt comfortable to help patient setting up an AD 2. HCPs who felt comfortable to help with the proxy appointment	1. 71% 2. 55%
2	Lam et al. [65]	2015	Hong Kong (Hospital)	Physicians	1. HCPs who felt uncomfortable to sign DNR form 2. HCPs who would refrain from signing DNR form when he was relieving the duty of another doctor	1. 32% 2. 47%
3	Hiraoka et al. [38]	2016	Japan (Hospital)	Physicians	HCPs who felt confident to discuss DNR order with patient	47%
4	Kwon et al. [53]	2016	South Korea (Geriatric institution)	Social workers	1. HCPs who felt comfortable to discuss death in general 2. HCPs who felt comfortable to discuss death with an older patient	1. 41% comfortable 2. 27% comfortable
5	Lee et al. [63]	2017	Hong Kong (no restriction)	Physicians, nurses, social workers attending palliative care conference	1. Overall beliefs in ACP discussion (range: 11-77) * 2. Had positive feelings toward ACP discussion with their family and it's outcomes (range: 2-14)* 3. Belief that society expected HCPs to discuss ACP and make advance care decisions for their the family (range: 2-14)* 4. Had the ability and supports to discuss ACP with their family (range: 5-32)* 5. HCP's readiness to discuss ACP with their family (range: 2-13)* *lower score represented more positive attitudes toward ACP	1. Physicians: 30.27 ± 10.25; Nurses: 33.78 ± 12.47; Social workers: 30.58 ± 4.5 2. Physicians: 4.45 ± 2.57; Nurses: 6.53 ± 2.60; Social workers: 5.17 ± 1.8 3. Physicians: 4.76 ± 2.67; Nurses: 5.3 ± 3.06; Social workers: 5.29 ± 2.2 4. Physicians: 13.94 ± 5.71; Nurses: 15.97 ± 5.93; Social workers: 14.71 ± 3.38 5. Physicians: 6.23 ± 3.09; Nurses: 6.12 ± 2.74; Social workers: 5.79 + 2.42

Appendix 7: Asian healthcare professionals' attitudes towards advance care planning *(continued)*

No	Author	Year	Country (Setting)	Type of HCPs	The role HCPs perceived for themselves in ACP	Main finding
1	Tee et al. [69]	1997	Singapore (Private clinic)	General practitioners	HCPs who believed that family physicians should initiate ACP	35%
2	Yee et al. [67]	2011	Singapore (Dialysis center)	Nephrologists, nurses, medical social workers	HCPs who believed that ACP is part of their role	82% (physicians); 100% (social workers); 37% (nurses)
3	Koh et al. [59]	2018	South Korea (no restriction)	Oncologists, residents	1. Who should initiate ACP: - Oncologist - Hospice care specialist or palliative care coordinator 2. Who should conduct the ongoing discussion of ACP: - Hospice care specialist or palliative care coordinator	1. - 83% - 15% 2. - 68%
4	Ke et al. [73]	2019	Taiwan (ICU)	Physicians, nurses	Whether nurse should participate in ACP	98% (physicians); 97% (nurses)
5	Koh et al. [60]	2016	South Korea (Hospital or hospice)	Physicians, nurses	The role HCPs perceived for themselves in ACP [Qualitative data]	HCPs thought that the attending physicians should deliver the bad news and the palliative care team should conduct the ongoing discussion of ACP
No	**Author**	**Year**	**Country (Setting)**	**Type of HCPs**	**HCPs' willingness to engage in ACP**	**Main finding**
1	Chao et al. [75]	2002	Taiwan (no restriction)	Internists, surgeons	HCPs willing to initiate DNR discussion with patient and families	78%
2	Luk et al. [62]	2015	Hong Kong (Hospital)	Physicians (various specialties)	HCPs willing to initiate AD discussions with terminally ill patients and their family	94%
3	Park et al. [34]	2018	China, South Korea, Japan (ICU)	Physicians	1. HCPs willing to discuss DNR orders with competent patient 2. HCPs willing to discuss DNR orders with patient's families	1. 13% (China); 20% (South Korea); 67% (Japan) 2. 90% (China); 74% (South Korea); 95% (Japan)

Appendix 7: Asian healthcare professionals' attitudes towards advance care planning *(continued)*

No	Author	Year	Country (Setting)	Type of HCPs	HCPs' willingness to engage in ACP	Main finding
4	Park et al. [50]	2019	South Korea (no restriction)	Physicians	HCPs willing to engage in ACP: 1. when patient is still in healthy condition 2. when patient had been diagnosed with serious illness 3. when patient has difficult prognosis 4. when patient's condition of a serious illness is worsening 5. when patient terminal stage is easy to predict 6. when patient had been diagnosed with terminal stage	1. 64% 2. 88% 3. 82% 4. 97% 5. 97% 6. 97%

No	Author	Year	Country (Setting)	Type of HCPs	Who HCPs believed should participate in ACP	Main finding
1	Yap et al. [61]	2004	Hong Kong (ICU)	Intensivists	1. About life-sustaining treatment: - Patient and/or families - Nurses 2. About DNR orders: - Families - Patient	1. - 89% - 55% 2. - 92% - 88%
2	Barnett et al. [80]	2008	India (no restriction)	Intensivists	About DNR orders: 1. Family 2. Patients 3. Patients and families	1. 92% 2. 5% 3. 3%
3	Lee et al. [49]	2010	South Korea (Hospitals)	Physicians, nurses	1. Both patient and families 2. Patient only	1. 63% (physicians); 74% (nurses) 2. 37% (physicians); 26% (nurses)
4	Weng et al. [83]	2011	China (ICU)	Physicians	Patient or families	96%
5	Yang et al. [70]	2012	Singapore (Oncology or palliative care wards)	Physicians, nurses	1. Patient 2. Families	1. 79% 2. 78%

Appendix 7: Asian healthcare professionals' attitudes towards advance care planning *(continued)*

No	Author	Year	Country (Setting)	Type of HCPs	Who HCPs believed should participate in ACP	Main finding
6	Syed et al. [81]	2017	Pakistan (Hospitals)	Physicians	About DNR-orders: Families	 82%
7	Koh et al. [59]	2018	South Korea (no restriction)	Oncologists, residents	1. Oncologist 2. Patient and their families 3. Only patient 4. Only families	1. 30% 2. 85% 3. 8% 4. 6%
No	**Author**	**Year**	**Country (Setting)**	**Type of HCPs**	**HCPs' willingness to follow an AD**	**Main finding**
1	Sehgal et al. [37]	1996	Japan (Dialysis clinic)	Nephrologists	HCPs willing to follow patient's AD to withdraw LST when patient's AD conflicts family's wishes	19%
2	Asai et al. [44]	1999	Japan (Hospital)	Physicians	HCPs willing to follow patient's AD to withdraw LST when family's wishes are to withdraw LST	17%
3	Hosaka et al. [43]	1999	Japan (Hospital)	Nurses	HCPs willing to follow DNR orders	95%
4	Hosaka et al. [42]	1999	Japan (Hospital)	Physicians	HCPs willing to follow DNR orders	70%
5	Yap et al. [61]	2004	Hong Kong (ICU)	Intensivists	HCPs willing to follow DNR orders	79%
6	Sittisombut et al. [82]	2009	Thailand (Hospital)	Physicians	HCPs willing to follow DNR orders	91%
7	Weng et al. [83]	2011	China (ICU)	Physicians	HCPs willing to follow DNR orders	42%
8	Park et al. [54]	2011	South Korea (ICU)	Nurse	HCPs not willing to follow patient's AD when in conflict with family request	73%
9	Foo et al. [68]	2013	Singapore (Cancer center hospitals)	Oncology or palliative care physicians and nurses	1. HCPs willing to follow patient's AD when it's conflicting with family's wishes 2. HCPs not willing to follow patient's AD when it's conflicting with family's wishes	1. 46% (physicians); 33% (nurses) 2. 46% (physicians); 65% (nurses)

Appendix 7: Asian healthcare professionals' attitudes towards advance care planning *(continued)*

No	Author	Year	Country (Setting)	Type of HCPs	Who HCPs believed should be the decision maker in ACP	Main finding
1	Tee et al. [69]	1997	Singapore (Private clinic)	General practitioners	Who HCPs believed as a better decision maker for the appropriateness of withholding LST: Physicians	70%
2	Hosaka et al. [42]	1999	Japan (Hospital)	Physicians	Who HCPs believed should make final decision on DNR: 1. Patient, family, and physician in charge 2. Physician in charge	1. 44% 2. 28%
3	Hosaka et al. [43]	1999	Japan (Hospital)	Nurses	Who HCPs believed should make final decision on DNR: 1. Patient, family and physicians 2. Physicians and ward director 3. DNR committee in the hospital	1. 44% 2. 18% 3. 13%
4	Barnett et al. [80]	2008	India (no restriction)	Intensivists	Who HCPs believed should make final decision on DNR 1. Patient 2. Family 3. Physician 4. Physician and family	1. 2% 2. 7% 3. 18% 4. 73%
5	Park et al. [54]	2011	South Korea (ICU)	Nurse	Who HCPs believed should make final decision on DNR 1. Patient and family 2. Patient only 3. Family and physicians	1. 53% 2. 23% 3. 21%
6	Yang et al.[70]	2012	Singapore (Oncology or palliative care wards)	Physicians, nurses	Who HCPs believed should make final decision on DNR: 1. Physicians 2. Physicians and patients or family 3. Patient or family	1. 70 % (physicians); 32% (nurses) 2. 24% (physicians); 39% (nurses) 3. 5% (physicians); 28% (nurses)

Appendix 7: Asian healthcare professionals' attitudes towards advance care planning *(continued)*

No	Author	Year	Country (Setting)	Type of HCPs	Who HCPs believed should be the decision maker in ACP	Main finding
7	Pinto et al. [78]	2013	Sri Lanka (Hospital)	Physicians	Who HCPs believed should have the right to decide on LST: 1. Patient 2. Physician 3. Family	 1. 63% 2. 63% 3. 47%
8	Menon et al. [71]	2018	Singapore (Geriatric or family medicine institution)	Physicians, nurses, medical social workers	Who HCPs believed should have the right to decide on health care related decision [Qualitative data]	The main decision lay with the family members, particularly with regard to elderly patients

No.	Author	Year	Country (Setting)	Type of HCPs	Which factors HCPs believed influenced decision-making	Main finding
1	Asai et al. [44]	1999	Japan (Hospital)	Physicians	Regarding life sustaining treatment: 1. Patient's written AD 2. Patient's oral AD 3. Families' wishes	 1. 91% 2. 73% 3. 76%
2	Hosaka et al. [42]	1999	Japan (Hospital)	Physicians	Regarding DNR order: 1. Patient's consent was indispensable 2. Patient's consent was preferable, but if it was not obtained, the patient's family and the physician could decide	 1. 14% 2. 78%
3	Hosaka et al. [43]	1999	Japan (Hospital)	Nurses	Regarding DNR order: 1. Patient's consent was indispensable 2. Patient's consent was preferable, but if it was not available family and physicians could decide	 1. 36% 2. 64%
4	Lam et al. [65]	2015	Hong Kong (Hospital)	Physicians	Regarding DNR decision: 1. Patient's wishes 2. Good medical practice 3. Family's wishes 4. Cost-effectiveness	 1. 93% 2. 91% 3. 47% 4. 38%

Appendix 7: Asian healthcare professionals' attitudes towards advance care planning *(continued)*

No.	Author	Year	Country (Setting)	Type of HCPs	HCPs' perceptions regarding the optimal timing to initiate ACP	Main finding
1	Tee et al. [69]	1997	Singapore (Private clinic)	General practitioners	Perceived optimal timing to initiate ACP: 1. When patient was still healthy 2. When patient had been diagnosed with terminal illness	 1. 42% 2. 30%
2	Lee et al. [49]	2010	South Korea (Hospitals)	Physicians, nurses	Perceived optimal timing to initiate ACP: 1. When patient had been diagnosed with cancer 2. Upon patient's first admission for cancer treatment 3. When patient was in the end stage or metastatic phase 4. When patient was in the terminal stage	 1. 13% (physicians); 12% (nurses) 2. 0% (physicians); 18% (nurses) 3. 60% (physicians); 59% (nurses) 4. 27% (physicians); 12% (nurses)
3	Park et al. [54]	2011	South Korea (ICU)	Nurse	Perceived optimal timing to initiate ACP (in ICU setting): 1. When the patient was admitted to the ICU 2. When the patient became comatose 3. When the patient stopped self-respiration	 1. 20% 2. 30% 3. 28%
4	Yang et al. [70]	2012	Singapore (Oncology or palliative care wards)	Physicians, nurses	Perceived optimal timing to initiate DNR discussion: 1. As early as possible, soon after patient had been diagnosed with incurable disease 2. When patient's life expectancy was 6-12 months 3. When patient's life expectancy was 3-6 months 4. When patient's life expectancy was less than 3 months 5. When patient was in the dying phase	 1. 24% (physicians); 39% (nurses) 2. 14% (physicians); 11% (nurses) 3. 19% (physicians);10% (nurses) 4. 41% (physicians); 31% (nurses) 5. 0% (physicians); 5% (nurses)
5	Keam et al. [51]	2013	South Korea (Hospital)	Oncologists	Perceived optimal timing to document an AD: 1. When patient was still healthy 2. When patient had been diagnosed with cancer 3. When patient had been diagnosed as terminally ill 4. When patient was in the dying phase	 1. 15% 2. 20% 3. 52% 4. 13%

Appendix 7: Asian healthcare professionals' attitudes towards advance care planning *(continued)*

No.	Author	Year	Country (Setting)	Type of HCPs	HCPs' perceptions regarding the optimal timing to initiate ACP	Main finding
6	Mori et al. [33]	2015	Japan (no restriction)	Medical oncologists	Perceived optimal timing to initiate: 1. DNR status discussion: - When patient was hospitalized - When patient had been diagnosed with metastasized cancer 2. Prognosis discussion: - When patient had been diagnosed with metastasized cancer - Only if the patient and/or family brought it up 3. Hospice enrollment discussion: - When there were no more non-palliative treatments - When patient had been diagnosed with metastasized cancer 4. Preferred site of death discussion: - When there were no more non-palliative treatments - When patient had been diagnosed with metastasized cancer	1. - 43% - 4% 2. - 34% - 32% 3. - 62% - 14% 4. - 61% - 10%
7	Lam et al. [65]	2015	Hong Kong (Hospital)	Physicians	Perceived optimal timing to initiate ACP: When patient was admitted to hospital	22%
8	Syed et al. [81]	2017	Pakistan (Hospitals)	Physicians (who discussed at least 5 code statuses)	Perceived optimal timing to initiate ACP: 1. Upon patient's first visit, irrespective of the severity of illness 2. When patient got sick	1. 29 2. 55%
9	Koh et al. [59]	2018	South Korea (no restriction)	Oncologists, residents	Perceived optimal timing to initiate ACP: 1. Upon exacerbation of patient's disease (metastasis or recurrence) 2. When patient discontinued chemotherapy	1. 36% 2. 33%
10	Lee et al. [56]	2019	South Korea (no restriction)	Physicians	Perceived optimal timing to initiate ACP: When patient's life expectancy was less than 6 months	97%

Appendix 7: Asian healthcare professionals' attitudes towards advance care planning *(continued)*

No.	Author	Year	Country (Setting)	Type of HCPs	HCPs' perceptions regarding the optimal timing to initiate ACP	Main finding
11	Park et al. [50]	2019	South Korea (no restriction)	Physicians	Perceived optimal timing to document an AD: 1. Upon hospitalization of patients with specific severe diseases 2. Before patient underwent high-risk procedures 3. Upon hospitalization of every older patient (above 65 years old) 4. Upon hospitalization of every patient	1. 44% 2. 29% 3. 14% 4. 6%
12	Koh et al. [60]	2016	South Korea (Hospital or hospice)	Physicians, nurses	Perceived optimal timing to initiate ACP [Qualitative data]	HCPs thought that ACP should be initiated upon diagnosis of a terminal disease or when a responsible physician believed that an impending terminal stage was imminent
13	Hirakawa et al. [46]	2018	Japan (Long-term care facilities)	Social workers	Perceived optimal timing to initiate ACP [Qualitative Data]	HCPs expressed that if ACP was initiated before signs of imminent death, patients and families would express higher degrees of discomfort and upset
14	Chan et al. [66]	2019	Hong Kong (Palliative care unit)	Physicians, social workers	Perceived optimal timing to initiate ACP [Qualitative Data]	When patient was cognitively competent

No.	Author	Year	Country (Setting)	Type of HCPs	HCPs beliefs on the need for ACP training and education	Main finding
1	Lee et al. [49]	2010	South Korea (Hospitals)	Physicians, nurses	HCPs who felt the need for education on AD	100% of nurses 87% of physicians
2	Yee et al. [67]	2011	Singapore (Dialysis center)	Nephrologists, nurses, medical social workers	HCPs who felt the need for training on ACP	83%
3	Lam et al. [65]	2015	Hong Kong (Hospital)	Physicians	1. HCPs who felt the need for training in handling DNR issue 2. HCPs who felt the need for training on EOLC	1. 40% 2. 77%

Appendix 7: Asian healthcare professionals' attitudes towards advance care planning *(continued)*

No.	Author	Year	Country (Setting)	Type of HCPs	HCPs beliefs on the need for ACP training and education	Main finding
4	Hirakawa et al. [46]	2018	Japan (Long-term care facilities)	Social workers	HCPs beliefs regarding the need for ACP training [Qualitative data]	Social workers felt lacking on the skills to discuss medical treatments and to meet patient's wishes
5	Lin et al. [76]	2019	Taiwan (Hospice and oncology wards)	Physicians, nurses, social worker, case managers	HCPs beliefs regarding the need for ACP training [Qualitative data]	Felt they lacked the communication skills necessary to engaging in ACP
No.	**Author**	**Year**	**Country (Setting)**	**Type of HCPs**	**HCPs' beliefs on the need for legislation and standardization of ACP**	**Main finding**
1	Tee et al. [69]	1997	Singapore (Private clinic)	General practitioners	1. Whether HCPs agreed that legislation of AD was needed 2. Reasons of disagreeing the need of AD legislation	1. 45% agreed; 31% disagreed 2. HCPs' concern that it may lead to euthanasia (73%)
2	Hosaka et al. [42]	1999	Japan (Hospital)	Physicians	HCPs who believed that the standardization of DNR order form was needed	49%
3	Hosaka et al. [43]	1999	Japan (Hospital)	Nurses	HCPs who believed that the standardization of DNR order form was needed	66%
4	Chao et al. [75]	2002	Taiwan (no restriction)	Internists, surgeons	HCPs who believed that the legislation of DNR order was needed	96%
5	Lee et al. [49]	2010	South Korea (Hospitals)	Physicians, nurses	1. HCPs who believed that the legal form for AD was needed 2. HCPs who believed that the legislation of AD was needed	1. 97% (physicians); 94% (nurses) 2. 87% (physicians); 100% (nurses)
6	Park et al. [54]	2011	South Korea (ICU)	Nurses	HCPs who believed that the standardization of DNR order was needed	93%
7	Luk et al. [62]	2015	Hong Kong (Hospital)	Physicians (various specialties)	HCPs who believed that the legislation of AD was needed	62%
8	Chen et al. [77]	2016	China (Hospital)	Physicians	HCPs who believed that the legislation of AD was needed	88%

Appendix 8: Asian healthcare professionals' experiences with advance care planning

No	Author	Year	Country (Setting)	Subjects	HCPs who had received an AD	Main finding
1	Sehgal et al. [37]	1996	Japan (Dialysis clinic)	Nephrologists	HCPs who had received an AD (of dialysis patients)	2 out of 62 (0.07%)
2	Asai et al. [40]	1998	Japan (no restriction)	Internists (members of cancer society)	HCPs who had received an AD	44%
3	Asai et al. [44]	1999	Japan (Hospital)	Physicians	HCPs who had received an AD (of persistent vegetative state patients): - from 10-100 patients - from 0-10 patients - no patients with AD	 - 3% - 15% - 82%
4	Yee et al. [67]	2011	Singapore (Dialysis center)	Nephrologists, nurses, medical social workers	HCPs who had received an AD - Physicians - Nurses - Social workers	 - 49% - 22% - 23%
5	Chen et al. [77]	2016	China (Hospital)	Oncologists	HCPs who had received an AD	69%
6	Coffey et al. [64]	2016	Hong Kong (Clinical and educational setting)	Nurses	HCPs who had received an AD	24%
7	Lee et al. [56]	2019	South Korea (no restriction)	Physicians	HCPs who had received an AD	22%
No	**Author**	**Year**	**Country (Setting)**	**Subjects**	**HCPs who had engaged in ACP**	**Percentage**
1	Hosaka et al. [42]	1999	Japan (Hospital)	Physicians	HCPs who had participated in DNR orders discussion	62%
2	Hosaka et al. [43]	1999	Japan (Hospital)	Nurses	HCPs who had participated in DNR orders discussion	42%

Appendix 8: Asian healthcare professionals' experiences with advance care planning *(continued)*

No	Author	Year	Country (Setting)	Subjects	HCPs who had received an AD	Main finding
3	Yap et al. [61]	2004	Hong Kong (ICU)	Intensivists	ICU nurses who had participated in life-sustaining treatment discussion	28%
4	Sittisombut et al. [82]	2009	Thailand (Hospital)	Physicians	1. HCPs who had initiated DNR discussion with terminally ill patients 2. HCPs who had initiated DNR discussion with terminally ill patient's family	1. 35% = yes; 62% = no 2. 95% = yes; 4% = no
5	Hu et al. [74]	2010	Taiwan (Oncology wards and palliative care unit)	Physicians, nurses	HCPs who had engaged in ACP	45% = always or often 56% = occasionally or not at all
6	Yee et al. [67]	2011	Singapore (Dialysis center)	Nephrologists, nurses, medical social workers	1. HCPs who had initiated ACP discussion 2. HCPs who had engaged in ACP with their patients	1. Physicians = 82%; nurses = 19%; social worker = 90% 2. Physicians = 84%, nurses = 30%, social worker = 77%
7	Nakazawa et al. [35]	2014	Japan (Palliative care unit)	Palliative care physicians	1. HCPs who had asked about the existing ADs to the patient 2. HCPs who had recommended patient to complete an AD 3. HCPs who had asked patient to designate a proxy	1. 47% = always or very often; 48% = sometimes or rarely; 5% = never 2. 30% = always or very often; 59% = sometimes or rarely; 10% = never 3. 40% = always or very often; 57% = sometimes or rarely; 3% = never
8	Luk et al. [62]	2015	Hong Kong (Hospital)	Physicians (various specialties)	1. HCPs who had initiated AD discussions 2. HCPs who had engaged in AD discussions: - Once or less per month - 2-5 times per month - 5-20 times per month	1. 49% 2. - 30%; - 10%; - 9%
9	Lam et al. [65]	2015	Hong Kong (Hospital)	Physicians	1. HCPs who had reached DNR consensus with family - In <50% cases - In >90% cases 2. HCPs who had never or seldom signed a DNR form	1. - 13% (in 2004) and 7% (in 2008) - 43% (2004) and 64% (2008) 2. 80% (in 2004) and 13% (in 2008)

Appendix 8: Asian healthcare professionals' experiences with advance care planning *(continued)*

No	Author	Year	Country (Setting)	Subjects	HCPs who had received an AD	Main finding
10	Kwon et al. [53]	2016	South Korea (Geriatric institution)	Social workers	HCPs who had engaged in ACP	3%
11	Hiraoka et al. [38]	2016	Japan (Hospital)	Physicians	HCPs who had ordered a DNR order	76%
12	Coffey et al. [64]	2016	Hong Kong (Clinical and educational setting)	Nurses	HCPs who had previous experience working with ADs	13%
13	Yokoya et al. [36]	2018	Japan (Geriatric health service facility)	Head nurses	1. HCPs who had asked to patients about the existing ADs 2. HCPs who had recommended patient to complete an ADs 3. HCPs who had asked patient to designate a proxy	1. 28 % = always or often; 39% = sometimes or rarely; 31% = never 2. 18% = always or often; 40% = sometimes or rarely; 41% = never 3. 30% = always or often; 34% = sometimes or rarely; 34% = never
14	Koh et al. [59]	2018	South Korea (no restriction)	Oncologists, residents	HCPs who had engaged in ACP discussion about: 1. Proxy appointments 2. Progress and prognosis of disease 3. Possibility of recovery	 1. 22% 2. 93% 3. 83%
15	Lee et al. [56]	2019	South Korea (no restriction)	Physicians	HCPs who had completed an AD for themselves	7%
16	Chan et al. [66]	2019	Hong Kong (Palliative care unit)	Physicians, nurses, social workers	HCPs who had discussed AD with patients	63%
17	Ke et al. [73]	2019	Taiwan (ICU)	Physicians, nurses	1. Who had initiated ACP: - Nurses - Physicians - Patient/family 2. Nurses who had participated in ACP together with the physician	1. - 0 (physicians); 22% (nurses) - 75% (physicians); 63% (nurses) - 25% (physicians); 15% (nurses) 2. 70% (physicians); 68% (nurses)

Appendix 8: Asian healthcare professionals' experiences with advance care planning *(continued)*

No	Author	Year	Country (Setting)	Subjects	Who (i.e., patients and families) had participated in ACP	Main finding
1	Yap et al. [61]	2004	Hong Kong (ICU)	Intensivists	1. About life-sustaining treatment: - Patient or patient's families 2. About DNR orders: - Patient - Patient's families	1. - 83% 2. - 52% - 89%
2	Sittisombut et al. [82]	2009	Thailand (Hospital)	Physicians	About DNR orders: - Patient (terminally ill) - Patient's families	- 35% - 95%
3	Koh et al. [59]	2018	South Korea (no restriction)	Oncologists, residents	About end-of-life discussion: - Both patient and patient's families - Patient's families only (without the patient)	- 63% - 36%
4	Park et al. [34]	2018	China, South Korea, Japan (ICU)	Physicians	About DNR orders: - Patient - Patient's families	- 56% Japanese, 5% Chinese and 6% South Korean - 86% Japanese, 80% Chinese, and 57% South Korean
No	**First author**	**Year**	**Country (Setting)**	**Subjects**	**Who had been the decision maker in ACP**	**Percentage**
1	Pinto et al. [78]	2013	Sri Lanka (Hospital)	Physicians	1. Physician 2. Patient 3. Families	1. 40% 2. 25% 3. 17%
2	Asai et al. [47]	1997	Japan (Medical institution)	Physicians	Who had been the decision maker regarding life-sustaining treatment [Qualitative Data]	Physicians and family members usually made decisions about life-sustaining treatment. Even when patients were competent, their wishes were not taken into account.

Appendix 8: Asian healthcare professionals' experiences with advance care planning *(continued)*

No	Author	Year	Country (Setting)	Subjects	HCPs who had followed an AD	Main finding
1	Sehgal et al. [37]	1996	Japan (Dialysis clinic)	Nephrologists	HCPs who had followed patient's AD	1 out of 2 (50%)
2	Asai et al. [40]	1998	Japan (no restriction)	Internists (members of cancer society)	1. HCPs who had followed: - All ADs - 50-75% AD - 25% AD 2. HCPs who had given priority to patients' wishes when known	1. · 35% · 57% · 7% 2. 51% (regardless of patient's competence); 59% (if patient is competent)
3	Hosaka et al. [43]	1999	Japan (Hospital)	Nurses	HCPs who had followed DNR orders	44%
4	Hosaka et al. [42]	1999	Japan (Hospital)	Physicians	HCPs who had followed DNR orders	58%
5	Masuda et al. [48]	2003	Japan (no restriction)	Physicians (presented with living will according to relatives)	1. HCPs who had followed patient's AD 2. HCPs who had changed the therapy as a result of receiving an AD 3. HCPs who had not changed the therapy as a result of receiving an AD	1. 73% 2. 19% 3. 69%
6	Yap et al. [61]	2004	Hong Kong (ICU)	Intensivists	HCPs who had applied DNR orders: 1. Written 2. Oral	1. 60% 2. 35%
7	Barnett et al. [80]	2008	India (no restriction)	Intensivist	HCPs who had applied DNR orders (written and oral)	41%
8	Nakazawa et al. [35]	2014	Japan (Palliative care unit)	Palliative care physicians	1. HCPs who had ordered DNR (after knowing that the patient wished for DNR) 2. HCPs who had ordered DNR (after knowing that the family wished for DNR)	1. 33% = always or very often; 48% = sometimes or rarely;17% = never 2. 71% = always or very often; 15% = sometimes or rarely; 12% = never
9	Lee et al. [56]	2019	South Korea (no restriction)	Physicians	1. HCPs who had followed an AD 2. HCPs who had changed treatment as a result of receiving an AD	1. 67% 2. 63%

Appendix 8: Asian healthcare professionals' experiences with advance care planning *(continued)*

No	Author	Year	Country (Setting)	Subjects	HCPs who had followed an AD	Main finding
10	Koh et al. [60]	2016	South Korea (Hospital or hospice)	Physicians, nurses	HCPs who had followed an AD [Qualitative data]	Despite recognition of the importance of ACP, many were noncompliant with patient preferences and were often reluctant to discuss these issues
No	**First author**	**Year**	**Country (Setting)**	**Subjects**	**When ACP had been initiated**	**Main finding**
1	Koh et al. [59]	2018	South Korea (no restriction)	Oncologists, residents	1. upon patient's cancer diagnosis 2. upon metastasis or recurrence of cancer 3. when chemotherapy was expected to be discontinued in a cancer patient 4. upon chemotherapy discontinuation 5. when patient's life expectancy was less than 6 months 6. when the patient's life expectancy was less than 2-3 months	1. 2% (oncologists); 5% (residents) 2. 10% (oncologists); 15% (residents) 3. 25% (oncologists); 17% (residents) 4. 24% (oncologists); 13% (residents) 5. 15% (oncologists); 23% (residents) 6. 22% (oncologists); 19% (residents)
No	**First author**	**Year**	**Country (Setting)**	**Subjects**	**Whether HCPs had had ACP-related training and education**	**Percentage**
1	Yee et al. [67]	2011	Singapore (Dialysis center)	Nephrologists, nurses, medical social workers	HCPs who had been exposed to ACP information during professional education	Physicians = 43%; nurses = 25%; medical social workers = 54%
2	Lee et al. [56]	2019	South Korea (no restriction)	Physicians	HCPs who had had ACP-related training during medical education	17%
No	**First Author**	**Year**	**Country (Setting)**	**Subjects**	**The presence of guideline or formal regulation for ACP**	**Main finding**
1	Chao et al. [75]	2002	Taiwan (no restriction)	Internists, surgeons	1. The presence of formal DNR order in institution 2. The presence of guidelines for DNR order	1. 47% 2. 27%

Appendix 8: Asian healthcare professionals' experiences with advance care planning *(continued)*

No	First Author	Year	Country (Setting)	Subjects	HCPs who had experienced any negative or positive consequences of ACP	Percentage
1	Hosaka et al. [42]	1999	Japan (Hospital)	Physicians	HCPs who had encountered legal problems due to performing a DNR order	3%
2	Masuda et al. [48]	2003	Japan (no restriction)	Physicians (who had been presented with living will according to relatives)	HCPs who had more opportunities to communicate with patient and family after receiving an AD	53%
3	Mori et al. [33]	2015	Japan (no restriction)	Medical oncologists	1. HCPs who had witnessed marked anxiety of patients/families caused by EOLD (mean score ± SD)* 2. HCPs who perceived that patients had spent terminal phase as desired because of EOLD* 3. HCPs who had experienced patients attempting/committing suicide just after EOLD *5-point Likert-type scale: 1 (never) to 5 (very frequently)	1. 2.2 + SD = 0.6* 2. 3.5 ±SD = 0.7* 3. 20%

Chapter 4

Asian Patients' Perspectives on Advance Care Planning: A Mixed-Method Systematic Review and Conceptual Framework

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ABSTRACT

Background: Asian healthcare professionals hold that patients' families play an essential role in advance care planning.

Aim: To systematically synthesize evidence regarding Asian patients' perspectives on advance care planning and their underlying motives.

Design: Mixed-method systematic review and the development of a conceptual framework (PROSPERO: CRD42018099980).

Data sources: EMBASE, MEDLINE, Web of Science, and Google Scholar were searched for studies published until July 27, 2020. We included studies concerning seriously-ill Asian patients' perspectives on advance care planning or their underlying motives for engaging or not engaging in it.

Results: Thirty-six articles were included; 22 were quantitative and 27 were from high-income countries. Thirty-nine to 90% of Asian patients were willing to engage in advance care planning. Our framework highlighted that this willingness was influenced not only by their knowledge of their disease and of advance care planning, but also by their beliefs regarding: 1. its consequences; 2. whether its concept was in accordance with their faith and their families' or physicians' wishes; and 3. the presence of its barriers. Essential considerations of patients' engagement were their preferences: 1. for being actively engaged or, alternatively, for delegating autonomy to others; 2. the timing, and 3. whether or not the conversations would be documented.

Conclusion: The essential first step to engaging patients in advance care planning is to educate them on it and on their diseases. Asian patients' various beliefs about advance care planning should be accommodated, especially their preferences regarding their role in it, its timing, and its documentation.

Keywords: Asian continental ancestry group, critical illness, attitude, patient preference, mixed design, systematic review.

INTRODUCTION

The implementation of advance care planning has become one of the indicators for high-quality palliative care.[1] Advance care planning enables patients to define, discuss, and record their goals and preferences for future medical treatment and care, and to review these preferences if appropriate.[2] It also aims to clarify and document patients' values and preferences regarding future medical care, and to ensure these are taken into account at the time of incapacity.[2] To ensure that these values and preferences are acknowledged and can be used to facilitate respectful and responsive care, patients' involvement in this process is deemed essential.[3]

The practice of advance care planning may be affected by societal norms and values.[4, 5] In our systematic review of Asian healthcare professionals' perspectives on advance care planning, we found that professionals regard families as playing the leading role in it.[6] However, we also observed that these professionals rarely engage patients in advance care planning, even when the patients retain their decision-making capacity. Among the reasons for not engaging patients was healthcare professionals' concern about patients' lack of readiness to engage in advance care planning.[6]

To better understand how advance care planning can best be delivered to Asian patients, it is essential to understand their preferences. Although various studies have been conducted in different Asian countries, they used various methodologies and conceptualizations of advance care planning. We therefore aimed to summarize and systematically synthesize the evidence on native Asian patients' perspectives on advance care planning and their underlying motives.

METHODS

This systematic review is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020.[7]

Design

This study obtained a phenomenological approach in which we integrated findings of primary quantitative and qualitative studies to build a network of related concepts that together provide a comprehensive understanding of Asian patients' perspectives on advance care planning.[8-10]

Data sources and searches

With the aid of a biomedical information specialist (WMB), we developed and deployed a systematic strategy for searching four electronic databases, EMBASE.com (1971-); MEDLINE ALL Ovid (1946-); Web of Science Core Collection (1975-); and Google Scholar from inception to July 27, 2020 (date last searched). Whenever applicable, search terms for each database were tailored using thesaurus terms (Emtree and MeSH; see Appendix 1 for the full search strategies). The searches contained terms to describe advance care planning and advance directives, and were also designed to retrieve articles on end-of-life decision-making in Asian countries or among Asian populations. Conference papers, letters, notes and editorials were excluded from the search, as were articles on children, and articles in languages other than English. We used no limit for publication date or study design. To ensure a comprehensive search, we scanned the reference lists in relevant literature reviews and in the included articles. Lastly, we inquired among different experts on advance care planning in Asia whether we had missed important studies that would met our inclusion and exclusion criteria.

Study selection

Studies were included on the basis of the following inclusion criteria: an original empirical study published in English in peer-reviewed journals that focused on patients with serious illness living in the southern, eastern, and southeastern Asia; and that reported patients' perspectives on advance care planning, their agreement or willingness to engage in it, the role of decision maker, and the motivational drivers for their willingness or unwillingness to engage in it.

We defined serious illness as a health condition that carried a high risk of mortality and either negatively impacted a person's daily function or quality of life, or placed an excessive burden on their caregivers.[11] This definition covers severe chronic conditions (such as cancer, renal failure and advanced liver disease); dementia; and elderly patients living in long-term care facilities.

We further operationalized advance care planning as: 1. activities the authors had labeled as "advance care planning"; and/or 2. activities that involve patients, their family and/or healthcare professionals in discussions of the patients' goals and/or preferences for future medical care and/or treatment; 3. activities that involve documentation processes of patients' preferences, including (a) the appointment of a personal representative; and (b) writing an advance directive.[2] Due to the vast area of the Asian continent, we focused our search on its southern, eastern, and southeastern regions, whose cultural backgrounds are relatively comparable.

[12] We excluded studies on patients under 18 years old or on those diagnosed with mental disorders other than early dementia according to the criteria of Diagnostic and Statistical Manual of Mental Disorders V.[13]

On the basis of the inclusion and exclusion criteria, three authors (DM, MSK, and OG) were involved in independently screening titles and abstracts for eligibility and then reviewing the full-text articles. If necessary, disagreements were discussed and resolved with JR and/or CR. References were managed using Endnote bibliographic software version X9.

Quality assessment and data extraction

Two of the three authors (DM and CPL or DM and OG) were involved in independently assessing the methodological quality of the included studies using the QualSyst tool, which has been described as suitable for various study designs.[14] We employed the ten standard criteria for qualitative studies and the 14 standard criteria for quantitative studies. Mixed-method studies were evaluated using both sets of criteria. We divided the sum of the scores by the total numbers of criteria. Any disagreements between reviewers were resolved through discussion. The summary scores were defined as strong (score of >0.80), good (0.71-0.80), adequate (0.51-0.70), or low (<0.50).[15] Studies were not excluded on the basis of their methodological quality. To ensure that the quality assessment was free of bias, the author who conducted the quality assessment of an included study had not authored that specific paper.

A tailored data-extraction form was developed by DM. After piloting by JR, it was used by DM to extract data that included: (a) study characteristics; (b) patients' perspectives on advance care planning, including their agreement with its concept and necessities, their willingness to engage in it, and their perspectives on the decision maker in it; (c) motives underlying patients' willingness or unwillingness to engage in it. The extracted data was then reviewed by OG.

Data synthesis and analysis

Figure 1 shows the multi-step synthesis and analysis performed on the data. First, to explore patients' perspectives on advance care planning, we conducted a narrative synthesis and thematic analysis according to Guidance on the Conduct of Narrative Synthesis in Systematic Reviews (Step-1),[16] which includes textual description of the extracted data, tabulation, grouping, and clustering of data obtained from quantitative findings of quantitative or mixed-method studies. In the second step, we further synthesized patients' underlying motives for willingness or unwillingness to engage in advance care planning, which we then analyzed on the basis of the

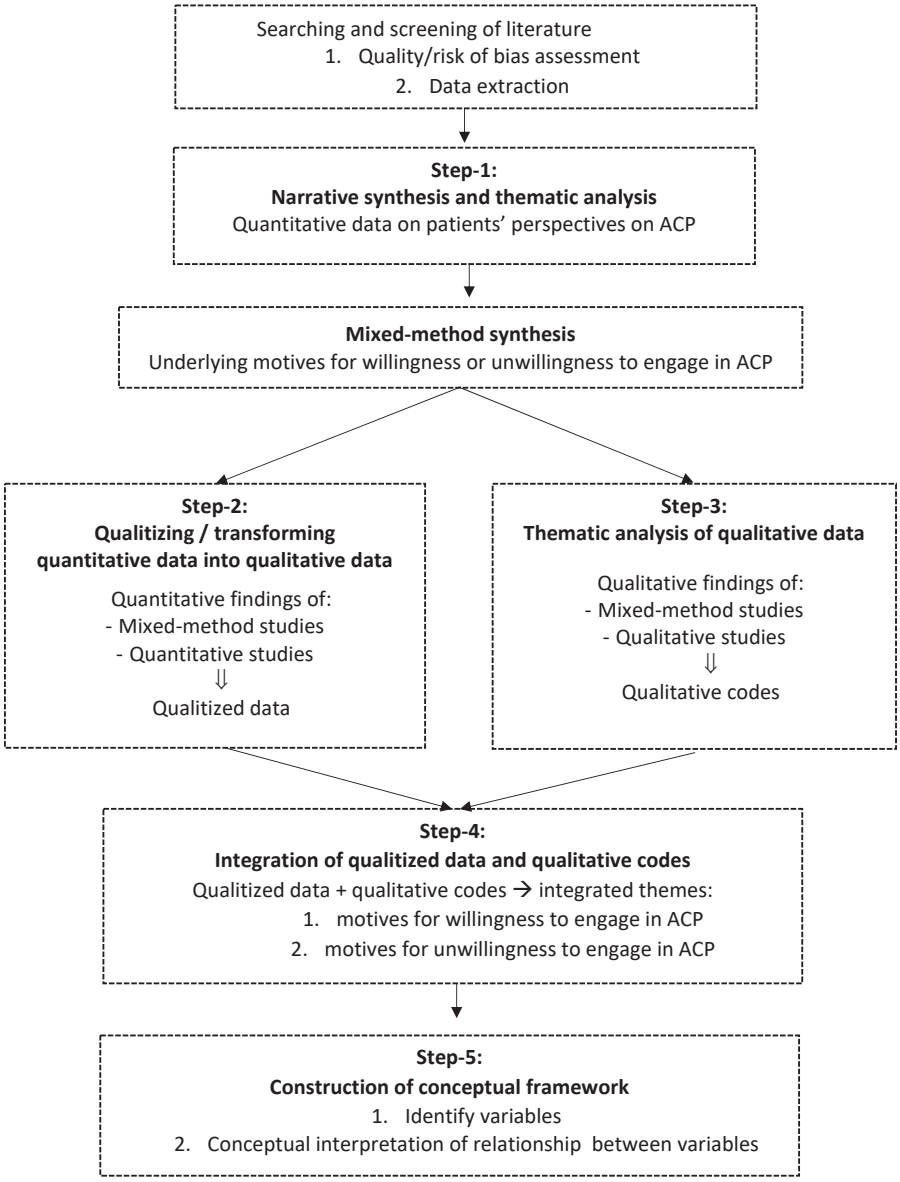

Figure 1. Multi-step synthesis and analysis
ACP: advance care planning

type of data. The quantitative data was qualitized – i.e., transformed into qualitative data – by attributing a qualitative thematic description to quantitative findings following the Bayesian conversion method.[17, 18] In the second step, the qualitative data was analyzed separately by DM and OG on the basis of Boeije's procedure

for thematic analysis.[19] Any disagreements were resolved through consensus. In the fourth step, DM and OG further integrated the qualitized data with qualitative codes, using a data-based convergent integrative synthesis design to produce a set of integrated themes.[20] This process was facilitated through a discussion with JR and CR. Qualitative analysis software (NVivo 12 Pro) was used to organize all qualitative data. Finally, in the fifth step we constructed a conceptual framework adapted from the Theory of Planned Behavior in order to visually display the interactions of the underlying motives with regard to patients' willingness or unwillingness to engage in advance care planning.[9, 21]

RESULTS

Study characteristics

Through our systematic search, we identified 7,118 potential studies. After de-duplication, 4,330 studies remained, which were then screened on the basis of their titles and abstracts. We further excluded 4,237 studies, primarily because they had not studied specific elements of advance care planning. After the addition of two studies identified by expert's input and a manual search of reference lists, 94 studies were assessed full-text. Ultimately, 36 were included (Figure 2), 22 of which had used quantitative methods, ten of which had used qualitative methods, and four of which had used mixed methods (Table 1 and Appendix 2). A majority of the studies (N=25) had been conducted in high-income countries:[22] Japan,[23-26] South Korea,[24, 27-35] Hong Kong,[36-41] Singapore,[42-44] and Taiwan.[45-50] The term advance care planning was used in 15 studies, most of which had been published in the last decade. Other studies, many of them less recent, used terms such as advance directive or do-not-resuscitate (DNR) order that were related mainly to advance care planning documents; or terms such as end-of-life discussion that were related to advance care planning. Fourteen studies conceptualized advance care planning as the completion of documents (advance directives or DNR orders), while 22 conceptualized advance care planning as a conversation process with or without documentation. Elderly patients (n=16) and cancer patients (n=14) were the most-studied patient populations. A majority of studies were conducted in a hospital-based setting (n=23). Methodological quality was categorized as being strong in 11 studies, good in 11, adequate in 12, and low in two (Appendix 3 and 4).

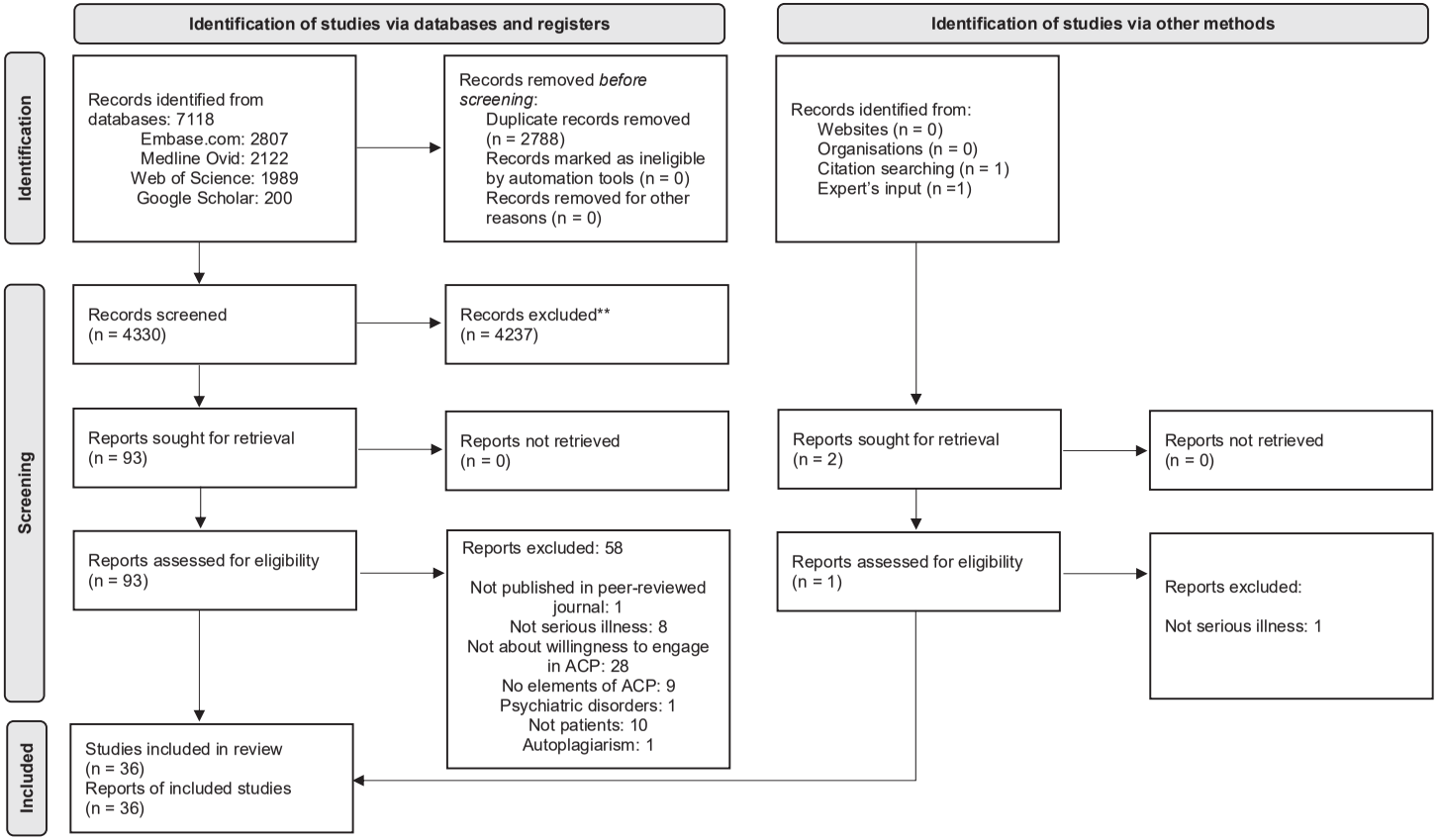

Figure 2. PRISMA flow diagram for study selection
ACP: advance care planning.

Table 1. Characteristics of the included studies (n = 36)

Study characteristics		N (%)
Type of study	Quantitative study	22 (61)
	Qualitative study	10 (28)
	Mixed-methods study	4 (11)
Country/region[(a)]	South Korea[(a)]	10
	China[(a)]	6
	Hong Kong	6
	Taiwan	6
	Japan[(a)]	4
	Singapore	3
	Malaysia	3
Term related to ACP used[(b)]	Advance care planning	15
	Term related to ACP documents:	
	Advance directive	19
	DNR order/directive	2
	Physician order for life-sustaining-treatment	3
	Term related to ACP conversation:	
	End-of-life decision-making	5
	Advance directive decision-making	1
The element of ACP studied	ACP as completion of documents	14
	ACP as process of discussion on preferences	13
	Both	9
Number of patients in the study	0-100	15
	101-500	17
	501-1000	1
	>1000	3
Type of subjects studied	Patients:	
	- Cancer	14
	- Non-cancer:	
	Elderly with chronic serious illnesses	16
	Chronic dialysis	1
	- Not-specified non terminal serious illnesses	4
	- Not-specified terminal illness	1
Setting	Hospital	23
	Palliative care unit or hospice	3
	Elderly facility	9
	No restriction in the setting	1

ACP: advance care planning; DNR: do-not-resuscitate; (a) One study was conducted in South Korea, China, and Japan; (b) Several studies used more than one terms related to advance care planning

Patients' perspectives on advance care planning

Patients' agreement with the importance of advance directive. Seven quantitative studies reported on whether or not patients thought advance directives were important[24, 31, 34, 46, 51-53] (Appendix 5). Three-quarters or more of Asian patients in six studies considered they were necessary: Malaysia (75%);[51] South Korea (85%;[24] 87%;[31] 93%[34]); China (74%;[52] 80%[24]; Japan (96%),[24] Taiwan (77%).[46] In the seventh study, also from China, 22% of patients agreed on it.[52]

Patients' willingness to engage in advance care planning or to draft an advance directive. Seven quantitative studies reported that 39-90% of Asian patients were willing to engage in advance care planning (Table 2). Two of these reported that 62-82% of patients' were willing to engage in it together with their family or healthcare professionals. The first of these studies involved patients with advanced cancer in South Korea; 62% of these patients were willing to engage in advance care planning with their family, and 61% with healthcare professionals.[27] In the second of these studies, from China, 82% of patients were willing to engage in advance care planning with their family and/or with their healthcare professionals).[54] In Japan, the willingness to engage in advance care planning with the family (mean score 3.3 + 0.61, range 1-4) was similar to the willingness to engage in advance care planning without families (mean score 3.2 + 0.52).among older patients with chronic diseases.[23] Four other studies reported Asian patients' willingness to engage in advance care planning (39-68%) without detailing their preferences on whom they would have the conversation with: Singapore (39-49% of older patients with mild dementia),[43, 44] Taiwan (42% of nursing home residents);[49] and Malaysia (68% of patients with kidney failure).[51]

Ten studies reported that 32-88% of Asian patients were willing to draft an advance directive: Hong Kong (88% of nursing home residents, 49% of critically-ill elderly patients, and 34% of cancer patients); [37-39] China (32% of nursing home residents and 80% of cancer patients);[55, 56] and South Korea (52-74% of advanced cancer patients; 59% of nursing home residents).[27, 28, 30, 33, 35]

Patient's perspectives on the decision maker in advance care planning

Seven quantitative studies reported the perspectives of Asian patients on their own role, and the roles of their family and physicians, regarding decision-making in advance care planning (Appendix 6). Fifty-one to 95% of Asian patients considered the main decision maker in advance care planning to be themselves, either alone or together with their family members and/or physicians.[24, 26, 28, 31, 37, 38] Five

Table 2. Patients' willingness to engage in advance care planning or to draft an advance directive

No	First author	Year	Country	Type of patient	Conceptualization of ACP	Patients' willingness to engage in ACP	Percentage
1.	Cheong K[44]	2015	Singapore	Patients with early cognitive impairment	Advance care planning is a process that aims to inform and facilitate medical decision-making to reflect patients' values and preferences in the event that they cannot communicate their wishes.	Willing to engage in ACP	39%
2.	Hing Wong A[51]	2016	Malaysia	Patients on routine hemodialysis	Advance care planning is a process of communication among the patients, their families, and professional caregiver, which include, but is not limited to discussing preferences for life-sustaining treatments	Willing to engage in ACP	68%
3.	Lo TJ[43]	2017	Singapore	Patients with early cognitive impairment	Advance care planning is a process that facilitates decision-making on future care and helps patients with chronic or terminal illnesses make known their wishes before they lose their ability to do so	Willing to engage in ACP	49%
4.	Sung HC[49]	2017	Taiwan	Elders living in long-term care facility	Advance care planning is a process of discussion between individuals and their physicians, formal caregivers, families and friends about their preferences and wishes for future care if the individual lacks the capacity to express their wishes	Willing to engage in ACP	42%
5.	Hou XT[54]	2018	China	Patients with advanced cancer	Advanced care planning is the process whereby there is a discussion between individuals and their physicians, family, and friends about their preferences and wishes for future care at a time when they may lack the capacity to express such wishes	Willing to engage in ACP: a) With HCPs and families b) With HCPs only c) With families only	 a) 59% b) 12% c) 11%
6.	Kizawa Y[23]	2020	Japan	Elderly patients with chronic disease	Not defined	Willingness to engage in ACP[a]: a) By themselves b) With families (Mean score ± SD; Range: 1-4)	 a) 3.2 ± 0.52 b) 3.3± 0.61

Table 2. Patients' willingness to engage in advance care planning or to draft an advance directive *(continued)*

No	First author	Year	Country	Type of patient	Conceptualization of ACP	Patients' willingness to engage in ACP	Percentage
7.	Yoo SH[27]	2020	South Korea	Patients with advanced solid and/or hematologic cancer	Not defined	a) Willing to engage in ACP with family • In total • among those who understand their illness • among those who don't understand their illness b) Willing to engage in ACP with physician • In total • among those who understand their illness • among those who don't understand their illness	a) 62% • 67% • 58% b) 61% • 68% • 56%

No	First author	Year	Country	Type of patient	Conceptualization of AD	Patients' willingness to draft an AD	Percentage
1.	Chu LW[39]	2011	Hong Kong	Elderly living in long-term care facility	An advance directive is a statement, usually in writing, in which a person, when mentally competent, indicates the form of healthcare he or she would like to have in a future time when he or she is no longer competent	Willing to draft an AD	88%
2.	Ting FH[37]	2011	Hong Kong	Elderly in-patients with chronic diseases	Not defined	Willing to draft an AD if formally legalized	49%
3.	Ni P[56]	2014	China	Elders living in long-term care facility	An advance directive is a legal document that outlines a person's care preferences and wishes, should their decision-making ability be diminished as a result of a critical illness or cognitive impairment	Willing to draft an AD	32%

Table 2. Patients' willingness to engage in advance care planning or to draft an advance directive *(continued)*

No	First author	Year	Country	Type of patient	Conceptualization of AD	Patients' willingness to draft an AD	Percentage
4.	Park J[35]	2016	South Korea	Elders living in long-term care facility	An advance directive is a written document specifying medical treatments that people want or do not want to receive in the event where the ability to communicate or make decisions is lost due to a progression of illness	Willing to draft an AD	59%
5.	Hui EC[38]	2017	Hong Kong	Patients with solid cancer (any stage)	Not defined	Willing to draft an AD	22% (and list treatment preferences); 12% (and assign proxy decision-maker)
6.	An HJ[30]	2019	South Korea	Patients with terminal cancer	An advance directive is a legal document written by anyone regardless of his/her illness, and it includes a future medical care plan, living will, or designation of power of attorney The POLST form is a medical document that mainly pertains to a patient's future care, including end of life care preferences in case they lose the capacity to make decisions	Willing to sign AD (POLST)	52%
7.	Kim JW[28]	2019	South Korea	Patients with advanced solid cancer	POLST is a part of an advance care planning with advance directives and is written by a doctor based on the patient's wishes at the terminal stage	Willing to draft AD (POLST)	71%

Table 2. Patients' willingness to engage in advance care planning or to draft an advance directive *(continued)*

No	First author	Year	Country	Type of patient	Conceptualization of AD	Patients' willingness to draft an AD	Percentage
8.	Park HY[33]	2019	South Korea	Patients with cancer (any stage)	Advance directives are statement that an adult could write about the determination of life-sustaining treatment and utilization of hospice at a terminal stage	Willing to draft an AD: a) In a healthy condition b) When diagnosed with serious illness c) When the terminal stage is difficult to predict d) When the condition of serious illness worsened e) When the terminal stage is easy to predict f) When diagnosed with terminal stage	a) 59% b) 69% c) 68% d) 73% e) 73% f) 74%
9.	Feng C[55]	2020	China	Patients with lung cancer (any stage)	Advance directives are legal documents in which people choose the medical treatments they are, or are not, willing to receive if in the future they lose the capacity to talk about their wishes	Willing to sign AD	80%
10.	Yoo SH[27]	2020	South Korea	Patients with advanced solid and/or hematologic cancer	Not defined	a) Willing to draft an AD: • among those who understand their illness • among those who don't understand their illness b) Willing to draft POLST • among those who understand their illness • among those who don't understand their illness	a) • 55% • 45% b) • 59% • 49%

ACP: advance care planning; AD: advance directive, CPR: cardiopulmonary resuscitation; HCPs: healthcare professionals; POLST: Physician order for life-sustaining-treatment; SD: standard deviation.
[a]Higher score indicates greater willingness.

to 31% of Asian patients preferred their family or physician to be the main decision maker in advance care planning.[24, 26, 28, 31, 37, 38]

Four studies compared preferred styles of decision-making, reporting a stronger preference for collective decision-making (i.e., patients together with their family and/or their physicians) than for individualistic decision-making: Japan (61% versus 33%),[24] South Korea (67% versus 27%),[24] China (48% versus 26%),[24] and Hong Kong (71% versus 21%).[38] These findings contrast with two studies among older people with serious illnesses in which individualistic decision-making was preferred: in Hong Kong (14% versus 55%)[37] and South Korea (32% versus 39%).[31]

Underlying motives for patients' willingness or unwillingness to engage in advance care planning

Twenty-two studies (eight quantitative, ten qualitative, and four mixed-method) examined patients' underlying motives for being willing or unwilling to engage in advance care planning. We summarized the quantitative data in Appendix 7 and further transformed them into qualitized data (Table 3). Our analysis of the qualitative data produced 29 qualitative codes (Appendix 8), five related to willingness, and 24 related to unwillingness to participate in advance care planning.

By integrating the qualitized and qualitative data, we developed seven integrated themes regarding patients' motives for willingness to engage in advance care planning (Table 3): (a) their belief that it would promote autonomy; (b) their belief that it would enable a comfortable end-of-life; (c) their belief that it would avoid burden on the family; (d) their belief that it would facilitate shared understanding between patient and family; (e) their past experiences with end-of-life or advance care planning; (f) their religious beliefs; and (g) their wish to follow their physician's recommendations.

Eleven integrated themes were developed as motives for patients' unwillingness to engage in advance care planning: (a) their lack of understanding of their illness; (b) their limited understanding of advance care planning; (c) their concerns about its implications; (d) their belief that it was not necessary or beneficial; (e) their uncertainty about its effectiveness in conveying their wishes; (f) their belief that healthcare professionals did not advocate advance care planning; (g) their belief that family did not support their engagement in it; (h) their belief that it went against their faith or religious beliefs; (i) their sense that the options for future care were limited; (j) their sense that it was not yet partially or fully supported by the

Table 3. Underlying motives for patients' willingness or unwillingness to engage in advance care planning

Motivational drivers for engagement in advance care planning			
Qualitized data	**Qualitative codes**	**Integrated themes**	**Conceptual framework variables**
Patients' belief that ACP would ensure their wishes to be respected[37] Patients' awareness of future incapacity[35, 56] Patients' wish to exercise self- determination[28, 35]	Patients' belief that ACP would promote autonomy[25, 42, 44, 57, 58]	**Patients' belief that ACP would promote autonomy**	**Behavioral beliefs**
Patients' belief that ACP would ensure a comfortable end of life[37] Patients' belief that quality of life is more important than length of life[37] Patients' belief that ACP would prevent them from the suffering due to meaningless treatment[28]	Patients' wish to have comfort near the end of their life[40, 57, 58]	**Patients' belief that ACP would enable a comfortable end of life**	
Patients' belief that ACP would avoid causing burden to the family with end of life decision[35, 37] Patients' belief that ACP would avoid burdening the society[37] Patients' wish to ease the economic burden on the family[28]	Patients' wish to avoid being a burden to their family[25, 42, 44, 57] or the society[47]	**Patients' belief that ACP would avoid causing burden to the family or society**	
Patients' belief that ACP would prevent conflict between family members[37] Patients wish that ACP would help family understand their wishes at an early stage[56]	Patients' belief that ACP would create connection with the family[42]	**Patients' belief that ACP would facilitate shared understanding between patient and family**	
Patients' experience with the death of a relative/ friend[37]	Patients' positive experience with ACP[45, 58]	**Patients' belief that ACP is beneficial after their experience with end of life or ACP**	
Patients' religious beliefs[37]		**Patients' religious beliefs**	**Normative beliefs**
Patients' wish to follow physician's recommendation for ACP[28]		**Patients' wish to follow physician's recommendation for ACP**	

Table 3. Underlying motives for patients' willingness or unwillingness to engage in advance care planning *(continued)*

Motivational drivers for non-engagement in advance care planning			
Qualitized data	**Qualitative codes**	**Integrated themes**	**Conceptual framework variables**
Patients' lack of knowledge of own disease state[30] Patients' concern of lacking the information needed for decision-making[55]	Patients' lack of illness understanding[25, 36, 44, 57]	**Patients' lack of illness understanding**	**Knowledge**
Patients' lack of awareness of AD[35, 37, 56] Patients' lack of knowledge about AD[30, 33] Patients' need of more information[38] Patients' lack of understanding of the policy[28] Patients' lack of idea on how to approach end of life communication[55]	Incomplete understanding / lack of awareness regarding ACP[41-44, 48, 50, 57, 58] Patients' lack of understanding of ACP relevance for planning beyond financial arrangements[43, 44]	**Patients' limited understanding of ACP**	
Patients' belief that ACP is not useful[56]	Patients inability to appreciate what intent of ACP[43, 50]	**Patients' belief that ACP is not necessary or beneficial**	**Behavioral beliefs**
Patients' belief that talking about ACP would make their relatives sad[55]	Patients' concern that ACP would cause distress or burden for family members[41, 42, 48, 50, 58] Patients' concern that ACP would cause conflict within their family members[44, 50, 58]	**Patients' concern of implications of ACP**	
Patients' concern of the psychological discomfort produced when thinking about a terminal illness[33] Patients' discomfort in talking about death[30] Patients' belief that talking about ACP would make them sad[55]	Patient's concern that they would feel uncomfortable discussing end of life issues / lose of hope[29, 41, 42]		
Patients' belief that drafting AD would mean giving up or result to being abandoned by the physicians[30] Patients' belief that signing AD would lead to bad things[30]	Patient's belief that discussing end of life would bring bad luck (taboo)[50, 58]		
Patients' uncertainty whether their wish would be respected[33]	Patients' doubted about the effectiveness of ACP in conveying their wishes[44]	**Patients' doubted about the effectiveness of ACP in conveying their wishes**	

Table 3. Underlying motives for patients' willingness or unwillingness to engage in advance care planning *(continued)*

Motivational drivers for non-engagement in advance care planning			
Qualitized data	**Qualitative codes**	**Integrated themes**	**Conceptual framework variables**
	Patients' belief that family does not support their engagement in ACP[43, 44, 47]	**Patients' belief that family does not support their engagement in ACP**	**Normative beliefs**
	Patients' belief that HCPs do not advocate ACP[41, 43]	**Patients' belief that HCPs do not advocate ACP**	
Patients' wish to let the nature take its course[37] Patients' religious beliefs[37]	Patients' wish to seek harmony with the mandate of nature[50] Patients' belief in providence[41, 44, 48, 50, 57, 58]	**Patients' belief that ACP goes against their faith / religious beliefs**	
Patients' concern of difficulties of making decisions in advance[38]	Patients' concern of difficulty in planning for the unknown / unpredictable disease course[25, 41, 45, 50]	**Patients' concern of difficulty in planning for the unknown**	**Control beliefs**
Patients' concern that their decision may change later[33, 37]	Patients' concern that their decisions may change in the future[29, 42]		
	Patients considered ACP irrelevant due to their socioeconomic dependency[25, 43, 44, 58]	**Patients' sense of limited options for future care**	
	Patients' belief of limited options available for them in the future care[25]		
	Patients' belief that limited care continuity hampers ACP[41] Patients' belief that time constraint from HCPs side hampers ACP[41]	**Patients' sense of the lack of healthcare supporting system for ACP**	
	Patients' belief that HCPs lack the communication skills and empathy for ACP[41]	**Patients' belief that HCPs lack the skills for ACP**	

Table 3. Underlying motives for patients' willingness or unwillingness to engage in advance care planning *(continued)*

Willingness to engage in ACP in particular approaches			
Qualitized data	**Qualitative codes**	**Integrated themes**	**Conceptual framework variables**
Patient act as sole primary decision maker in ACP[24, 28, 31, 37, 38]	Patient as independent decision maker in ACP[25, 42, 57, 58]	**Patients' preference for active involvement in decision-making, individually**	**Actors and roles**
Patient, together with family and/or HCPs, as decision maker in ACP[24, 31, 37, 38] Patients' wish to discuss with the family[28]	Patient, together with family and/or HCPs, as decision maker in ACP[42]	**Patient preference for active involvement in decision-making, together with the family and/or HCPs**	
Patients' wish to entrust decision-making to the relatives[30, 35, 37, 38, 55, 56] Patients belief the family will make the best decision on their behalf[33, 43]	Patients' wish to entrust decision-making to family members[25, 36, 41-44, 50, 57, 58]	**Patients' preference for passive involvement in decision-making**	
Patients' wish to entrust decision-making to the physicians[30, 35, 37, 55]	Patients' belief that the physicians would "do what is right"[41, 50, 57, 58]		
Patients' belief that there is no need to think about drafting an AD now[37] Patients' belief that it's too early for ACP[56] Patients' belief that ACP is not necessary in their current age[35] Patients' belief that it's not the right time yet[28] Patients' need of more time to think[28, 38]	Patients' belief that it's too early to engage in ACP[25, 50]	**Patients' preference of timing for initiation of ACP**	**Timing**
Patients belief that drafting an AD is important[24, 31, 34, 54]		**Patients' preference of ACP formality**	**Formality**
Patients' preference to further discuss with family[43]	Patients' belief that informal planning would suffice[29, 44, 57]		

ACP: advance care planning; AD: advance directive, HCPs: healthcare professionals.

healthcare system; and (k) their belief that healthcare professionals lacked the skills needed for advance care planning.

Conceptual framework for patients' willingness to engage in advance care planning

Next, we used these integrated themes to develop a conceptual framework organized on the basis of knowledge, beliefs, and willingness to engage in advance care planning (Figure 3). According to the Theory of Planned Behavior,[21] beliefs in advance care planning were further divided into three types: (a) behavioral beliefs in advance care planning (i.e., patients' beliefs regarding the likely consequences of engaging in advance care planning); (b) normative beliefs in advance care planning (i.e., the normative expectations of others regarding their engagement in advance care planning); and (c) control beliefs in advance care planning (i.e., the presence of factors that might facilitate or hinder their engagement in advance care planning).

Patients' knowledge. Patients who lacked awareness of their disease severity and prognosis[25, 30, 36, 44, 54, 57, 58] and/or knowledge regarding advance care planning.[27, 28, 30, 33, 35, 37, 38, 41-44, 48, 50, 54, 56-58] were less likely to engage in it. For instance, patients who had mistakenly understood that advance care planning

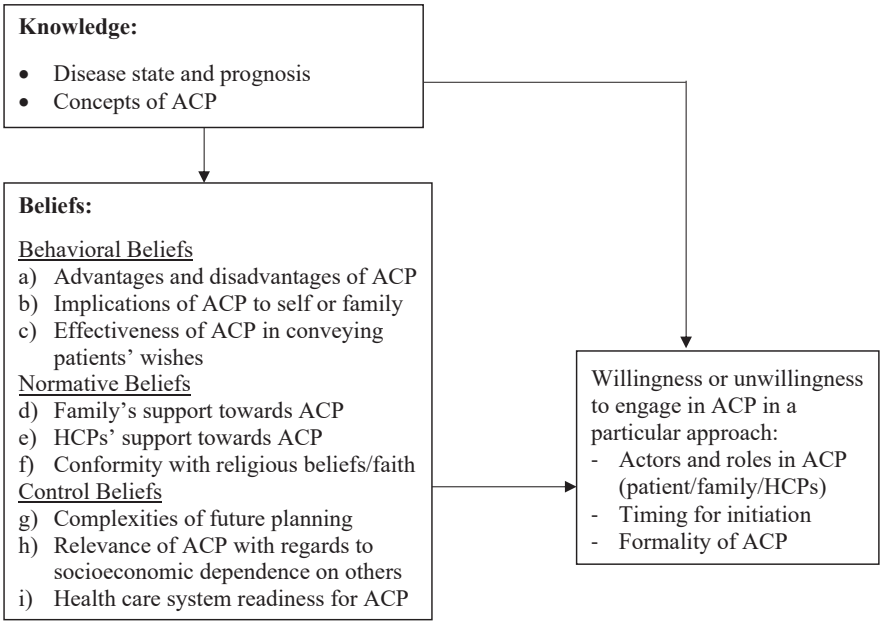

Figure 3. Conceptual Framework for Patients' Willingness to Engage in ACP.
ACP: advance care planning; HCPs: healthcare professionals.

was merely a discussion about financial arrangements decided not to engage in it if their planning was already sufficient or if they had no assets to plan for.[43, 44] Our model was based on the hypothesis that patients' beliefs and willingness to engage in advance care planning were influenced by their knowledge of its concept and of their illness.

Patients' behavioral beliefs about advance care planning. Studies reported that patients' beliefs about the benefits of advance care planning were important motivators of their engagement in it; such benefits include the belief that advance care planning promoted autonomy,[25, 28, 35, 37, 42, 44, 56-58] enabled a comfortable end-of-life,[28, 37, 40, 57, 58] avoided burdening family members, [25, 28, 35, 37, 44, 57] and facilitated shared understanding with family members.[37, 42, 56] Conversely, five groups of patients would be less likely to engage in advance care planning: (a) those who believed that it was not beneficial;[43, 56] (b) those who believed that engaging in it might cause conflict between their family members or distress to them[41, 42, 44, 48, 50, 54, 58] or to themselves;[29, 30, 33, 41, 42, 54] (c) those who believed that discussing death would bring bad luck;[30, 50, 58] (d) those who believed that signing the advance care planning document would lead to substandard care;[30] and (e) those who were not sure that it would guarantee their wishes were respected.[33, 44]

Patients' normative beliefs about advance care planning. We identified three normative components of beliefs pertaining to engagement in advance care planning. The first was related to family: patients who believed that their family did not support their engagement in advance care planning[43, 44, 47] would be less likely to engage in it. The second was related to healthcare professionals: patients would be less likely to engage in advance care planning if their physicians did not advise them to do so.[41, 43] The third was related to faith or religious belief. Seven studies found that patients' faith or spiritual beliefs were motives for non-engagement in advance care planning.[37, 41, 44, 48, 50, 57, 58] Like those who believed that their future was predetermined by God or their past actions and those who believed in the mandate of nature would be likely to accept what they regarded as their predetermined fate rather than attempting to take control of it or modify it through advance care planning.

Patients' control beliefs about advance care planning. Patients were particularly concerned about the complexities of advance care planning with regard to the difficulties of planning for the unknown[25, 38, 41, 45, 50] and the possibility of a future change of mind.[29, 33, 37, 42] As their socioeconomic dependency on others gave them

only limited options for future care, they were concerned that planning for various future scenarios might not be relevant to them.[25, 44, 58] Patients were also concerned that, as they had never had the chance to develop a long-term relationship with a healthcare professional that would make advance care planning possible, the healthcare system might not be supportive of it.[41] They were also concerned that healthcare professionals lacked the skills and empathy needed to engage in it.[41]

Patients' willingness or unwillingness to engage in advance care planning. Our data also shows that willingness or unwillingness depended on three factors: (a) which role people have in advance care planning; (b) when it is initiated; and (c) how formally it is carried out. Patients tended to expect one of the following: (a) active engagement that involved the patient with their family members and/or healthcare professionals;[24, 28, 31, 37, 38, 42] or (b) passive involvement in which they preferred to extend their autonomy and entrust decision-making to their family members or healthcare professionals.[25, 30, 33, 35-38, 41-44, 50, 54, 56-58] The motivations for entrusting decision-making to family included beliefs that: the family knew the appropriate decision for the patient,[41, 43, 44, 50] such decision making was the children's responsibility to the parents,[50] family would carry out the patient's wishes,[43] and the patients would have no control over future decision-making.[58] A further motivation was patients' experience of being treated well by the family.[25] A reason for entrusting decision-making to physicians was a belief that physicians would do what was best for the patient.[41, 50, 57, 58] Those who preferred to be their own primary decision maker were motivated by their doubts that the family would honor their wishes,[57] and by their expectation that they would be able to maintain control of their life.[25, 58]

Our findings also show that patients were willing to initiate advance care planning at a particular time in the future or later in the course of their illness.[25, 28, 33, 35, 37, 38, 50, 56] With regard to patients' preferences for documenting their conversations, our findings were varied: while some preferred a written document,[24, 31, 34, 51] others preferred verbal communication with their family and/or healthcare professionals without drafting or signing a written document.[29, 43, 44, 57]

DISCUSSION

To better understand Asian patients' perspectives on advance care planning and the motives underlying their willingness or unwillingness to engage in it, we systematically synthesized and integrated outcomes from different types of studies, and

then developed a conceptual framework on the basis of our findings. Most of these findings originated in high-income Asian countries. Acknowledging the limit we set to our search, the term 'Asian patients' we used to describe our findings refers to Asian patients in southern, southeastern, and eastern Asia. Our most important finding is that a majority of Asian patients agreed that advance care planning was necessary. The main motive for their engagement in it concerned its benefits, such as promoting autonomy, allowing a comfortable end of life, avoiding burden on family members, and facilitating shared understanding with family members. Conversely, a range of motives characterized those who were unwilling to engage in it: patients' lack of understanding of their disease, their misperceptions about advance care planning, and the following beliefs: that it was not beneficial, that it was potentially harmful, that it was not consistent with their religious beliefs or with the wishes of their family or healthcare professionals, and that there were various barriers to it. Our findings suggest that Asian patients would benefit from an individual approach with regard to the individual(s) who should communicate values or be present during advance care planning, the right time for initiating advance care planning conversations, and the formality of advance care planning.

Our study confirms previous findings suggesting that proper understanding of their illness (e.g., prognosis) is an important initial step to patients' realization of whether or not they would need further conversations on their goals and future care plan.[59, 60] The poor illness understanding identified in our study is likely to have been caused by limited truth-telling – a common aspect of communication with seriously ill patients in Asia,[6] which leads to their exclusion from conversations about poor diagnosis and prognosis. Healthcare professionals' tendency towards partial disclosure or non-disclosure is not compatible with most Asian patients' reported preference for truth-telling communication.[61-64] Our study thus provides further confirmation of the fact that clarifying patients' understanding of their illness (including prognosis) by encouraging truth-telling communication is an important prerequisite for engagement in advance care planning.

Our study also shows that Asian patients have only a limited understanding of what advance care planning entails. Three misperceptions of advance care planning are particularly common: that it is purely a financial planning process, a completion of a formal document, or a conversation related to death and dying. These may be due to the facts that advance care planning is a relatively new concept in Asia that is both complex and continuously evolving, various terms of legislation on advance directives in different countries and that there is little or no public education on it in Asia.[3, 65] Correcting these misperceptions whilst simultaneously taking proper

account of the Asian context – for example by engaging family members earlier – is central to the promotion of positive attitudes to it. A similar phenomenon has been reported by studies from non-Asian countries, which solidify the influence of participants' knowledge regarding advance care planning on its delivery across different cultures.[66-68]

Our earlier systematic review showed that Asian healthcare professionals rarely engaged patients in advance care planning and, in the event of disagreement between patients' advance directive and the family's wishes, would defer to the family.[6] However, it is clear from our current findings that a meaningful number of Asian patients expect and prefer active participation in advance care planning, either together with their families, or, to a lesser extent, individually. This suggests that the commonly stereotyped Asian values of passive or family-centered decision-making may in fact be too narrow, and, due possibly to modernization and globalization, that a shift may also be taking place towards more autonomous forms of decision-making.[69] This evidence further emphasizes the importance of avoiding East-West cultural stereotypes and of identifying individual patients' personal values and preferences for engaging in medical decision-making.

Other important motives for patients' willingness or unwillingness to engage in advance care planning are beliefs about its harms and benefits. Central to these beliefs is the motivation to protect oneself and one's loved ones from future suffering, whether (a) physical (such as that due to unwanted treatment in the absence of advance care planning, or to substandard treatment after signing an advance directive); (b) financial (such as that caused by economic burdens on the family); (c) social (such as that due to family conflict); or (d) psychological (such as the distress caused by decision-making as a surrogate or by loss of hope).

Our findings also suggest that certain normative beliefs play an important role in patients' engagement in advance care planning. Asian patients will favor advance care planning when it is in accordance with a physician's advice, families' wishes, or patients' religious beliefs about the end of life. Particularly in Asian collectivist culture, it is essential to seek harmony with others, including family members, society, and nature. While death is often regarded as God's will or the mandate of nature, discussing it openly may also be believed to cause bad luck. Open and honest communication on these beliefs and related concerns is therefore essential, not only to allow misperceptions or false beliefs to be corrected, but also to allow approaches to the topic that are more acceptable to a specific patient's personal

values. Acknowledging such beliefs is essential to facilitating an appropriate and patient-centered approach to advance care planning.

Our model also suggests that these beliefs have led to various preferences for role in advance care planning, one of which involves granting autonomy to their family or healthcare professionals, and thus allowing their own values to be communicated, and decisions to be made, by family or healthcare professionals. In this case, advance care planning should facilitate mutual understanding of patients' values. This would allow for the further translation of these values into relevant goals and preferences without limiting the context of conversations and the patient's eventual role in the process.

STRENGTHS AND LIMITATIONS

To the best of our knowledge, this is the first systematic review to explore Asian patients' perspectives on and willingness to engage in advance care planning, and also their underlying motives for this. As advance care planning is an emerging concept in Asia, our comprehensive conceptualization of it made it possible to conduct a sensitive search that did not necessarily use advance care planning as a search term, but nonetheless identified studies examining its relevant elements. The use of mixed-method systematic review enabled us to gain a deeper understanding of the findings by integrating different types of evidence from various types of studies.

When interpreting this systematic review, three main limitations should be taken into account. Firstly, our inclusion solely of studies published in English may have led valuable contributions to be excluded. However, we believe that our comprehensive search strategy, wide inclusion criteria, and mixed-method strategy enabled us to identify sufficient number of studies to answer our research questions. Secondly, there was a possibility of selection bias, as patients with a greater interest in advance care planning may have been more inclined to participate in the studies in question. Finally, our results may lack generalizability to low and middle-income Asian countries, other regions of Asia (i.e. northern, western and central Asia), and patients with mental disorders.

WHAT THIS REVIEW ADDS

Our study suggests the importance of developing a culturally sensitive model of advance care planning for Asia. Because decision-making in Asia is primarily family driven, advance care planning should focus on achieving a shared understanding of patients' values by encouraging open communications and establishing the connection between patients and their family. Our findings may also be relevant to the practice of advance care planning in Western countries, particularly when engaging patients or family members of Asian descent. Healthcare professionals who engage in advance care planning with patients of Asian origin should avoid stereotyping Asian collectivist culture and bear in mind that these patients may prefer active involvement in it. To facilitate a proper approach to advance care planning conversations, healthcare professionals should also familiarize themselves with various beliefs about advance care planning that are commonly found in Asian culture. With regard to these beliefs, our findings suggest that the focus of advance care planning conversations should be shifted from merely communicating care objectives towards exploring and establishing values, and thereby achieving truly value-concordant care. A separate review is currently underway and aims to explore whether the phenomenon in Asians living in foreign countries is comparable to our current findings and how acculturation may play role in it.[70]

CONCLUSION

The essential first steps towards engaging Asian patients in advance care planning involve a process of education and clarification, in which various misperceptions about their illness and prognosis are resolved, and it is clearly established what advance care planning entails. Advance care planning for Asian patients should be able to accommodate the diversity of patients' beliefs; their preferences with regard to their role in it, either as active participants, or by delegating responsibility to family members or healthcare professionals; decisions on the best time to initiate it; and decisions on formally documenting it.

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Appendix 1. Search strategies

Medline Ovid

(exp Advance Directives/ OR Resuscitation Orders/ OR ((Decision Making/ OR Communication/ OR Physician-Patient Relations/ OR Patient Preference/ OR Personal Autonomy/ OR Knowledge/) AND (Terminal Care/ OR Palliative Care/ OR Terminally Ill/OR Resuscitation/ OR Life Support Care/ OR Euthanasia/ OR Hospice/)) OR (((Advance) ADJ3 (plan* OR directive*)) OR ((living-will*)) OR ((decision* OR decid* OR plan OR plans OR planning OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice* OR communication OR talking OR disclos* OR autonom* OR attitude* OR practice* OR perspective*) ADJ6 (terminal* OR end of life OR palliativ* OR serious*-ill* OR severe*-ill* OR death OR dying OR advanced*-cancer* OR euthanas* OR hospice*)) OR ((do-not OR refus*) ADJ3 resuscit*) OR ((decision* OR decid* OR plan OR plans OR planning OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice* OR communication OR talking OR disclos* OR autonom* OR attitude* OR practice* OR perspective*) ADJ6 life ADJ (saving OR saver* OR sustain* OR resuscit* OR threat* OR support*))).ab,ti.) AND (Asia/ OR exp Asia, Southeastern/ OR exp Far East/ OR Asia, Western/ OR Bangladesh/ OR Bhutan/ OR exp India/ OR Nepal/ OR Pakistan/ OR Sri Lanka/ OR Asian Continental Ancestry Group/ OR (Asia* OR Afghan* OR Bangla* OR Bhutan* OR Borne* OR Brunei* OR Cambod* OR China* OR Chinese* OR India OR Indonesia* OR Japan* OR Korea* OR Laos* OR Laotion* OR Malaysia* OR Mongolia* OR Myanmar* OR Birmese* OR Birma OR Nepal* OR Pakistan* OR Papua* OR Philippin* OR Singapore* OR Sri-Lank* OR Taiwan* OR Thailand* OR Thai OR Timor* OR Viet-Nam* OR VietNam* OR mekong OR (eastern NOT ((middle OR mediterr* OR europe) ADJ3 eastern)) OR far-east).ab,ti,jn,cp.) NOT (exp Emigration and Immigration/ OR exp Tissue Donors/ OR exp Transients and Migrants/ OR exp transplantation/ OR (immigr* OR migrant* OR emigra* OR refugee* OR donor* OR donation OR transplant* OR chinese american* OR japanese american* OR korean american* OR asian american*).ab,ti.) NOT (letter* OR news OR comment* OR editorial* OR congres* OR abstract* OR book* OR chapter* OR dissertation abstract*).pt. AND english.la. NOT (exp child/ NOT exp adult/

Web of science

TS=(((((("Advance") NEAR/2 (plan* OR directive*)) OR ((living-will*)) OR ((decision* OR decid* OR "plan" OR "plans" OR "planning" OR preference* OR "want" OR wish* OR dilemma* OR refus* OR choos* OR choice* OR "communication" OR "talking" OR disclos* OR autonom* OR attitude* OR pratice* OR perspective*) NEAR/5 (terminal* OR "end of life" OR palliativ* OR serious*-ill* OR severe*-ill* OR death OR dying OR advanced*-cancer* OR euthanas* OR hospice*)) OR (("do-not" OR refus*) NEAR/2 resuscit*) OR ((decision* OR decid* OR "plan" OR "plans" OR "planning" OR preference* OR "want" OR wish* OR dilemma* OR refus* OR choos* OR choice* OR "communication" OR "talking" OR disclos* OR autonom* OR attitude* OR pratice* OR perspective*) NEAR/5 life NEAR/1 (saving OR saver* OR sustain* OR resuscit* OR threat* OR support*)))) AND ((Asia* OR Afghan* OR Bangla* OR Bhutan* OR Borne* OR Brunei* OR Cambod* OR China* OR Chinese* OR India OR Indonesia* OR Japan* OR Korea* OR Laos* OR Laotion* OR Malaysia* OR Mongolia* OR Myanmar* OR Birmese* OR Birma OR Nepal* OR Pakistan* OR Papua* OR Philippin* OR Singapore* OR Sri-Lank* OR Taiwan* OR Thailand* OR Thai OR Timor* OR Viet-Nam* OR VietNam* OR mekong OR ("eastern" NOT (("middle" OR mediterr* OR "europe") NEAR/2 "eastern")) OR far-east)) NOT ((immigr* OR migrant* OR emigra* OR refugee* OR donor* OR donation OR transplant* OR "chinese american*" OR "japanese american*" OR "korean american*" OR "asian american*")) NOT (child* NOT adult*))

Appendix 1. Search strategies *(continued)*

Embase.com

('living will'/exp OR (('patient decision making'/exp OR 'decision making'/de OR 'interpersonal communication'/exp OR 'doctor patient relation'/de OR 'patient information'/de OR 'patient preference'/de OR 'patient autonomy'/de OR 'personal autonomy'/de OR 'patient attitude'/de OR 'knowledge'/exp OR 'personal experience'/de) AND ('terminal care'/exp OR 'palliative therapy'/exp OR 'terminally ill patient'/exp OR 'terminal disease'/de OR 'life threat'/exp OR 'advanced cancer'/de OR resuscitation/de OR 'life sustaining treatment'/de OR euthanasia/de OR hospice/de)) OR (((Advance) NEAR/3 (plan* OR directive*)) OR ((living-will*)) OR ((decision* OR decid* OR plan OR plans OR planning OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice* OR communication OR talking OR disclos* OR autonom* OR attitude* OR pratice* OR perspective*) NEAR/6 (terminal* OR 'end of life' OR palliativ* OR serious*-ill* OR severe*-ill* OR death OR dying OR advanced*-cancer* OR euthanas* OR hospice*)) OR ((do-not OR refus*) NEAR/3 resuscit*) OR ((decision* OR decid* OR plan OR plans OR planning OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice* OR communication OR talking OR disclos* OR autonom* OR attitude* OR pratice* OR perspective*) NEAR/6 life NEXT/1 (saving OR saver* OR sustain* OR resuscit* OR threat* OR support*))):ab,ti) AND ('Asia'/de OR 'Asian'/de OR 'South Asian'/exp OR 'Southeast Asian'/exp OR 'Far East'/exp OR 'South Asia'/exp OR 'Japanese (people)'/exp OR 'Korean (people)'/exp OR 'Sino-Tibetan people'/exp OR (Asia* OR Afghan* OR Bangla* OR Bhutan* OR Borne* OR Brunei* OR Cambod* OR China* OR Chinese* OR India OR Indonesia* OR Japan* OR Korea* OR Laos* OR Laotion* OR Malaysia* OR Mongolia* OR Myanmar* OR Birmese* OR Birma OR Nepal* OR Pakistan* OR Papua* OR Philippin* OR Singapore* OR Sri-Lank* OR Taiwan* OR Thailand* OR Thai OR Timor* OR Viet-Nam* OR VietNam* OR mekong OR (eastern NOT ((middle OR mediterr* OR europe) NEAR/3 eastern)) OR far-east):ab,ti,ta,cy) NOT ('immigration'/exp OR 'donor'/exp OR 'migrant'/exp OR 'transplantation'/exp OR (immigr* OR migrant* OR emigra* OR refugee* OR donor* OR donation OR transplant* OR 'chinese american*' OR 'japanese american*' OR 'korean american*' OR 'asian american*'):ab,ti) NOT ([Conference Abstract]/lim OR [Letter]/lim OR [Note]/lim OR [Editorial]/lim) AND [english]/lim NOT (child/exp NOT adult/exp)

Google scholar (top 200 ranked)

"living will|wills"|"advance directive|directives"|"advance care planning|plans|plan" Asia|China|Chinese|India|Indonesia|Japan|Japanese|Korea -immigration -donor -migrant -transplantation -american

Appendix 2. Description of included studies

No.	First author (year)	Study Design	Country or region	Setting	Subjects	Number of participants	Element of ACP being studied	Term related to ACP studied
1.	Voltz R (1998) [26](a)	Cross sectional survey	Japan	Hospice or palliative care unit in hospital	Patients with terminal illness	34 (out of 252). Other participants: American and German patients and healthcare professionals from US and Germany	Discussion, documentation	Advance directive; end-of-life decision
2.	Htut Y (2007) [57]	In-depth (semi-structured) interview	Malaysia	Hospitals (4 outpatient clinic and 11 inpatient ward)	Elderly patients	15	Discussion, documentation	Advance care planning, advance directive
3.	Lee J (2010) [32]	Cross sectional survey	South Korea	Hospital	Patients with advanced lung cancer	30 patients (out of 124 participants). Other participants: family members, physicians, nurses	Documentation	Advance directive
4.	Chu LW (2011)[39]	Cross-sectional survey	Hong Kong	Long-term care facilities	Elders living in long-term care facility	1600	Documentation	Advance directive
5.	Ting FH (2011)[37]	Cross sectional survey	Hong Kong	Hospital (inpatient, acute wards)	Elderly in-patients with chronic diseases	219	Documentation	Advance directive
6.	Ivo K (2012) [24]	Cross-sectional survey	South Korea, Japan, China	Hospital	Seriously-ill patients with cancer	205: 91 (South Korea); 52 (Japan); 62 (China)	Documentation	Advance directive
7.	Keam B (2013) [34]	Cross-sectional survey	South Korea	Hospital	Patients with cancer (any stage)	1242 (out of 3840). Other participants: family caregivers, oncologists, and general public	Documentation	Advance directive
8.	Ni P (2014) [56]	Cross-sectional survey	China	Long-term care facilities	Elders living in long-term care facility	467	Documentation	Advance directive
9.	Cheong K (2015)[44]	Mixed method	Singapore	Hospital	Patients with early cognitive impairment	93	Discussion	Advance care planning

Appendix 2. Description of included studies *(continued)*

No.	First author (year)	Study Design	Country or region	Setting	Subjects	Number of participants	Element of ACP being studied	Term related to ACP studied
10.	Park SY (2015) [31]	Cross sectional survey	South Korea	Long-term care facilities	Elders living in long-term care facility	150 (out of 300). Other participants: elders living at home	Discussion, documentation	DNR decision, DNR order
11.	Hing Wong A (2016)[54]	Pre and post-test survey	Malaysia	Hospital	Patients on routine hemodialysis	58	Discussion	Advance care planning
12.	Hui EC (2016) [38]	Cross-sectional survey	Hong Kong	Hospital	Patients with solid cancer (any stage)	288 (149 palliative and 139 non-palliative)	Documentation	Advance directive
13.	Lee HTS (2016)[50]	In-depth interview	Taiwan	Long-term care facilities	Elders living in long-term care facility	11	Documentation	DNR directive
14.	Park J (2016) [35]	Cross-sectional survey	South Korea	Community centers and nursing homes	Elders living in long-term care facility	156	Documentation	Advance directive
15.	Zhang Q (2016)[52]	Cross sectional survey	China	Cancer center hospital (inpatient wards)	In-patients with solid cancer (any stage)	209 (out of 424). Other participants: family caregivers	Documentation	Advance directive
16.	Zheng RJ (2016)[51]	Cross-sectional survey	China	Cancer center hospitals (inpatient wards)	In-patients with solid cancer (any stage)	526	Documentation	Advance directive
17.	Hirakawa Y (2017)[25]	Semi-structured interview	Japan	Home care support	Elders requiring home care services	102	Discussion	End-of-life care decision
18.	Koh SJ (2017) [29]	Focus group interview	South Korea	General hospital (inpatient wards)	Elderly inpatients with major diseases	12 (out of 28). Other participants: family caregivers	Discussion, documentation	Advance care planning, advance directive
19.	Lo TJ (2017) [43]	Mixed-method	Singapore	Hospital	Patients with early cognitive impairment	158	Discussion	Advance care planning
20.	Sung HC (2017)[49]	Quasi-experimental	Taiwan	Long-term care facilities	Elders living in long-term care facility	57 (29 experimental and 28 control group)	Discussion	Advance care planning
21.	Hou XT (2018) [55]	Cross sectional survey	China	Cancer hospital	Patients with advanced cancer	264	Discussion	Advance care planning

Appendix 2. Description of included studies *(continued)*

No.	First author (year)	Study Design	Country or region	Setting	Subjects	Number of participants	Element of ACP being studied	Term related to ACP studied
22.	Menon S, 2018[42](a)	Focus group and individual in-depth interview	Singapore	Geriatrics or family medicine institutions	Patients with life-limiting illness	15 (out of 61). Other participants: family caregivers and healthcare professionals	Discussion	Advance care planning
23.	An HJ (2019) [30]	Cross sectional survey	South Korea	General hospitals	Patients with terminal cancer	336	Discussion, documentation	End-of-life decision-making, POLST
24.	Chan CWH (2019)[40]	Semi-structured interview	Hong Kong	Hospital	Patients with life-limiting illness	24 (out of 96). Other participants: healthcare professionals, patient's family members, volunteers	Discussion, documentation	Advance directive, AD-decision-making, AD discussion
25.	Cheng HB (2019)[36]	Mixed-method	Hong Kong	Palliative care clinic	Patients with non-cancer life limiting illness	119	Discussion, documentation	Advance directive, end-of-life decision-making
26.	Kim JW (2019)[28]	Cross-sectional survey	South Korea	Cancer center hospital	Patients with advanced solid cancer	101	Documentation	POLST
27.	Lin CP (2019) [47]	Semi-structured qualitative interview	Taiwan	Oncology unit	Patients with advanced cancer	15 (out of 45). Other participants: family caregivers, healthcare professionals	Discussion	Advance care planning
28.	Lee HTS (2019)[48]	Qualitative study (Action research)	Taiwan	Long-term care facilities	Elders living in long-term care facility	10 (out of 34). Other participants: family, medical staff	Discussion	Advance care planning
29.	Park HY (2019)[33]	Cross sectional survey	South Korea	Hospital (outpatient clinic)	Patients with cancer (any stage)	1001 (out of 4176). Other participants: family caregivers, physicians, and general public	Discussion, documentation	Advance care planning, advance directive

Appendix 2. Description of included studies *(continued)*

No.	First author (year)	Study Design	Country or region	Setting	Subjects	Number of participants	Element of ACP being studied	Term related to ACP studied
30.	Cheung JTK (2020)[41]	Focus group and individual semi-structured interview	Hong Kong	Palliative day care center	Patients with serious illness	17 (out of 30). Other participants: family caregivers	Discussion	Advance care planning
31.	Chou HH (2020)[46]	Cross-sectional survey	Taiwan	Hospital (Neurology clinic)	Patients with early cognitive impairment	260	Documentation	Advance directive
32.	Feng C (2020) [53]	Cross-sectional survey	China	Hospital outpatient clinic	Patients with lung cancer (any stage)	148 (out of 297). Other participants: family caregivers	Documentation	Advance directive
33.	Jiao NX (2020) [58]	Semi-structured interview	Malaysia	Long-term care facility	Elders living in long-term care facility	13	Discussion	End-of-life communication
34.	Kizawa Y(2020)[23]	Pilot randomized controlled trial	Japan	No restriction on the setting	Elderly patients with chronic disease	220	Discussion	Advance care planning
35.	Lin CP (2020) [45]	Mixed-method	Taiwan	Hospital	Patients with advanced cancer	10 (out of 29). Other participants: family members and healthcare professionals	Discussion	Advance care planning
36.	Yoo SH (2020) [27]	Prospective cohort study	South Korea	Academic hospitals	Patients with advanced solid and/or hematologic cancer	150: (out of 251). Other participants: family caregivers	Discussion, documentation	Advance directive, POLST

ACP: advance care planning; AD: advance directive; DNR: do-not-resuscitate; POLST: physician orders for life-sustaining treatment
[(a)]Studies including participants other than patients
[(b)]Multi-country study: US, Germany, Japan

Appendix 3. Quality assessment scores for included quantitative and mixed-method studies

No.	First author (year)	Objective	Study design	Subject selection	Subject characteristics	Random allocation	Blinding of investigator	Blinding of subjects	Outcome measures	Sample size	Analytic method	Estimate of variance	Control for confounding	Result	Conclusion	Total Sum	Summary score	Quality
1.	Voltz R (1998)[26](a)	2	1	1	1	N/A	N/A	N/A	1	1	1	1	N/A	1	0	10	0.50	Low
2.	Htut Y (2007)[57]	2	2	1	2	N/A	N/A	N/A	2	2	1	1	0	2	2	17	0.77	Good
3.	Lee J (2010)[32]	2	2	2	2	N/A	N/A	N/A	2	2	2	2	N/A	2	2	20	1.00	Strong
4.	Chu LW (2011)[39]	2	2	2	2	N/A	N/A	N/A	2	2	1	2	N/A	2	2	19	0.95	Strong
5.	Ting FH (2011)[37]	2	2	1	1	N/A	N/A	N/A	2	1	1	1	0	2	2	13	0.59	Adequate
6.	Ivo K (2012)[24]	2	2	2	1	N/A	N/A	N/A	2	2	2	2	2	2	2	21	0.95	Strong
7.	Keam B (2013)[34]	2	2	2	2	N/A	N/A	N/A	2	1	2	2	N/A	2	2	19	0.95	Strong
8.	Ni P (2014)[56]	2	1	1	2	N/A	N/A	N/A	1	0	1	1	0	1	1	11	0.50	Adequate[a]
9.	Cheong K (2015)[44]	2	2	2	2	N/A	N/A	N/A	1	2	2	0	0	2	1	16	0.73	Good
10.	Park SY (2015)[31]	2	1	1	1	N/A	N/A	N/A	1	0	2	0	N/A	2	2	12	0.60	Adequate
11.	Hing Wong A (2016)[54]	1	1	1	1	N/A	N/A	N/A	1	1	2	1	0	2	1	12	0.55	Adequate
12.	Hui EC (2016)[38]	2	2	1	1	N/A	N/A	N/A	1	1	2	2	N/A	1	2	15	0.75	Good
13.	Lee HTS (2016)[50]	2	2	1	2	N/A	N/A	N/A	2	0	2	2	N/A	1	2	16	0.80	Good
14.	Park J (2016)[35]	2	2	2	2	N/A	N/A	N/A	1	0	2	2	N/A	1	2	16	0.80	Good
15.	Zhang Q (2016)[52]	2	1	2	2	N/A	N/A	N/A	1	1	1	1	N/A	1	2	14	0.68	Adequate[a]
16.	Zheng RJ (2016)[51]	2	2	1	2	0	0	N/A	2	1	2	1	0	2	2	17	0.65	Adequate
17.	Hirakawa Y (2017)[25]	2	1	1	2	N/A	N/A	N/A	1	0	2	1	N/A	2	1	13	0.75	Good
18.	Koh SJ (2017)[29]	2	1	1	2	N/A	N/A	N/A	2	1	1	0	N/A	1	1	12	0.60	Adequate
19.	Lo TJ (2017)[43]	2	1	1	1	N/A	N/A	N/A	2	1	2	1	N/A	2	2	16	0.8	Good[a]
20.	Sung HC (2017)[49]	2	2	1	2	N/A	N/A	N/A	1	1	2	1	0	2	2	16	0.73	Good

Appendix 3. Quality assessment scores for included quantitative and mixed-method studies *(continued)*

No.	First author (year)	Objective	Study design	Subject selection	Subject characteristics	Random allocation	Blinding of investigator	Blinding of subjects	Outcome measures	Sample size	Analytic method	Estimate of variance	Control for confounding	Result	Conclusion	Total Sum	Summary score	Quality
21.	Hou XT (2018)[55]	2	2	2	2	N/A	N/A	N/A	2	2	2	2	2	2	2	22	1.00	Strong
22.	Menon S, 2018[42](a)	2	2	1	1	N/A	N/A	N/A	1	1	1	1	1	1	1	13	0.50	Low
23.	An HJ (2019)[30]	1	2	0	2	N/A	N/A	N/A	1	1	2	0	N/A	1	2	12	0.6	Adequate
24.	Chan CWH (2019)[40]	2	2	2	1	1	1	0	1	2	2	2	1	2	2	21	0.75	Good
25.	Cheng HB (2019)[36]	2	2	2	1	N/A	N/A	N/A	2	1	2	2	N/A	2	2	18	0.93	Strong[a]
26.	Kim JW (2019)[28]	2	2	1	2	N/A	N/A	N/A	1	1	2	2	N/A	2	2	17	0.85	Strong

N/A: not applicable.

[a]Mixed-method study: summary score is the sum of quality assessment scores for qualitative and quantitative divided by two.

Appendix 4. Quality assessment scores for included qualitative and mixed-method studies

No.	Author (Reference)	Objective	Study design	Context of the study	Theoretical framework	Sampling strategy	Data collection	Data analysis	Verification procedure	Result and conclusion	Reflexivity of the account	Total sum	Summary Score	Quality
1.	Htut Y[57]	2	2	2	0	1	2	1	2	2	0	14	0.70	Adequate
2.	Cheong K[44]*	2	1	2	1	2	1	2	2	2	0	15	0.75	Adequate[a]
3.	Lee HTS[50]	2	2	2	1	2	2	2	2	2	2	19	0.95	Strong
4.	Hirakawa Y[25]	2	2	2	1	1	2	2	2	2	0	16	0.80	Good
5.	Koh SJ[29]	1	2	2	1	1	2	2	0	1	0	12	0.60	Adequate
6.	Lo TJ[43]*	2	1	2	1	1	1	2	2	1	0	13	0.68	Adequate[a]
7.	Menon S[42]	2	2	2	1	2	2	2	2	2	0	17	0.85	Strong
8.	Chan CWH[40]	2	2	1	1	2	0	1	0	2	0	11	0.55	Adequate
9.	Cheng HB[36]	2	1	2	0	1	2	0	0	2	0	10	0.8	Good[a]
10.	Lin CP[47]	2	2	2	1	2	2	2	2	2	1	18	0.90	Strong
11.	Lee HTS[48]	2	2	2	2	2	2	2	2	2	0	18	0.90	Strong
12.	Cheung JTK[41]	2	1	2	1	2	2	2	2	2	0	16	0.80	Good
13.	Jiao NX[58]	2	2	2	0	1	1	1	2	2	0	13	0.65	Adequate
14.	Lin CP[45]*	2	2	2	2	1	2	2	2	2	2	19	0.95	Strong[a]

N/A: not applicable.

[a]Mixed-method study: summary score is the sum of quality assessment scores for qualitative and quantitative divided by two.

Appendix 5. Asian patients' agreement with the importance of advance directive

No	First author	Year	Country/Region	Type of patients	Asian patients' perspectives on their agreement with importance of advance directives	Percentage
1.	Ivo K[24]	2012	South Korea, China, Japan	Seriously-ill patients with cancer	Agree with the importance of AD	South Korea: 85%; China: 80%; Japan: 96%
2.	Park SY[31]	2015	South Korea	Elders living in long-term care facility	Agree with the potential importance of DNR order	87%
3.	Keam B[34]	2013	South Korean	Patients with cancer (any stage)	Agree with the importance of AD	93%
4.	Hing Wong A[54]	2016	Malaysia	Patients on routine hemodialysis	Agree with the importance of AD	75%
5.	Zhang Q[52]	2016	China	Patients with cancer	Agree with the importance of AD Disagree with the importance of AD	74% 26%
6.	Zheng RJ[51]	2016	China	In-patients with solid cancer (any stage)	Agree with the importance of AD Disagree with the importance of AD	22% 78%
7.	Chou HH[46]	2020	Taiwan	Patients with early cognitive impairment	Agree with the importance of AD	77%

AD: advance directive; DNR: do-not-resuscitate.

Appendix 6. Patients' perspectives on the decision maker in advance care planning

No	First author	Year	Country	Type of patient	Patients' perspectives on decision maker in ACP	Major findings
1.	Voltz R[26]	1998	Japan	Patients with terminal illness	Family	29%
2.	Lee J[32]	2010	South Korea	Patients with advanced lung cancer	a) Patient b) Patient and family c) Family	a) 27% b) 63% c) 10%
3.	Ting FH[37]	2011	Hong Kong	Elderly in-patients with chronic diseases	a) Patient a) Patient, family, and physician	a) 55% a) 14%
4.	Ivo K[24]	2012	South Korea, China, Japan	Seriously-ill patients with cancer	b) Patient c) Patient and family d) Patient and physician e) Patient, family, and physician f) Family g) Physician	b) 27% (South Korea); 26% (China); 33% (Japan) c) 40% (South Korea); 37% (China); 49% (Japan) d) 6% (South Korea); 11% (China); 8% (Japan) e) 21% (South Korea); 0 (China); 4% (Japan) f) 3% (South Korea); 18% (China); 4% (Japan) g) 2% (South Korea); 8% (China); 2% (Japan)
5.	Park SY[31]	2015	South Korea	Elders living in a long-term care facility	a) Patient b) Patient and family c) Family and physician d) Other	a) 39% b) 32% c) 25% d) 4%
6.	Hui EC[38]	2017	Hong Kong	Patients with solid cancer (any stage)	a) Patient b) Patient and family c) Patient and physician d) Patient, family, and physician e) Family and physician f) Physician g) Family	a) 21% b) 13% c) 3% d) 55% e) 3% f) 4% g) 1%
7.	Kim JW[28]	2020	South Korea	Patients with advanced solid cancer	a) Patient b) Family c) Physician	a) 51% b) 21% c) 18%

ACP: advance care planning

Appendix 7. Underlying motives for patients' willingness or unwillingness to engage in ACP (Quantitative data)

No	First author	Year	Country	Type of patient	Motives for patient's willingness to engage in ACP	Percentage
1.	Ting FH[37]	2011	Hong Kong	Elderly in-patients with chronic diseases	a) Patients' belief that ACP would ensure comfortable end-of-life b) Patients' belief that ACP would avoid causing burden to the family c) Patients' belief that ACP would ensure their wishes will be respected d) Patients' belief that ACP would prevent conflict between family members e) Patients' experience with the death of a relative/friend f) Patients' belief that ACP would avoid causing burden to the society g) Patients' belief that quality of life is more important than the length of life h) Patients' religious beliefs	a) 71% b) 39% c) 35% d) 14% e) 9% f) 8% g) 8% h) 4%
2.	Ni P[56]	2014	China	Elders living in long-term care facility	a) Patients' wish to make AD when they are still cognitively intact b) Patients' wish that ACP would help the family understand their wishes at an early stage	a) 44% b) 39%
3.	Park J[35]	2016	South Korea	Elders living in long-term care facility	a) Patients wish to avoid causing a burden to the family with end-of-life decisions b) Patients' wish to decide for themselves c) Patients' belief of the possibility of incapacity due to their illness	a) 61% b) 61% c) 54%
4.	Kim JW[28]	2020	South Korea	Patients with advanced solid cancer	a) Patients' wish to exercise self-determination b) Patients' wish to follow physician's recommendation c) Patients' belief that ACP would prevent them from suffering due to meaningless treatment d) Patients' wish to ease the economic burden on the family	a) 39% b) 35% c) 26% d) 13%

Appendix 7. Underlying motives for patients' willingness or unwillingness to engage in ACP (Quantitative data) *(continued)*

No	First author	Year	Country	Type of patient	Motives for patient's unwillingness to engage in ACP	Percentage
1	Ting FH[37]	2011	Hong Kong	Elderly in-patients with chronic diseases	a) Patients' wish to entrust decision-making to the relatives b) Patients' belief to let nature take its course c) Patients' belief that there is no need to think about drafting an AD now d) Patients' wish to entrust decision-making to the physicians e) Patients' belief that they may want to change their decision later f) Patients' belief that they are not familiar with the concept of AD g) Patients' religious beliefs	a) 39% b) 25% c) 23% d) 13% e) 3% f) 3% g) 2%
2	Ni P[56]	2014	China	Elders living in a long-term care facility	a) Patients' lack of awareness about AD b) Patients' wish to entrust decision-making to the family c) Patients' belief that ACP is not useful even when it is completed d) Patients' belief that it is too early for ACP	a) 66% b) 23% c) 6% d) 3%
3	Park J[35]	2016	South Korea	Elders living in a long-term care facility	a) Patients' wish to entrust decision-making to the family b) Patients' wish to entrust decision-making to the physician c) Patients' belief that ACP is not necessary for their current age d) Patients' lack of knowledge regarding ADs	a) 67% b) 60% c) 44% d) 30%
4	Hui EC[38]	2017	Hong Kong	Patients with solid cancer (any stage)	a) Patients' belief that it is difficult to make such medical decisions before it happens b) Patients' belief that they need more information and time for ACP c) Patients' wish to entrust decision-making to the family	a) 72% b) 55% c) 53%
5	Hou XT[55]	2018	China	Patients with advanced cancer	a) Patients' wish to entrust decision-making to the relatives b) Patients' wish to entrust decision-making to their physicians c) Patients' belief that talking about ACP would make their relatives sad d) Patients' belief that talking about ACP would make them sad e) Patients' belief that they do not have enough information needed for decision-making f) Patients' belief that they have a lack of understanding of how to approach end-of-life communication	a) 31% b) 29% c) 23% d) 19% e) 19% f) 17%

Appendix 7. Underlying motives for patients' willingness or unwillingness to engage in ACP (Quantitative data) *(continued)*

No	First author	Year	Country	Type of patient	Motives for patient's unwillingness to engage in ACP	Percentage
6	An HJ[30]	2019	South Korea	Patients with terminal cancer	a) Patients' belief that they have lack knowledge about AD b) Patients' belief that drafting AD would mean giving up or result in being abandoned by the physicians c) Patients' belief that signing AD would lead to bad things d) Patients' discomfort in talking about death e) Patients wish to entrust decision-making to the family f) Patients' wish to entrust decision-making to the physician g) Patients' lack of understanding/denial of their prognosis	a) 65% b) 30% c) 44% d) 30% e) 44% f) 35% g) 14%
7	Park HY[33]	2019	South Korea	Patients with cancer (any stage)	a) Patients' belief that they may change their mind in the future when facing the real situation b) Patients belief that ACP would cause psychological discomfort c) Patients' belief that their wish would not be respected d) Patients' belief that they have a lack of understanding about AD e) Patients' belief that the family will make the best decision on their behalf	a) 22% b) 22% c) 21% d) 13% e) 12%
8	Kim JW[28]	2020	South Korea	Patients with advanced solid cancer	a) Patients' belief that they need to further discuss with the family b) Patients' belief that they require more time prior to completion of ACP documentation c) Patients' belief it is too early for ACP d) Patients' belief that they have a lack of understanding of local policy	a) 38% b) 28% c) 21% d) 17%

ACP: advance care planning; AD: advance directive.

Appendix 8. Motives for patients' willingness or unwillingness to engage in advance care planning (Qualitative data)

No	Motives for patient's willingness to engage in ACP	Related findings or quotes	Number of studies (References)
1.	Patients' belief that ACP would promote autonomy	*"I want to manage my life on my own until the end"*	5 [25, 42, 44, 57, 58]
2.	Patients' wish to have comfort near the end of their life	*"Don't wake me up when I die. Just imagine when you wake up, you might find yourself paralyze. What's the point of living when paralyzed? You're only surviving for your friends and love ones. I don't want that, that's suffering"*	3 [40, 57, 58]
3.	Patients' wish to avoid being a burden to their family	*"If I develop severe dementia, I would like to be institutionalized to avoid becoming a burden on my wife"*	4 [25, 42, 44, 57]
4.	Patients' belief that ACP would create a connection with the family	Patients thought they could get closer to their families, made it easier for their caregivers to look after them, and gave them the opportunity to fulfill their wishes	1 [42]
5.	Patients' experience with ACP	*"Finally ... it is a form of relief. At last, I can speak up openly. Thank you for giving me this chance. I suppose it was not that hard to open up about this topic. I want to find some time to discuss this with my family"*	2 [45, 58]
No	**Motives for patient's unwillingness to engage in ACP**	**Related findings or quotes**	**Number of studies (References)**
1.	Patients' lack of illness understanding	The majority of them did not seem to understand the gravity or seriousness of their illness. For instance, a fairly educated gentleman with severe chronic obstructive airway disease, who was recently admitted to the high dependency unit, stated that he was very hopeful and very optimistic of making a complete recovery	4 [25, 36, 44, 57]
2.	Incomplete understanding/lack of awareness regarding ACP	Lack of awareness of early discussion A patient believed that she could not participate in ACP discussion, because she would not be able to do so at the end-of-life stage *"At that moment (end of life) I am already...how can I make a decision? I will leave it to my family for sure"*	8 [41-44, 48, 50, 57, 58]
3.	Patients' lack of understanding of ACP relevance for planning beyond financial arrangements	Patients who claimed to "have no property" to plan for and only "relied on children's monthly contribution" for their living expenses also did not complete advance care plans as they failed to appreciate the need for ACP beyond financial concerns Patient (53) thought that *"it is important to complete ACP but thinks he does not have much assets to worry"*, while patient (51) reported that *"she has little property and finances, so no immediate need [for ACP]"*	2 [43, 44]
4.	Patient's concern that they would feel uncomfortable discussing end-of-life issues/loss of hope	Patients were concerned that discussions about end-of-life matters may cause them to become sad or fearful *"When I was healthy, I sometimes thought about it, but I don't think it is necessary, and I feel sad…. I just don't want to talk about it ever since I became sick"*	3 [29, 41, 42]

Appendix 8. Motives for patients' willingness or unwillingness to engage in advance care planning (Qualitative data) *(continued)*

No	Motives for patient's unwillingness to engage in ACP	Related findings or quotes	Number of studies (References)
5.	Patients' concern that ACP would cause distress for family members	Patients were concerned that the ACP may burden family members who had problems of their own to manage *"Death is just death…why should I worry right now? If I talk to my family about end-of-life care…it will seem that I am threatening my family and making them feel sorrow…I don't want to do this"*	5 [41, 42, 48, 50, 58]
6.	Patients' concern that ACP would cause conflict within their family members	Patient (3) shared that "she is wary about doing (advance directive) as she is worried that it will cause conflict between her two sons", whereas patient (75) expressed "she does not want her children to be unhappy that she is 'playing favorites' by appointing certain children as 'done'"	3 [44, 50, 58]
7.	Patient's belief that discussing end-of-life would bring bad luck (*taboo*)	Not wanting to cause problems, no participant wanted to discuss death or end-of-life care with family. Most of the participants and their children believed that discussing end-of-life-care-related concerns would bring them bad luck *"No, [frown] in fact this kind of issue (end-of-life planning) shouldn't be discussed openly as it is a taboo subject and not something we can discuss openly. I can't tell you why, but like I said just now, you can't simply open-up and discuss this thing. You might not know, something bad might happen after the discussion"*	2 [50, 58]
8.	Patients inability to appreciate what intent of ACP	*"It is unnecessary and ridiculous for me to think about whether to receive CPR or not…or…what kind of care I want to have at the end of life right now…the only thing I want to do right now is to live here happily and smoothly"*	2 [43, 50]
9.	Patients' doubted the effectiveness of ACP in conveying their wishes	Patient (54) reported he was "not keen to consider ACP as he has reservations and lack of trust over wife and children's abilities to follow his wishes"	1 [44]
10.	Patients' belief that HCPs do not advocate ACP	*"The consultant told me if I received the treatment then my life could be extended for 2 months. If not, my life would be shortened for 2 months … At that time, I didn't want to receive (the treatment). But eventually I received the treatment three times. Later, he said I could continue to undergo the treatment. The more treatments I received, the more sluggish I was. I asked whether I could quit. The consultant questioned me, "Really?"… And in the next consultation, the doctor told me, I could keep receiving treatment in view of my condition … He asked 'How about getting the treatment again?'"*	2 [41, 43]
11.	Patients' belief that family does not support their engagement in ACP	*"In my experience, you are concerned mainly about your family's opinions [when you make a decision] rather than your own opinions at the end of life. (PT15: 57 y/o lung cancer female)"*	3 [43, 44, 47]
12.	Patients' wish to seek harmony with the mandate of nature	Furthermore, they expressed that death is a natural event and that a human must seek harmony with nature rather than try to change it *"I don't want to think or talk too much about end-of-life care…just let it happen naturally…everything must follow the mandate of nature… just as that tree outside the window accepts its situation from nature without questioning"*	1 [50]

Appendix 8. Motives for patients' willingness or unwillingness to engage in advance care planning (Qualitative data) *(continued)*

No	Motives for patient's unwillingness to engage in ACP	Related findings or quotes	Number of studies (References)
13.	Patients' belief in providence	*"Let me tell you…when you will die and how to die… these things have been decided already by what you have done in present and past lives…it is really complex…we may never be able to understand the language of providence"*	7 [41, 44, 48, 50, 57, 58]
14.	Patients' concern that their decisions may change in the future	*"I don't want to discuss or decide in advance because nobody knows what will happen in the future. New treatment could be introduced in the future, and I may change my mind even…."*	2 [29, 42]
15.	Patients' concern of difficulty in planning for the unknown/ unpredictable disease course	*"I have no idea about things related to end-of-life care or signing DNR papers…they are too complex for me to make decisions by myself without their [my children's] permission…so, please ask my children…they are smarter than I am, and they can make any decision for me by themselves"*	4 [25, 41, 45, 50]
16.	Patients considered ACP irrelevant due to their socioeconomic dependency	She leaves long-term planning to her niece's family as she does not have the resources to plan for herself and trusts them to make plans for her	4 [25, 43, 44, 58]
17.	Patients' belief of limited options available for them in the future care	*"I think I would have no choice but to be institutionalized in the future, just as my sister was"*	1 [25]
18.	Patients' belief that limited care continuity hampers ACP	Under the healthcare system of Hong Kong, patients usually are seen by different doctors across visits in the same clinical settings. They could hardly develop a long term relationship and have continual communication with the same doctors. This might also prevent continual ACP discussion *"Consultations are delivered by different doctors. It is not the same person every time"*	1 [41]
19.	Patients' belief that time constraint from HCPs side hampers ACP	*"I want to know the diagnosis and prognosis. I want to know what will happen if the condition keeps worsening. But doctors (in acute setting) were really too busy. He (doctor) talked with me in the corridor. That's depressing."*	1 [41]
20.	Patients' belief that HCPs lack the communication skills and empathy for ACP	*"A doctor yelled "if you don't receive the treatment you will die" (in an oncology inpatient setting). From the perspective of patients, such words will make us feel down. So I think doctors, I don't know the reasons, but I think as a professional, the best way to communicate is not to say those words to a person in need … Sometimes their words are discouraging."*	1 ([41]
21.	Patients' wish to entrust decision-making to family members	*"Ideally, these end-of-life decisions should be left with your family, because they know your wishes and can fulfil them in the way you want when your life ends. [Laugh] Die in your own way ... You see, we can prepare and cope with the cycle of life, from birth, growing old and sickness, but when it comes to death how many of us are able to die in our own way? [Frown] No .. . your body might belong to you, but how you die and what happens next is for others, especially your family"*	9 [25, 36, 41-44, 50, 57, 58]

Appendix 8. Motives for patients' willingness or unwillingness to engage in advance care planning (Qualitative data) *(continued)*

No	Motives for patient's unwillingness to engage in ACP	Related findings or quotes	Number of studies (References)
22.	Patients' belief that the physicians would "do what is right"	*"Doctors are professionals…if doctors think I can't be saved…just let me die soon…if doctors think I will have the chance to live longer…let me have CPR…I have told my children that they need to trust doctors' ability and follow their orders without question"*	4 [41, 50, 57, 58]
23.	Patients' belief that informal planning would suffice	*"I already talked to my children about how I want to be treated and to spend the rest of my life."*	3 [29, 44, 57]
24.	Patients' belief that it is too early to engage in ACP	*"Because…I am healthy presently and too young to think about issues related to death or end-of-life care… would you please not talk about these issues until I am more than 70 years old?"*	2 [25, 50]

ACP: advance care planning; CPR: cardiopulmonary resuscitation; DNR: do-not-resuscitate; HCPs: healthcare professionals.

Part II

Advance Care Planning in Indonesia

Chapter 6

Opportunities and Challenges for Advance Care Planning in Strongly Religious Family-Centric Societies: A Focus Group Study of Indonesian Cancer-Care Professionals

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ABSTRACT

Background: Most studies on advance care planning in Asia originate in high-income Asian countries. Indonesia is a middle-income Asian country characterized by its religious devoutness and strong family ties. This study aims to explore the perspectives and experiences of Indonesian healthcare professionals on advance care planning for cancer patients.

Methods: Focus-group discussions were conducted in July and August 2019 and were analyzed using thematic content analysis enhanced by dual coding and exploration of divergent views. Purposive sampling of physicians and nurses actively engaged in cancer care in a national cancer center and a national general hospital.

Results: We included 16 physicians and 16 nurses. These participants were open to the idea of advance care planning. We further identified four aspects of this planning that the participants considered to be important: 1) the family's role in medical decision-making; 2) sensitivity to communication norms; 3) patients' and families' religious beliefs regarding the control and sanctity of life; and 4) the availability of a support system for advance care planning (healthcare professionals' education and training, public education, resource allocation, and formal regulation). Participants believed that, although family hierarchical structure and certain religious beliefs may complicate patients' engagement in advance care planning, a considerate approach to involving family and patients' religious perspectives in advance care planning may actually facilitate their engagement in it.

Conclusion: Indonesian healthcare professionals believed that, for culturally congruent advance care planning in Indonesia, it was essential to respect the cultural aspects of collectivism, communication norms, and patients' religious beliefs.

Keywords: advance care planning, oncology, Asia, culture, spirituality, health personnel

INTRODUCTION

Advance care planning is a process in which patients reflect upon the meanings and consequences of serious illness. It enables them to identify their values, and define their goals and preferences for future care, and discuss them with their family and healthcare professionals.[1] A recent review of studies from Western countries showed that it improves patients' and surrogates' satisfaction with communication, and reduces surrogates' and clinicians' distress.[2]

Interest and research in advance care planning have been growing not only in Western countries,[3] but also in Eastern ones.[4-6] Our review on advance care planning in southern, south-eastern, and eastern Asian countries showed that even though Asian healthcare professionals acknowledge its importance, and are willing to engage in it, they find it very challenging to do so.[7] However, while most research on advance care planning in Asia has been conducted in high-income countries,[3, 8] few studies have examined it in low and middle-income Asian countries, including Indonesia.[8]

Indonesia is the fourth most populous country in the world whose incidence of cancer has increased 29% over the last five years since 2013.[9] Seventy percent of these patients are at an advanced stage, where advance care planning is especially important to enabling their autonomy at the end of life.[9] However, the uptake of advance care planning may be influenced by Indonesia's culture of collectivism, in which family plays a major role in medical decision-making.[10, 11] In addition to this, it may be further influenced by most Indonesian people's religious devotion.[11-15]

A recent survey among the general population showed that 75% of Indonesians were willing to engage in end-of-life care conversations, and 60% of them expected healthcare professionals to initiate it.[16] However, a study on the actual use of advance care planning and the potential facilitators and challenges faced by healthcare professionals has not been performed in Indonesia. This study therefore aimed to better understand Indonesian healthcare professionals' perspectives on and experiences with advance care planning in oncology care by conducting exploratory focus-group discussions.

METHODS

Study Design

Focus-group discussions were conducted to enable active interaction between participants and to stimulate clarification of views and sharing of various perspectives on and experiences with advance care planning that might otherwise be less evident in the context of individual interviews.[17] The interpretative phenomenological analysis approach was used to study how phenomena appear to the subject and how his or her experience is established.[18] Reporting was guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ).[19]

Study setting

The study was conducted in the only national cancer centre in Indonesia and in a top-referral academic general hospital, both situated in Jakarta, the capital city of Indonesia.

Sampling and recruitment

Physicians and nurses who were actively engaged in the treatment and care of patients with cancer were invited to participate. To capture the diversity of clinical specialties, age, and gender, participants were then purposively sampled. Participants at Dharmais National Cancer Centre were selected and invited by RD, and participants at Cipto Mangunkusumo National General Hospital by DM. Specific inclusion criteria included: (1) experience for at least five years with the provision of care to patients with cancer, and (2) the provision of informed consent.

Focus-group discussions and data collection

All focus-group discussions were moderated by DM (Indonesian female researcher and physician specializing in internal medicine and palliative care, trained in performing qualitative studies), who also encouraged group members to exchange opinions. The discussions were observed and recorded by RD (Indonesian female physician specialized in psychiatry and palliative care, experienced in qualitative studies), who also made additional notes based on her observations.

Before starting these discussions, we developed a topic guide based on our systematic reviews of advance care planning in Asia[5, 7] and on consultation of various experts on palliative and cancer care, with backgrounds in medical oncology, palliative care, research, and psychology. The focus-group topic guide (Appendix 1) addressed: (1) an introduction to the study; (2) participants' prior knowledge of advance care planning; (3) participants' perspectives on advance care planning; (4) whether and how

advance care planning was practiced at participants' current workplace, and their ideas about it; and (5) barriers and facilitators for advance care planning. Due to the lack of an Indonesian term for or concept of advance care planning, the concept used in this study was consistent with the international consensus definition of the European Association for Palliative Care: "a process that enables individuals with decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and healthcare professionals, and to record and review these preferences if appropriate."[1]

Data Processing and Analysis

All discussions were audio-recorded and transcribed verbatim in Indonesian, the official language at the study sites, by DM and RD. DM and CYK (Indonesian female nurse and researcher, trained and experienced in qualitative studies, and fluent in English) then analysed the data following the inductive thematic analysis approach.[20] First, DM and CYK familiarized themselves with the data by reading the transcripts several times before identifying ideas. Second, DM and CYK independently generated initial codes by allocating codes to these ideas. Third, DM and CYK independently grouped the codes under broader themes. To achieve consensus, the generation of codes and themes was followed by discussions between DM and CYK. To enhance the validity and confirmability of the findings, we performed investigator triangulation (DM, CYK, CE, JR, AH, and CR), by translating codes and themes into English to facilitate the discussions with the non-Indonesian-speaking co-authors (JR, AH and CR). Prior to these discussions, DM and CYK selected two transcripts based on the richness, had them translated into English by a professional translator, and shared them with JR, AH, and CR. In the fourth phase, meetings were held between DM, CYK, CE, JR, AH, and CR to review the themes and ensure each theme had a specific identity. All of these processes were iterative and reflective, developing over time and involving a constant moving back and forward between phases. To assist in data management, N-Vivo qualitative data analysis software (version 12) was used.

RESULTS

Participants' Demographics

We included 16 nurses and 16 physicians and held five focus-group discussions between July and August 2019. We conducted two focus-group discussions in Dharmais (one with seven physicians and one with eight nurses); and three in Cipto Mangunkusumo: (one with four physicians, one with five physicians and one with

Table 1. Characteristics of the participants

	Physicians (N=16)	Nurses (N=16)
Sex		
Male	10	5
Female	6	11
Age (years)		
<40	6	14
40-60	9	1
>60	1	1
Specialty		
Medical oncology	3	
Surgical oncology	2	
Neuro-oncology	1	
Pulmonology	1	
Geriatrics	2	2
Anaesthesiology (intensive care)	2	2
Palliative care	2	1
Head and neck oncology	1	
Uro-oncology	1	
Hepato-gastroenterology	1	
Oncology		11

eight nurses). Each discussion lasted approximately 90 minutes. We terminated the data collection after discovering no additional data that would add further insights to the findings. The participants' characteristics are summarized in Table 1.

Thematic Findings

Four main themes were identified as key features of healthcare professionals' perspectives on and experiences with advance care planning (Figure 1): 1) family's role in medical decision-making; 2) sensitivity to communication norms; 3) patients' religious beliefs regarding the control and sanctity of life; and 4) the availability of a support system for advance care planning.

Theme 1: Family's role in medical decision-making

In Indonesia, many elderly patients live together with their children, and participants often reported that patients greatly appreciated the input from their family members.

> *"Patients are often not capable of making decisions [by themselves]. They'll say, 'let me ask my family first, Doc.'" (P04: male, head-and-neck oncologist)*

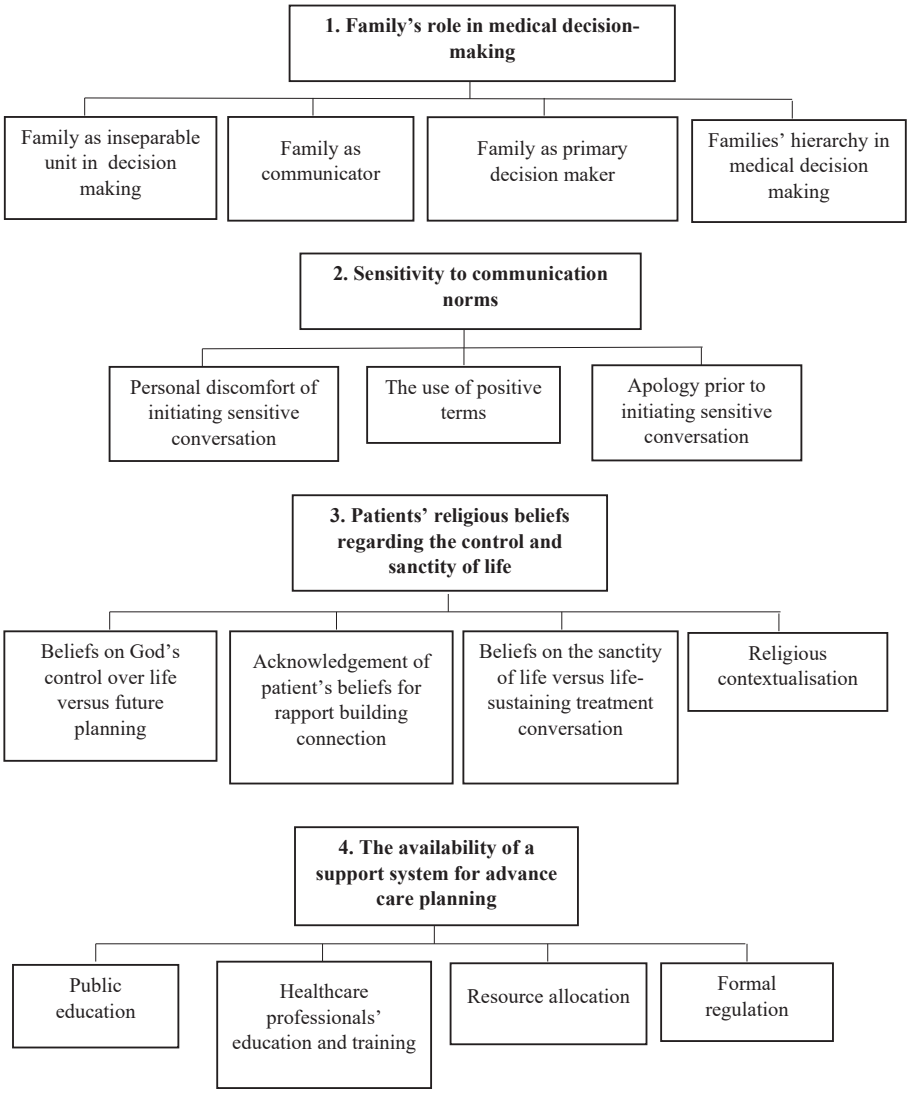

Figure 1. Coding Tree

Due to the importance of families in medical decision-making, participants believed that gaining their support in advance care planning is essential. Families may also serve as patients' proxies for collecting meaningful information.

> *"Some patients may have communicated their wishes to the family… as already mentioned, the role of family in Indonesia is very dominant, and they may be the ones we approach before the patient… that is the reality. Some patients have already shared*

their wishes in detail with their children. By involving the family, much information can be obtained, but not all of it will be verified with the patient. I usually only clarify the major things." (P09: female, geriatrician)

Nevertheless, participants stated that patients were particularly deprived of opportunities for meaningfully engaging in advance care planning if their family took the leading role in decision-making.

"What needs to be underlined in our culture in Indonesia is that patients often cannot determine their fate, because their family will decide [for them]." (N12: male, oncology nurse)

Participants described that disclosing bad news was a necessary yet difficult precondition for advance care planning. Families' reluctance to inform patients about their poor prognosis contributed to missed opportunities for the timely engagement of patients in advance care planning.

Certain families' structures and dynamics, in which hierarchy played an important role, were reported to potentially complicate advance care planning, in ways that sometimes prevented patients' wishes from being acted upon.

"The family member who takes care of the patient closely can usually understand his suffering and respect his wishes. But once another family member with a higher position or who is more respected [by other members of the family] comes, he/she may cancel everything [that has been agreed upon]." (N05: male, oncology nurse)

Theme 2: Sensitivity to communication norms

Due to the sensitive nature of advance care planning conversations, many participants felt uncomfortable about initiating them. They also reported that some patients may not appreciate them.

"I don't have the heart to talk about it [advance care planning]. Our patients are also very rarely willing to engage in such a conversation." (P03: female, medical oncologist)

Most participants felt the need to know how to approach advance care planning in a way that would be acceptable to patients and their families. The use of positive terms was reported as being more appreciated by them.

> *"We would not use the term 'refusal of resuscitation' rather than 'allow natural death' when asking them to sign the DNR form." (P11: male, intensivist)*

Another participant mentioned the importance of apologizing before introducing sensitive topics that could be offensive to some patients.

> *"We will say 'I'm sorry, I don't want to make it [death] come sooner, I just want to ask if your condition… you know, sometimes a person's condition can improve, but sometimes it can deteriorate... I want to ask if… once more, I apologize for asking this, but what if your condition deteriorates, what will be your wishes?'." (N15: female, palliative care nurse)*

Theme 3: Patients' religious beliefs about the control and sanctity of life

Participants reported that patients' religious beliefs play a significant role in their engagement in advance care planning. Patients who believed in God's control over life may consider the concept of future planning to be contradictory with their beliefs.

> *"We often communicate about the fact of their terminal condition and what could be their plans [for the end-of-life phase], but they [patients and their families] would argue that we would then be acting before God acts." (N08: male, oncology nurse)*

The acknowledgement of patients' religious beliefs and the incorporation of these beliefs into the conversation was reported to facilitate the rapport building necessary for advance care planning.

> *"When initiating the conversation, we have to acknowledge their beliefs. After that, we need to acknowledge that we [doctors] are also humans. We have our limitations. We are not the solutions for every illness. If we do that, they are usually more open [to advance care planning] and accepting." (P07: female, hepato-oncologist)*

Patients who believed that life is a sacred loan that should be protected were reported to often avoid conversations about limiting aggressive interventions. One participant shared her experience of using appropriate religious term to navigate the conversation, contextualize the message, and help clarify misconceptions. For instance, the use of the term "*mudarat,*" which means harm and is forbidden in an Islamic context, was reported to help Muslim patients better understand the concept of futile intervention and distinguish it from "giving up."

"We tell them that if we do this [futile] intervention, the 'mudarat' [harm] will be greater [than the benefit]. Doing harm to yourself is prohibited by our religion. This helps them appreciate our intention." (N08: female, emergency care nurse)

Nevertheless, while some participants reported their practice of integrating religious beliefs in the conversations, another participant felt the need to involve spiritual care providers to facilitate such a conversation.

Theme 4: The availability of a support system for advance care planning

Most participants reported their need for clear recommendations and guidelines for advance care planning, particularly pertaining to who should take the role in delivering it.

"We frequently have these patients [appropriate for advance care planning], but as long as the primary physicians don't feel the need to consult [a palliative care team], then this conversation will not occur." (N10: female, oncology nurse)

"The way I see it, most of the time, we don't know to which caregiver the patient should be referred [for advance care planning]? A psychiatrist? A spiritual caregiver? Hospice or palliative care team?." (P05: male, pulmonologist)

They also reported the need for a formal law to safeguard them from the legal consequences of engaging in advance care planning. Additionally, participants mentioned that integrating advance care planning into financial platforms would be essential to ensure patients' access to it.

"Unfortunately, in this hospital, it [advance care planning] is not covered by the national health insurance yet." (N02: male, oncology nurse)

The workload and time constraints were mentioned as important barriers to advance care planning. Also, the paper-based medical record system in a majority of Indonesian healthcare facilities hampered the accessibility and accountability of advance care planning related documents.

"One day, I had documented the conversation, but when we wanted to retrieve the document upon the patient's admission, it was gone." (P10: female, geriatrician)

Participants reported that patients' opportunities for timely engagement in advance care planning was reduced by their late presentation to medical facilities – a com-

mon problem. Therefore, awareness of the benefits of advance care planning should be raised in the community.

> *"Educating communities about advance care planning is important so they know that they have the right [to decide for themselves]" (P01: female, palliative care physician)*

Lastly, participants argued that patients' health literacy would influence their ability to understand and appreciate the aim of advance care planning.

DISCUSSION

Our study showed that several Indonesian healthcare professionals were open to advance care planning but also considered that cultural sensitivity mattered to their engagement in it. They believed that its uptake would be facilitated by the family's support for advance care planning, and for culturally sensitive communication, contextualization of advance care planning within the patient's religious beliefs, and the establishment of public education, financial support, a legal platform, and proper training.

Being strongly collectivists, Indonesian people consider the maintenance of social harmony crucial.[21-24] Our study showed that, due to families' leading role and their hierarchical structure, which may complicate advance care planning, healthcare professionals considered that gaining families' support in advance care planning was essential to ensuring patients' engagement in it. Therefore, the initial step towards patients' successful engagement in advance care planning included careful consideration of family dynamics and how these may facilitate the conversation without disrupting the harmonious relationship between doctor, patient, and families. Indonesian culture is characterized by its indirect communication style, which prioritizes the maintenance of other people's honour.[25] Our study showed that the use of indirect and positive terms was preferred both by healthcare professionals and by their patients. Available evidence has shown that patients' preferences for communication approach vary across different cultures. For instance, Asian immigrants in Western countries[26, 27] and Japanese patients[28] were likely to prefer implicit communication. In contrast, Western patients preferred information delivered straight to the point and professionally.[29] They appreciated open discussion about how much detailed information they would want.[30] Our study also showed that offering an apology before introducing sensitive issues was another strategy that was reported to initiate advance care planning. Great caution

should be exercised when approaching this conversation indirectly, as the main aim – exploring patients' values – must still be attained.[1] Therefore, it is essential to develop a special training on end-of-life-related conversation into current medical curricula for healthcare professionals in Indonesia.

Our study showed that religious belief was considered as an important factor due to its role in facilitating message interpretation and its meaning-making among religiously devoted patients. Exploration and use of these patients' beliefs in navigating the advance care planning conversation were believed to facilitate its uptake. Furthermore, our study suggested that Indonesian healthcare professionals believed that patients appreciated conversations about their religious beliefs. This finding supports the emerging evidence that religiosity does not necessarily negate the desire for prognostic communication and preparation for the end of life.[31, 32] It also supports the importance of the spiritual dimension of palliative care in Indonesia.[33-35]

Lastly, our findings showed an urgent need for advance-care capacity building planning in Indonesia, which lagged behind other Asian countries.[8] In our study, the lack of agreement on the role of different healthcare professionals (nurses versus physicians, primary physicians versus palliative care team) in advance care planning led to a lack of leadership in it. Additionally, the lack of financial support inevitably hampered patients' access and providers' engagement. To aid the advocacy efforts on advance care planning, evidence of its value in Indonesia is needed.

IMPLICATIONS

Our study indicates the importance of developing cultural sensitivity of advance planning. This requires healthcare professionals to create a meaningful understanding of the common features of patients' cultures while avoiding stereotypical characterizations. An example of such a step is evaluating patients' family dynamics and their communication norms, particularly when engaging with patients from a culture where family-centered decision-making and indirect communication are the norms. Likewise, in order to facilitate the engagement of religiously devoted patients, it is necessary to consider and contextualize their beliefs carefully.

STRENGTH AND LIMITATIONS

This study has several strengths. First, to capture a comprehensive range of participants' experiences, we purposively sampled two types of healthcare professional. Second, the consistency of data collection was sustained by a single interviewer (DM) and observer (RD). However, several limitations must be considered when interpreting the findings. Firstly, it is possible that the use of a single interviewer led to systematic bias. However, this concern was addressed by 'investigator triangulation', which involved all researchers in analyzing and discussing the findings. Secondly, we are aware that the participants' meaning may have been clouded throughout the analysis by Indonesian-English language differences. Lastly, the study was undertaken in two tertiary, national referral hospitals, which limits its generalizability to other settings.

CONCLUSION

Future directions for advance care planning in Indonesia should include sensitive cultural adaptation to the values of family harmony, communication norms, and religious beliefs. To complement current evidence and facilitate advocacy efforts, further study is needed on patients' perspectives and the value of advance care planning in Indonesia.

DECLARATIONS

Ethical approval and consent to participate

All methods were carried out in accordance with relevant guidelines and regulations. The study protocol was approved by the Ethical Committee at Dharmais National Cancer Center Hospital (Ref: 101/KEPK/VI/2019) and Cipto Mangunkusumo National General Hospital (Ref: KET-809/UN2.F1/ETIK/PPM.00.02/2019). Written informed consents were obtained from all of the participants.

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Chapter 7

Advance Care Planning for Patients with Cancer and Family Caregivers in Indonesia: A qualitative study

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ABSTRACT

Background: Individuals' willingness to engage in advance care planning is influenced by factors such as culture and religious beliefs. While most studies on advance care planning in Asia have been performed in high-income countries, Indonesia is a lower-middle-income country, with a majority of strongly collectivist and religiously devout inhabitants. We studied the perspectives of Indonesian patients with cancer and family caregivers regarding advance care planning by first exploring their experiences with medical information-disclosure, decision-making, and advance care planning and how these experiences influence their perspectives on advance care planning.

Methods: We conducted semi-structured interviews among 16 patients with cancer and 15 family caregivers in a national cancer center in Jakarta and a tertiary academic general hospital in Yogyakarta. We performed an inductive thematic analysis using open, axial, and selective coding. The rigor of the study was enhanced by reflective journaling, dual coding, and investigator triangulation.

Results: Twenty-six of 31 participants were younger than 60 years old, 20 were Muslim and Javanese, and 17 were college or university graduates. Four major themes emerged as important in advance care planning: (1) participants' perceptions on the importance or harmfulness of cancer-related information, (2) the importance of communicating bad news sensitively (through empathetic, implicit, and mediated communication), (3) participants' motives for participating in medical decision-making (decision-making seen as patients' right or responsibility, or patients' state of dependency on others), and (4) the complexities of future planning (e.g., due to its irrelevance to participants' religious beliefs and/or their difficulties in seeing the relevance of future planning).

Conclusions: Culturally sensitive approaches to advance care planning in Indonesia should address the importance of facilitating open communication between patients and their families, and the various perspectives on information provision, bad news communication, and decision-making. Advance care planning should focus on the exploration of patients' values, rather than drafting treatment plans in advance.

Key words: advance care planning, patient, cancer, family, collectivist, religiosity, Asia, Indonesia

BACKGROUND

Advance care planning is a process of defining and discussing values, goals and preferences for future medical treatment and care.[1] It is increasingly seen as an essential element of high-quality end-of-life care. However, as the concept is rooted in the Western philosophy of person-centered care and self-determination, it may not always be relevant in countries where the cultures favor collectivism and the maintenance of social harmony over individual autonomy.[2-4] Our recent systematic reviews of studies from southern, south-eastern, and eastern Asian countries showed that proper understanding of one's illness (including its prognosis) is regarded as an important initial step towards engagement in advance care planning.[5] The uptake of advance care planning is further influenced by patients' beliefs and healthcare professionals' fear of creating conflict with family members.[5-7] Few studies provided in-depth insight into patients' and families' perspectives on advance care planning, and few were conducted in low and middle-income Asian countries, including Indonesia.[5-7]

Indonesia is the fourth most populous country in the world, with the prevalence of cancer increasing from 1.4 per 1,000 people in 2013 to 1.8 per 1,000 in 2018.[8] In 70% of these patients, the illness is at an advanced stage,[8] where advance care planning may have added value. Although a survey among participants from a general population in Indonesia showed that the majority wished to be informed about a possible life threatening disease and be engaged in end-of-life communication, a study on the perspectives of Indonesian patients has not been performed.[9] However, the stigma surrounding cancer prevented people to have an open communication about it.[10] In addition to that, Indonesia not only follows Asian traditions of family-centeredness in medical decision-making, it is also one of the most religious countries in the world where the majority of its population consider religious values to be important to their lives.[11-13] These factors may all influence people's perspectives on advance care planning and their willingness to engage in it.[5]

To better understand the possible value of advance care planning for cancer patients in Indonesia, we aimed to provide in-depth insight into the perspectives of patients with cancer and family caregivers. To facilitate the exploration of participants' perspectives in advance care planning, we first explored their experiences with medical information-disclosure, decision-making, and advance care planning before exploring how these experiences influence their perspectives on advance care planning.

METHODS

Study Design

This exploratory qualitative study involved in-depth interviews with patients with cancer and family caregivers. We performed inductive thematic analysis using open, axial, and selective coding.[14, 15] Firstly, we facilitated participants' self-conscious reflection of their experience with living with cancer, particularly with medical information disclosure, decision-making, and advance care planning. We further explore participants' perspectives on advance care planning drawn from their reflection and meaning-making of these experiences.[16, 17]Reporting was guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ).[18]

Study setting

The study was conducted in an Indonesian national cancer centre in Jakarta and a tertiary academic general hospital in Yogyakarta.

Sampling and recruitment

Oncologists in participating wards selected patients with cancer who were at least 18 years of age, spoke Indonesian, had been diagnosed with cancer for at least six months, were aware of their diagnosis, and agreed to participate in the study. The oncologists also selected family caregivers of patients with cancer who were also at least 18 years of age, spoke Indonesian, were the primary caregiver for the patient, and agreed to participate in the study. These participants were purposively sampled to capture the diversity of their demographic characteristics (age, sex, cancer diagnosis, education).

In-depth interviews and data collection

Semi-structured in-depth interviews were conducted face-to-face from July to September 2019 by DM, a female Indonesian physician specializing in internal medicine and palliative care, who was also trained to perform qualitative studies, and CYK, a female Indonesian nurse and researcher, trained and experienced in qualitative studies. RD, a female Indonesian physician, who specialized in psychiatry and palliative care and was also experienced in qualitative studies, made additional notes based on her observations during the interviews.

We developed a topic guide for the interviews based on our systematic reviews of advance care planning in Asia[5, 6] and consultations with various experts in medical oncology, palliative care, psychosomatic medicine, psychology, and research. The interview guide (Appendix 1 and 2) contained an introduction to the study and

to advance care planning and was designed to elicit (1) participants' experience and preferences regarding information provision; (2) their values and preferences regarding current and future care; (3) their experience with and perspectives on advance care planning; and (4) their perspectives on their role in advance care planning.

As the concept of advance care planning is unfamiliar in Indonesia, there is no Indonesian term for it. In this study, we therefore used the international consensus definition of the European Association for Palliative Care: "advance care planning enables individuals with the decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, to discuss these with family and healthcare professionals, and to record and review these preferences if appropriate."[1]

Data Processing and Analysis

All interviews were audio-recorded and transcribed verbatim in Indonesian (the official language at the study sites) by DM and CYK. We conducted an inductive thematic analysis using open, axial, and selective coding of these interview transcripts and the field notes. We followed six phases of thematic analysis by Braun & Clarke (Figure 1, Appendix 3).[14, 15] Before identifying ideas, two coders (DM and CYK) familiarized themselves with the data by reading all of the transcripts several times (Phase-1). After DM and CYK gained trustworthy familiarity and captured the core meaning of the empirical materials, they selected four transcripts (two transcripts of patients interviews and two of family caregiver interviews) on the basis of their richness ¬¬¬– e.g., the transcripts that reveal the complexities and the richness of the topic that is being studied.[19] Independently, they then generated initial codes (open coding) of the transcripts (Phase-2). Afterwards, they independently grouped the codes under broader themes (Phase-3). To achieve consensus, codes and themes were discussed several times between DM and CYK.

To enhance the validity of the findings, we performed investigator triangulation, where two or more researchers were involved in observing and generating a conclusion (Phase-4). For this purpose, the four selected transcripts were then translated into English by a professional translator and shared with JR, AH, and CR (the non-Indonesian-speaking investigators). This process allowed the non-Indonesian-speaking investigators to gain familiarity with the materials.[19] Likewise, codes and themes were translated into English to facilitate the discussions. Codes, themes, quotes, and empirical materials (Indonesian transcripts of all interviews) were also

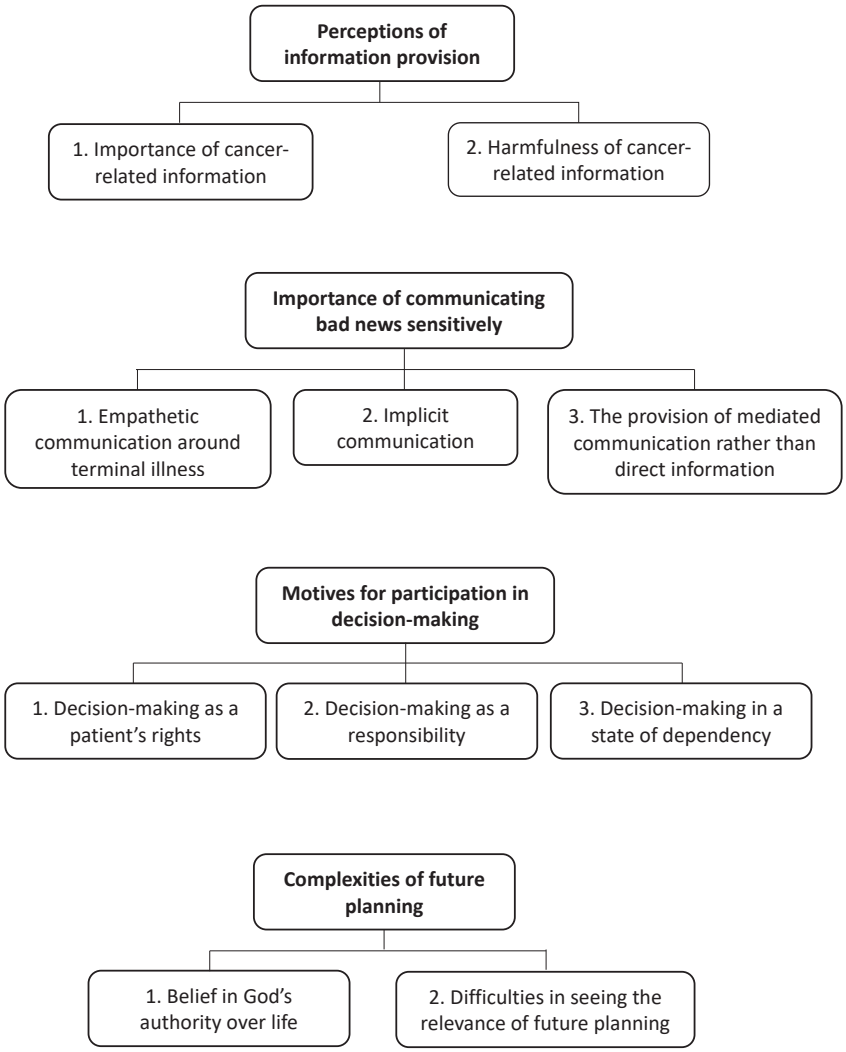

Figure 1. Coding tree of the perspectives on serious illness communication

shared with bilingual co-investigators (CE, RP, HS, RD, NS). Finally, codes and themes were discussed with members of the research team, with backgrounds in oncology, nursing, psychiatry, epidemiology, health sciences, palliative medicine, and psychosomatic medicine. The open codes were then organised into an initial coding tree, by going back and forth through the themes and the transcripts, using the constant comparative method (axial coding). The initial coding tree that had been discussed with the team members was tested by DM and CYK on another four transcripts. These newly developed codes were discussed with the larger team, and the coding tree was adjusted accordingly. This process was completed when all transcripts had

been coded and the final coding tree had been developed. Members of the research team met several times to refine this final coding tree (Phase-5), by selecting core concepts, systematically connecting these core concepts with other categories, and filling in the categories that need to be refined (selective coding). All steps were iterative and reflective, developing over time and involving a constant moving back and forward between phases. Finally, all investigators were involved in the writing of the manuscript (Phase-6). Qualitative data analysis software (N-Vivo version 12) was used to assist in data analysis.

The qualitative rigor of the study was enhanced through the stimulation of credibility, confirmability, reflexivity, and transferability. Credibility was stimulated through investigator triangulation and data source triangulation where we explored various participants' perspectives: patients with cancer and family caregivers. Confirmability and reflexivity were stimulated through reflective journaling by dual coders to enable reflection on the findings as well as their own emotions during the interviews. In addition, during regular meetings with team members, reflective journaling was used to discuss interviewers' and researchers' potential biases and subjectivities to the studied topic and how these might affect their interpretations. Transferability was stimulated through 'thick description' – a rich account of descriptive data including the context in which the research was carried out – of the participants and the research process (setting, sample, sample size, sample strategy, demographic and clinical characteristics, and interview guide) to enable the reader to assess whether our findings are transferable to their own settings.

RESULTS

Participants' Demographics

We interviewed 16 patients and 15 family caregivers from unrelated families. All of the participants that were approached agreed to participate in the study. Each interview lasted approximately 45 minutes. After the analysis of the last interviews (with a patient and with a family caregiver), we did not find new themes, and therefore we concluded to have reached data saturation.

Table 1 summarizes the participants' characteristics. Eight of the 15 family-caregiver participants were spouses, and 26 of the 31 participants were younger than 60 years old, 20 were Muslims and Javanese, and 17 were college or university graduates.

Table 1. Participants' demographic characteristics

	Patients (N =16)	Family caregivers (N=15)
Sex		
Male	7	9
Female	9	6
Age (years)		
<40	6	4
40-60	7	9
>60	3	2
Types of cancer*		
Blood cancer	5	3
Lung cancer	1	2
Gastrointestinal cancer	2	2
Breast cancer	6	4
Cervical cancer	2	4
Stage		
I	1	1
II	3	4
III	5	3
IV	4	5
No stage (Leukaemia)	3	2
Education		
No formal education	1	0
Elementary school	1	1
High school	5	6
College/university	9	8
Relationship with patient		
Spouse	-	8
Parent	-	0
Child	-	5
Daughter/son-in law	-	2
Religious affiliation		
Islam	10	10
Catholic	2	4
Christian	4	1
Race		
Javanese	12	8
Sundanese	2	5
Chinese	-	1
Batak	1	-
Malay	1	-
Minangkabau	-	1

*Cancer diagnosis of the patient participants or of the relatives of family caregiver participants

Thematic Findings

Four main themes were identified as key features of the perspectives on serious illness communication (Figure 1): 1) perceptions of information provision; 2) importance of communicating bad news sensitively; 3) motives for participation in decision-making; and 4) complexities of future planning.

Theme-1: Perceptions of information provision

Our study showed that participants' wishes for cancer-related information were influenced by their perceptions of (a) whether the information was important or relevant to them, and (b) whether they considered the information harmful.

1.1 Importance of cancer-related information

Many patient participants wished to receive information about their illness, particularly their diagnosis, treatment options, and, to a certain extent, their prognosis. They considered such information important because it would foster their autonomy in further decision-making.

> *"So I'll know what will be the next [step] is, and so I won't have to depend on my children, right? They have their own jobs and live far away… I must know, so I'll have no regret in the future." (YK3A: female patient (age 62) with stage III breast cancer, Christian, Javanese.)*

Likewise, some family caregiver participants who acknowledged the patients' main role in decision-making thought it was important that provision of information is guided by patients' needs.

While the information was often delivered to the patient through family members, those who considered it to be the patients' right to receive information indicated that they would support truth-telling.

> *"At the beginning, I was the only one who knew [about the patient's illness]. But as time went by, I asked the doctor 'Doc, I'd like your help in explaining my husband's illness to him. I don't want to lie to him. He has the right to know.´ That's what I said to the doctor." (RSKD3B: wife (age 47) of a patient with stage IV lung cancer, Muslim, Sundanese.)*

Some family caregiver participants believed that providing patients with medical information is necessary to maintain trust within the family.

"If my wife doesn't know and later she would find out from somebody else, it could be serious. She might think that we [as her family] had not been open [with her]." (YK3B: husband (age 49) of a patient with stage II cervical cancer, Muslim, Javanese.)

Nevertheless, while most patient participants considered truth-telling important, some patients and family caregivers regarded certain information as irrelevant, particularly information on estimated life expectancy, due to their belief that death is unpredictable or predetermined by God.

"As for myself, I don't need a number (for life expectancy) because, once we know that we're ill [i.e., have been diagnosed with cancer], the number is unnecessary. It (death) can happen anytime." (RSKD9A: female patient (age 32) with acute lymphocytic leukaemia, Islam, Javanese.)

1.2 Harmfulness of cancer-related information

Participants who believed that certain information could harm their loved ones indicated that they would conceal such information to protect their loved one's psychological wellbeing.

Patients and family caregivers alike said they would conceal information: patient participants would conceal "harmful" information to their family members and vice versa. Withholding burdensome information was commonly considered to be an act of love.

"I would feel sorry for my family [if they knew about my poor prognosis]. Let me bear the burden myself." (YK6A: female patient (age 67) with stage II lung cancer, Christian, Javanese.)

"If my mother were present [when bad news was communicated], it would burden her thoughts. It would be enough to discuss the more detailed and deeper information with me. My mother doesn't need to know. [I believe that] one's thoughts can influence one's condition." (YK2B: daughter (age 39) of a patient with stage II cervical cancer, Christian, Javanese.)

Some family caregiver participants believed it was their duty to preserve patients' hope.

"Family members are the ones who should encourage and keep the patient's spirits up… Mom knows about her illness, but the full risk [of death] – we don't have the heart [to tell

her].” (YK1B: Son (age 34) of a patient with advanced non-Hodgkin lymphoma, Muslim, Javanese.)

Theme-2: Importance of communicating bad news sensitively

Patient and family caregiver participants expected empathetic communication with their preferences for how information should be delivered being taken into account. Overall, participants mentioned three preferred ways for the delivery of bad news, namely: (a) through empathetic communication around terminal illness; (b) through implicit (i.e. indirect or euphemistic) communication; or (c) through mediated rather than direct truth-telling.

2.1 Empathetic communication around terminal illness

Patient and family caregiver participants considered it important to approach the communication of bad news surrounding terminal illness empathetically. Communication that takes away hope (e.g. hope for cure) is not considered empathetic

“It actually depends on how it is communicated. Sometimes, for example, a doctor said, ‘This is already severe; it can’t be treated any more’. It shouldn’t be presented like that, right? But I’m sorry, sometimes it happens.” (YK5A: female patient (age 48) with recurrent metastatic breast cancer, Muslim, Javanese.)

Similarly, communication that created a sense of abandonment was not seen as empathetic communication either.

“If you’d heard the doctor’s statement when he gave up, you’d have been shocked, because he said ‘oh, that’s how it is, let’s hand it to God and hope for a miracle’ in front of the patient and family, and also the nurses. People were speechless! How can a doctor say anything like that?” (YK4B: husband (age 51) of a patient with stage IV breast cancer, Catholic, Javanese.)

2.2 Implicit communication

Throughout the interviews, many patient and family caregiver participants used implicit formulations (euphemisms) to avoid direct communication, saying for example “illness” rather than “cancer”; “it” or “leave” rather than “death;” and “serious” rather than “malignant”. Accordingly, as they considered the use of direct words to be blunt, they appreciated communication that was more euphemistic.

“So the [doctor’s] communication was very pleasant. I mean, not too serious – quite relaxed. When the pathology results came in, the doctor told me, not that it was malig-

nant, only that in the next hospital I may receive chemo or radiation according to what they would conclude there. [The doctor said] 'The most important thing is that you keep the spirit, eat a lot, take good care of your condition'." (YK7A: female patient (age 45) with cervical cancer stage IIB, Muslim, Javanese.)

2.3 The provision of mediated communication rather than direct information

Some participants considered conveying bad news through family members a sensitive approach. One patient participant felt that information about life expectancy could best be delivered through family members. She believed that her family members could better judge than healthcare professionals whether such information was necessary because they knew her personality.

> *"It [life expectancy] needs to be communicated, but not to the patient – there has to be a mediator for that. And it is up to the family whether they want to deliver it to the patient or not." (RSKD9A: female patient (age 32) with acute lymphocytic leukemia, Muslim, Javanese.)*

Several family caregiver participants believed they could convey sensitive information better than healthcare professionals as they would be able to minimize its harm to patients' mental wellbeing. They believed that, given their longer and closer relationship with the patient, they knew the best approach and timing for conveying such information.

> *"Every family has its own communication techniques. Once, I took over the conversation because the doctor was too spontaneous, bla, bla, bla, as is. I just followed. Mmm… we've often seen on television that there's always a separate communication between family and patient [after the communication between the doctor and the family]. It should be like that, not too vulgar, though afterwards, the patient must still know about her condition." (YK4B: husband (age 51) of a patient with stage IV breast cancer, Catholic, Javanese.)*

Nevertheless, some patient participants reported their preference for direct, non-mediated communication with healthcare professionals.

> *"I must discuss it with my family, though I'll be the one who talks [to the physician]." (RSKD9A: female patient (age 32) with acute lymphocytic leukemia, Muslim, Javanese.)*

Theme-3: Motives for participation in decision-making

Our study showed that participants' preferences for involvement in decision-making ranged from a patient-centered style, through a family-led style, to a physician-led (paternalistic) style.

These preferences were influenced by: (a) whether patients considered involvement in decision-making to be a patient's right; (b) whether they believed patients should be given the opportunity to take control of their care; (c) whether they considered it as patients' or family caregiver's responsibility; and (d) whether they were in a state of dependency regarding decision-making. Regardless of their motives, many patient participants greatly valued family involvement and a guiding role from physicians.

3.1 Decision-making as a patient's right

Patient participants who considered decision-making their right were likely to take an active role while still seeing family involvement as essential.

> *"As long as I can still take a role [in decision-making], then I will. Unless my condition is already… when I can only lie down or am unconscious… then maybe somebody else can take the decision. My Mom or someone else. But as long as I still have the right to do it and am still capable of doing it, then I'll do it." (RSKD9A: female patient (age 32) with acute lymphocytic leukemia, Muslim, Javanese.)*

Some participants considered that patients' involvement in decision-making was an opportunity for patients to take control of their care, even when seeing their family's involvement as important.

> *"Actually, I would like to communicate the options with my family. Although their opinions may differ from mine, I will be the one who eventually decides. The most important thing is that, later, I will have no regrets." (YK6A: female patient (age 67) female patient with stage II lung cancer, Christian, Javanese.)*

Likewise, family caregiver participants who agreed that decision-making is a patient's right were likely to acknowledge and respect the patient's leading role in it.

> *"Everyone [in the family] would be invited to join the discussion, but the patient will make the final decision. We only provide her with considerations." (YK4B: husband (age 51) of a patient with stage IV breast cancer, Catholic, Javanese)*

3.2 Decision-making as a responsibility

While some patient participants considered decision-making – and its possible consequences – to be their responsibility, they would prefer to share this responsibility with others. Some patient participants would prefer to share the responsibility of decision-making to avoid regret and blame for any adverse outcomes of their decision.

> *"Yes, I always involve all the family members [in decision-making]: that would be the best [decision]. Like that, everyone will know, and everything will be clear. Otherwise, if something goes wrong later, I will be the one who is blamed (laughed)." (YK3A: female patient (age 62) with stage III breast cancer, Christian, Javanese)*

Other family caregiver participants believed it was their duty to decide on the patient's care and would voluntarily fulfil that duty by taking up this role.

Likewise, some family caregiver participants considered it important to include more family members, as spreading responsibility over a group would make them less accountable than if they acted alone.

> *"Everyone [in the family], everyone's opinion [should be taken into account], not just one person's. As we're afraid that we'll be blamed later on. So, it should be a majority vote, let's say." (RSKD4B: daughter (age 35) of a patient with acute myeloid leukemia, Muslim, Sundanese.)*

As most patient and family caregiver participants saw it as the physicians' responsibility to make the best recommendation, they would trust the physicians to make it and sometimes even to decide on their behalf.

> *"Usually, we put our trust in the doctor, as that makes it simpler for us and [the doctor], as he/she is certainly more experienced [than us]". (RSKD4A: male patient (age 39) with stage 3A non-Hodgkin lymphoma, Catholic, Javanese)*

3.3 Decision-making in a state of dependency

One patient participant, who found it difficult to understand the complex medical information given by her physician, stated that she would rely on her children due to her self-perceived inability to process such information.

> *"I'll follow what my children say. The most important thing is that I follow [what they have decided for me] and [that I] prepare myself. That's it. So, when the doctor asks for a*

discussion, I only listen – my children are the ones who ask more questions. I'm not smart enough [to understand the discussion]. Things were always explained, but I just couldn't understand…" (YK2A: female patient (age 53) with advanced non-Hodgkin lymphoma, Muslim, Javanese)

Some patient participants who lived with or were cared for by family members often felt dependent on them for decision-making.

"To make decisions, our Dad always depends on us. He said, 'As long as I'm being taken care of, I'll follow [your decision].' He also said, 'Well, since I'm being taken care of by my children, I'm dependent on them'." (RSKD4B: daughter (age 35) of a patient with acute myeloid leukaemia, Muslim, Sundanese.)

Theme-4: Complexities of future planning

Our study showed that two factors made it difficult for most participants to plan for the future: (a) their belief in God's authority over life and (b) their difficulties in seeing the relevance of future planning.

4.1 Belief in God's authority over life

For participants who believe that God is the only one who can determine their fate in life, conversations on future care planning can be difficult, particularly those about the end-of-life phase. As these participants believed that they have to accept whatever God has planned for them or their family members, they viewed planning for future care to be irrelevant.

"In my opinion, since we have faith, we are merely God's creatures, [and we must remain certain that] everything has its written destiny. We certainly don't know what will happen in future. But we just need to give up everything to God and to be sure that whatever is destined is best for us." (RSKD2A: male patient (age 36) with acute lymphocytic leukemia, Muslim, Sundanese.)

Some participants also believed that thinking about death and dying would mean that they failed to think positively about God's will.

"We must believe that God has the best plan for everyone, whatever their condition. We don't need to think negatively, especially not regarding God." (RSKD2B: husband (age 64) of a patient with stage II breast cancer, Catholic, Chinese.)

As many participants believed in the sanctity of life and their obligation to preserve one's sacred life, they preferred to focus on making an effort to preserve life rather than thinking about and planning for adverse events.

> *"No, I never think about that [i.e., possible bad scenarios]. I believe only in God, that humans must only make an effort, and that God is the one who will decide everything." (RSKD6A: female patient (age 54) with metastatic breast cancer, Muslim, Sundanese.)*

These participants believed that before accepting and surrendering to God's decision, they must first make their utmost effort to preserve sacred life.

> *"For me, this [pursuing treatment] is one of our ikthiar [utmost effort]. According to Islam, we must first do ikhtiar, and after that, if anything bad happens to my husband, then it's God's will." (RSKD3B: wife (age 47) of a patient with stage IV lung cancer, Muslim, Minangkabau.)*

4.2 Difficulties in seeing the relevance of future planning

Some participants felt that it was not necessary to discuss future planning, as they believed that scenarios for the end-of-life phase were not relevant to the situation at the time of the interview.

> *"Up till now, I've never thought about that, as I think a situation in which her vital organs fail, or something like that, may not happen. I'm still optimistic that the prediction is that she's still going to be okay." (RSKD2B: husband (age 64) of a patient with stage II breast cancer, Catholic, Chinese.)*

Similarly, participants who were unable to reflect upon the consequences of their advanced illness considered such planning unnecessary.

> *"I always think positively [about my future], that I need to recover completely, be cancer free whatever it takes. I have to keep the spirit to recover and always think positively." (RSKD7A: female patient (age 30) with metastatic breast cancer, Muslim, Sundanese.)*

Most participants preferred to keep a positive mindset. To spare themselves from the consequences to their mental wellbeing, they refrained from thinking about possible adverse events in the future.

> *"Sometimes, I don't want to think too much about this [end-of-life care preferences]. Not because I underestimate my illness, but sometimes I just don't want to overthink it. I just*

wish for everything to go as it's going now." (RSKD 4A: male patient (age 39) with stage 3A non-Hodgkin lymphoma, Catholic, Javanese.)

Other patient participants thought that they already had enough of a burden and that future planning should be done by family members.

"In my opinion, patients with cancer already have quite a burden, so there's no need to add to it with such questions [i.e., about preferences for future care]. Those can be asked to the family members." (RSKD9A: female patient (age 32) with acute myeloblastic leukemia, Muslim, Javanese.)

To be able to plan for death, some family caregiver participants argued that one would first needs to be mentally ready.

"Actually, it includes making a living will, right? In Islam, when we're ready to face death, we should in fact make a living will. But it really depends on each individual. Although we're Muslim, we're not always ready to make living wills. Sometimes, we aren't ready to face death." (RSKD3B: wife (age 47) of a patient with stage IV lung cancer, Muslim, Minangkabau.)

While discussing future decisions could be challenging for many of our participants, they were more open to discussing what mattered most to them, both in the moment and the future.

"My wish for the future is not for myself but my family. I don't want my condition to burden anyone else." (RSKD7A: female patient (age 30) with metastatic breast cancer, Muslim, Javanese.)

"Yes, now, motivation, accompaniment, and spirituality are the most important for her." (YK4B: husband (age 51) of a patient with stage IV breast cancer, Catholic, Javanese.)

DISCUSSION

In this qualitative interview study on Indonesian patients' and family caregivers' perspectives on serious illness communication in oncology care, we found that four important factors influenced their engagement in serious illness communication. First, patients' and family caregivers' wish to be informed about the disease and its consequences depended on whether they perceived the information as impor-

tant, relevant, or harmful. Patients and family caregivers alike tended to conceal 'harmful' information to protect their loved ones. Second, they wished bad news to be communicated empathetically and sensitively, particularly by using implicit words (euphemisms). Family caregivers found that mediating the delivery of bad news required a sensitive approach. Third, participants' preferences for involvement in decision-making varied. Their preference for patient-centered, family-led or physician-led decision-making, was influenced by their ideas on patients' rights, their perceived responsibilities, or patients' state of dependency on others. Finally, most participants found future care planning to be challenging, due either to their religious beliefs, or to their difficulties in seeing its relevance for future care planning. Discussing what mattered most in the moment seemed more appropriate.

Our study indicates that different individuals appreciate different amounts of information about their illness and that information provision without careful consideration of patients' preferences may disrespect patients' values and religious beliefs. Although most patient participants reported that they wished to receive certain information on their illness (e.g., diagnosis, treatment options), many of them considered information on estimated life-expectancy harmful or irrelevant because of their religious beliefs. Available evidence shows that patients with cancer in general have various preferences for prognostic disclosure, with more people preferring broad indications of prognosis rather than concrete estimations.[20] More recent studies in Asia showed that open communication on prognosis might cause psychological distress or decrease patients' quality of life.[21-23] Accordingly, an important first step before providing medical information to patients is to assess which information is preferred and could be helpful for patients.

Another important consideration regarding information provision was the cultural sensitivity of its delivery. Indonesia is known for its relatively high-context culture in which messages are not necessarily expressed explicitly but can be implied implicitly.[7, 24-26] For this reason, Indonesian healthcare professionals are often expected to convey a message gently while being sensitive to subtle non-verbal cues transmitted by their patients.[7, 26] Our study, as well as other studies among Asians,[7, 27-29] indicate that euphemisms may facilitate communication with individuals who appreciate implicit communication. Additionally, our study showed that patients and family caregivers often see hope as an aspiration to fight illness and escape death, and thus consider communication that takes away such hope to be unempathetic. Healthcare professionals should be able to facilitate redefining of hope within the context of terminal illness by identifying short-term, realistic, and attainable goals[30, 31] while providing reassurance of non-abandonment.[32]

Our study also identifies a cultural dilemma in which patients and family members alike tend to conceal harmful information, limiting the opportunity for their loved ones to be involved in further decision-making. Such common non-disclosure indicates the need for an approach that focuses more closely on the culturally related dilemmas of breaking bad news. Recently, the ARCHES framework (an acronym for Acknowledge concern, build Relationship, Common ground, Honour patient's preferences, Emotional support, and supportive Solution) was developed.[33] This framework focuses on maintaining cooperative relationships with family, for example by showing sensitivity to family's concerns, by finding shared goals, by ensuring the sensitive delivery of information to the patient, and, in order to uphold patient's rights for information, by achieving consensus with the family on the best way forward.[33] Such initiatives, along with promoting honest communication between patient and their family members, could help overcome cultural barriers to information provision and advance care planning. Similar dilemmas may occur when engaging in advance care planning with Asian patients living in non-Asian countries. Therefore, further efforts to complement current Western-oriented curricula with communication strategies that address various cultural dilemmas is warranted.

Finally, our study showed that patients' and family caregivers' willingness to engage in advance care planning was affected by various beliefs about death and dying. Those who believed in God's authority over life and their obligation to preserve their life would likely be less open to engaging in discussions about taking control of death or the withdrawal of life-sustaining treatments. Sufficient understanding of these beliefs could help practitioners determine whether and to what extent a patient could engage in advance care planning and how the conversation could be navigated while being respectful to patients' beliefs. Our previous qualitative study of Indonesian healthcare professionals suggested that the transfer of sensitive medical information among religiously devout patients and family caregivers could be facilitated by circumspect conversation within their religious contexts.[7] For example, religious terminology such as "mudharah" (or harm) could help address the distant concept of "futile treatments" as the avoidance of greater mudharah.[7] Other studies in Western countries have shown the value of trained spiritual care providers in facilitating the exploration of patients' values, goals, and preferences.[34, 35] Additionally, our study showed that advance care planning for future treatment can be very difficult for those who are not ready to engage in discussions of death and dying, or for those in a stable condition who cannot reflect on future deterioration. In such instances, exploration of patients' values is one of the important

goals of advance care planning, rather than merely focusing on eliciting patients' preferences for future care, our findings.

STRENGTHS AND LIMITATIONS

To the best of our knowledge, this is the first study to explore the perspectives of Indonesian cancer patients and their family caregivers on advance care planning. Due to the important role of family in Indonesia, we explored the perspectives of both these groups in order to disentangle the factors that play important roles in patients' engagement in advance care planning. Based on our systematic reviews in Asia and consultation to a panel of Indonesian multidisciplinary experts, we developed an interview guide that enabled us to prompt culturally relevant questions. The robustness of our analysis was improved by using dual coders and triangulation by experts from various disciplines and cultural backgrounds.

When interpreting this study, two main limitations need to be considered. First, selection bias may have resulted from the fact that most of our participants had completed higher education and had been selected based on their willingness to participate in the study. This means that our findings may not be relevant for those with lower educational backgrounds and/or those who were not willing to participate in the study. Second, the interviewers' background as healthcare professionals may have obscured participants' responses during the interview. This risk was minimized by ensuring participants that any responses would not be disclosed to attending physicians and would not affect their care.

CONCLUSIONS

Our study indicated that engagement in serious illness communication and advance care planning in Indonesia would be facilitated by several important factors, including culturally sensitive awareness of various perspectives on information provision, bad-news communication, decision-making, and future care planning. Advance care planning in Indonesia should address the importance of collective decision-making, religious beliefs, and the maintenance of social harmony, and should regard value exploration as its main goal. Further study is needed to explore the different perspectives of patients with various religious affiliations, races, and non-cancer life-limiting illnesses.

DECLARATIONS:

Ethical approval and consent to participate

All methods were carried out in accordance with relevant guidelines and regulations. The study protocol was approved by the Ethical Committee at Dharmais National Cancer Center (Ref: 101/KEPK/VI/2019) and at the Faculty of Medicine, Public Health, and Nursing, Universitas Gadjah Mada (Ref: KE/FK/0811/EC/2019). Participants received verbal and written information about the study and provided signed informed consent to participate before the interviews took place. Participants were also informed about the voluntary nature of their participation and that they had the option to withdraw anytime from the study without the need to specify their reason for doing so.

Acknowledgement

The authors would like to thank the patients and family caregivers who participated in this study.

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Chapter 8

Cancer Survivors' Experiences with and Preferences for Medical Information Disclosure and Advance Care Planning: An Online Survey Among Indonesian Cancer-Support Groups

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ABSTRACT

Purpose: To understand the experiences and preferences of Indonesian cancer survivors regarding medical information disclosure and advance care planning.

Methods: Based on systematic reviews of the scientific literature, qualitative studies, and expert-panel input, we developed an online survey that was distributed to nine cancer survivor support groups in Indonesia.

Results: A total of 1,030 valid responses were received. Most participants were under 60 years old (92%), female (91%), married (78%), Muslim (75%), diagnosed with breast cancer (68%), highly educated (64%), and more than one year beyond diagnosis of their cancer. If diagnosed with a life-limiting illness, participants wished to be informed about their diagnosis (74%), disease severity (61%), estimated curability (81%), expected disease trajectory (66%), and estimated life expectancy (37%). Between 46-69% of the participants wished to discuss four topics of advance care planning (end-of-life treatments, resuscitation, healthcare proxies, and what matters at the end of life); 21-42% had done so. Of those who wished to discuss these topics, 36-79% preferred to do so with their family members. The most important reasons for not being willing to engage in advance care planning were the desire to surrender to God's will and to focus on here-and-now.

Conclusions: In a group of cancer survivors, most of them were highly educated, young, female, and diagnosed with breast cancer. Their preferences for medical information and advance care planning varied, with the majority wishing for information and involvement in advance care planning. Culturally sensitive advance care planning involves healthcare professionals eliciting individuals' preferences for medical information disclosure and discussing different topics in advance care planning conversations.

Keywords: prognosis disclosure, advance care planning, Indonesia, cancer survivors, community support groups

BACKGROUND

Advance care planning enables individuals to define, discuss, and record their goals and preferences for future medical treatment and care. Its aim is to ensure that their treatment and care are aligned with these goals and preferences and in situations in which patients later lose their mental capacity[7]. To allow meaningful engagement in advance care planning, individuals need sufficient knowledge of their medical condition[150]. However, both advance care planning and disclosure of medical information are culturally sensitive[150, 151]. For instance, the common partial or non-disclosure of bad news surrounding life-limiting illnesses in Asia may limit patients' understanding of their illness[150, 151]. Similarly, their uptake of advance care planning can be limited by beliefs about death and dying, or by the role of family in decision-making [150, 151].

A declaration issued by a panel of Asian experts in 2019 recommended that studies on advance care planning prioritize cultural sensitivity[84]. To date, however, most Asian studies have been performed in high-income countries[12, 150, 151] and have not taken into account the combination of collectiveness (a culture that prioritizes the group over the individual) and religiosity (self-identified religious importance) that are central to medical decision-making in low-and middle-income countries such as Indonesia[178]. Evidence suggests that people living in low- and middle-income countries tend to be more collectivistic and Advance care planning enables individuals to define, discuss, and record their goals and preferences for future medical treatment and care. Its aim is to ensure that their treatment and care are aligned with these goals and preferences and in situations in which patients later lose their mental capacity[1]. To allow meaningful engagement in advance care planning, individuals need sufficient knowledge of their medical condition[2]. However, both advance care planning and disclosure of medical information are culturally sensitive[2, 3]. For instance, the common partial or non-disclosure of bad news surrounding life-limiting illnesses in Asia may limit patients' understanding of their illness[2, 3]. Similarly, their uptake of advance care planning can be limited by beliefs about death and dying, or by the role of family in decision-making [2, 3].

A declaration issued by a panel of Asian experts in 2019 recommended that studies on advance care planning prioritize cultural sensitivity[4]. To date, however, most Asian studies have been performed in high-income countries[2, 3, 5] and have not taken into account the combination of collectiveness (a culture that prioritizes the group over the individual) and religiosity (self-identified religious importance) that are central to medical decision-making in low-and middle-income countries such

as Indonesia[6]. Evidence suggests that people living in low- and middle-income countries tend to be more collectivistic and place higher importance on religion in their lives than those living in high-income countries.[7, 8] In Indonesia, advance care planning is not widely recognized as a useful concept, and do-not-resuscitate (DNR) forms are the only recognized type of advance care planning document[5].

Although it is difficult for many people in Indonesia to talk about death and dying[6], cancer survivors have been confronted with potential life-limiting illnesses and their possible recurrence. Therefore, they may have contemplated an adverse future and/or engaged in advance care planning. This study aimed to elicit some of these survivors' experiences and perspectives on the provision of medical information and advance care planning. We particularly focused on members of cancer support groups who were open to participation in this study[9, 10].

METHODS

Study Design and Setting

An open web-based survey of Indonesian cancer survivors was conducted between July and September 2021. The results were reported according to the Checklist for Reporting Results of Internet E-Surveys (CHERRIES)[11].

Population

We conceptualized a cancer survivor as any individual who has been cured, is in remission, or has active cancer[12]. We included individuals who (1) were aged 18 years or older, (2) had been diagnosed with a solid or hematologic malignancy at least 6 months before completing the survey, and (3) agreed to participate in the survey and provided informed consent for the study. Considering that Indonesia has no national registry of cancer survivors, we decided to conduct convenience sampling by approaching nine cancer survivor support groups in Indonesia, including five groups with national coverage (Figure 1). Two of the nine groups were breast cancer survivors. All the cancer survivor support groups agreed to distribute the survey to their members.

Data Collection

This study was conducted during the Covid-19 pandemic in Indonesia in 2021. Because of the implementation of semi-lockdown measures[13], we used an online platform for our survey.

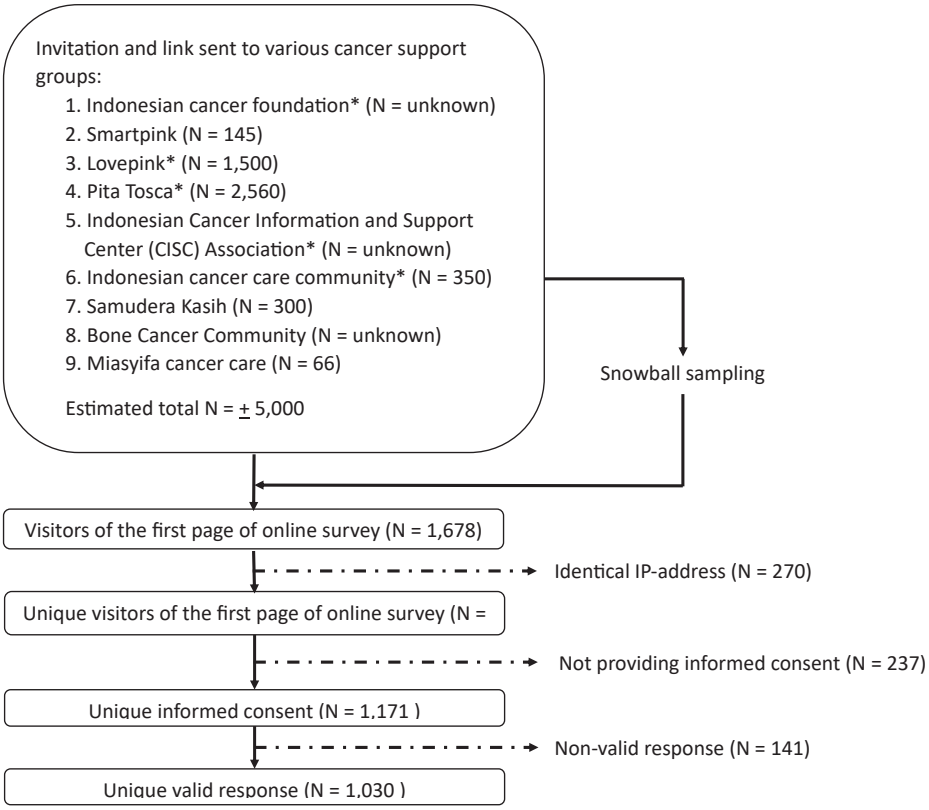


Figure 1. Flowchart of inclusion
* Cancer support group with national member coverage

The survey was advertised by distributing the study announcement and a link to the online survey (Appendix 1) through WhatsApp groups of cancer survivor support groups. WhatsApp is the most popular instant messaging platform and the most frequently used group-based communication tool in Indonesia[14, 15]. We also used the snowball sampling method; we asked participants to send the WhatsApp link to other potential participants for the study. This method was utilized to sample participants in difficult-to-reach or "hidden populations"[16].

Questionnaire Development and Pre-testing

First, DM, JR, CR, and AH developed a questionnaire based on previous systematic reviews on ACP in Asia[2, 3], qualitative studies in Indonesia[6, 17], and a cross-sectional survey of the Dutch general population[18]. The questionnaire was translated from English into Bahasa, the main Indonesian language. To ensure that it would maintain the meaning of the original version, a bilingual researcher first

forward-translated every item of the questionnaire into Bahasa. It was then back translated by an independent bilingual researcher who was blinded to the original questionnaire. A comparison of the original and back-translated questionnaires by DM revealed no differences in meaning. Next, the translated questionnaire was sent to ten Indonesian experts: two medical oncologists, three palliative care physicians, two oncology nurses, two palliative care nurses, and one psychologist for review. Based on their feedback, revisions were made to clarify the meaning and make the text easier to understand. Finally, the questionnaire was piloted among 15 cancer survivors to determine whether they found the questions clear and whether there were technical difficulties in completing the electronic questionnaire. Based on their feedback, final adjustments were made.

The questions were intended to assess the following: (1) participants' sociodemographic characteristics (age, gender, marital status, living situation, education, employment status, monthly household income, medical insurance, and religion); (2) their clinical characteristics (self-perceived health status, cancer diagnosis, time since initial cancer diagnosis, treatment for cancer, time of the last cancer treatment, and comorbid illnesses); (3) their experiences with and perspectives on the provision of medical information related to cancer and life-limiting illnesses; and (4) their experiences with and perspectives on advance care planning.

Data Management and Analysis

The data were collected using a secured online survey system "LimeSurvey"[19] and locked before the data analysis. Given the open recruitment of the participants, the response rate could not be determined. Based on the CHERRIES framework, we calculated the participation rate by dividing the total number of unique participants who provided informed consent by the total number of unique visitors who visited the survey landing page[11]. To minimize duplicate responses, we performed an IP check. In the case of duplicate IP addresses, we included only the first completed survey for further analysis. To protect against unauthorized access, pseudo-anonymized information was collected and stored where it was accessible only to the primary investigator. A response was considered valid and analyzed when it reached the question about advance care planning (question 19 out of 25). We further determined the completion rate by dividing the number of participants who responded to all the questions by the total number of unique participants who had completed the informed consent[11].

We used descriptive analyses to describe cancer survivors' demographic and clinical characteristics, and their perspectives on information disclosure and advance

care planning. Depending on the data distribution, data in numerical values are displayed as means and standard deviations (SDs) or medians and ranges. SPSS v.25 was used for data analysis.

RESULTS

Characteristics of the participants

The first page of the online survey was visited 1,678 times (Figure 1). After removing identical IP addresses (N=270) and questionnaires where the informed consent question was not answered (N=237), we obtained 1,171 unique responses (participation rate = 83%). Subsequently, we removed invalid responses or responses that did not answer the first question related to advance care planning (Question 19, N = 141). This left 1,030 valid responses; 960 participants completed all questions in the survey (completion rate = 82%). Our analysis was based on 1,030 valid responses.

The majority of the participants (Table 1) were aged under 60 years (92%), female (91%), married (78%), and Muslim (75%), considered themselves to be in a healthy state (84%), had been diagnosed with breast cancer (68%), and had completed higher education (64%). Seventy seven percent of the participants were more than one year beyond their diagnosis of cancer, 19% were more than 5 years beyond diagnosis, 47% had completed cancer treatment, and 41% were still receiving such treatment when they participated in the survey.

Participants' experiences with and preferences regarding the provision of information related to serious illness

Ninety-four percent of the participants were informed about their initial cancer diagnosis by a physician and 3% by family members (Table 2). While most participants were informed about their type of cancer (90%) and stage (68%), few had been informed about the curability of their cancer (54%), the risk of recurrence (37%), or their life expectancy (19%). When asked what information they would wish to receive if they were diagnosed with a life-limiting illness, 81% of participants answered that they would appreciate information on the curability of the disease, 66% information about the expected disease trajectory, and 37% information about their life expectancy. Seventy-five percent of the participants who were willing to be informed about their illness wished to be informed directly by their physician with or without the presence of their family members.

Table 1. Participants' characteristics

Characteristics	Frequency (N = 1,030)	%
Age		
18-40	293	28.4
41-60	655	63.6
>60	82	8.0
Gender		
Male	96	9.3
Female	934	90.7
Marital status		
Married	802	77.9
Divorced	53	5.1
Widowed	62	6.0
Never married	113	11.0
Educational status		
Never attended formal education	8	0.7
Elementary school	17	1.7
Junior high school	48	4.7
Senior high school	295	28.6
College/Universities	662	64.3
Employment status		
Employed	449	43.6
Unemployed	122	11.8
Retired	57	5.5
Housewife	402	39.1
Monthly income		
Less than minimum regional wage	176	17.1
1-2 times minimum regional wage	231	22.4
More than 2 times minimum regional wage	238	23.1
I don't know	150	14.6
I prefer not to answer	235	22.8
Health insurance		
Not insured	33	3.2
Subsidized public insurance	229	22.2
Non-subsidized (paid) public insurance	623	60.5
Private insurance	32	3.1
More than one insurance	113	11.0
Religion		
Islam	772	75.0
Christian	146	14.2
Catholic	97	9.4
Buddhism	7	0.7
Hindu	7	0.7
Confucian	1	0.1
I prefer not to answer	0	0

Table 1. Participants' characteristics *(continued)*

Characteristics	Frequency (N = 1,030)	%
Cancer volunteer activities		
Yes	264	25.6
No	724	70.3
I am not sure	42	4.1
Self-perceived health status		
Very healthy	134	13.0
Healthy	734	71.3
Unhealthy	153	14.9
Very unhealthy	8	0.8
History of cancer treatment		
No history of treatment	52	5.0
Completed cancer treatment	479	46.5
Currently receiving initial cancer treatment	417	40.5
Currently receiving cancer treatment for recurrence	53	5.1
Not sure	9	0.9
History of not completed treatment	20	2.0
Time of cancer diagnosis		
6 months -1 year before completion survey	234	22.7
1-5 year etc	604	58.7
>5 year etc	192	18.6
Type of cancer diagnosis[a]		
Breast	695	67.5
Cervical	67	6.5
Colorectal	31	3.0
Gastric	6	0.6
Lung	17	1.7
Liver	10	1.0
Nasopharyngeal	17	1.7
Prostate	4	0.4
Lymphoma	28	2.8
Leukemia	16	1.6
Ovarian	44	4.3
Thyroid	37	3.7
Not sure	36	3.5

[a]More than one answer possible

Table 2. Participants' experiences with and preferences for information provision

	Frequency (N=1,030)	%
Who initially disclosed your cancer diagnosis?		
Physician	966	93.8
Nurse	4	0.4
Family member	31	3.0
Other	29	2.8
What information did you receive from your healthcare professionals?[a]		
Type of cancer	925	89.8
Cancer stage	703	68.3
Curability	554	53.8
Risk of recurrence	385	37.4
Life expectancy	199	19.3
If you were diagnosed with a life-limiting illness, what information would you like to receive?[a]		
The name of the disease	762	74.0
The severity of the disease	631	61.3
The curability of the disease	834	81.0
Expected disease trajectory	678	65.8
Life expectancy	376	36.5
I don't want any information	57	5.5
How do you want the information to be delivered to you?[b]	**Frequency (N = 973)**	
The physician tells me first	333	34.2
The physician tells me and my family at the same time	439	45.1
The physician tells my family first	31	3.2
It doesn't matter to me	170	17.5

[a]More than one answer possible
[b]Of those who are willing to receive the information

Participants' experiences with and preferences regarding advance care planning

Sixty-five percent of the 1,030 participants (Figure 2a) had thought about the possible future worsening of their condition. More specifically, 51% had thought about the medical treatments they would prefer at the end of life, 33% about resuscitation, 47% about healthcare proxies, and 53% about what would be important for them at the end of life. Fewer of them had discussed these topics with others (36%, 21%, 35%, and 42%, respectively) or had documented their preferences in an advance directive (26%, 12%, 24%, and 27%, respectively).

Approximately two-thirds of the 1,030 participants (Figure 2b) indicated that they were willing to discuss their medical treatment at the end of life (67%), healthcare proxies (66%), and what would be important for them at the end of life (69%). Fewer participants (46 %) were willing to discuss resuscitation. Half of the participants were willing to make written statements about who would be their healthcare proxy and what would be important for them at the end of life. Fewer were willing to document preferences for medical treatment and care at the end of life (42%) and whether or when they would opt for resuscitation (34%).

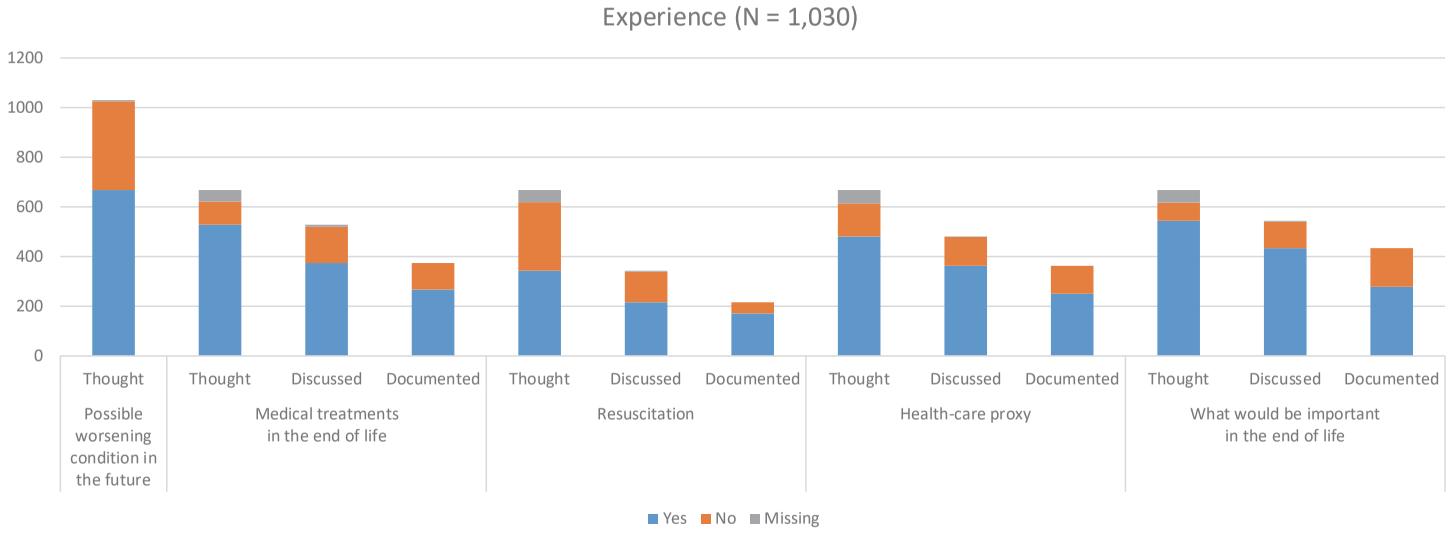
Over half of those who had thought about advance care planning topics but had never discussed them with others were willing to do so (55-69%) (Table Appendix 4). Less than half of those who had not documented their preferences for future treatment and care (34-50%) were willing to do so (Table Appendix 5).

Regarding the initiation of advance care planning conversations, 31% of all participants (Appendix 6) wished to do so when they were still healthy, 30% when diagnosed with an incurable illness, and 5% when their life expectancy was less than six months. Seventeen percent had no clear idea of their preferences and 9% wanted not to have an advance care planning conversation.

Most of the participants who had discussed elements of advance care planning (Appendix 7) had discussed them with their family members (78-96%), some of them with (13-38%) and without (40-84%) healthcare professionals. Likewise, most participants (50-97%) were willing to discuss these topics with their family members, some of them with (14-50%) and without (36-79%) healthcare professionals.

As shown in Appendix 8, the reasons for willingness to engage in advance care planning were that the family would then understand the participants' values, wishes, and preferences for end-of-life care (61%); that participants wanted to decide on their own future care (60%); that they wanted to avoid end-of-life suffering (46%); and that they did not want to put the burden of decision-making on their family (46%). Frequently cited reasons for not wanting to engage in advance care planning were the belief that it is more important to surrender to God's will than to have control over the future (53%), belief that death is a natural event (40%), and desire to focus on the present (40%).

a. Cancer survivors' experiences with advance care planning



b. Cancer survivors' willingness to engage in advance care planning

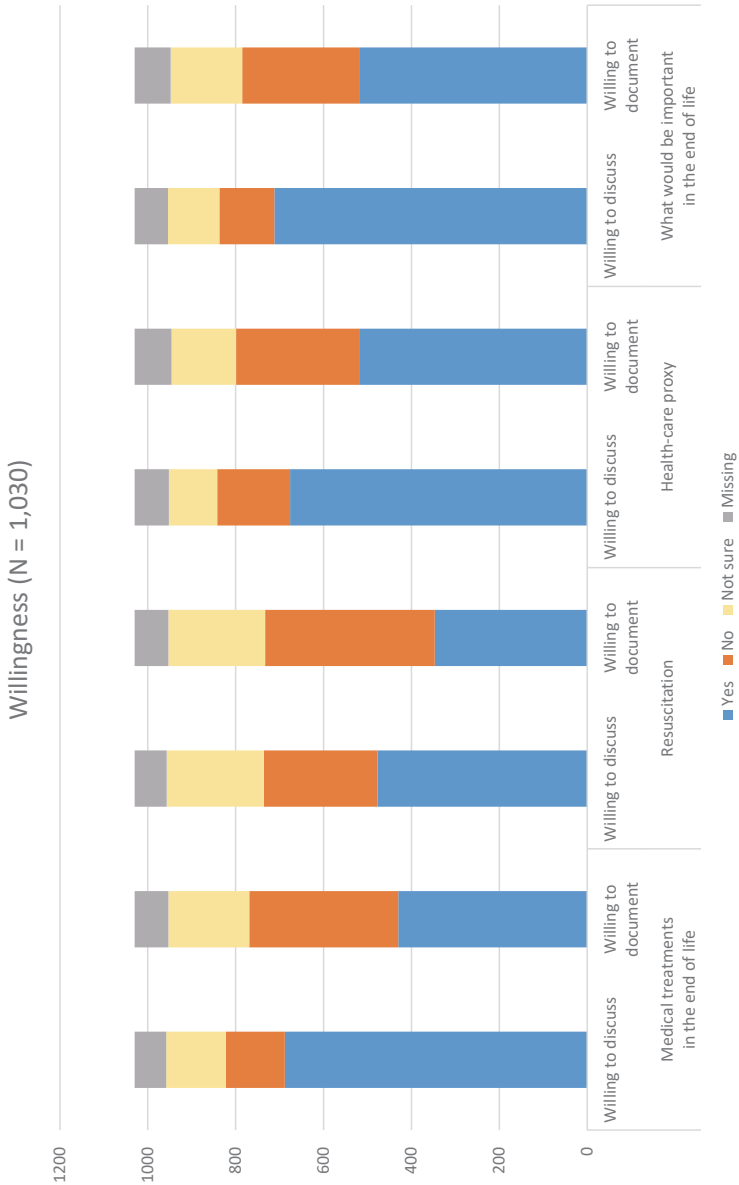


Figure 2. Cancer survivors' experiences with and willingness to engage in advance care planning

DISCUSSION

More than half of the participating cancer survivors in this study were under 60 years of age, female, had completed higher education, were diagnosed with breast cancer and were more than one year from diagnosis of their cancer. They wished to be informed about their illnesses and were willing to engage in advance care planning. While many participants were willing to discuss several elements of advance care planning, they had not yet discussed them all. The majority of those willing to engage in advance care planning preferred to do so before becoming terminally ill. The most important reasons for not wanting to engage in advance care planning were the desire to surrender to God's will, the belief that people should not intervene in the natural process of dying, and the wish to focus on here-and-now.

Our study showed that three-quarters of the participants wished to be informed about their illness by their physicians rather than by family caregivers. Whereas family caregivers in a previous study considered mediated information provision to be a sensitive way of delivering bad news[17], the majority of cancer survivors in the current study preferred information provision not to be mediated. A minority wished to be informed about their estimated life expectancies. A previous study showed that some patients considered such information irrelevant, believing life to be God's sole authority[17]. Others would avoid such information to preserve hope[17]. These findings demonstrate that accurate prognostic awareness can have both benefits and disadvantages. On the one hand such awareness may promote informed and value-based decision making, thus enabling the attainment of goal-concordant care[20, 21]. On the other hand, prognostic awareness has been found to be associated with a worse quality of life, higher anxiety and depression levels, and a higher sense of burden[22-24]. Patients with cancer worldwide have various preferences for prognostic disclosure, with people preferring a broad indication of prognosis rather than exact quantitative information[25]. Accordingly, before medical information is disclosed to a patient, it is important to determine the information they prefer.

Nearly 70% of the participants in this study who had thought about one or more aspects of advance care planning but had never discussed them with others were actually willing to do so. Furthermore, the majority of participants who had engaged or would be willing to engage in advance care planning conversations had done so or would do so with their family members, sometimes without the presence of healthcare professionals. Therefore, most cancer survivors seem to consider family involvement in advance care planning essential. Prior evidence suggests that

patients from countries with collectivist cultures more often wish to involve their family members in such conversations than patients from Western countries[26]. Therefore, supporting family members' engagement in advance care planning could indirectly facilitate patient engagement[27]. We also found that one-third of our participants wished to initiate advance care planning conversations upon being diagnosed with an incurable illness and one-third even earlier, when they were still healthy. These findings indicate the scope for extending advance care planning initiatives from healthcare settings to community settings (e.g., within families, faith groups, or cancer support groups). Cancer support groups might serve as an effective platform for promoting advance care planning among their members, considering their effectiveness in fostering confidence and self-efficacy in decision-making through the provision of a safe, trusting, and empowering environment[28].

Although a do-not-resuscitate order is currently the only available form of an advance directive in Indonesia[5], our findings show that few cancer survivors were willing to discuss resuscitation. Resuscitation may be a relatively difficult topic in advance care planning conversations[29], especially in Asia, where death and dying are taboo topics[3]. Indonesian healthcare professionals should, therefore, be educated to approach advance care planning as a discussion that not only addresses resuscitation but also value exploration. Individuals' reluctance to consider certain topics does not necessarily exclude them from engaging in advance care planning. Instead, engaging them in a topic they are ready to discuss is necessary to creating meaningful conversations and a trusting relationship between patient and healthcare professionals, which may further facilitate their' readiness to talk about other "difficult" topics[29]. Our finding of this reluctance also supports the need for a wider conceptualization of advance care planning as a process of value exploration, rather than merely conversations about future treatment planning.

STRENGTHS AND LIMITATIONS

To our knowledge, this is the first survey to explore Asian cancer survivors' perspectives on advance care planning. Second, our study included a large number of participants: a wide variety of major Indonesian cancer support groups, five of which covered national membership and high participation and completion rates. Third, our methodology allowed us to evaluate sensitive topics in a selective population, which was presumably more open and motivated to engage in discussing culturally sensitive topics regardless of the Covid-19 pandemic situation.

Two main limitations need to be considered when interpreting this study. First, our study is an open web-based survey involving convenience sampling, which can be subject to considerable bias due to the self-selection of participants who needed to be able to access the Internet. Second, based on patients' self-perceived health status and the low percentage (5.1%) of patients who were receiving cancer treatment for recurrence, many patients may have been treated with curative intent, limiting its generalizability to patients in their last 12 months of life. Further research is needed to examine preferences for medical information and advance care planning across various cultures while taking into account the patients' disease trajectory and prognosis. The high representation of young, female, educated breast cancer survivors in our study is consistent with the characteristics of online survey participants in prior studies of cancer support groups[9]. Therefore, the findings of this study may not be generalizable to cancer survivors with other characteristics.

CONCLUSION

The majority of the participating members of the Indonesian cancer survivor support groups were highly educated, motivated, female, relatively young, and more than one year beyond diagnosis of their cancer. The participants' preferences for medical information and involvement in advance care planning varied widely. Those who were willing to engage in advance care planning rarely had done so. Culturally sensitive advance care planning involves healthcare professionals eliciting individuals' preferences for medical information disclosure and engagement in discussing different topics in advance care planning conversations.

DECLARATIONS

Ethics Approval

This study was approved by the Ethical Committee of the Faculty of Medicine at Universitas Indonesia—Cipto Mangunkusumo Hospital on May 10th, 2021 (KET-453/UN2.F1/ETIK/PPM.00.02/2021).

Consent to Participate

Participants were informed of the purpose and design of the study and provided informed consent on the first page of the online survey (Data Supplement). Participants who completed the survey were offered a token of appreciation in the form of a data bundle worth around 3.5 USD.

Consent for Publication

The authors affirm that participants provided informed consent for publication.

Acknowledgement:

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Appendix 1.
The announcement to the survey and link to access the survey

Dear Sir/Madam/Miss,

We invited you to participate in the survey "Advance care planning discussion." This survey aimed to understand the perceptions of individuals who have been diagnosed with cancer regarding the discussion of their values, wishes, or preferences for their future care. This is a collaborative study between: (1) Erasmus Medical Center, Rotterdam, the Netherlands; (2) Psychosomatic and Palliative Division, Department of Internal Medicine, Faculty of Medicine, Universitas Indonesia; and (3) the Indonesian Cancer Foundation, which has been granted ethical clearance from the Faculty of Medicine Universitas Indonesia Ethical Committee (No: KET-453/UN2.F1/ETIK/PPM.00.02/2021).

You can participate in this survey if you are 18+ years old and diagnosed with cancer at least six months prior to participation in this survey (including those who are cured or in remission). This survey contains 25 questions, and its completion takes approximately 15 minutes. You can access the survey through the following link: https://erasmusmcsurvey.erasmusmc.nl/mgz/ls/index.php/943735?lang=id

Upon completing the survey, you will be entitled to a data bundle worth 50,000 IDR as compensation for your time and valuable contributions. Further information regarding this will be provided at the end of the survey.

Appendix 2.
First page of the online survey (information of the study and informed consent)

Advance care planning: A survey study of Indonesian cancer survivors' perspectives

Dear Sir/Madam/Miss

Thank you very much for your willingness to participate in the "Advance Care Planning: A survey study of Indonesian cancer survivors' perspectives." This survey will explore the perceptions of individuals who have been diagnosed with cancer regarding the discussion of their values, wishes, or preferences for future care.

We invited you to participate in this survey because you were 18+ years old and had been diagnosed with cancer at least six months prior to participation in this survey. The completion of this survey will take approximately 10–15 minutes.

Participation in the survey was voluntary. If you decide not to participate, you will not have to take further action. You may quit participation at any time you wish without justification.

All the information will be treated with confidentiality. Scientific data is stored for a maximum of 15 years after the termination of the study. Only the research team will have access to the information provided. Because it may be necessary to trace data to an individual subject, a subject identification code list will be used to link the data to the subject. In this way, the data will be anonymized and given a unique identification number, for example, IDN01001. Forms with identifiable data will be saved separately from the research data. For the purpose of data analysis, research data will be shared among the researchers. The study results will be sent to scientific journals for dissemination, but no data will be transmitted that could lead to participant identification.

If you have any additional questions, please feel free to contact the researcher: Diah Martina, MD (email: d.martina@erasmusmc.nl; WhatsApp message: +316837XXXXX) or Dr. Rebecca Angka, MBiomed (+628181XXXXX).

If you were interested in joining the study and completing the survey, kindly provide your consent by ticking in the agreement box (informed consent). By means of your

written consent, you indicate that you have understood the information provided and approved your participation in the study and the use of your data as described above.

Upon completing the survey, you will be entitled to a data bundle worth 50,000 IDR as compensation for your time and valuable contributions. Further information regarding this will be provided at the end of the survey.

☐ I understand the information related to the survey and agree to participate.

Appendix 3.
The lists of questions in online survey

I. Sociodemographic characteristics

The following information will help us understand who you are

1. What is your current age (years)? : …
2. Gender:
   a) Male
   b) Female
   3. Current marital status:
   a) Single
   b) Married
   c) Separated/divorced
   d) Widowed
4. I am currently living with (check on every options relevant for you):
   a) Alone
   b) With nuclear family members
   c) With extended family
   d) Living with other than family members:…….
5. Completed highest level of education:
   a) Never attended formal education
   b) Elementary school
   c) Junior high school
   d) Senior high school
   e) College/University
   f) Others: …….
6. Current employment status:
   a) Employed
   b) Unemployed
   c) Retired
   d) Housewife
7. Monthly household income (the total amount of money earned by every member of a single household in a month, including wages, salaries, investment returns, retirement accounts, and welfare payments):
   a) I don't know
   b) Less than regional minimum wage*
   c) 1-2 times of regional minimum wage*
   d) More than 2 times of regional minimum wage*

e) I prefer not to answer

* refers to the regional minimum wage:

Daftar Upah Minumum Provinsi 2021

1. Aceh	Rp 3.165.031,00
2. Sumatera Utara	Rp 2.499.423,06
3. Sumatera Barat	Rp 2.484.041,00
4. Sumatera Selatan	Rp 3.043.111,00
5. Riau	Rp 2.888.564,01
6. Kepulauan Riau	Rp 3.005.460,00
7. Jambi	Rp 2.630.162,13
8. Bangka Belitung	Rp 3.230.023,66
9. Bengkulu	Rp 2.215.000,00
10. Lampung	Rp 2.432.001,57
11. DKI Jakarta	Rp 4.416.186,548
12. Jawa Barat	Rp 1.810.351,36
13. Jawa Tengah	Rp 1.798.979,12
14. Jawa Timur	Rp 1.868.777,08
15. D.I Yogyakarta	Rp 1.765.000,00
16. Banten	Rp 2.460.996,54
17. Bali	Rp 2.494.000,00

Daftar Upah Minumum Provinsi 2021

18. Kalimantan Selatan	Rp 2.877.448,59
19. Kalimantan Timur	Rp 2.981.378,72
20. Kalimantan Barat	Rp 2.399.698,65
21. Kalimantan Tengah	Rp 2.903.144,70
22. Kalimantan Utara	Rp 3.000.804,00
23. Sulawesi Selatan	Rp 3.165.876,00
24. Sulawesi Utara	Rp 3.310.723,00
25. Sulawesi Tenggara	Rp 2.552.014,52
26. Sulawesi Tengah	Rp 2.303.711,00
27. Sulawesi Barat	Rp 2.678.863,10
28. Gorontalo	Rp 2.788.826,00
29. NTB	Rp 2.183.883,00
30. NTT	Rp 1.950.000,00
31. Maluku	Rp 2.604.961,00
32. Maluku Utara	Rp 2.721.530,00
33. Papua	Rp 3.516.700,00
34. Papua Barat	Rp 3.134.600,00

8. My current medical insurance:
   a) Not insured
   b) Public health insurance; recipient of contribution assistance
   c) Public health insurance; non-recipient of contribution assistance
   d) Private health insurance
   e) More than one medical insurance
   f) Others: …
9. Religion:
   a) Islam
   b) Christian
   c) Catholic
   d) Buddhism
   e) Hindu
   f) Khong Hu Cu (Confucian)
   g) I prefer not to answer
   h) Others: ……..

II. Clinical characteristics

The following information will help us understand about your current health condition.

10. How do you consider your current health condition in general?
    a) Very healthy

b) Healthy
c) Not healthy
d) Very unhealthy

11. Have you ever received medical treatment for your cancer (e.g., chemotherapy, radiotherapy, surgery, targeted therapy)?
    a) No
    b) Yes, and I am currently being treated for cancer
    c) Yes, and I have completed it
    d) Yes, but I didn't complete it
    e) Yes, and I am now being treated / had been treated again for recurrence
    f) I don't know
    g) Others: ……
12. Do you know what kind of treatment you have received in the past for your cancer (You can choose more than one option)?
    ☐ Chemotherapy
    ☐ Radiotherapy
    ☐ Surgery
    ☐ Hormonal therapy
    ☐ Immunotherapy
    ☐ Targeted therapy
    ☐ Alternative therapy
    ☐ I don't know
    ☐ Others: …….
13. Do you have any other illness (other than cancer) right now (you can choose more than one option)?
    ☐ Diabetes
    ☐ Heart disease
    ☐ Kidney disease
    ☐ Respiratory disease
    ☐ Stroke
    ☐ Hypertension
    ☐ I don't have other illness
    ☐ I don't know (not sure)
    ☐ Others: ……

III. Experiences with the provision of cancer-related information

The following questions will ask about your past experience with your cancer and how the information related to the cancer was communicated to you.

14. Which year were you informed that you had cancer for the first time?: ….
15. What type of cancer have you been diagnosed (You can choose more than one option)?
    - ☐ Breast
    - ☐ Cervix
    - ☐ Colorectal (intestine)
    - ☐ Stomach
    - ☐ Lung
    - ☐ Liver
    - ☐ Nasopharynx
    - ☐ Prostate
    - ☐ Lymphoma
    - ☐ Leukemia
    - ☐ Ovary
    - ☐ I don't know (not sure)
    - ☐ Others: …….
16. Who initially told you about the diagnosis of your cancer?
    a) Physician
    b) Nurse
    c) Family member
    d) Others: ….
17. What kind of information has you received from your healthcare professionals in the past? (You can choose more than one option.)
    - ☐ The name of the cancer
    - ☐ The stage of the cancer
    - ☐ Whether it is curable or not
    - ☐ The possibility of recurrence
    - ☐ Life expectancy
    - ☐ Others: …….

IV. Perspectives on the provision of serious illness related information

The following questions will ask about your wishes or preferences regarding the kind of information you would want and how would you want it to be communicated.

18. If you were diagnosed with a life-threatening illness (a disease that is generally incurable and can result in a shortened life expectancy), what information would you like to receive? (You can choose more than one option.)

- ☐ The name of the disease
- ☐ The severity of the disease
- ☐ Whether it is curable or not
- ☐ The course of the disease (trajectory of the disease)
- ☐ Life expectancy
- ☐ I don't want to be informed at all
- ☐ Others: …….

* Participants who check 'I don't want to be informed at all' are directly referred to question 19

How do you want the information (number 18) be delivered to you?

a) No one / I prefer not to be informed about any of the aforementioned information
b) Physician
c) Nurse
d) Family member
e) It doesn't matter who convey the information

19. Have you ever thought about a situation in which your illness worsens in the future?
    a) Yes
    b) No

    * Participants who answer "Yes" are referred to question 20, participants who answer "No" are directly referred to question 23

V. Experiences with and perspectives on advance care planning

In certain situations, a person may experience a decline in his/her health condition so that he/she is no longer able to communicate or make decisions for him/herself.

The following questions will ask about what seems important for you in the future:

20. Have you ever thought about any of the following:
    a) Medical treatment that I would or would not want at the end of life (Yes/No)
    b) Whether and in which circumstances I would want resuscitation* (Yes/No)
    c) Who would be my health-care proxy** (Yes/No)
    d) What would be important to me at end-of-life (Yes/No)?

* e.g., chest compression, electric shock, or drugs to stimulate heart when it stops

** someone who will make decision on your behalf regarding your future care if at some point you are unable to do so due to worsening of your health condition

* Participants who answer "Yes" to subquestion (a) are referred to question 21 subquestion (a), participants who answer "Yes" to subquestion (b) are referred to question 21 subquestion (b), and so on.

21. You have answered "Yes" to the previous question. Have you ever discussed the following points?
    a) Medical treatment that I would or would not want at the end of life (Yes/No)
    b) Whether and in which circumstances I would want resuscitation* (Yes/No)
    c) Who would be my health-care proxy** (Yes/No)
    d) What would be important to me at the end-of-life (Yes/No)

    * e.g., chest compression, electric shock, or drugs to stimulate heart when it stops

    ** someone who will make decision on your behalf regarding your future care if at some point you are unable to do so due to worsening of your health condition

    * Participants who answer "Yes" to subquestion (a) are referred to question below subquestion (a), participants who answer "Yes" to subquestion (b) are referred to as question (b) below, and so on.

    With whom have you discussed these topics (you can choose more than one option)?
    a) Medical treatments that I would or would not want at the end-of-life (my family/physician or other HCPs/both family and HCPs/others)
    b) Whether and in which circumstances I would want resuscitation* (my family/physician or other HCPs/both family and HCPs/others)
    c) Who would be my healthcare proxy** (my family/physician or other HCPs/both family and HCPs/others)
    d) What would be important to me at the end-of-life (my family/physician or other HCPs/both family and HCPs/others)

22. I have made a written statement or signed a form including the following topics:
    a) Medical treatment that I would or would not want at the end of life (Yes/No)
    b) Whether and in which circumstances I would want resuscitation* (Yes/No)
    c) Who would be my health-care proxy** (Yes/No)
    d) What would be important to me at the end-of-life (Yes/No)

    * e.g., chest compression, electric shock, or drugs to stimulate heart when it stops

    ** someone who will make decision on your behalf regarding your future care if at some point you are unable to do so due to worsening of your health condition

23. Would you be willing to discuss any of the following topics:
    a) Medical treatments that I would or would not want at the end of life (Yes/No/Not sure)
    b) Whether and in what circumstances I would want resuscitation* (Yes/No/Not sure)
    c) Who would be my healthcare proxy** (Yes/No/Not sure)
    d) What would be important to me at the end of life (Yes/No/Not sure)

    * e.g., chest compression, electric shock, or drugs to stimulate heart when it stops

    ** someone who will make decision on your behalf regarding your future care if at some point you are unable to do so due to worsening of your health condition

    With whom do you want to discuss these topics (you can choose more than one option)?
    a) Medical treatments that I would or would not want at the end-of-life (my family/physician or other HCPs/both family and HCPs/others)
    b) Whether and in which circumstances I would want resuscitation* (my family/physician or other HCPs/both family and HCPs/others)
    c) Who would be my healthcare proxy** (my family/physician or other HCPs/both family and HCPs/others)
    d) What would be important to me at the end-of-life (my family/physician or other HCPs/both family and HCPs/others)

    * e.g., chest compression, electric shock, or drugs to stimulate heart when it stops

    ** someone who will make decision on your behalf regarding your future care if at some point you are unable to do so due to worsening of your health condition

24. Would you be willing to make a written statement (living will) on one of these topics?:
    a) Medical treatments that I would or would not want at the end of life (Yes/No/Not sure)
    b) Whether and in what circumstances I would want resuscitation* (Yes/No/Not sure)
    c) Who would be my healthcare proxy** (Yes/No/Not sure)
    d) What would be important to me at the end of life (Yes/No/Not sure)

    * e.g., chest compression, electric shock, or drugs to stimulate heart when it stops

    ** someone who will make decision on your behalf regarding your future care if at some point you are unable to do so due to worsening of your health condition

You have answered "Yes" to one or more of the questions above (number 21-24), can you provide your reason? (You can choose more than one option.)

- ☐ I want to decide on treatment at the end of my life, following my values, wishes, and preferences.
- ☐ I don't want to suffer at the end of my life
- ☐ I want my family to understand my values, wishes, and preferences regarding my future care at the end-of-life.
- ☐ I want to prevent conflict within my family
- ☐ I want to avoid placing burden of decision making on my family
- ☐ Others: ……..

You have answered "No" or "Not sure" in one or more of the statement above (number 21-24), tell us your reason (You can choose more than one option):

- ☐ It makes me feel anxious or uncomfortable
- ☐ I might change my mind in the future
- ☐ I am not sure if my wishes or preferences will be respected when the time comes.
- ☐ I'm afraid my family will feel sad
- ☐ I'm afraid it will cause conflict within my family
- ☐ My family or my physician will make a wise decision for me
- ☐ I believe that surrendering in God's will is more important than thinking about the future.
- ☐ I believe that talking about death would cause bad luck
- ☐ I just want to focus on my current condition
- ☐ I believe that death is a natural event
- ☐ I don't think my physician will have the time for this conversation
- ☐ I don't know how to start the conversation with family and/or physician
- ☐ Others: …..

25. In your opinion, when is it the most appropriate time to start a discussion about your wishes and preferences for treatment and care at the end of life?
    a) When I'm still healthy
    b) When I am diagnosed with incurable illness
    c) When my life expectancy is less than 6 months
    d) When death is imminent
    e) Not at all
    f) I don't know
    g) Others: ….

Thank you very much for your valuable contribution to this study.

We value your participation in this study and would like to offer a token of participation in the form of a data bundle worth 50,000 IDR. If you are willing to accept this offer, we will need the mobile number to be topped up and your consent to provide this information. The information will be treated confidentially and disposed of after we finalize the data bundle transfer.

☐ I agree to provide my mobile number to facilitate the transfer of data bundle.

- Mobile number to be topped up:…

Appendix 4.

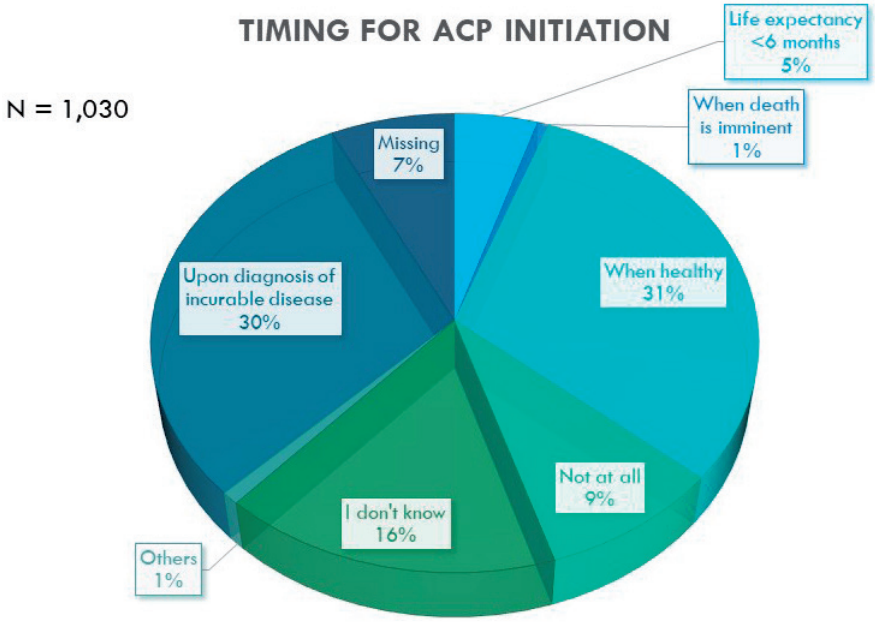
Experiences with and willingness to engage in advance care planning conversations among participants who had thought about different advance care planning topics

			N	Willing to discuss (n, %)
				Medical treatments at the end of life
Had discussed*	Medical treatments at the end-of-life	Yes	374	340 (91%)
		No	146	90 (62%)
				Whether and in which circumstances I would want resuscitation
	Whether and in which circumstances I would want resuscitation	Yes	216	194 (90%)
		No	123	67 (55%)
				Who would be my health-care proxy
	Who would be my health-care proxy	Yes	363	331 (91%)
		No	116	80 (69%)
				What would be important to me at the end of life
	What would be important to me at the end of life	Yes	434	383 (88%)
		No	106	67 (63%)

Appendix 5.
Experiences with and willingness to make a written statement of advance care planning conversation among participants who had thought about different advance care planning topics

			N	Willing to make written statement (n, %)
				Medical treatments at the end of life
Have made written statement*	Medical treatments at the end-of-life	Yes	267	187 (70%)
		No	253	92 (36%)
				Whether and in which circumstances I would want resuscitation
	Whether and in which circumstances I would want resuscitation	Yes	171	128 (75%)
		No	169	58 (34%)
				Who would be my health-care proxy
	Who would be my health-care proxy	Yes	250	196 (78%)
		No	229	115 (50%)
				What would be important to me at the end of life
	What would be important to me at the end of life	Yes	278	214 (77%)
		No	260	111 (43%)

Appendix 6
Timing of advance care planning conversations



Appendix 7.
Participants' experiences with and preferences about whom to engage in advance care planning (among those who had discussed or were willing to discuss it)

	N (%)				
	Family	Family and HCPs	HCPs	Others	Missing
With whom did you discuss the following topics?[a]					
Medical treatments that I would or would not want at the end-of-life (N = 374)	204 (54.5)	140 (37.5)	28 (7.5)	2 (0.5)	0
Whether and in which circumstances I would want resuscitation (N = 216)	86 (39.8)	82 (38.0)	43 (19.9)	2 (0.9)	3 (1.4)
Who would be my health-care proxy (N = 363)	303 (83.5)	46 (12.7)	11 (3)	3 (0.8)	0
What would be important to me at the end-of-life (N= 434)	339 (78.1)	76 (17.5)	12 (2.8)	7 (1.6)	0
With whom would you be willing to discuss the following topics?[b]					
Medical treatments that I would or would not want at the end-of-life (N = 688)	277 (40.3)	344 (50.0)	60 (8.7)	5 (0.7)	2 (0.3)
Whether and in which circumstances I would want resuscitation (N = 477)	172 (36.1)	68 (14.3)	228 (47.8)	5 (1.0)	4 (0.8)
Who would be my health-care proxy (N = 676)	534 (79.0)	123 (18.2)	10 (1.5)	6 (0.9)	3 (0.4)
What would be important to me at the end of life (N = 712)	462 (64.9)	210 (29.5)	22 (3.0)	14 (2.0)	4 (0.6)

[a]Among participants who had discussed advance care planning topics
[b]Among participants who wanted to discuss advance care planning topics

Appendix 8.
Reasons for willingness or unwillingness to engage in advance care planning

Reasons for willingness to engage in advance care planning	Total = 852[a]		Reasons for unwillingness to engage in advance care planning	Total = 779[b]	
	N	%		N	%
I want my family understand my values, wishes and preferences with regards to my future care at the end of life	517	61	I believe that to surrender in God's will is more important than to think over the future	410	53
I want to decide on treatments at the end of my life following my values, wishes and preferences	511	60	I believe that death is a natural event	310	40
I don't want to suffer at the end of my life	394	46	I just want to focus on my current condition	312	40
I want to avoid placing burden of decision making on my family	394	46	I'm afraid my family will feel sad	257	33
I want to prevent conflict within my family	175	21	It makes me feel psychologically anxious or uncomfortable	225	29
Other reasons: I believe that the final decision/ ending is God's absolute right and that we must be prepared and be able to accept it	1		I might change my mind in the future	216	28
My family guide me to cite talqin (prayer before death) and remind me to pray	1		My family or my physician will make a wise decision for me	202	26
I just want to get closer to God	1		I don't know how to start the conversation with family and/or physician	73	9
I want to prepare my family to accept the worst scenario of my condition	1		I'm not sure if my wishes or preferences would be respected when the time comes	68	9
I want to be useful to others and live a peaceful life until the end of my life	1		I believe that talking about death would cause bad luck	41	5
			I don't think my physician will have the time for this conversation	38	5
			I'm afraid it will cause conflict within my family	37	5

[a]: Participants who answered "Yes" to any question on their willingness to engage in one or more advance care planning topics or documentation.
[b]: Participants who answered "No" or "Not sure" to any question on willingness to engage in one or more advance care planning topics or documentation

Chapter 9

General Discussion

This thesis aims to provide insight into the perspectives of Asians in general, and Indonesians in particular, regarding advance care planning. In this general discussion, the main findings of the studies presented in this thesis are described and interpreted, methodological considerations are discussed, and implications and recommendations for clinical practice and future research are given.

MAIN FINDINGS

Part I. Advance care planning in Asia

Research question 1: What recommendations do Asian experts have with regard to research priorities for advance care planning in Asia?

Thirty-one multidisciplinary experts from six Asian sectors recommended prioritizing research on a culturally sensitive model of advance care planning. This model should acknowledge the important cultural values in Asia relevant to advance care planning while avoiding stereotypical characterization.

Research question 2: What are Asian healthcare professionals' knowledge of, attitudes towards, and experiences with advance care planning, and perceived barriers and facilitators related to their engagement in it?

Our review showed that most Asian healthcare professionals acknowledge the potential value of advance care planning. Yet, they acknowledge the essential role of families in advance care planning and rarely engage the patient in it. They consider advance care planning challenging to initiate, partly because of their lack of knowledge and skills in advance care planning, personal uneasiness to conduct advance care planning conversations, fear of conflicts with the family members and its legal consequences, and the lack of a standard system to support advance care planning. Most studies in this review indicated low engagement and late initiation of advance care planning by healthcare professionals.

Research question 3: What are Asian patients' perspectives on advance care planning?

Our second review showed that although most Asian patients acknowledge the importance of advance care planning, findings regarding their actual willingness to engage in it and to formally document it varied. Willingness to engage in advance care planning was affected by patients' knowledge of their disease and advance care planning and by their beliefs about its advantages or disadvantages, about its concept that should be in accordance with patients' faith and their families' or

physicians' wishes, and about potential barriers. These factors were found to affect patients' preferences about their role in advance care planning, when it should be initiated, and how formally it should be used.

Research question 4: What is the role of acculturation in the engagement in advance care planning among Chinese immigrants in Western countries?

Our review of Chinese immigrants showed that their engagement in advance care planning was influenced by their self-perceived cultural identity (native or non-native), their interpretation of filial piety (which is a set of norms, values, and practices regarding how children should behave toward their parents; traditional or modern), and their interpretation of autonomy (individual or familial). To facilitate their engagement in advance care planning, Chinese immigrants mostly preferred an implicit approach, initiation of advance care planning by non-family members, contextualization of advance care planning in the Chinese culture and the use of Chinese language.

Part II. Advance care planning in Indonesia

Research question 5: What are Indonesian cancer care professionals' perspectives on and experiences with advance care planning?

In a qualitative study of Indonesian cancer care professionals, we found that they were open to engaging in advance care planning, mainly when the advance care planning approach is sensitive to Indonesia's collectivism, communication norms, and religious beliefs. Due to families' leading role and hierarchical structure, which may challenge patients' engagement in advance care planning, Indonesian cancer care professionals believed that gaining families' support is essential for facilitating patients' engagement in advance care planning. They also believed that support systems for advance care planning should include education and training of healthcare professionals, public campaigns, resource allocation, and legal standard of advance care planning.

Research question 6: What are the perspectives of Indonesian patients with cancer and family caregivers on advance care planning?

In a qualitative study of Indonesian patients with cancer and family caregivers, four factors were found to influence the engagement in advance care planning: their perceptions on the importance or harmfulness of cancer-related information, the importance of discussing bad news sensitively through empathetic, implicit, and mediated communication, people's motives for participating in medical decision-making where decision-making can be seen as patients' right or responsibility but

patients can also be in a state of dependency, and perspectives on the usefulness of planning for the future, where people can e.g. find it irrelevant because of religious beliefs or other considerations.

Research question 7: What are Indonesian cancer survivors' perspectives on and experiences with medical information provision and advance care planning?
More than half of the participants in a survey study among cancer survivor support groups were young, female survivors who were highly educated and diagnosed with breast cancer. In case of a diagnosis of life-limiting illness, the majority of participants wished to be informed about their illness – preferably by their healthcare professionals – and were willing to engage in advance care planning, particularly with their family members and before they would become terminally ill. However, relatively few of them wished to know about their estimated life expectancy, to discuss resuscitation, or to document advance care planning conversations. The most important reasons for not being willing to engage in advance care planning were the wish to surrender to God's will and to focus on the here and now.

METHODOLOGICAL CONSIDERATIONS

Position statement: Chapter 2 → This is the first position statement in Asia regarding advance care planning based on the opinion of a multidisciplinary team of experts in six Asian sectors. The team consisted of 31 Asian professionals with various areas of expertise (e.g., palliative care, family medicine and public health, nursing, gerontology, biomedical ethics and healthcare law) which allowed the incorporation of diverse perspectives to inform our understanding of advance care planning in Asia. The consensus in this position statement was reached through a face to face discussion session to generate initial ideas. This was followed by multiple rounds of online discussion sessions for further ideation, clarification and feedback. The potential limitation of this methodology was the selection by the initiators of experts based on pre-existing social networks and past collaboration which may have resulted in similarity of views on advance care planning and missing of diverting views of experts from outside the networks. Further, this study did not use predefined criteria for reaching consensus and should therefore not be considered to result in consensus but rather in an opinion statement. However, this study set a stepping stone for a currently ongoing Delphi study in Asia aiming to reach a consensus on recommendations for a culturally sensitive advance care planning model based on more varied perspectives of a multidisciplinary group of Asian experts.[1]

Reviews: Chapter 3-5 → The reviews of scientific literature were the first to synthesize the available evidence pertaining to their respective research questions. The incorporation of all published studies, regardless of their designs (qualitative, quantitative, or mixed), enabled us to get a deeper and broader understanding of the research questions. In Chapters 3 and 5 we performed a narrative synthesis with the inclusion of various perspectives (Chapter 3: various types of healthcare professionals, Chapter 5: Chinese immigrants – including patients, family caregivers, healthy participants – and healthcare professionals). A mixed-method analysis in Chapter 4 enabled us to integrate different types of evidence from various studies, further supporting us in developing a conceptual framework. All reviews adopted a broad conceptualization of advance care planning that allowed us to include studies on specific elements of advance care planning. The potential limitations of these reviews were the possible exclusion of meaningful studies published in non-English languages, a potential lack of generalizability to regions in Asia that lack scientific studies (i.e. Northern, Western, and Central Asia) and low-middle income Asian countries.

Qualitative studies: Chapter 6-7 → These qualitative studies were the first to explore the perspectives of Indonesian healthcare professionals, patients, and family caregivers on advance care planning. These studies' possible limitation was selection bias due to the fact that most of our participants were highly educated and had been selected based on their willingness to participate in the study. We are also aware that the meaning of what participants said may have been clouded throughout the process of translation and analysis due to Indonesian-English language differences. Lastly, the interviewers' background as healthcare professionals may have affected patients' and family caregivers' responses during the interview. This risk was minimized by ensuring the participants that their responses would not be disclosed to their attending physician and would not affect their care.

Survey: Chapter 8 → Due to the unavailability of a cancer survivor registry and semi-lockdown measures during the Covid-19 pandemic in Indonesia, we needed to conduct convenience sampling through an online platform (WhatsApp). A possible limitation of this study was a potential selection bias due to the non-representativeness of a population sampled through the internet and the self-registered participants. Another potential limitation is that this study may be subject to recall bias and inaccurate medical information caused by participants' limited understandings of their illnesses. Nevertheless, our survey focused on exploring participants' perspectives and preferences rather than their accurate understanding of their medical condition.

INTERPRETATION AND INTEGRATION OF THE FINDINGS

Our findings showed that for supporting individuals in understanding and sharing their personal values, life goals, and preferences about future medical care, we should consider how individuals, within their individual context and culture, prefer to interact, their styles of communication, their perceived roles and relationships, and their personal values and beliefs. We found that these factors influenced their preferences for medical information provision, their roles in advance care planning, and their preferred focus of advance care planning conversations.

Preferences for medical information provision and advance care planning

Differences in individual's preferences for types of medical information

Our Asian systematic review **(Chapter 4)** showed that adequate illness understanding facilitates patients' readiness to engage in advance care planning. However, our interview studies **(Chapter 3 and 6)** showed that Asian – including Indonesian – healthcare professionals often conceal medical information from their patients, partly due to their belief that patients may be unready for such information or concerns about getting into conflict with family members. Meanwhile, our studies of patients' perspectives **(Chapter 7-8)** showed that some of them wished for more information than what they had received, while others considered provision of information without consideration of their specific preferences to be insensitive.

Our findings indicate that different individuals prefer different types of information. Our survey study of Indonesian cancer survivors **(Chapter 8)** showed that if diagnosed with life-limiting illnesses, the majority wished to be informed about their diagnosis (74%) and the chance of cure (81%), and more than half wished to know about the severity of their illness (61%) and the expected trajectory (66%). In contrast, only one-third wished to know about their estimated life-expectancy. Our Indonesian qualitative studies **(Chapter 6-7)** showed that some patients tended to avoid information they consider 'harmful' and irrelevant to their religious beliefs, while others hoped to receive this information and were concerned that their family members would conceal it to protect them. For instance, information about their estimated life expectancy could be considered harmful and irrelevant ¬– believing death is unpredictable or predetermined by God. A previous systematic review showed that patients with cancer worldwide have various preferences for information about the prognosis of their illnesses, with more people preferring broad indications of prognosis rather than specific quantitative information.[2] Another

systematic review showed the potential cultural influence on such variances of preferences, where fewer Asian patients wished to know about their estimated life expectancy compared to Western patients.[3]

Poor assessment of patients' preferences for medical information might have two consequences. Firstly, no or only partial disclosure of illness-related information without assessing whether this is the patient's preference would deny patients the chance to engage in advance care planning conversations. Secondly, the provision of unwanted information might lead to patient dissatisfaction with the communication or jeopardize the doctor-patient relationship. Both might hinder further engagement in advance care planning. Assessment of patients' preferences for medical information therefore seems an important prerequisite for advance care planning discussions in clinical practice. Therefore, it is essential to comprehensively explore patients' preferences for information, including their reasons for wanting or not wanting certain information. For instance, whether there is anxiety component that could be addressed or whether there are certain beliefs or norms that healthcare professional should take into account when communicating with the patient.

Culturally sensitive approach of communicating medical information

Another important aspect of information provision is how it is communicated. Our studies of healthcare professionals' perspectives **(Chapter 3, 5, and 6)** showed that among the important barriers to information provision and advance care planning was a perceived lack of skills and confidence to initiate culturally sensitive communication. Our studies of patients' perspectives **(Chapter 5 and 7**) showed that individuals have different preferences for communicating sensitive medical information. Among these preferences **(Chapter 5-7)** were the use of implicit, positive terms (euphemisms) or metaphors when communicating bad news, non-targeted communication, and framing of advance care planning within religious faith or cultural practices.

It is known that preferences for implicit or explicit communication vary across different cultures. In countries with a high-context culture such as Indonesia and China, in which a large amount of meaning is not explicitly mentioned but is rather embedded in the situation (or context) in which communication is occurring[4], such as Indonesia and China **(Chapter 5 and 7)**, the use of explicit and direct words can sometimes be considered as overly blunt and unempathetic. People in China and Indonesia considered euphemisms or metaphors as appropriate ways of communicating sensitive medical information. Likewise, other studies showed that Japanese, Chinese American, and South Asian patients often prefer implicit medical

communication.[5-7] In contrast, Western patients often prefer explicit, straight to the point, medical communication.[8, 9] An implicit approach to communication is perceived as prioritizing the maintenance of other people's honor, preserving and strengthening relationships by saving face and ensuring harmony.[10] It helps create a safe environment to facilitate the communication of challenging topics.[11] Other studies in Asia and Western countries showed that communicating prognosis with several possible future health scenarios (best case, worst case, and most likely scenarios) was preferred over just one worst-case scenario.[12-14]

The use of a "non-personally-targeted" approach **(Chapter 5)** was found to be another strategy to communicate medical topics sensitively. For instance, introducing an advance care planning conversation as a part of a general routine assessment in the clinic or during community activities **(Chapter 5)** would facilitate the sharing of personal values without necessarily exposing someone's vulnerability. The ACP awareness week in Singapore to educate the public about having dinner table conversations about what a "good life" and "good death" meant sets an example.[15] Lastly, a recent meta-analysis showed that gamification might be a way to introduce advance care planning in non-clinical settings by broaching sensitive topics in a fun and enjoyable way.[16] All of these implicit approaches stem from people's need to maintain some ambiguity about the future as one of their coping mechanisms. Not only were these approaches preferred by some patients, they might also help healthcare professionals in finding comfort in initiating conversations about such difficult topics **(Chapter 5-7).** Lastly, our studies (**Chapter 5-7)** showed the role of framing advance care planning in a religious and cultural context. For instance, contextualizing advance care planning in ancient Chinese culture, in which prearranging death was considered a privilege for the emperor. Advance care planning is sometimes seen as challenging Indonesian patients' religious beliefs. Framing advance care planning in a certain religious faith **(Chapter 6)** could enable sensitive communication with devout patients. For instance, the use of the religious term "mudarat," which is known as "harm" among Indonesian Muslims – as a way to explain the concept of futile intervention in an Islamic context – was reported to help Muslim patients distinguish it from "giving up."

Cultural contexts and perceived roles in advance care planning

Our findings **(Chapter 3-8)** confirmed that family involvement in advance care planning is essential in Asia. Most Asian patients highly value family involvement in advance care planning. If they believed it could also benefit their family members they tend to be willing to engage in advance care planning, while others felt concerned

that engaging in advance care planning would cause their family undue distress of foreseeing a poor future scenario for their loved one.

In a context where families play a major role in the medical decision making, understanding and addressing the family's concerns and emotions could be equally important as understanding and addressing those of the patient.[17, 18] A systematic review of family-integrated advance care planning indicated that patients value healthcare professionals' support for their family members during advance care planning and that psychological distress among family members could impact the patients.[18] In such circumstances, supporting family members indirectly supports patients.[17, 18] Future research should attempt to examine contributing factors of positive outcomes of family involvement in advance care planning.

Shifting advance care planning's focus of formalizing future care planning towards creating a shared understanding of individuals' values

Originally, documenting the outcomes of advance care planning, e.g., in an advance directive, was considered an important measure of its outcome.[19] However, evidence is accumulating that advance care planning that focuses on formalizing and documenting the planning, rather than on the conversation itself, fails to achieve goal-concordant care.[19-24] Our Asian and Indonesian studies **(Chapter 3, 4, 7, 8)** showed that relatively few people prefer documenting advance care planning conversations into advance directives. Among the reasons are patients' belief that family members would act in their best interest, and the complexities of envisioning personal preferences in uncertain future scenarios. People often lack the needed experience to help them envision hypothetical future scenarios including what they would want in such circumstances. They also often lack the knowledge about detailed technical information regarding various options of future care and treatments.[19] In addition to that, the desire to be in control of one's life may not be a universally shared interest.[7] For example, in our studies, individuals with strong religious devoutness might feel that such desire challenges their beliefs in God's control over life **(Chapter 4, 6-8)**. Therefore, our findings support the current recommendations[19-21] to focus advance care planning more on the conversation rather than the documentation, also in an Asian context.

Our studies **(Chapter 6-8)** showed that Indonesian patients and family caregivers appreciate and wish to engage in conversations that explore meanings (e.g. what a "good life" or "good death" means for individuals) and what they consider important for themselves in different health scenarios. Such conversations understand-

ably promote understanding of patients' deeply held personal values, by patients themselves, their family caregivers, and healthcare professionals. This can in turn support the development of a trusting relationship. Such a trusting relationship has been shown to enable difficult conversations – such as those related to death and dying.[25]

RECOMMENDATIONS FOR CLINICAL PRACTICE, POLICY AND FUTURE RESEARCH

Recommendations for clinical practice

Careful assessment of the patient's needs for information and preferences for an approach to communicating it

- To enable person-centered care, healthcare professionals should assess the patient's need for medical information and their preferences for the communication styles and approaches.
- Healthcare professionals should explore the patient's understanding of their illness and advance care planning and provide relevant information based on their assessment of patients' readiness and preferred approach.
- Healthcare professionals should engage patients in advance care planning conversation based on the patient's readiness to engage in advance care planning aspects.

Careful assessment of the family's role in facilitating advance care planning

- Healthcare professionals should conduct a careful assessment of the family's role in facilitating the patient's engagement in advance care planning.
- Healthcare professionals should provide the needed support for the family members to facilitate patient engagement in advance care planning.
- Healthcare professionals should encourage open communication between patients and family members to enable a shared understanding of values and preferences for future care and treatment.

Advance care planning as an ongoing value-exploration process rather than a single-point documentation process of the future care plan

- Healthcare professionals should approach advance care planning as an ongoing process of understanding the patient's concerns and personal values across the physical, psychological, social, and spiritual domains.

- Healthcare professionals should consider advance care planning an ongoing conversation of value exploration rather than merely a documentation process of patients' future care plans.

Recommendations for policy

Integration of advance care planning in the national health care system

- To enable advance care planning implementation, national health policy should acknowledge the importance of respecting patients' autonomy and right to be involved in decision-making for their care at the end of life.
- Policy makers should integrate advance care planning into the national healthcare system and establish a financing platform.

Education and training on culturally sensitive advance care planning for healthcare professionals

- In a national level, the government in collaboration with professional organizations should establish systematic training programs on advance care planning, including its culturally sensitive approach, for all healthcare professionals
- Professional organizations should integrate culturally sensitive approach to advance care planning into the formal education and training curriculum for healthcare professionals

Build capacity as well as develop institutional support for advance care planning

- The government should develop national practice guidelines for advance care planning for various conditions (oncology, dementia, etc.)
- Health care institutions should develop protocols for advance care planning and establish the documentation system for advance care planning

Raising public awareness on advance care planning

- Civil society organizations and media should engage and raise public awareness through public education and campaign about advance care planning.

Recommendations for future research

Implementation research on advance care planning that considers cultural sensitivity for Indonesian oncology and non-oncology patients

- Further studies are needed to explore the role of implicit communication and religious beliefs in facilitating engagement in advance care planning

- The studies in this thesis established the need for a culturally sensitive approach to advance care planning in Indonesia, particularly among oncology patients. Similar research on should be conducted among non-oncology patients in Indonesia.
- Future study should focus on developing an intervention program of advance care planning and its evaluation.

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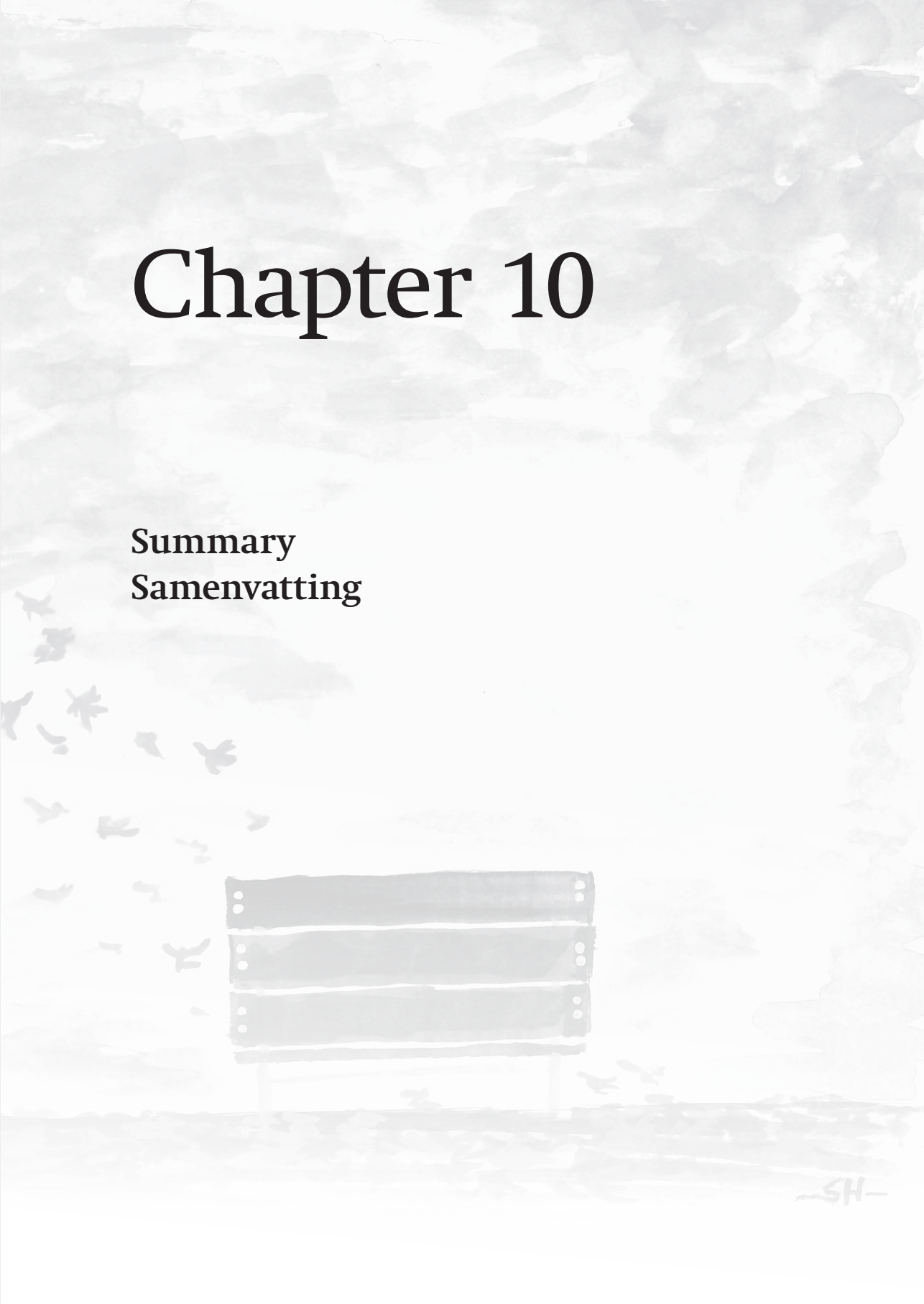
Chapter 10

Summary
Samenvatting



SUMMARY

Chapter 1 introduces advance care planning as well as Asian and Indonesian cultures and the context that these cultures provide for advance care planning practice in Asia and Indonesia. It elaborates on the development of advance care planning that originated in Western countries and its different conceptualizations. In the studies in this thesis, advance care planning was defined as a process that "enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate." Asian countries are primarily collectivist-oriented, where care for an individual is viewed mainly as a family responsibility, and social harmony is often valued over individual autonomy. Further studies are needed to better understand the Asians' perspectives on advance care planning, including its cultural barriers and potential facilitators. Indonesia, like many other Asian countries, also has a collectivist culture. In addition, Indonesia has the largest Islamic population in the world and is one of the most religious countries worldwide, where faith drives many aspects of life, including decision-making in health care. Furthermore, most Indonesian patients with cancer present late during their disease trajectory, making that their palliative care needs are often unaddressed. Little is known about the perspectives of Indonesians on advance care planning. Therefore, this thesis aimed to provide insight into Asian and Indonesian perspectives on advance care planning, including their perceived barriers and facilitators to engaging in it. Our Asian studies focused on Asian experts in advance care planning, healthcare professionals, seriously ill patients living in Asia, and Chinese immigrants living in Western countries. Meanwhile, our Indonesian studies focused on professionals working in oncology, patients with cancer, family caregivers, and cancer survivors.

Chapter 2 presents a position paper of a multidisciplinary group of 31 experts from six Asian sectors regarding the roles of different stakeholders, including researchers, regarding advance care planning. After several online and offline discussions among experts with various areas of expertise (e.g. palliative care, family medicine and public health, nursing, gerontology, biomedical ethics and healthcare law), this group recommended a research priority tailoring a culturally sensitive model of advance care planning that is relevant to the Asian cultural context and local jurisdictions in order to guide its future implementation in Asia.

Chapter 3 describes the results of a systematic review of Asian healthcare professionals' knowledge of, attitudes towards, and experiences with advance care plan-

ning and perceived barriers and facilitators related to their engagement in it. Four databases were systematically searched, and 51 out of 3,887 identified articles were included. These studies, of which 42 were quantitative, 7 were qualitative, and 2 were mixed-methods, and 43 were conducted in high-income countries, reported on knowledge (13 studies), attitudes (44 studies), experiences (29 studies), and barriers and facilitators (36 studies) of advance care planning. Although most studies have operationalized advance care planning as the completion of an advance directive, some recent studies have focused on advance care planning as a value-exploration process. Most Asian healthcare professionals considered the family's role in advance care planning essential. Most of them thought that advance care planning should be initiated when the patient's disease was no longer curable, particularly when his or her life expectancy was less than six months. Despite a general willingness to engage in advance care planning, Asian healthcare professionals found it challenging to initiate it. This led to relatively low engagement. This chapter concluded that capacity building for advance care planning in Asia should focus on culturally adapting advance care planning models concerning the essential role of the family in Asia, education for healthcare professionals and the public, and providing institutional support for advance care planning.

Chapter 4 presents the results of a mixed-method systematic review of Asian patients' perspectives on advance care planning and their underlying motives. Four databases were systematically searched, and 36 out of 4,330 identified articles were included: 22 were quantitative and 27 were from high-income countries. A narrative synthesis and thematic analysis were performed to integrate outcomes from different types of studies. We further developed a conceptual framework based on our findings. We found that most Asian patients agreed that advance care planning was important, but more varied results were found in studies that examined their actual willingness to engage in it. The main underlying motives for their willingness to engage in advance care planning were their perceived benefits of advance care planning, such as promoting autonomy, allowing a comfortable end of life, avoiding burden on family members, and facilitating shared understanding with family members. Conversely, a range of motives were related to patients' unwillingness to get engaged in it: patients' lack of understanding of their disease, their misperceptions about advance care planning, and the beliefs that advance care planning is not beneficial, that it is potentially harmful, that it is not consistent with their religious beliefs or with the wishes of their family or healthcare professionals. Various barriers for patients to engage in advance care planning were the complexities of future planning, their socioeconomic dependency on others, and the lack of support from the healthcare system. Essential considerations of patients' engagement were their

preferences: (1) for being actively engaged or for delegating autonomy to others; (2) for the timing; and (3) for whether or not the conversations would be documented.

Chapter 5 presents the results of a systematic review of the role of Chinese immigrants' acculturation in their engagement in advance care planning. Four databases were systematically searched, and 21 out of 1,112 identified articles were included in the analysis, of which 17 had a qualitative design, and 13 originated from the United States. Our review showed that Chinese immigrants differ in their willingness to engage in advance care planning. We found that Chinese immigrants' acculturation influenced their perceptions of their cultural identity and their interpretation of filial piety and autonomy. These various interpretations further influenced their perceptions of advance care planning and whether and how they would engage in it. To facilitate their engagement, many Chinese immigrants preferred having advance care planning conversations initiated by non-family members, using an implicit communication approach, and contextualizing advance care planning in Chinese culture and using the Chinese language. Finally, to engage Chinese immigrants in advance care planning, healthcare professionals should initiate advance care planning by addressing Chinese immigrants' perceptions of their cultural identity, filial piety, and autonomy, as well as their preference for a certain approach, initiators, context, and language.

Chapter 6 elaborates on the perspectives of Indonesian healthcare professionals regarding advance care planning through focus group interviews, including 16 physicians and 16 nurses who were actively engaged in cancer care. We found that Indonesian healthcare professionals considered a culturally sensitive approach to advance care planning important. The essential aspects of advance care planning, according to Indonesian healthcare professionals, were the family's role in medical decision-making, the sensitivity to communication norms, patients' and families' religious beliefs regarding the control and sanctity of life, and the availability of a support system for advance care planning (healthcare professionals' education and training, public education, resource allocation, and formal regulation). We concluded that Indonesian healthcare professionals believe that, for culturally congruent advance care planning in Indonesia, it is essential to respect the cultural aspects of collectivism, communication norms, and patients' religious beliefs.

Chapter 7 elaborates on the results of an in-depth qualitative interview study including 16 Indonesian cancer patients and 15 family caregivers about their perspectives on advance care planning. We found that four important factors influenced their engagement in advance care planning. First, patients' and family caregivers'

wish to be informed about the disease and its consequences depended on whether they perceived the information as important, relevant, or harmful. Patients and family caregivers alike tended to conceal 'harmful' information to protect their loved ones. Second, they wished bad news to be communicated empathetically and sensitively, particularly by using implicit words (euphemisms). Family caregivers considered mediating the delivery of bad news as a sensitive approach. Third, participants' preferences for involvement in decision-making varied. Their preference for patient-centered, family-led or physician-led decision-making was influenced by their ideas on patients' rights, their perceived responsibilities, or patients' state of dependency on others. Finally, most participants found future care planning challenging due to their religious beliefs or difficulties in seeing its relevance for future care planning. Discussing what mattered most in the moment was found to be more appropriate. This chapter concluded that culturally sensitive approaches to advance care planning in Indonesia should address the importance of facilitating open communication between patients and their families and the various perspectives on information provision, bad news communication, and decision-making. Advance care planning should focus on the exploration of patients' values, rather than drafting treatment plans in advance.

Chapter 8 presents the results from an online survey among Indonesian cancer survivors to study their perspectives regarding medical information provision and advance care planning. The survey was distributed to nine cancer survivor support groups, A total of 1,030 valid responses were received. More than half of the participating cancer survivors were under 60 years old, female, had completed higher education, and were diagnosed with breast cancer. We found out that most of them wished for some information about their illness (except estimated life expectancy) and were willing to engage in advance care planning, although not necessarily in all topics of it. Many of those willing to discuss advance care planning had not done so. Most of those who were willing to engage in advance care planning conversations preferred to engage in it with their family members and before becoming terminally ill. The most important reasons for not wanting to engage in advance care planning were the desire to surrender to God's will, the belief that people should not intervene in the natural process of dying, and the wish to focus on the here and now. This chapter concluded that culturally sensitive advance care planning among Indonesian cancer survivors involves healthcare professionals eliciting individuals' preferences for medical information disclosure and discussing different topics of advance care planning conversations.

Chapter 9 summarizes the key findings of the studies presented in this thesis, provides methodological considerations, and gives reflections on overarching topics and recommendations for clinical practice and future research. This chapter discussed the cultural sensitivity of medical information provision and the family's role in Asia and Indonesia. Culturally sensitive advance care planning in Asia and Indonesia requires careful consideration of individuals' preferences for receiving medical information and the ways of communicating it, perceptions of patients' and their family's role in advance care planning, and their personal beliefs. For the Indonesian setting, the role of religious beliefs in relation to advance care planning was discussed. Lastly, the findings of all studies in this thesis showed the need to shift the focus of advance care planning from documentation of care preferences to ongoing open communication about individuals' values, wishes, and preferences.

The chapter concluded that culturally sensitive advance care planning involves healthcare professionals understanding individuals' preferences for medical information disclosure (what they want to know) while respecting their limits (how much they want to know) and preferences for engagement in discussing different advance care planning topics. To enable person-centred care, healthcare professionals should engage patients in advance care planning conversations based on the patient's readiness and preferences for communication, roles, and context. Furthermore, a culturally sensitive approach to advance care planning requires healthcare professionals to support family members in facilitating patient engagement in advance care planning. Finally, capacity building for advance care planning should include establishing education, guidelines, regulation, and integration in the national healthcare system.

SAMENVATTING

Hoofdstuk 1 introduceert het concept 'proactieve zorgplanning', zoals het is ontwikkeld in de westerse landen. Het hoofdstuk beschrijft ook de Aziatische en, meer specifiek, de Indonesische cultuur en de context van deze culturen voor de praktijk van proactieve zorgplanning in Azië en Indonesië. In de onderzoeken die worden beschreven in dit proefschrift, werd proactieve zorgplanning gedefinieerd als een proces dat "individuen in staat stelt doelen en voorkeuren voor toekomstige medische behandeling en zorg te definiëren, deze doelen en voorkeuren te bespreken met familie en zorgverleners, en deze voorkeuren vast te leggen en indien nodig te herzien." Aziatische landen zijn voornamelijk collectivistisch georiënteerd: de zorg voor een individu wordt hier vooral gezien als een verantwoordelijkheid van het gezin; daarbij wordt sociale harmonie vaak hoger gewaardeerd dan individuele autonomie. Verder onderzoek is nodig om de perspectieven van Aziaten op proactieve zorgplanning beter te begrijpen, inclusief de culturele barrières en potentiële facilitators. Indonesië heeft, net als veel andere Aziatische landen, een collectivistische cultuur. Bovendien heeft Indonesië de grootste islamitische bevolking ter wereld en is het één van de meest religieuze landen ter wereld, waar geloof vele aspecten van het leven beïnvloedt, waaronder besluitvorming in de gezondheidszorg. Daarnaast presenteren de meeste patiënten met kanker in Indonesië zich laat in het ziektebeloop, waardoor hun behoeften op het gebied van palliatieve zorg niet bekend zijn. Er is weinig bekend over de perspectieven van Indonesiërs ten aanzien van proactieve zorgplanning. Daarom had dit proefschrift tot doel inzicht te verschaffen in de Aziatische en Indonesische perspectieven ten aanzien van pro-actieve zorgplanning, inclusief de barrières en facilitators om eraan deel te nemen. De Aziatische studies richtten zich op Aziatische experts op het gebied van proactieve zorgplanning, zorgverleners, ernstig zieke patiënten die in Azië wonen en Chinese immigranten die in westerse landen wonen. De Indonesische studies richtten zich op professionals die werkzaam zijn in de oncologie, patiënten met kanker, mantelzorgers en overlevenden van kanker.

Hoofdstuk 2 presenteert een position paper van een multidisciplinaire groep van 31 experts uit zes Aziatische sectoren over de rol van verschillende belanghebbenden, waaronder onderzoekers, met betrekking tot proactieve zorgplanning. De groep met experts uit verschillende disciplines (bijv. palliatieve zorg, huisartsgeneeskunde en volksgezondheid, verpleegkunde, gerontologie, biomedische ethiek en gezondheidsrecht), adviseerde de ontwikkeling van een model van proactieve zorgplanning passend bij de Aziatische cultuur te prioriteren. Door het model passend te maken

aan de culturele en de juridische context zou de implementatie van proactieve zorgplanning in Azië gestimuleerd kunnen worden.

Hoofdstuk 3 beschrijft de resultaten van een systematische review over van de kennis, de attitudes en de ervaringen die Aziatische zorgverleners hebben ten aanzien van proactieve zorgplanning; daarbij werden barrières en facilitators die verband houden met hun betrokkenheid bij proactieve zorgplanning onderzocht. Vanuit vier databases werden 3.887 artikelen geïdentificeerd; 51 waren geschikt voor analyse. Het betrof 42 kwantitatieve en 7 kwalitatieve studies en 2 studies met een gemengd design; 43 studies waren uitgevoerd in landen met een hoog inkomen; 13 studies rapporteerden over kennis, 44 over attitudes, 29 over ervaringen van zorgverleners en 16 over barrières en facilitators voor proactieve zorgplanning. De meeste studies operationaliseerden proactieve zorgplanning als de voltooiing van een wilsverklaring, maar sommige recente studies richtten zich op proactieve zorgplanning als een proces waarin waarden verkend worden. De meeste Aziatische zorgverleners vonden de rol van het gezin bij proactieve zorgplanning essentieel. De meesten van hen waren van mening dat proactieve zorgplanning moet worden gestart wanneer de ziekte van de patiënt niet langer te genezen is, vooral wanneer zijn of haar levensverwachting minder dan zes maanden is. Hoewel Aziatische zorgverleners positief waren over het inzetten van proactieve zorgplanning, vonden zij het een uitdaging om hiermee te beginnen. Dit leidde tot een relatief lage betrokkenheid. Vanuit deze resultaten werd geconcludeerd dat het model van proactieve zorgplanning aangepast zou moeten worden aan de essentiële rol die de familie in Azië heeft rond het levenseinde van een patiënt, onderwijs voor zorgverleners nodig is, het publiek eveneens wordt meegenomen en institutionele inbedding van proactieve zorgplanning nodig is, voordat dit op grote schaal in Azië kan worden geïmplementeerd.

Hoofdstuk 4 presenteert de resultaten van een mixed-method systematische review over de perspectieven van Aziatische patiënten ten aanzien van proactieve zorgplanning met de onderliggende motieven. Vier databases werden systematisch doorzocht en 36 van de 4.330 geïdentificeerde artikelen werden opgenomen in de review: 22/36 studies waren kwantitatief en 27/26 studies waren afkomstig uit landen met een hoog inkomen. Een narratieve synthese en thematische analyse werden uitgevoerd om de resultaten van de verschillende typen studies te integreren. Op basis van de bevindingen werd een conceptueel kader ontwikkeld. De meeste Aziatische patiënten vonden proactieve zorgplanning belangrijk, maar in studies waarin de daadwerkelijke bereidheid van patiënten om deel te nemen aan proactieve zorgplanning werd onderzocht, werden meer uiteenlopende resultaten

gevonden. De belangrijkste onderliggende motieven voor hun bereidheid om deel te nemen aan proactieve zorgplanning waren de waargenomen voordelen van proactieve zorgplanning, zoals het bevorderen van autonomie, het mogelijk maken van een comfortabel levenseinde, het vermijden van last voor gezinsleden en het bevorderen van gedeelde kennis en begrip van gezinsleden. Onderliggende motieven om niet te willen deelnemen aan proactieve zorgplanning waren: onvoldoende kennis van patiënten over hun ziekte, hun misvattingen over proactieve zorgplanning en de overtuiging dat proactieve zorgplanning niet gunstig is, dat het potentieel schadelijk is, dat het niet in overeenstemming is met hun religieuze overtuigingen of met de wensen van hun familie of zorgverleners. Verschillende belemmeringen voor patiënten om deel te nemen aan proactieve zorgplanning waren de complexiteit van proactieve zorgplanning, hun sociaaleconomische afhankelijkheid van anderen en het gebrek aan ondersteuning binnen het gezondheidszorgsysteem. De betrokkenheid van patiënten bij proactieve zorgplanning was verder afhankelijk van hun voorkeuren: (1) om wel of niet actief betrokken te zijn of om hun autonomie aan anderen te delegeren; (2) voor de timing; en (3) of de gesprekken al dan niet zouden worden gedocumenteerd.

Hoofdstuk 5 presenteert de resultaten van een systematische review over de rol van de acculturatie van Chinese immigranten ten aanzien van hun betrokkenheid bij proactieve zorgplanning. Vier databases werden systematisch doorzocht en 21 van de 1.112 geïdentificeerde artikelen werden in de analyse opgenomen; 17/21 studies hadden een kwalitatief design en 13/21 studies waren verricht in de Verenigde Staten. Uit ons onderzoek bleek dat Chinese immigranten verschilden in hun bereidheid om aan proactieve zorgplanning deel te nemen. De acculturatie van Chinese immigranten beïnvloedde hun perceptie van hun culturele identiteit en hun interpretatie van volgzaamheid en autonomie. Deze verschillende interpretaties beïnvloedden hun perceptie van proactieve zorgplanning en of en hoe ze daaraan zouden deelnemen. Om hun betrokkenheid te vergemakkelijken, gaven veel Chinese immigranten er de voorkeur aan dat gesprekken over proactieve zorgplanning geïnitieerd werden door niet-familieleden, dat de communicatie impliciet was en dat proactieve zorgplanning werd gecontextualiseerd uitgaande van de Chinese cultuur en het gebruik van de Chinese taal. Concluderend, om Chinese immigranten te betrekken bij proactieve zorgplanning, zouden zorgverleners bij het initiëren ervan dan ook rekening moeten houden met hoe immigranten hun culturele identiteit zien, of ze volgzaam zijn of autonomie belangrijk vinden, en wat hun voorkeuren zijn voor wat betreft de praktische benadering van proactieve zorgplanning zoals taal en context.

Hoofdstuk 6 gaat dieper in op de perspectieven van Indonesische zorgverleners ten aanzien van proactieve zorgplanning. Via focusgroepen werden 16 artsen en 16 verpleegkundigen die actief betrokken waren bij de oncologische zorg geïnterviewd. Indonesische zorgverleners vonden het belangrijk dat proactieve zorgplanning past binnen de cultuur, met andere woorden cultureel-sensitief wordt toegepast. Essentiële aspecten waarmee, volgens hen, rekening moet worden gehouden bij het toepassen van proactieve zorgplanning zijn de rol van het gezin in de medische besluitvorming, eerbied voor communicatienormen, de religieuze overtuigingen van patiënten en families met betrekking tot het leven, en de beschikbaarheid van een ondersteuningssysteem voor proactieve zorgplanning (opleiding en training van zorgverleners, publieke bewustwording, logistieke beschikbaarheid en formele regelgeving). Concluderend zijn Indonesische zorgverleners van mening, dat het voor cultureel congruente proactieve zorgplanning in Indonesië essentieel is om de culturele aspecten van collectivisme, communicatienormen en religieuze overtuigingen van patiënten te respecteren.

Hoofdstuk 7 gaat dieper in op de resultaten van een kwalitatieve interviewstudie met 16 Indonesische patiënten met kanker en 15 mantelzorgers over hun perspectieven ten aanzien van proactieve zorgplanning. We ontdekten dat vier belangrijke factoren van invloed waren op hun betrokkenheid bij proactieve zorgplanning. Ten eerste hing de wens van patiënten en mantelzorgers om geïnformeerd te worden over de ziekte en de gevolgen ervan af van het belang dat zij hechten aan de informatie en of ze die als relevant of schadelijk ervaarden. Zowel patiënten als mantelzorgers hadden de neiging om 'schadelijke' informatie achter te houden om hun dierbaren te beschermen. Ten tweede wilden ze dat slecht nieuws empathisch en voorzichtig werd gecommuniceerd, vooral door impliciete woorden (eufemismen) te gebruiken. Mantelzorgers wilden dat slecht nieuws via hen met de patiënt gecommuniceerd werd in het kader van een sensitieve aanpak. Ten derde varieerden de voorkeuren van de deelnemers voor wat betreft hun betrokkenheid bij gedeelde besluitvorming. Of er een voorkeur bestond voor besluitvorming samen met de patiënt, of dat familie of artsen het best een besluit over de zorg konden nemen, was afhankelijk van de ideeën die de deelnemers hadden over de rechten van patiënten, hun vermeende verantwoordelijkheden ten opzichte van naasten en de mate waarin patiënten afhankelijk waren van anderen. Ten slotte vonden de meeste deelnemers het moeilijk om na te denken over hun voorkeuren van zorg in de toekomst vanwege hun religieuze overtuigingen of omdat ze de relevantie van proactieve zorgplanning niet zagen. Bespreken wat er op dat moment het meest toe deed, werd passender gevonden. In dit hoofdstuk werd geconcludeerd dat voor een cultuur-sensitieve benadering van proactieve zorgplanning, er aandacht moet

zijn voor het faciliteren van open communicatie tussen patiënten en hun naasten, de verschillende perspectieven die patiënten en naasten hebben rond het communiceren van slecht nieuws en hun rol bij gedeelde besluitvorming. Daarbij werd het belang van het exploreren van de waarden en voorkeuren van patiënten benadrukt, boven het maken van concrete afspraken over toekomstige zorg.

Hoofdstuk 8 presenteert de resultaten van een online survey onder Indonesische overlevenden van kanker naar hun perspectieven ten aanzien van het willen ontvangen van medische informatie en ten aanzien van proactieve zorgplanning. De survey werd verspreid onder negen patiëntenorganisaties. Er werden in totaal 1.030 ingevulde vragenlijsten ontvangen. Meer dan de helft van de deelnemende overlevenden van kanker was jonger dan 60 jaar, vrouw, had een hogere opleiding genoten en was gediagnostiseerd met borstkanker. De meeste overlevenden wensten in meer of mindere mate geïnformeerd te worden hun ziekte; een minderheid over de levensverwachting in geval van een levensbedreigende aandoening. Ook wilden zij het gesprek aangaan over proactieve zorgplanning, hoewel niet voor alle onderwerpen ervan. Veel van degenen die bereid waren om proactieve zorgplanning te bespreken, hadden dit niet gedaan. De meeste van degenen die bereid waren om proactieve zorgplanningsgesprekken te voeren, gaven er de voorkeur aan dit met hun familieleden te doen en wel, voordat ze terminaal ziek werden. De belangrijkste redenen om niet aan proactieve zorgplanning te willen doen, waren de wens om zich over te geven aan Gods wil, de overtuiging dat mensen niet moeten ingrijpen in het natuurlijke proces tot aan het overlijden en de wens om te focussen op het hier en nu. In dit hoofdstuk werd geconcludeerd dat voor cultuur-sensitieve proactieve zorgplanning zorgverleners in eerste instantie moeten nagaan wat de wensen en behoeften van patiënten zijn rond het bespreken van hun ziekte en aspecten van toekomstige zorg.

Hoofdstuk 9 vat de belangrijkste bevindingen van de studies die in dit proefschrift worden gepresenteerd samen, geeft methodologische overwegingen en geeft reflecties op overkoepelende onderwerpen en aanbevelingen voor de klinische praktijk en toekomstig onderzoek. In dit hoofdstuk is ingegaan op de culturele sensitiviteit van het bespreken van diagnose en medische informatie en de rol van het gezin in Azië en Indonesië. Cultureel-sensitieve proactieve zorgplanning in Azië en Indonesië vraagt een zorgvuldige afweging van de voorkeuren van patiënten voor wat betreft het al dan niet geïnformeerd willen worden over hun ziekte, de wijze van communicatie, de gewenste rol van patiënten en hun familie ten aanzien van proactieve zorgplanning, en hun persoonlijke overtuigingen. Voor de Indonesische setting worden wensen van patiënten rond proactieve zorgplanning medebepaald

door geloofsovertuigingen. Ten slotte tonen de bevindingen van de studies in dit proefschrift aan, dat de focus van proactieve zorgplanning moet worden verlegd van het documenteren van voorkeuren voor toekomstige zorg naar voortdurende open communicatie over de waarden, wensen en voorkeuren van mensen.

Het hoofdstuk concludeerde dat cultureel-sensitieve proactieve zorgplanning van zorgverleners vraagt dat zij de voorkeuren van patiënten rond het bespreken van diagnose en medische informatie kennen, de grenzen die patiënten aangeven respecteren en rekening houden met de voorkeuren van patiënten ten aanzien van het bespreken van verschillende onderwerpen binnen proactieve zorgplanning. Bij persoonsgerichte zorg voeren zorgverleners het gesprek met proactieve zorgplanning op geleide van de bereidheid en de voorkeuren van de patiënt voor wat betreft de wijze van communicatie, de rol van de patiënt en zijn familie en de context van het gesprek. Bovendien vereist een cultureel sensitieve benadering van proactieve zorgplanning dat zorgverleners familieleden ondersteunen bij het faciliteren van de betrokkenheid van de patiënt bij proactieve zorgplanning. Ten slotte wordt aandacht gevraagd voor het opzetten van een systeem voor de ondersteuning van proactieve zorgplanning, te weten het opzetten van onderwijs, richtlijnen, regulering en integratie hiervan in het nationale gezondheidszorgsysteem.

Chapter 11

PhD Portfolio
List of Publications
About the Author
Words of Gratitude | Dankwoord

Erasmus MC
Universitair Medisch Centrum Rotterdam

PHD PORTFOLIO

Summary of PhD training and teaching

Name PhD student	Diah Martina
Erasmus MC Department	Medical Oncology Public Health
Research School	Netherlands Institute for Health Sciences (NIHES)
PhD period	2018-2022
Promotor	Prof. dr. Carin CD van der Rijt, PhD
	Prof. Judith A.C. Rietjens, PhD Prof. dr. Agnes van der Heide, PhD
ECTS	63

	Year	Work-load
1. PhD training		
General courses		
Specific courses (e.g. Research school, Medical Training)		
Introduction to Global Public Health (NIHES)	2018	0.7
Principles of Research in Medicine and Epidemiology (NIHES)	2018	0.7
Methods of Public Health Research (NIHES)	2018	0.7
Methods of Health Services Research (NIHES)	2018	0.7
Primary and Secondary Prevention Research (NIHES)	2018	0.7
Value Based Health Care	2018	0.7
Endnote course	2018	0.2
Course literature research Pubmed – 1	2018	0.3
Course literature research Pubmed - 2	2018	0.3
Course literature research in other databases	2018	0.3
Basic introduction Course on SPSS	2018	1
Course Scientific Integrity	2018	0.3
Course qualitative research in healthcare	2018	3

Biostatistical Methods I: Basic Principles (NIHES)	2019	2
CPO Course	2019	0.3
Leadership Workshop	2019-2020	3
Scientific Writing Course for Juniors, December 2019-April 2020 Erasmus MC, Rotterdam, the Netherlands	2019-2020	0.5
Presentation skills for all audiences (LLS10) (14-17 Feb)	2022	1
Personal Leadership & Communication for PhD students and Post Docs (18 Feb & 4 March; 09.30-16.30)	2022	1
Seminars, meetings and conferences		
Weekly Research Seminars Department of Public Health, Rotterdam, The Netherlands	2018-2022	4
Two-weekly research meeting Medical Care and Decision Making at the End of Life, Rotterdam, The Netherlands	2018-2022	4
Two-weekly Skype Meeting Task Force Team of ACP Delphi Study in Asia, collaboration of six Asian countries	2018-2022	4
Monthly Webinar Meeting of Asia Pacific Regional Council of American Society of Clinical Oncology	2019-2022	1.5
Seminar 'Do you want to be resuscitated?', Rotterdam, The Netherlands	2018	0.1
Seminar 'Euthanasia and Psychiatric Patients, Rotterdam, The Netherlands	2018	0.1
Extra Seminar: The persistence of social inequalities in health: do we need a cultural perspective? (9th Jan; NA-1203 EMC)	2019	0.1
Extra Seminar: Inference After Machine Learning for Causal Effects (21st March, 2019; Collegezaal 1, EMC)	2019	0.1
Extra Seminar: Publish or Perish: How to Convince the Editor of Your Brilliant Work (27th Nov; OWR-36 EMC)	2018	0.1
Extra Seminar: Maternal Immunization in Low and Middle Income Countries (5th Sept; Na-2402, EMC)	2018	0.1
Extra Seminar: Promoting Young People's Sexual Health: the Role of Parents, health professionals and policy makers (27th May; OWR-5, EMC)	2019	0.1
Extra Seminar: How to Break Something by Fixing It (14th May; SP-2407, EMC)	2019	0.1
Seminar 'Good Representative', Rotterdam, The Netherlands	2019	0.1
PsychoPal Meeting and Guest Lecture: Enhancing Palliative Care in the Hospital, 30th July, Cipto Mangunkusumo Hospital, Jakarta, Indonesia	2019	0.1
Guest Lecture: Palliative Care Organization in the Netherlands, What Can We Learn, 31st July, Dharmais Cancer Center Hospital, Jakarta, Indonesia	2019	0.1

13th Asia Pacific Hospice Conference (APHC), 1-4th August, Surabaya, Indonesia	2019	1
7th Advance Care Planning – International (ACP-I) Conference, 13-16th March, Rotterdam, the Netherlands	2019	1
16th World Congress of the European Association for Palliative Care (EAPC), 23-25th May, Berlin, Germany,	2019	1
Asia-Pacific Region on ACP Consensus Taipei Forum, 19-20th April, Taiwan	2019	0.5
Asia Pacific Regional Council Face to Face Meeting, 10th October, Bangkok, Thailand	2019	0.5
Asian Task Force Team on ACP Delphi Study Meeting, 1-4th August, Surabaya, Indonesia	2019	0.5
ASCO Breakthrough Summit, 11-13th October, Bangkok, Thailand	2019	1

Presentations

Invited keynote lectures, plenaries, workshops (selections)

Palliative Care Around the World Pre-EAPC Seminar (Leiden, 14 June 2023): Palliative care landscapes in Indonesia *Organizer: ERC Globalizing Palliative Care project, Leiden University and the University of Amsterdam*	2023	1
8th International Advance Care Planning (ACP-I) conference (Singapore, 24-27 May 2023): Plenary session on "Religion and Spirituality in Advance Care Planning" *Organizer: Agency for Integrated Care (AIC), Singapore*	2023	1
8th International Advance Care Planning (ACP-I) conference (Singapore, 24-27 May 2023): "Advance Care Planning in Indonesia" *Organizer: Agency for Integrated Care (AIC), Singapore*	2023	1
International Expert Meeting, one of the invited international experts to discuss "What (Not) to Say": Unravelling the (un)questionable ideal of open information-provision in advanced cancer Collaborating countries: Indonesia, United Kingdom, the Netherlands, the United States of America, India, Czech, Japan, and Uganda *Funded by: European Research Council (ERC) Starting Grant and The Royal Netherlands Academy of Arts and Sciences (Koninlijke Nederlandse Akademie van Wetenschappen, KNAW)*	2022	1
6th South East Asia Breast Cancer Symposium (SEABCS) (Philippines, 23-25 September 2022): Advance care planning in Asia *Organizer: Philippine Society of Medical Oncology, Philippine Society of Breast Surgeons, American Society of Clinical Oncology, Global Focus on Cancer, Union for International Cancer Control (UICC), and ABC Global Alliance*	2022	1

[Digital] ACP-Clan 2022: Continuous Learning and Networking: The Cultural Perspectives of Advance Care Planning among Asians in Asia and in Western Countries *Organizer: Agency for Integrated Care (AIC), Singapore*	2022	1
[Digital] 5th Annual Southeast Asia Breast Cancer (SEABCS) 2021: Overview of ASCO Asia Pacific Regional Council *Organizer: Indonesian Breast Cancer Foundation and the Global Focus on Cancer*	2021	1
[Digital] Advance Care Planning International Digital Exchange (ACP-I 2021): Approaching Advance Care Planning in a Society with Strong Religiosity *Organizer: Advance Care Planning International (ACP-I)*	2021	1
[Digital] Japanese Society for Palliative Medicine Annual Meeting 2020: International session: Advance Care Planning in Asia – Differences and similarities focusing on autonomy *Organizer: Japanese Society for Palliative Medicine (JSPM)*	2020	1
Asia Pacific Hospice Conference 2019 Pre-conference workshop, 1st August, Surabaya, Indonesia: Integration & Standard of Palliative Care in Clinical Oncology: Scope, challenges, and opportunities in Asian countries *Organizer: Asia Pacific Hospice Palliative Care Network (APHN)*	2019	1
Asia Pacific Hospice Conference 2019 Scientific Session, 4th August, Surabaya, Indonesia: How to overcome challenges and implement IOP in Asian countries: Future directions *Organizer: Asia Pacific Hospice Palliative Care Network (APHN)*	2019	1
Taipei Forum on Advance Care Planning Consensus (Taipei, Taiwan): Current status of Advance Care Planning in Indonesia (Invited speaker) *Organizer: Taiwan Medical Association*	2019	1
Oral presentations		
Oral presentation at the 30th International Conference of Indian Association of Palliative Care, Bengaluru, India	2023	0.5
Oral presentation at the 7th Advance Care Planning International Conference, Rotterdam, The Netherlands	2019	0.5
Poster presentations		
Poster at the 17th World Congress of the European Association for Palliative Care (EAPC),	2021	0.3
Poster at the 13th Asia Pacific Hospice Conference (APHC), Surabaya, Indonesia	2019	0.3
Poster at the 16th World Congress of the European Association for Palliative Care (EAPC), Berlin	2019	0.3

Prizes

First prize for oral presentation in the 30th International Conference of Indian Association of Palliative Care, Bengaluru, India **(INR 15,000)** *By: Asia Pacific Hospice and Palliative Care Network*	2023	0.3
Grant for WHO National Project: "Assessment of Palliative Care Integration into the Primary Health Care System of Indonesia" **(IDR 763,544,000**) *By: World Health Organization, Indonesia*	2022	1
Selected as a participant in a Harvard Palliative Care Education Program *By: Harvard Medical School*	2022	1
Nominated as the best publication of the year (nominated as one of five best papers from over 400 publications) – primary investigator *By: Public Health Department, Erasmus MC, University Medical Centre, Rotterdam, the Netherlands*	2022	1
Nominated as one of 20 best posters in Asia Pacific Hospice Conference, Surabaya, Indonesia *By: Asia Pacific Hospice and Palliative Care Network*	2019	0.1
Featured Voice for ASCO Breakthrough Summit in Bangkok, Thailand *By: American Society of Clinical Oncology*	2019	0.1

2. Teaching activities

Lecturing

SURE Erasmus MC Online PhD Speed-date Event (120 minutes) "Ready to quench your curiosity about PhD-life and beyond?" Attended by MSc students	2021	0.1
Advance Care Planning Lecture Session (120 minutes) Organizer: Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada, Yogyakarta, Indonesia Attended by master students	2021	0.3
Advance Care Planning Lecture Session (120 minutes) Organizer: Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada, Yogyakarta, Indonesia Attended by master students	2020	0.3
Monthly Palliative Care Webinar Program together with Prof. Janet L. Abrahm, MD, FACP, FAAHPM and Barbara Anne Reville, DNP, ANP-BC, ACHPN (Dana Farber Cancer Institute), participated by public hospitals in Indonesia	2018-2022	2

Others

Co-author of a book chapter "Cultural communication in palliative care" in a Research Handbook on End of Life Care and Society Editor: Annemarie Samuels and David Clark Publisher: Edward Elgar	2023-2025	2
Editor of a book "Advance care planning in Asia Pacific" Team of editors: Diah Martina (Indonesia), Raymond Ng (Singapore), Masanori Mori (Japan), Cheng-Pei Lin (Taiwan) Sponsored by: Agency for Integrated Care (AIC) Singapore Supported by Asia Pacific Hospice Palliative Care Network (APHN)	2022-2023	2
Invited guest editor for the Asia Pacific Special Series in the Journal of Clinical Oncology Global Oncology (JCO GO): Q1 in the oncology field, Impact Factor: 4.3 By: JCO Global Oncology, an American Society of Clinical Oncology	2022-2023	2
Contributor in American Society of Clinical Oncology's (ASCO) patient information Web site: Cancer.net Cancer in My Community: Improving Access to Palliative Care in Indonesia	2022	0.5
Featured podcast in SAGE Palliative Medicine & Chronic Care to share about the findings of my literature review on Asian patients' willingness to engage in Asia.	2021	0.3
Collaborator in a cross-cultural study on prognostic communication with advanced cancer patients in Asia and the West Collaborating countries: Indonesia, Japan, Taiwan, Hong Kong, South Korea, Singapore, Netherlands, United States of America Funded by: Japanese Ministry of Health	2022-2026	2
Collaborator in a comparative study on the state of development of advance care planning in the Asia Pacific region Collaborating countries: 18 Asia Pacific country members of APHN Funded by: Asia Pacific Hospice Palliative Care Network (APHN)	2021-2023	2
An invited member of Asia Pacific Regional Council for American Society of Clinical Oncology (ASCO)	2019-present	2
Invited member of Working Group on Leadership Development Program (LDP) for Asia Pacific By: American Society of Clinical Oncology (ASCO)	2019	0.3
Task force member in a Delphi Study of Advance Care Planning in Asia (Task Force Member) Collaborating countries: Indonesia, Japan, Taiwan, Hong Kong, South Korea, Singapore Funded by: grant from Japanese Ministry of Health	2018-2023	2

Others

The Erasmus MC PhD day, 12th July, Rotterdam, The Netherlands	2018	0.1
The Seminar Career Opportunities 2019: "Where your PhD can take you", 12th July, Rotterdam, the Netherlands	2018	0.1
Research Day "Health(y) Sciences", 11th April	2019	0.3
The Erasmus MC PhD day, 9th July, Rotterdam, The Netherlands	2019	0.1
The Seminar Career Opportunities 2019: "Where your PhD can take you", 9th July, Rotterdam, The Netherlands	2019	0.1
TOTAL		**63**

LIST OF PUBLICATIONS

In this thesis

1. Lin CP, Cheng SY, Mori M, Suh SY, Chan HY, **Martina D**, et al. 2019 Taipei Declaration on Advance Care Planning: A Cultural Adaptation of End-of-Life Care Discussion. *J Palliat Med.* 2019 Oct;22(10):1175-1177.
2. **Martina D**, Lin CP, Kristanti MS, Bramer WM, Mori M, Korfage IJ, van der Heide A, van der Rijt CCD, Rietjens JAC. Advance Care Planning in Asia: A Systematic Narrative Review of Healthcare Professionals' Knowledge, Attitude, and Experience. *J Am Med Dir Assoc.* 2021 Feb;22(2):349.e1-349.e28.
3. **Martina D**, Geerse OP, Lin CP, Kristanti MS, Bramer WM, Mori M, Korfage IJ, van der Heide A, Rietjens JA, van der Rijt CCD. Asian patients' perspectives on advance care planning: A mixed-method systematic review and conceptual framework. *Palliat Med.* 2021 Sep 6.
4. Zhu T, **Martina D**, van der Heide A, Korfage IJ, Rietjens JAC. The role of acculturation in Chinese immigrants' engagement with advance care planning: A narrative systematic review *(under consideration for publication in Palliative Medicine)*
5. **Martina D**, Kustanti CY, Dewantari R, Sutandyo N, Putranto R, Shatri H, Effendy C, van der Heide A, Rietjens JAC, van der Rijt CCD. Opportunities and challenges for advance care planning in strongly religious family-centric societies: a focus group study of Indonesian cancer-care professionals. *BMC Palliat Care.* 2022; 21: 110
6. **Martina D**, Kustanti CY, Dewantari R, Putranto R, Shatri H, Effendy C, van der Heide A, van der Rijt CCD, Rietjens JAC. Advance care planning for patients with cancer and family caregivers in Indonesia: a qualitative study. *BMC Palliat Care.* 2022; 21: 204
7. **Martina D**, Angka RM, Putranto R, Shatri H, Sudoyo, AW, van der Heide A, van der Rijt CCD, Rietjens JAC. Medical Information Disclosure and Advance Care Planning Among Cancer Survivors in Indonesia: a nationwide online survey. *JCO Global Oncology no. 9 (2023) e2300003*

Other publications

1. Cheng SY, Lin CP, Chan HY, **Martina D**, Mori M, Kim SH, Ng R. Advance care planning in Asian culture. *Jpn J Clin Oncol.* 2020; 50: 976-89
2. Lin CP, Peng JK, Hsieh WT, **Martina D**, Mori M, Takenouchi S, Chan HYL, Suh SY, Kim SH, Yuen KK, Kizawa Y, Cheng S. Improving access to advance care planning in current and future public health emergencies: international challenges and recommendations. *J Palliat Med.* 2023 Apr;26(4):462-463

3. **Martina D**, Segelov E (Editorial for Special Series of Cancer Care in Asia Pacific). Improving equity across cancer care continuum in Asia Pacific. 2023 *(accepted for publication in JCO Global Oncology)*
4. Mori M, Lin CP, Cheng SY, Suh SY, Takenouchi S, Ng R, Chan HYL, Kim SH, Chen PJ, Yuen KK, Fujimori M, Yamaguchi T, Hamano J, Kizawa Y, Morita T, **Martina D**. Communication in cancer care in Asia: A review article. 2023 *(accepted for publication in JCO Global Oncology)*
5. **Martina D**, Witjaksono M, Putranto R. Advance care planning in Indonesia: Current State and Future Prospects. 2023 *(invited submission in ZEFQ Journal as part of Special Series of Advance Care Planning-International 2023)*
6. Mori M, Chan HYL, Lin CP, Kim SH, Ng R, **Martina D**, Yuen KK, Cheng SY, Takenouchi S, Suh SY, Menon S, Kim J, Chen PJ, Iwata F, Tashiro S, Kwok OLA, Peng JK, Huang HL, Morita T, Korfage IJ, Rietjens JAC, Kizawa Y. Definition and recommendations of advance care planning: A Delphi study in five Asian sectors *(under consideration in Lancet for Regional Health Open)*
7. Van Vliet L, Koffman J, Back A, Sanders J, **Martina D**, et al. "What (Not) to Say": Unravelling the (un)questionable ideal of open information-provision in advanced cancer *(manuscript in preparation)*

ABOUT THE AUTHOR

Diah Martina was born on March 14, 1986, in Yogyakarta, Indonesia, as the youngest of four. Her mother was a chemistry teacher, and her father was an engineer, both working as civil servants in governmental institutions. She moved to Jakarta, Indonesia's capital city, after completing her senior year of high school in order to study medicine at Universitas Indonesia in 2003 and later pursue a specialty in internal medicine in 2010. She discovered that palliative care was her passion during her residency. After completing her residency in 2016, she began working as a faculty member at the Department of Internal Medicine, Division of Psychosomatic and Palliative Medicine, Faculty of Medicine Universitas Indonesia, as well as a medical staff member at Cipto Mangunkusumo Hospital (the top referral national academic hospital in Indonesia). At the end of 2016, Diah and her family—her husband and son—moved to the Netherlands, following her husband's PhD program at Erasmus MC, Rotterdam. She made the decision to pursue palliative education in the same nation and at the same institution as her husband. She, therefore, applied and was awarded a grant from the European Society of Medical Oncology (ESMO) for a fellowship program in palliative care at the Erasmus MC Cancer Institute, for which she learned Dutch. After completing her fellowship, Diah applied for and received an International Development and Education Award in Palliative Care (IDEA-PC) from the American Society of Clinical Oncology (ASCO). This allowed her to visit a palliative care unit at the Dana Farber Cancer Institute (DFCI), Boston, and connected her with a DFCI palliative care mentor. With a scholarship from the Indonesian Ministry of Finance, she began her PhD in 2018 at the same institution as her fellowship, with a focus on culturally sensitive advance care planning in Asia and Indonesia. Not long after starting her PhD, she discovered she was expecting her second child. In addition to working on her PhD and raising her two children, Diah actively participates in global volunteering activities, serving as a member of the ASCO council for the Asia-Pacific area (as of 2019). Additionally, Diah takes part in numerous international research and academic collaborations, particularly in serious illness communication and its cultural sensitivity. Recently, she has been involved in an advocacy effort for palliative care in the country by collaborating with several national stakeholders, including WHO-Indonesia, and the Indonesian Ministry of Health. Diah and her family relocated to Lyon in 2021 after her husband's post-doctoral employment at the World Health Organization's International Agency for Research on Cancer (IARC). She intends to return to Indonesia after completing her PhD to teach and conduct research in palliative care, participate in community activities, and advocate for palliative care in the country. Diah enjoys traveling around the world to learn about

history, enjoy nature, and sample diverse international delicacies; therefore, she enjoys cooking.

WORDS OF GRATITUDE | DANKWOORD

All praise to Allah, The Most Gracious, The Most Merciful, who has bestowed countless of blessings, including the opportunity to enroll in this PhD program and all the supports needed for me to accomplish it.

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matters. Your sincere thoughtfulness brought light into the darkest of times. I am truly blessed to be one of your mentees.

Agnes, I've been a fan of yours since before I even met you. I admire your wisdom in every situation, as well as your calmness, which is always comforting and healing. You are also extremely sensitive. You'd be the one to realize that I had something to say in a forum and that I needed a little encouragement to speak up. You have the ability to establish a secure atmosphere where people may discuss any subject without fear of being judged. To me, you are the pinnacle of wisdom obtained via experience.

Karin, Judith, and Agnes, you would not realize how much lessons I have learnt from our encounters. Not only have I learnt how to be a good scholar, but also how to be a good mentor, and a better person.

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This thesis would not have been possible without the generous support from the Medical Oncology Dept and the Public Health Dept. Therefore, my gratitude goes to the heads of both departments, as well as Gerdien, Margot, Linda, and Ruth from the Medical Oncology Department; and Marieke, Judith, Kai Rock, Olaf, and Petra from the Public Health Department; for all of their assistance during my PhD and also fellowship. As a foreign PhD student at Erasmus MC, I want to thank Raoul Tan for his never-ending support and assistance.

I would like to thank the staffs of the Division of Psychosomatic and Palliative Medicine Faculty of Medicine Universitas Indonesia: dr. Hamzah, dr. Rudi, dr. Mudjaddid, dr. Adli, Mba Murti, Mba Tini, dr. Edward, and dr. Nita for all of the guidance, resources and support they provided for this study. I would also thank the late dr. Ali, dr. Wika, dr. Asyiqa, and dr. Arina for their friendship and inspiration.

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