


What influences patients' decisions regarding palliative care in advance care planning discussions? Perspectives from a qualitative study conducted with advanced cancer patients, families and healthcare professionals

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Abstract

Background: The concept of advance care planning is largely derived from Western countries. However, the decision-making process and drivers for choosing palliative care in non-Western cultures have received little attention.

Aim: To explore the decision-making processes and drivers of receiving palliative care in advance care planning discussions from perspectives of advanced cancer patients, families and healthcare professionals in northern Taiwan.

Method: Semi-structured qualitative interviews with advanced cancer patients, their families and healthcare professionals independently from inpatient oncology and hospice units. Thematic analysis with analytical rigour enhanced by dual coding and exploration of divergent views.

Results: Forty-five participants were interviewed ($n = 15$ from each group). Three main decision-making trajectories were identified: (1) 'choose palliative care' was associated with patients' desire to reduce physical suffering from treatments, avoid being a burden to families and society, reduce futile treatments and donate organs to help others; (2) 'decline palliative care' was associated with patients weighing up perceived benefits to others as more important than benefits for themselves; and (3) 'no opportunity to choose palliative care' was associated with lack of opportunities to discuss potential benefits of palliative care, lack of staff skill in end-of-life communication, and cultural factors, notably filial piety.

Conclusion: Choice for palliative care among advanced cancer patients in Taiwan is influenced by three decision-making trajectories. Opinions from families are highly influential, and patients often lack information on palliative care options. Strategies to facilitate decision-making require staff confidence in end-of-life discussions, working with the patients and their family while respecting the influence of filial piety.

Keywords

Palliative care, decision-making process, cancer, advance care planning, drivers of decision-making

What is already known about the topic?

1. Advance care planning is widely adapted to support decision-making in advanced diseases and is largely driven from Western cultures.

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2. Despite evidence of effectiveness, appraisal of the evidence underpinning the mechanisms of action of advance care planning demonstrates it may not be relevant to non-Western cultures on communication and decision-making process.

What this paper adds?

1. Drivers to choose palliative care were the expectation to relieve physical and psychological distress and re-allocate health resources to help others.
2. Discussions regarding palliative care with advanced cancer patients are rare, leaving some patients no opportunity to choose palliative care.
3. Key barriers to choosing palliative care were (1) clinicians' perceived challenges in talking openly with patients about cancer progression; (2) family-led decision-making with clinicians about care and treatments; (3) patients' understanding of the term 'palliative care'; and (4) lack of trusting clinician–patient relationships to facilitate dialogue regarding choices and likely outcomes.

Implications for practice, theory or policy

1. The practice of advance care planning in Taiwan appears to be influenced by three main patterns of palliative care decision-making, emphasising the importance and urgent need for high-quality end-of-life discussions among patients, family and healthcare professionals from authors' recommendation.
2. The importance of involving family members in patients' palliative care decision-making process should be used to inform the development of advance care planning beyond Western cultures with wider utility in Asia-Pacific.

Background

Misperceptions or little understanding of a patient's preferences, goals and wishes in end-of-life care leads to unwanted or inappropriate clinical interventions and outcomes.¹ Minimising the gap between patients' preferences and care received should involve patients and their families in the decision-making process. Advance care planning is a voluntary process of discussion that supports adults at any age or stage of health in understanding and who possess mental capacity sharing their personal values, life goals and preferences regarding future (medical) care.² This approach has been proven to improve outcomes of care, notably increasing patients' satisfaction with care, their knowledge regarding life-sustaining treatments, reducing futile treatments and decreasing emotional distress of relatives.^{3,4} Advance care planning is accepted as an effective component for high-quality palliative care delivery (a patient and family-centred care that optimises quality of life by anticipating, preventing and treating suffering)⁵ and is deemed to be a means to coordinate end-of-life care proposed by End of Life Care Strategy in the United Kingdom.⁶ However, patients' preferences for end-of-life care are sometimes little discussed with the healthcare professionals or fully understood before a patient loses the capacity to speak for themselves.^{7–9} This lack of congruence between patient preferences and understanding by healthcare professionals can compromise

patients' quality of life as a consequence of receiving interventions a patient may not have chosen.^{10,11} Advance care planning is increasingly recognised in palliative care as a solution to address these concerns.

Advance care planning discussions create potential opportunities for individuals to autonomously make important decisions about the possibility of receiving palliative care at some point in the future. This is particularly crucial for people living with cancer since its progression might affect a person's mental capacity to make and express decisions for themselves.⁸ However, the manner in which an individual's autonomy is understood and the decisions they make, and potentially re-make, might vary due to a combination of complex interactions that include, among others', their progressing disease, family members' opinions, different healthcare system and legal frameworks. This suggests that advance care planning is a highly complex process.¹²

A better understanding of advance care planning focused on the process of advanced cancer patients' deliberate decision-making to receive palliative care will have ramifications for local clinical practice and patient-centred outcomes.¹³ This is more evident when it is acknowledged that the majority of research on advance care planning is developed from Western-centric understanding of autonomy.^{11,14,15} To date, little research has focused on understanding advance care planning in influencing palliative care decisions from non-Western cultures. In Asia-Pacific countries, there is a rapid increase in

cancer and requirements for palliative care and advance care planning,¹⁶ but with limited evidence to inform implementation. One such example is Taiwan, where there are increasing numbers of patients living with and dying from cancer. According to the Cancer Registry Annual Report 2016 in Taiwan, around one-third of all deaths were due to cancer.¹⁷ Many of whom would benefit from palliative care, but the decision-making process and influential drivers to request this care in advance care planning discussions remain unknown. Another impetus is to better understand this area of healthcare results changes to Taiwan legislation system and Asian context.⁷ The newly rolled-out legislation 'Patient Right of Autonomy Act' in 2016 has made truth-telling by physicians about diagnosis and likely outcomes a compulsory element in advance care planning discussions and is considered to influence patients' decision-making (see Appendix A for the legislative framework regarding patients autonomy and advance care planning in Taiwan).¹⁸ This has informed the wider implementation of advance care planning and the intended content of the decision-making process among patients.

The aim of this study was therefore to explore the decision-making processes and drivers associated with receiving palliative care in advance care planning discussions from perspectives of people living with advanced cancer, their families and healthcare professionals in northern Taiwan.

Methods

Study design

Face-to-face, semi-structured qualitative interviews were conducted with advanced cancer patients, their family members (including close friends and significant others) and healthcare professionals. The Consolidated Criteria for Reporting Qualitative Research (COREQ) guided the reporting.¹⁹

Theoretical underpinning

This study is a part of a wider project of advance care planning, adopting a sequential explanatory qualitative mixed-methods approach guided by a philosophical paradigm of social constructionism.^{20,21} The social constructionism informed the sampling method and study design to focus understanding on lived experiences of stakeholders' perspectives. The design of this study and topic guides were underpinned by a 'logic framework' on the individual, organisational and social factors that influence an individual's decision-making process from systematic review on advance care planning in our previous work.³

Study setting and participants

One oncology unit and one hospice unit in a tertiary hospital in northern Taiwan. All participants were purposively sampled by key characteristics to capture diversity. Patients were selected by different age, gender, cancer type and educational levels. Family members were selected by different age, gender and relationship to patients (sibling, spouse or children). Healthcare professionals were selected by different professionals.

Recruitment and sampling

Guided by the first author (C.-P.L.), oncology and hospice units' staff assisted in identifying potential patients, family and healthcare professional participants to present the range characteristics and their potential views.

Eligible patient participants were required to be in the last 12 months of life judged by clinical staff as specified by the surprise question 'Would you be surprised if this patient died within the next year?',²² which has been used to effectively identify cancer patients with poor prognosis, and those have the capacity to participate in an interview.

Clinical staff introduced the study to potential patient participants. With permission of potential participants, the clinical staff shared their contact details with the first author (C.-P.L.) to organise a convenient time to explain study to potential participants and address any questions. Participants were given at least 24 hours to consider the study participation. Those who wished to be interviewed were required to provide written informed consent.

Family members (including close friends and significant others) were identified by the patient as providing care and support. Healthcare professionals were identified from the participating units, with a minimum of 6 months' experience caring for patients with advanced cancer. A distress protocol was devised, in which a cancer resources centre with multidisciplinary team provided support to participants if appropriate.

Due to the nature of the study aim, the specific population, research design and cross-sectional data analysis plan, recruitment terminated when 'information power' was sufficient to answer the study aim among these population.²³ We did not seek for theoretical data saturation as developing a theory was not the purpose of this study.²⁴

Ethical consideration and informed consent

Ethical approval was obtained from King's College London Research Ethics Committee (Ref: HR-17/18-5331) and Taipei City Hospital Research Ethics Committee

(Ref: TCHIRB-10609118-E), and all procedures followed the regulation of Declaration of Helsinki.²⁵

Data collection

Interviews were conducted with patients, family members or healthcare professionals independently in either the oncology unit or hospice unit. The interviews were all conducted by a male researcher (C.-P.L.) with a background in nursing and training in qualitative research and interviewing. A quiet room was identified for interviews to protect the privacy of participants. In some instances, it was necessary to conduct an interview with the patients by their bedside due to patients' immobility. While not ideal, curtains were drawn around the patients and interviewer (C.-P.L.) to provide a degree of privacy.

The semi-structured qualitative interview topic guides (see Appendix B in the supplementary material) were informed by systematic reviews^{3,11} and feedback from a multidisciplinary academic centre in London, United Kingdom, and academic and clinical experts in Taiwan. The topic guides were initially piloted with clinical academic colleagues and amended. They were then embedded to modify the questions required to probe any relevant issues that arose alongside the process of interviews.

Field notes were recorded after each interview by C.-P.L. to reflect on the interview encounter including participants' responses to the questions in topic guides.

Data processing and analysis

All interviews were audio-recorded and transcribed verbatim in Chinese, the official language at the study site. Data were analysed independently by two authors (C.-P.L. and S.-J.S.) using thematic data analysis involving five stages: (1) data familiarisation by repeated reading of the transcripts, (2) developing and refining deductive and inductive codes, (3) applying the codes systematically to generate themes, (4) reviewing the themes with the extracted codes to assess the applicability and (5) reporting the themes with codes and quotes to perform a convincing and coherent story.^{26,27} N-Vivo qualitative data analysis software (version 11) was used to assist in data management. The analysis used an iterative approach of coding and describing the data, generating categories and themes. All the interview transcripts were analysed and discussed in Chinese between C.-P.L. and S.-J.S. Consensus was sought in relation to any disagreement. The main themes, codes and key quotes were then translated to English (forward translation) by C.-P.L. (a bilingual nurse and researcher in palliative care) to enable analysis by the English-speaking co-authors and then back translated again (backward translation) by S.-J.S. and S.-H.H. into Chinese to ensure the fidelity.

To ensure analytical rigour, investigator triangulation²⁸ (C.-P.L., S.-J.S., J.K., C.J.E., and R.H.) was used to enhance the validity and confirmability of the findings. Where disagreements were presented, discussions took place between R.H., C.J.E., J.K. and S.-J.S. to reach consensus. Member checking²⁹ was not possible with patients as many had deteriorated to such an extent that it would not have been ethically reasonable to re-approach them. A decision was made not to approach family members and healthcare professionals because recent evidence suggested that the time lags between data collection and analysis may legitimately change participants' perspectives on the research topic and would not necessarily enhance the validity.²⁴

Results

Forty-five participants were recruited and interviewed between December 2017 and April 2018 and comprised $n = 15$ patients with advanced cancer, $n = 15$ family members and $n = 15$ multidisciplinary healthcare professionals. The duration of interviews was on average 45 minutes (range, 20–96 minutes). The cancer patients were on average 61.8 years old (SD \pm 12.6 years; range, 40–90 years) and represented eight males and seven females. The most common cancer were those with liver ($n = 3$), lung ($n = 3$), colon ($n = 2$) and oesophageal cancer ($n = 2$). More than half ($n = 8$) of those interviewed possessed a college degree. Family members were on average 55.2 years old (SD \pm 12.5 years; range, 37–80 years). The majority ($n = 11$) were patients' children. Among others, health and social care professionals included four physicians, four nurses and one social worker (see Table 1).

The analysis of the transcripts identified three main themes that related to patients' decisions to receive palliative care in advance care planning discussions (Figure 1). A full coding frame is presented in Appendix C in the supplementary material.

Theme 1: decisions to choose palliative care to reduce physical and psychological distress, re-allocate health resources and altruism

Patients, family members and health and social care professionals indicated that the choice of palliative care was driven by a desire to reduce physical suffering from treatments and to avoid being a burden to their families and society at large. Furthermore, views were shared regarding reducing resources devoted to patient, particularly when they were considered to be futile. Some spoke of donating organs to help others as being a key

Table 1. Sample characteristics of advanced cancer patients, family members and healthcare professionals.

Characteristics of cancer patients	N = 15	Characteristics of families	N = 15	Characteristics of HCPs	N = 15
Gender (male/female)	8/7	Gender (male/female)	5/10	Gender (male/female)	4/11
Age (years)		Age (years)		Age (years)	
Mean average (SD)	61.8 (12.6)	Mean average (SD)	55.2 (12.5)	Mean average (SD)	42.7 (7.5)
Range	40–90	Range	37–80	Professionals	
Cancer diagnosis		Marital status		Physician	4
Lung	3	Married	11	Nurse	4
Colon	2	Single	4	Social worker	1
Oesophageal	2	Relationship to patients		Case manager	3
Liver	3	Son	5	Psychologist	1
Ovarian	1	Daughter	6	Chaplain	1
Lymphoma	2	Spouse	3	Volunteer	1
Prostate	1	Sibling	1	Working years	
Urinary	1			Mean average (SD)	14.1 (6.7)
Educational level					
Illiterate	1				
Elementary school	2				
Senior high school	4				
College	6				
University	2				
Marital status					
Married	8				
Single	4				
Divorced	3				

SD: standard deviation; HCPs: healthcare professionals.

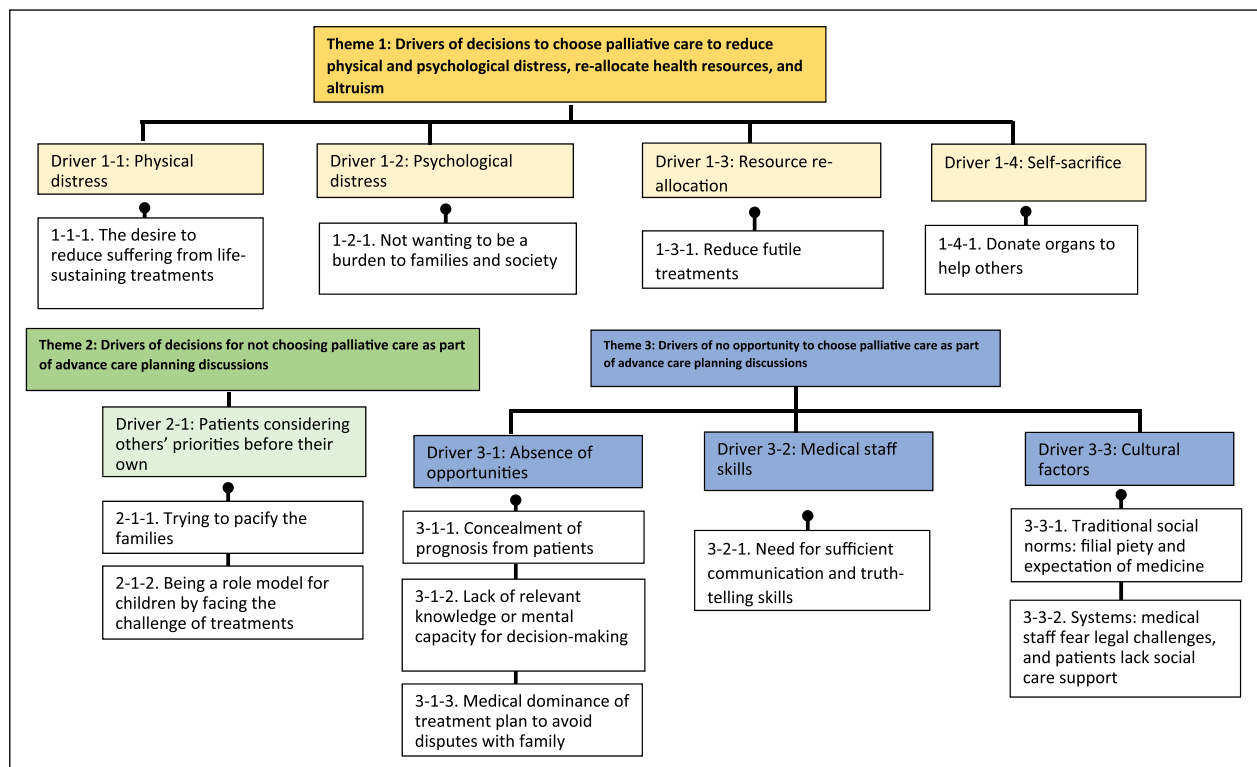


Figure 1. Diagram of different themes and drivers to influence cancer patients' decisions about receiving palliative care in advance care planning discussion.

factor to facilitate the decision-making to receive palliative care.

Driver 1-1: physical distress

Driver 1-1-1: the desire to reduce suffering from life-sustaining treatments. Patients believed that receiving life-sustaining treatments including intubation and resuscitation prolonged their dying and increased their pain at the end of life:

I told my family that having resuscitation will only prolong my death. My life won't be extended very long by having a resuscitation. It's just temporary. Sometimes it might add only a few more months or days, but not years. My life would be prolonged by intubation . . . it's very painful, and pricy [to receive life-sustaining treatment]. (PT11: 55 y/o lymphoma male)

Driver 1-2: psychological distress

Driver 1-2-1: not wanting to be a burden to families and society. Patients stressed that they might represent a financial burden to their family members if they chose to receive life-sustaining treatments at end of life and stay in the hospital:

I will increasingly become a burden on my children rather than taking care of them if I have to live like this [lying in bed receiving life-sustaining treatment] and stay here [hospital]. (PT09: 58 y/o lung cancer female)

Furthermore, some patients reported that after receiving life-sustaining treatment, they felt they represented a burden to not only families, but also the society:

It becomes very difficult when you are so sick. You can't take care of yourself. You rely on others [once receiving life-sustaining treatment]. I think it is a big problem now being dependent on others. You can't always rely on others or society. (FY07: Son of a prostate cancer patient)

Driver 1-3: resource re-allocation and notions of unselfishness

Driver 1-3-1: reduce futile treatments. When death was inevitable, some patients and families reported they would be willing to contribute to society by refusing futile treatments:

He [patient] said to me that if disease can't be cured then it is a waste of medical resources at the end of life. (FY02: 58 y/o daughter of a liver cancer patient)

Driver 1-4: self-sacrifice

Driver 1-4-1: donate organs to help others. Participants also expressed altruistic sentiments requesting organ donation to help others in need after they passed away:

If the day [death] is coming, I would like to die earlier. If my organs are still in good condition after I die, I hope to donate them to others who are in need. I will feel better if I can still help. (FY10: 41 y/o daughter-in-law of a liver cancer patient)

Theme 2: decisions for not choosing palliative care as part of advance care planning discussions

Patients reported they often sacrificed their right to self-determination by putting others' priorities before them. Meanwhile, trying to be a role model for children represented another driver to influence patients' decisions not to receive palliative care.

Driver 2-1: patients weighing others' benefits more important than benefits to themselves

Driver 2-1-1: trying to pacify the families. A number of patients stated that instead of fulfilling their own preferences, they made choices they believed their family members would want. Moreover, wishing to maintain family harmony was considered to be a priority and sometimes outweighed what patients' thought of benefit to themselves:

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)

Driver 2-1-2: being a role model for children by facing the challenge of treatment. A small number of participants reported that they did not believe palliative care was always appropriate, stating that making the choice to continue with active treatments enabled patients to serve as a role model to their children:

He [the patient] told me: 'Why would I like to receive chemotherapy? I want our daughter to know that dad has been fighting against the disease. Dad has no fear'. (FY14: 57 y/o wife of a pancreatic cancer patient)

Theme 3: no opportunity to choose palliative care as part of advance care planning discussions

Participants reported that patients with advanced cancer chose not to receive palliative care due to a lack of opportunities to discuss this decision. Furthermore, some health care professionals reported they lacked the necessary communication skills to engage in the difficult conversations required to discuss palliative care with patients as part of the advance care planning process. Others focused on the challenges associated with the cultural context considered to be essential in the initiation of

advance care planning discussions for cancer patients when considering palliative care.

Driver 3-1: absence of opportunities

Driver 3-1-1: concealment of prognosis from patients. ‘Mutual protection’, a subtle interaction between patients and families was identified during the decision-making process. Family members tried to protect patients from potential emotional distress by avoiding discussing the disease prognosis, while patients suggested they knew nothing about their prognosis to pacify their family members. This was achieved by attempting to cover up their emotions related to their conditions and uncertain future. This bidirectional relationship shaped the ambiguity of this complex decision-making process:

Between patients and families, there is a very subtle relationship called ‘mutual protection’. The families feel that they protect the patients by not telling them the truth about the prognosis. On the other hand, the patients pretend that they don’t know the prognosis to protect their families from becoming upset. (HCP12: Case manager)

The concealment of prognosis also occurred among medical staff. Physicians used carefully chosen words to shield the prognosis from patients, instead sharing the truth with their families:

In general, we are used to talk very little about the prognosis to patients. We won’t go into a lot of detail. I won’t tell him [the patient] about his lung metastasis or liver metastasis . . . but I will explain the details to the families. (HCP06: Physician)

Driver 3-1-2: lack of relevant knowledge or mental capacity for decision-making. Some patients and their family members possessed poor awareness of the severity of patients’ disease and often could not imagine the disease prognosis as a result of lack of medical relevant knowledge. This affected their ability to make informed decisions:

We don’t understand [the medical terms and knowledge]. It seems that I can do nothing for my mother but let it [disease deteriorating, then having cardiopulmonary resuscitation] happen. I can’t blame the doctor. I can only accept it. There is nothing we can do [about the disease]. (FY15: 50 y/o son of a bladder cancer patient)

Meanwhile, the capacity for decision-making among advanced cancer patients was mentioned as a necessity to facilitate patients’ palliative care decision-making. Medical staff stressed that they are willing to provide care in accordance with the patient’s preferences, but only if they possessed the capacity to make a decision:

If we assume that the patient has the capacity then our team will remind the families to let the patient make his own

decisions because he possesses the capacity. He has the right to know and choose how he will be taken care of. (HCP10: Case manager)

Driver 3-1-3: medical dominance of treatment plan to avoid disputes with family. Physicians provided as many treatments as possible to patients at their end of life to prevent legal disputes with families. They believed that ‘the dead won’t sue, but the living will’, so that they preferred to provide more treatments for the patients as a symbolic gesture of ‘caring’ to avoid any accusation of poor care:

Some doctors are afraid of medical disputes. They feel that ‘if I do not provide all treatments available to the patients at their end of life, their families may sue me’. (HCP08: Matron)

Driver 3-2: medical staff skills

Driver 3-2-1: need for sufficient communication and truth-telling skills. Insufficient communication between patients and the medical team, combined with the inconsistent information about disease prognosis from medical staff, compromised the trust within the clinician–patient relationship and patients’ expectations for the rest of their life. Subsequently, the initiation of future care discussions and corresponding treatments decision-making may not be optimal:

The doctor told me that I could live for at least three to five years when I was diagnosed. Now I am told that I have less than half a year left. No one told me this before. It’s a huge gap between the expectation and the reality. (PT13: 46 y/o bladder cancer female)

Driver 3-3: cultural factors

Driver 3-3-1: traditional social norms: filial piety and expectation of medicine. The traditional social expectation and pressure of being a filial child was another reason why family members could not let go, which will hamper a patient’s palliative care–related decisions. Receiving palliative care represented giving up, and filial piety is considered to be a virtue from older participants’ perspectives. The stress and judgement from the older generation and public influenced patients’ decisions for palliative care:

We are under pressure because people think that initiating palliative care represents ‘giving up’. This is passed on to people from the older generations such as their parents and elders. [Patients don’t receive palliative care] because ‘filial piety’ is very important. (HCP13: Hospice nurse)

Nevertheless, the expectation of medical education for physicians to typically focus on cure instead of palliative care increased the difficulty to initiate a discussion to facilitate patient’s access to palliative care as this might have been considered as a failure:

In their [doctors'] training, the education they received is all about saving life and curing patients. When they face a patient where there no curative treatments are available, they don't know how to deal with this. They don't know how to tell the patient: 'Sorry, I can't save you!' (HCP12: Case manager)

Meanwhile, physicians considered they disappointed themselves and patients by telling them the truth about their incurable prognosis:

It is their [doctors'] duty to cure patients' diseases. How can they tell the patients that they can not do anything for them? This disappoints the patients and also themselves despite all their efforts. (HCP12: Case manager)

Driver 3-3-2: systems: medical staff fear legal challenges, and patients lack social care support. It is noteworthy that the medical staff did not trust that the legal system to protect them. As a consequence, they provided care to patients according to families' requests to protect themselves:

If the medical staff have been accused once, or if there is legislation against them, they will keep providing certain treatments to patients according to families' opinions, rather than honouring patients' preferences to avoid disputes. (PT08: 40 y/o colon cancer female)

In contrast, lack of support systems including poor family and social care networks were considered as hampering patient's decision-making and autonomy for palliative care:

To be honest, it is obvious that if patients have a weak supporting system then they possess less autonomy when making medical decisions [at the end of life]. (HCP14: Hospice home care nurse)

Discussion

The findings from this work identify, for the first time, three key domains that underpin decision-making processes and their influencing drivers. This is in addition to highlighting important cultural differences^{9,30,31} patients with advanced cancer make decisions about receiving palliative care as part of the advance care planning process.

The triangulation analysis among participants towards patients' palliative care decision-making in advance care planning discussions, drawing out different perspectives across the different groups. In this study, family members played a vital role in a patient's decision-making process. The intended positive impact of enabling a patient to engage in shared decision-making has been shown to vary in relation to different cultural perspectives. By understanding these decision-making patterns,

the feasibility and acceptability of introducing a novel communication model, in this case advance care planning, may assist in the process of making decisions to receive palliative care more culturally acceptable and feasible.

Discussions regarding death and dying issues are still considered as taboo in Taiwan.^{7,32,33} This is considered to deprive patients of hope and increase tension between them and their family members (drivers 3-1-1 and 3-2-1).¹¹ Consequently, palliative care is not typically presented as an option (Theme 3). The introduction of advance care planning alongside the newly rolled-out Patient Right of Autonomy Act (see Appendix A for the legislative framework) in Taiwan has challenged the traditional truth-telling model among healthcare professionals. Sharing the truth with patients is now requested in legislation and considered a necessity during the advance care planning process based on the Patient Right of Autonomy Act.¹⁸ This is likely to change clinician-patient communication as clinicians will be required to assist patients in making their own decisions rather acquiescing to decisions from others associated with a 'good death'. To make this a reality, greater skills in advanced communication will be required leading to favourable patient-centred clinical outcomes. A training programme for staff focused on the difficult conversation with serious illness patients (e.g. Serious Illness Conversation Programme^{34,35} and Brief Negotiable Interview³⁶ developed in North America) is suggested to better equip healthcare professionals before conducting end of life or palliative care-related discussions with patients, and their families.

In this study, the importance of involving family members in a patient's decision-making process was identified (drivers 1-2-1, 2-2-1, 2-2-2, 3-1-1 and 3-1-3). This contributes to the ongoing development of a culturally specific approach referred to as 'collective decision-making'. The collective decision-making has been dominant in Asia for some time, relying on family members to make health-care-related decisions.^{8,9,33} This approach is believed to be derived from a deeply ingrained family-centred culture,³⁷ underpinned by traditional Chinese culture within Taiwanese society³⁸ (driver 3-3-1). This phenomenon is also present in Japan and Singapore; in Japan, older people tend to delegate their right of decision-making to family members, usually children or siblings to avoid them needing to consider their future care.³⁰ While, in Singapore, the value of advance care planning discussions is limited due to the family members representing the key decision-makers.⁹ Interestingly, collective decision-making is not only exclusive in Asia but also present in other countries. For example, Sinclair and colleagues identified that people from Italy tended to seek out family member's opinions when making medical decisions, whereas people from the Netherlands preferred to decide for themselves.³¹ This highlights the universal importance to

value family members' opinions in advance care planning discussions across many cultures.

Advance care planning is essentially a process of patient-centred communication between patients, family members and healthcare professionals to discuss future care options. The interpersonal relationship is key for a successful advance care planning process which may, in part, be due to the benefits of a bidirectional effect. Having advance care planning may improve trust and understanding regarding palliative care choices between patients, families and healthcare professionals. Moreover, having a medical team consistently providing palliative care for patients helps to establish better relationship between patients and healthcare professionals.³⁹ The strength of the connection between patients and healthcare professionals does not necessarily rely on the documentation (e.g. advance directives) to offer patients preferred palliative care. In contrast, documentations are more important when relationships have not been formed. Therefore, detailed discussions within a trusting clinician–patient relationship need to take place early on regarding palliative care if advance care planning is to be a success. However, the process of engaging in advance care planning can also cause harm. For example, when a patient is emotionally distant from his or her family or where family conflict is present, there may be a reluctance to engage in advance care planning.³⁹ This might explain the presence of driver 3-1-1: 'mutual protection', which occurred in the decision-making process. Furthermore, the commencement of advance care planning might also present a means to avoid litigation from healthcare professionals. This fails the main intention of advance care planning discussion and damages the trusting relationship between patients and healthcare professionals.

Strengths and limitations of the study

This study has number of strengths. First, we adopted purposive sampling to capture a comprehensive range of experiences among the study participants. Second, we use a number of sources of data (patients, family members and healthcare professionals) to enhance the trustworthiness and validity of the data.⁴⁰ Third, the interviews were conducted by a single interviewer (C.-P.L.), which strengthened the consistency by using a standardised approach. However, there are a number of limitations that must be considered when making inferences from the findings presented. First, the possibility of systematic bias might present as a result of using a single interviewer. However, this concern was addressed by using the 'investigator triangulation' which involved the participation of all researchers when analysing the data and when discussing the study

findings. This served to enhance the credibility and confirmability of the findings.⁴⁰ Second, the findings may have been constrained the willingness of participants to be open about their views on palliative care and advance care planning. Third, the term 'advance care planning' did not exist when conducting this study in Taiwan; therefore, authors used alternative terms (e.g. future care, palliative care and end-of-life care discussion). This may have increased the difficulty of eliciting participants' direct perspectives on this topic since these might be hidden. Fourth, we are aware there may be consequences of differences in language employed throughout this study which threatens the meanings and insight of study participants. We have attempted to overcome this issue by adopting a rigorous process of 'forward and backward translation' of accounts and views shared by participants.⁴¹

Conclusion

Three main patterns of decision-making among advanced cancer patients for receiving palliative care along with their respective drivers were identified in advance care planning discussions, detailing the subtle interaction between patients, family members and healthcare professionals in Taiwan. Furthermore, important elements that influence the palliative care decision-making were identified that include the following:

1. Clinician's perceived challenges in talking openly with patients about cancer progression, and the importance of patients' involvement when making palliative care decisions in advance care planning process;
2. Family-led decision-making with clinicians about their dependents' future care and treatment;
3. Patients' understanding of the term 'palliative care' to tailor future care plan;
4. The presence, or absence, of trusting clinician–patient relationship to facilitate dialogue regarding choices for care and treatment and likely outcomes.

These are central ingredients to initiate palliative care discussions and help cancer patients lead to informed choices when engaging in advance care planning. The practice of advance care planning in Taiwan is heavily influenced by these factors that drive three types of palliative care decision-making. These may inform advance care planning clinical practice in Taiwan and development of advance care planning beyond Western culture with wider utility in Asia-Pacific countries. Strategies to facilitate communication are required to improve outcomes for patients with advanced cancer and their families.

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Author contributions

C.-P.L., C.J.E., J.K. and R.H. contributed to conception and design. C.-P.L. contributed to collection and assembly of data. C.-P.L. and S.-J.S. contributed to data coding. C.-P.L., S.-J.S. and S.-H.H. contributed to translation of the themes, coding and quotes. C.-P.L., C.J.E., J.K., S.-J.S. and R.H. contributed to data analysis and interpretation. C.-P.L., C.J.E., J.K., S.-J.S. and R.H. contributed to manuscript writing. All authors contributed to final approval of manuscript.

Data management and sharing

All the relevant data is available. The method of data collection and analysis were reported in the main text. The full coding frame can be found in Appendix C in the supplementary material.

Ethical approval

The description regarding ethical approval was reported in the main text.

Declaration of conflicting interests

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Supplemental material

Supplemental material for this article is available online.

References

1. Kagawa-Singer M and Blackhall LJ. Negotiating cross-cultural issues at the end of life: 'You got to go where he lives'. *JAMA* 2001; 286(23): 2993–3001.
2. Sudore RL, Lum HD, You JJ, et al. Defining advance care planning for adults: a consensus definition from a multi-disciplinary Delphi panel. *J Pain Symptom Manage* 2017; 53(5): 821–832.e1.
3. Lin CP, Evans CJ, Koffman J, et al. The conceptual models and mechanisms of action that underpin advance care planning for cancer patients: a systematic review of randomised controlled trials. *Palliat Med* 2019; 33(1): 5–23.
4. Sudore RL, Heyland DK, Barnes DE, et al. Measuring advance care planning: optimizing the advance care planning engagement survey. *J Pain Symptom Manage* 2017; 53(4): 669–681.e8.
5. *Clinical practice guidelines for quality palliative care*. 3rd ed. Pittsburgh, PA: National Consensus Project for Quality Palliative Care 2013.
6. Department of Health. *End of Life Care Strategy: promoting high quality care for adults at the end of their life*. London: Department of Health, 2008.
7. Ke LS. Advance care planning in Taiwan. *Patient Educ Counsel* 2012; 89: 213.
8. Lin CP, Cheng SY and Chen PJ. Advance care planning for older people with cancer and its implications in Asia: highlighting the mental capacity and relational autonomy. *Geriatrics* 2018; 3(3): 43.
9. Menon S, Kars MC, Malhotra C, et al. Advance care planning in a multicultural family centric community: a qualitative study of health care professionals', patients', and caregivers' perspectives. *J Pain Symptom Manage* 2018; 56(2): 213–221.e4.
10. Detering KM, Hancock AD, Reade MC, et al. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010; 340: c1345.
11. Johnson S, Butow P, Kerridge I, et al. Advance care planning for cancer patients: a systematic review of perceptions and experiences of patients, families, and healthcare providers. *Psychooncology* 2016; 25(4): 362–386.
12. Craig P, Dieppe P, Macintyre S, et al. Developing and evaluating complex interventions: the new medical research council guidance. *BMJ* 2008; 337: a1655.
13. Lapré F and Wright G. Stakeholder strategies for service: conceptualising user-focused service in nursing home care. *J Strategic Mark* 2015; 23: 412–422.
14. Weathers E, O'Caioimh R, Cornally N, et al. Advance care planning: a systematic review of randomised controlled trials conducted with older adults. *Maturitas* 2016; 91: 101–109.
15. Brinkman-Stoppelenburg A, Rietjens JA and Van Der Heide A. The effects of advance care planning on end-of-life care: a systematic review. *Palliat Med* 2014; 28(8): 1000–1025.
16. Stewart BW and Wild CP. World cancer report 2014. Technical report, International Agency for Research on Cancer, Lyon, February, 2014.
17. Health Promotion Administration-Ministry of Health Welfare. *Cancer registry annual report, 2014, Taiwan*. Taipei: Health Promotion Administration-ministry of Health and Welfare, 2016.
18. Laws Regulations Databases of The Republic of China. Patient right to autonomy act. Taipei: Ministry of Health and Welfare, 2016.
19. Tong A, Sainsbury P and Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item check-

- list for interviews and focus groups. *Int J Qual Health Care* 2007; 19(6): 349–357.
20. Morse JM. Simultaneous and sequential qualitative mixed method designs. *Qual Inquir* 2010; 16: 483–491.
 21. Ritchie J, Lewis J, McNaughton Nicholls C, et al. *Qualitative research practice: a guide for social science students and researchers*. 2nd ed. London: SAGE, 2014.
 22. Moss AH, Lunney JR, Culp S, et al. Prognostic significance of the ‘surprise’ question in cancer patients. *J Palliat Med* 2010; 13(7): 837–840.
 23. Malterud K, Siersma VD and Guassora AD. Sample size in qualitative interview studies: guided by information power. *Qual Health Res* 2016; 26: 1753–1760.
 24. Varpio L, Ajjawi R, Monrouxe LV, et al. Shedding the cobra effect: problematising thematic emergence, triangulation, saturation and member checking. *Med Educ* 2017; 51(1): 40–50.
 25. World Medical Association. WMA Declaration of Helsinki: ethical principles for medical research involving human subjects. *JAMA* 2013; 310: 2191–2194.
 26. Braun V and Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77–101.
 27. Braun V and Clarke V. What can ‘thematic analysis’ offer health and wellbeing researchers. *Int J Qual Stud Health Well-being* 2014; 9: 26152.
 28. O’Cathain A, Murphy E and Nicholl J. Three techniques for integrating data in mixed methods studies. *BMJ* 2010; 341: c4587.
 29. Birt L, Scott S, Cavers D, et al. Member checking: a tool to enhance trustworthiness or merely a nod to validation. *Qual Health Res* 2016; 26(13): 1802–1811.
 30. Hirakawa Y, Chiang C, Hilawe EH, et al. Content of advance care planning among Japanese elderly people living at home: a qualitative study. *Arch Gerontol Geriatr* 2017; 70: 162–168.
 31. Sinclair C, Smith J, Toussaint Y, et al. Discussing dying in the Diaspora: attitudes towards advance care planning among first generation Dutch and Italian migrants in rural Australia. *Soc Sci Med* 2014; 101: 86–93.
 32. Hsieh JG and Wang YW. Promoting advance care planning in Taiwan: a practical approach to Chinese culture. *BMJ Support Palliat Care* 2011; 1: 79.
 33. Lee HTS, Cheng SC, Dai YT, et al. Cultural perspectives of older nursing home residents regarding signing their own DNR directives in Eastern Taiwan: a qualitative pilot study. *BMC Palliat Care* 2016; 15: 45.
 34. Bernacki R, Paladino J, Neville BA, et al. Effect of the serious illness care program in outpatient oncology: a cluster randomized clinical trial. *JAMA Intern Med*. Epub ahead of print 14 March 2019. DOI: 10.1001/jamainternmed.2019.0077.
 35. Paladino J, Bernacki R, Neville BA, et al. Evaluating an intervention to improve communication between oncology clinicians and patients with life-limiting cancer: a cluster randomized clinical trial of the serious illness care program. *JAMA Oncol*. Epub ahead of print 14 March 2019. DOI: 10.1001/jamaoncol.2019.0292.
 36. Leiter RE, Yusufov M, Hasdianda MA, et al. Fidelity and Feasibility of a brief emergency department intervention to empower adults with serious illness to initiate advance care planning conversations. *J Pain Symptom Manage* 2018; 56(6): 878–885.
 37. Wang SC, Chang CJ, Fan SY, et al. Development of an advance care planning booklet in Taiwan. *Tzu Chi Medical J* 2015; 27: 170–174.
 38. Wen KY, Lin YC, Cheng JF, et al. Insights into Chinese perspectives on do-not-resuscitate (DNR) orders from an examination of DNR order form completeness for cancer patients. *Support Care Cancer* 2013; 21(9): 2593–2598.
 39. Rhee JJ, Zwar NA and Kemp LA. Advance care planning and interpersonal relationships: a two-way street. *Fam Pract* 2013; 30(2): 219–226.
 40. Carter N, Bryant-Lukosius D, DiCenso A, et al. The use of triangulation in qualitative research. *Oncol Nurs Forum* 2014; 41: 545–547.
 41. Van Nes F, Abma T, Jonsson H, et al. Language differences in qualitative research: is meaning lost in translation. *Eur J Ageing* 2010; 7(4): 313–316.