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Advantages, barriers, and cues to advance care planning engagement in elderly patients with cancer and family members in Southern Thailand: a qualitative study

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Abstract

Background Older cancer patients are vulnerable to poorer health outcomes during cancer treatment. Although the Thai elderly had their own preferences towards future medical care and advance care planning (ACP) could help cancer patients make informed decisions, Thai physicians report a low ACP engagement rate. Thus, this study aimed to explore the perceptions of older cancer patients and their families towards ACP engagement.

Method We used a qualitative approach to explore the perceptions of non-haematological cancer patients aged ≥ 60 years old and their primary caregivers. The study was conducted at the Oncology Radiotherapy Referral Center, Songklanagarind Hospital in Southern Thailand. Semi-structured in-depth interviews were conducted with the patients and their caregivers. Thematic analysis was used to identify and analyze recurring patterns and themes of perceptions regarding ACP engagement within the interview transcripts.

Results Among the 138 families approached, 32 interviews were conducted. Three themes were found: (1) Advantageous opportunity: the patients believed ACP would help them realize their life values, and ensure that their preference would be respected; (2) contemplation and barriers to ACP: ACP is unfamiliar and unnecessary, might have low utility, worry patients and family members, take away optimism, would not be a proper activity for the patient at the current health situation; and (3) Cues for ACP initiation: perceived conformity with one's religion, awareness of the current cancer state, having multiple comorbidity or experience suffering related with medical care, wishing not to burden family, having close family members, and trust in physicians.

Conclusion ACP engagement could be hindered or promoted by perceptions of older patients and/ or their family members, as well as the communication skills of the care providers. Care professionals who aim to initiate ACP should minimize the potential barriers, make the ACP benefits salient, and watch for cues indicating a propitious time to start the ACP conversation.

Keywords Advance care planning, Elderly, Cancer, Oncology, Behavior change, Determinants, Qualitative research

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Introduction

Palliative care is specialized care which aims to reduce suffering and improve the quality of life for people who have life-threatening or life-limiting illnesses, and it has been recognized in many countries as a basic health right [1]. Palliative care functions through thorough assessments and comprehensive care, which are person-centered and goal-oriented [1]. Advance care planning (ACP) is a voluntary process of communication between a doctor, the patient, and the patient's relatives which is important in gaining a clear understanding of the individual's values and goals of care over time [2, 3]. ACP can help improve the quality of the palliative care the individual receives as it helps ensure that the individuals receive care that is consistent with their values, goals, and preferences [4]. ACP ranges from speaking with the patient to help understand the patient's values, and if there are preferred or non-preferred options for care, to preparing legal documents such as a power of attorney stating the legal decision maker(s) for the patient if or when they become incapacitated [2, 5]. Previous studies reported that ACP helped individuals to have peace of mind [6], reduced psychological distress among surviving family members [7], improved the patient's satisfaction and quality of life [8], and lead to fewer hospitalizations and more hospice use, which in turn helped reduce health-care costs [9–11]. Nevertheless, applications and recognition of ACP varied across countries [12].

The World Health Organization reported that 56.8 million people globally require palliative care, however, only fourteen per cent are receiving it [13]. The main barriers to high-quality palliative care include a lack of health system provision and awareness, misconceptions about palliative care eligibility and opioid use, and cultural and social barriers to communications involving death and dying [13]. In recent decades in Thailand, palliative care has been advocated by the Ministry of Public Health (MOPH) and non-government organizations [14, 15], and a living will has been recognized as legally binding in the National Health Act, section 12, since 2007. However, their use and the concepts of ACP have not been widely recognized by either general Thai citizens or most healthcare professionals. The Thai government started to actively promote ACP through a National Steering Committee and cooperation agreements with the Thai Palliative Care Society (THAPS) and other civil society organizations [16], and Thai standards for advance care planning were later published in 2022. The provision of ACP was also supported under the Thai national health system by national health policies, resulting in continuous training for palliative care providers and service reimbursement for government hospitals [14]. Despite these efforts, care providers found that ACP has not yet been commonly adopted by Thai families [14, 17] and

it was uncommon for conversations about ACP to be directed by a physician or the patient's family [14, 18]. This phenomenon could result from the members prioritizing seniority and respect for elders, and older family members are treated as saints in the family [12, 14, 18]. Nevertheless, the elderly might have missed the important chance to say if they would like to stay at home for the final years, and do not wish to be admitted to a hospital for burdensome treatments if the chance of survival is low [19].

Cancer is a group of diseases of which the incidences commonly peaks in older adults and the patients likely experience an acute decline in health when their cancer advances [20, 21]. Also, the elderly are an age group in which the persons are susceptible to multiple morbidities and ageing changes; even those without significant morbidities could experience fragility and functional impairment as they age [21]. When the elderly get cancer, they are more likely to experience poorer cancer outcomes compared with younger patients, for example, they tend to have higher mortality and are at risk of adverse reactions resulting from chemotherapy and radiotherapy [22–25]. ACP is an important element in cancer care since it helps cancer patients establish informed decisions for their future cancer treatment [26–28]. However, it is common for cancer patients to refuse to consider ACP [28, 29].

A systematic review evaluating the ACP context in cancer care in several Western countries summarized that ACP had a bidirectional relationship between patient and family, as well as health professionals; it can provoke fear and distress due to the timing of initiation and the person who initiates talking about the decision for the end of life. In addition, there were also complexities in views of autonomy and institutional effects on ACP, and knowledge in ACP and experience towards end-of-life care [29]. More locally, a previous study in Thailand showed that older cancer patients preferred to be told the full truth about their illness, to have their family fully informed, and to pass away at home [30]. However, it appears consistently that Thai physicians and families do not normally engage the patients in conversations regarding treatments and prognoses owing to a lack of confidence to convey the messages, fears of negative psychological consequences to the patients and their beliefs that talking about bad things would make them happen [14, 17]. However, we could expect these ACP engagement modifiers to differ across settings even in the same country. The South of Thailand is an area where people have multicultural backgrounds [31], and we still have had a low level of understanding of ACP engagement in older patients and their families in this part of Thailand. Thus, the current study aimed to explore the perceptions and attitudes of older cancer patients in Southern

Thailand and their caregiving family members towards ACP engagement.

Methods

Our study applied a qualitative approach to explore the perceptions and attitudes of older patients with cancer and their caregiving family members towards advance care planning, and applied content analysis as recommended in the thematic analysis framework [32].

Informant selection

We purposively selected patients who were 60 years of age or older, with non-haematological cancer, and able to understand and communicate in Thai and their caregiving family members who were 18 years old or older and had contributed the highest number of hours (compared with the other family members) for the patient's care. Such criteria were applied to identify and select patients who potentially had rich information to describe the patient's perceptions towards ACP in older people with a solid tumor, of which the cancer types share similar disease trajectories [33, 34]. Patients who could not tolerate the interview, had obvious cognitive impairment or mental problems, had moderate to severe pain, or had brain lesions were excluded. Patients who had regular radiotherapy sessions and were having a follow-up visit were considered potential study informants. After the routine care, potential informants were preliminarily informed about the study by the registered nurses who were knowledgeable of the selection criteria. If the potential participants seemed amenable, the nurse then informed the researcher. SS invited interested patients and their caregivers to the consultation room for a face-to-face discussion to provide full information on the study. The patients and caregivers who agreed to participate were then asked to sign an informed consent form and arrange an appointment for an in-depth interview.

Setting

The study was conducted from January 2023 – April 2023 at the Oncology Radiology Clinic, Songklanagarind Hospital, the major referral center for cancer patients in Southern Thailand.

Data collection

The interview guide was first developed by the research team, incorporating questions from a previous study [6] and suggestions from local palliative care consultants. Due to a concern of unfamiliarity with the concept of ACP in some of the informants, we designed our interview guide to let the interviewer provide basic information about the ACP concepts. The additional files show interview guides for patients and caregivers in more detail (see Additional file 1 and 2). We pilot-tested the

interview guide with 3 patients who had the same features as the formal informants to evaluate the comprehensibility of the questions. SS (previously trained in qualitative research methods and currently working as a palliative care physician at the study center) conducted all the semi-structured in-depth interviews with each informant. The interview took place at a consultation room to ensure that we could effectively address any potential mental or physical issues, such as psychological reactions, that might arise. While we were carrying on with our data collection, a few questions were later added to capture more detailed data based on what the interviewer learned from the previous interviews. To be aware of potential sensitive points about and avoid difficult areas of questioning, the caregivers were interviewed first and then the older patients. The interviews took approximately 45 min per session and the interviewer had not known the informants before the interviews. Each session was audio recorded and field notes were used to make notes of body language input or unclear words. In the case where the informant's answer was not clear the interviewer would ask further questions to clarify the meaning at each point by a validation question, for example, "Am I understanding correctly that you are feeling/thinking ...". The audiotapes were transcribed verbatim into the Thai language. Saturation of the data was discussed among the researchers, including one experienced palliative care nurse and one oncology nurse, to decide no emerging data and whether the collected data was sufficient to exemplify the study theoretical concept [35].

Data analysis

We applied a thematic analysis framework [32] and several approaches to ensure trustworthiness, credibility and transferability of the data [36]. Credibility was established through investigator triangulation and peer debriefing. Transferability was established through thick descriptions of the data. The first four transcripts, including the field note data, were given to two coders, SS and PL. The coders first familiarized themselves with the data by going through the transcripts line by line. The initial codes were compared, critically discussed, and initially agreed upon by the two coders. SS continued to code the remaining transcripts and record emerging codes in a form of coding dictionary. Additions or modifications of the codes and their dictionary were logged on a daily basis for subsequent auditing. Broader meanings of the codes were identified in terms of themes after examining the whole dataset. The components of the Health Belief Model (HBM) [37] were identified a priori as a beneficial approach to theming the informants' thoughts. The HBM framework encompasses beliefs and perceptions which could potentially modify the readiness of a patient to engage in advance care planning. The themes and

Table 1 Characteristics of the informants

| Characteristic | Patients | Family caregiver |
|------------------------|----------|------------------|
| Gender | | |
| Female | 5 | 16 |
| Male | 11 | 0 |
| Age group | | |
| 60–69 | 10 | 8 |
| 70–79 | 4 | 1 |
| 80 or more | 2 | 7 |
| Religion | | |
| Buddhist | 13 | 13 |
| Islam | 3 | 3 |
| Occupation | | |
| Agriculture/fishery | 2 | 2 |
| State officer | 5 | 6 |
| Private employee | 1 | 1 |
| Retired officer | 2 | 0 |
| Self-employed | 4 | 3 |
| Unemployed | 2 | 4 |
| Marital status | | |
| Married, with children | 15 | 12 |
| Married, no children | 1 | 1 |
| Single | 0 | 3 |
| Education | | |
| > Bachelor's degree | 2 | 0 |
| Bachelor's degree | 3 | 6 |
| Diploma | 0 | 1 |
| High school | 5 | 5 |
| Primary school | 6 | 4 |

Table 2 Characteristics of the cancers

| Characteristic | N (total = 16) |
|------------------------------|----------------|
| Type of primary cancer | |
| Breast | 2 |
| Colon | 1 |
| Esophagus | 2 |
| Head and neck | 3 |
| Lung | 1 |
| Prostate | 3 |
| Rectum | 2 |
| > 1 type | 2 |
| Metastatic cancer | 4 |
| Years after cancer diagnosis | |
| < 1 year | 8 |
| 1–3 years | 3 |
| > 3 years | 5 |
| Performance status | |
| ECOG 1 | 8 |
| ECOG 2 | 3 |
| ECOG 3 | 5 |

subthemes were debriefed with PL and RK to ensure solid interpretations and conclusions. The data were managed and analyzed by Microsoft Excel and R software. Themes and subthemes are provided with descriptions and examples of the relevant verbatim quotes.

Results

We invited 138 patients for an interview. One hundred and six (76.8%) declined to participate and ten (7.2%) did not come to the scheduled interviews. The common reasons for non-participation were that the interview took too long thus did not suit their travel plan to their accommodation (87 patients), they were busy with several ongoing treatments at the time (16 patients), and were uncomfortable with discussing their situation (13 patients). Finally, we conducted in-depth interviews with sixteen patients and sixteen caregiving family members (Table 1). Thirteen families were Buddhist. Five patients and six caregivers had a bachelor's degree or higher. The median family size was 4 (range 2–10) people. Fifteen patients were married and currently staying with their children.

Head and neck cancer and prostate cancer were the two most common primary cancer types (Table 2). Two patients had two primary cancer sites. Metastasis was present in four patients. Most of the patients were recently diagnosed with cancer (less than one year) and were undergoing cancer treatment. In general, the informants were well-functioning (Eastern Cooperative Oncology Group grade 1; ECOG1).

Themes

We found three themes reflecting perceptions and attitudes of the informant towards ACP. First, the older patients and families saw ACP as an advantageous opportunity for their medical care. Secondly, there were certain beliefs or quality which reflect contemplation and hinderances of ACP engagement. And finally, a third group could be defines as cues to ACP initiation also emerged from the interviews, in which different situations or qualities can be observed to decide timely ACP discussions. Table 3 summarizes themes and subthemes found in our study.

Theme 1: advantageous opportunity

Many individuals believed that ACP had significant benefits. The informants saw ACP as fostering introspection about their life values, and ensuring the preservation of their dignity when life-sustaining decisions arose.

Introspection of life values through invited communications

It was uncommon for older patients with cancer to feel that writing down their preferences would be a good idea. However, some patients saw ACP as exercise to

Table 3 Themes and subthemes

| Theme | Subtheme |
|--------------------------------------|---|
| 1. Advantageous opportunity | 1. Introspection of life values through invited communications 2. Conveying one's will to trustable others while still capable |
| 2. Contemplation and barriers to ACP | 1. Perceived potential low utility of ACP 2. Rely on capable others 3. Perceived functional gap 4. Unfamiliarity of advance directives and living wills 5. Maintaining optimism by avoiding bad news 6. Prioritizing the family decision making authority over one's own |
| 3. Cues for ACP initiation | 1. Perceived conformity with religious principles 2. Multiple health conditions 3. Awareness of a low chance for recovery 4. Experience suffering from medical treatments 5. Not wishing to burden the family 6. Having a close caretaker 7. Trusting doctor-patient relationship |

contemplate one's values and beliefs, in terms of medical care preferences.

"They (healthy persons) should be able to think about what they would want at the end of life, and thus be able to do it (write a living will). Eventually, persons who become sick and have troublesome symptoms would be aware of what treatments were about to be given to them." (Male, 78, prostate cancer).

When timing is appropriate, an invitation to ACP would help them consider what they wished to have and wished not to have, ahead of time:

"I would be feeling neutral if my doctor started the conversation. I think we (the patient and the doctor) should always discuss this. The first time is when a patient is still healthy. Second, the discussion should be done when the patient has or is informed of some abnormal symptoms. Third, it should be done when the symptoms worsen. (Male, 60, prostate cancer)

His wife also expressed the same feeling:

"It is sensible that "If we did this, it would somewhat affect something else." It is the same as general prescriptions which sometimes affect the liver or the kidney then it requires us to decide whether or not we want to refuse the treatment to save the organs... It is better to have information so we can decide what we want. I am not negative about this; at least we can choose for ourselves. It would be beneficial because I would be knowledgeable about how to take care of him." (Female, 60, caregiver – wife).

Conveying one's will to trustable others while still capable

ACP was perceived as a process to convey messages regarding one's preferences to family members and their doctors. Some informants felt that taking part in ACP meant a thoughtful act to express their values at a time when they were still well-functioning and to link their values with future potential changes in their health, especially if it started to deteriorate.

"If she (the daughter) thinks I should be intubated, I should follow her. This is an actual plan made in advance. If any bad things happen, this thing (the document indicating the surrogate) can authorize her for decision-making." (Female, 66, breast cancer). "It is good because I can leave my instructions for my doctor to follow. Those punctures, those resuscitations, are not preferred." (Female, 96, advanced rectal cancer).

Another informant, who was a soldier, shared that living will could carry his preferences to ensure that his dignity would be preserved while he could also do good things for other people.

"The doctor would help me to see which state is a life without quality, meaning that I am at a time I cannot either serve this country or enjoy eating or traveling. We should not end up in a bed in an ICU, should we? Let the younger and healthier people use the facility." (Male, 64, advanced lung cancer).

Theme 2: contemplation and barriers to ACP

In some cases, the patients and their families had different perceptions of the value of ACP. These expressed their concerns regarding ACP, in which some caretakers felt they could contemplate being in the patient's situation. Apart from someone else trying to understand their feelings, the patients expressed concerns related to how the family caregivers would be affected by the patient's decisions.

Perceived potential low utility of ACP

ACP utility was contemplated on its currency and the chance of being applied. One informant expressed concerns regarding the currency of advance directives and living wills despite their potential benefits.

"The document (living will) can instruct the families clearly, but we cannot be sure if they are up to date. However, if there is no document at all, the communication would be limited to 'at the present,' so we cannot understand much about what the patient's preferences are. Most people would easily say some-

thing like he/she could face the end of life and not require any resuscitations. But if they severely suffered from such conditions, they might instead ask for full medical support.” (Male, 60, prostate cancer).

In addition, although the directives could be helpful at the time death is approaching and/or the doctor is going to put them on long-term machine dependence, a patient might think such conditions have a very low chance of occurring in most people’s treatments; such individuals can speak for themselves until the very last minute.

“(Advance directives) would not be useful if they were still able to speak for themselves. In my experience, some people can speak until their last breaths. For me, I think I need some time to think if the documentation suited me. I think I better not do it (document the will) at this time because there would be a small chance for general patients to apply this. Let’s say, I have never seen or heard of them being applied.” (Male, 64, nasopharyngeal cancer).

Rely on capable others

It was not uncommon that advance decisions in some elderly patients with cancer were transferred to some important others. Some patients thought that they had a limited capacity to decide on medical treatments, unlike their physician or their children, who had more knowledge and a better understanding of the topic.

“It is up to my doctor how the treatment would be chosen ... It is up to my kids. These or those treatments are all up to them, all of them. I am used to relying on them. I am incapable of deciding about these things (medical treatments).” (Male, 83, rectal cancer).

Another patient said that she would always agree with what was advised by the clinicians.

“If the doctor advises me to receive any treatments, I will follow her advice. That’s it. It is unnecessary to tell her. She just does her job, so do I ... she does her job; I follow her advice, this and that. That’s all, nothing more than that.” (Female, 60, cervical cancer).

Perceived functional gap

Some patients perceived that health deterioration was too far ahead to be worth considering at the moment while they were generally well-functioning; thinking about potential treatments received while the patient was

living almost normally did not sound reasonable. This interpretation of the current situation led to the conclusion that advance care decisions should not be made too early.

“(A living will) is suitable for people who are already sick. Some people cannot devise this kind of thing because they are currently active, and they might be still ignorant of the chance of becoming ill.” (Male, 63, advanced nasopharyngeal cancer).

His wife also shared similar thoughts.

“We are worried about what has not arrived yet. Thinking about having him (the patient) intubated is [briefly silent]. We are still at the point that he is still capable of eating. If it is already the time, we must make up our minds and let the physician do their work.” (Female, 62, caregiver – wife).

Unfamiliarity of advance directives and living wills

Living wills and advance directives were new to fifteen dyads. After such terms were introduced, some of the informants misunderstood that it was the same as the will to arrange individual’s properties, as they were more familiar with the term ‘general will’.

“Living will ... I haven’t heard about that, only the will for the property that I have heard about.” (Female patient, 66, breast cancer).

Only one family had knowledge about living wills and advance directives. In this family, most of the patient’s children were well-educated and had high-income jobs. The patient shared that the document had functioned well in her son’s (who was a clinician) case when he was severely ill.

“When Doc (her son) was alive, he also instructed us (via his advance directives), no more pain and no further procedures.” (Female, 96, advanced rectal cancer).

Maintaining optimism by avoiding bad news

Some of the participants were uncomfortable with ACP as they tried to maintain an optimistic caring environment for both the patient and the family. They focused on fostering hope for a cure for themselves (cancer patients) or their patients (family members), while discussing values and preferences for medical care seemed to be all about handling incurableness and dying.

"I preferred not to talk with my family about this (advance decisions) because my mom is quite old. She does not seem prepared for this. We often mention pleasant stuff and rarely talk about something that could be stressful. My wife might be ok to plan for stuff like this, but it could also be another story because she is still young, and we don't have kids. She is scared that she will lose me ... I think we should not discuss about this... because sometimes it feels like cursing myself." (Male, 62, advanced nasopharyngeal cancer).

A family member of a 96-year-old cancer patient also shared similar thoughts.

"I have never asked the physician if the cancer is at what stage. Whether she could ... she could live for how long further; I have never asked because I thought it would create pressure in the atmosphere. I know it is close. It is surely about to happen ... We, her kids, never asked something like that because we have prepared ourselves for things that would occur to our mother. But it is better not to learn about it." (Female, 68, caregiver – daughter).

Sometimes, family members and the clinician might conspire to withhold actual information disclosure and prevent the patient from participating in ACP discussions.

"At the hospital, the doctor let only me know the information. She said "It is inoperable. It is far gone, and the risk (of surgery) is too high to take". The doctor only told me, and I would take the information to my brothers, but not my mom ... The doctor said "You (the patient) don't need to go into the room. You must be tired because of getting the X-ray so you can wait in front of the room". Although the patient was very willing to learn about the results, we avoided telling her the major ones." (Female, 24, caregiver – daughter).

Prioritizing the family's decision-making authority over one's own

An advance directive was seen as a document which can help communicate the patient's wishes for future care, especially when there are no immediate relatives. However, some patients expressed a concern about conflicts in views in the family despite a clear understanding about the rationale, owing to differences in values.

"If the family is multi-generational, I think this kind of document (advance directive) has limited benefits because at that time it could be used, there could be

husband or wife, their kids, or even their parents for some patients thus the document could create conflicts among people. Suppose I wrote it in my way, but my kids instead say, "It is worthwhile to just add one minute to my life", and then the document is there forcing them to follow it. These troubles would not happen to a writer like me, but the families could feel guilty for what they have decided." (Male, 60, prostate cancer).

Similarly, a patient who had spent 18 years as a monk expressed that his experience made him feel his wife might see things differently so what he wanted might not be accepted. Such contemplation had kept his willingness to share his preferences with his wife quiet until the present.

"I could have donated my body to the hospital already if I was not considerate of my wife. We have never talked about this, but this is what I have been thinking about ... It has been 2 years since she has been involved in the treatments and everything, so it is somewhat difficult. If I do not tell her, there could be quarrels." (Male, 63, nasopharyngeal cancer).

Theme 3: cues for ACP initiation

Both patient and caregiver informants shared some patients' qualities which might have prompted a patient to participate in ACP communications with loved ones or with the treating physicians. These qualities convey the sense of a patient being ready for end-of-life care decisions or appointing a surrogate decision maker for healthcare.

Perceived conformity with religious principles

ACP is analogous with an important religious principle in both Buddhism and Islam, which is to always be aware of uncertainty in life and be prepared for it.

"I have no problem because I am aware that our time will soon come. We should not be ignorant (about uncertainties in health). Such ignorance ... it is not acceptable in Islam. Ignorance of the uncertainties in life and health is like a living person putting oneself into the grave. God would not forgive ignorant persons." (Female, 66, breast cancer).

Her daughter also expressed similar thoughts:

"It (deterioration of health) could be expected at some point for everyone. She is, in my opinion, a kind of religious person... She always says something like loss is certain for us; we are born, grow, fall ill,

and die... It is good to let her know that she could plan for herself if (the cancer) is incurable [lowering voice]. (Female, 34, caregiver – daughter)

Multiple health conditions

One cancer patient had been thinking about uncertainty in health due to multiple comorbidities. The patient's contemplation might have prompted him to share his wishes with his family members.

"He (the patient) looked depressed at that time. For me, his reaction was understandable because he was old and had multiple conditions. He might feel uncertain about what would happen in the future, so I think we must start talking [quietly subdued laughter]. We must talk and prepare; I ask him "What do you think about that?"; we talk about this kind of stuff. He is a person who is already aware of the uncertainty, I think." (Female, 60, caregiver – wife).

Awareness of a low chance for recovery

When there are certain possibilities for irreversible or aggressive cancer, some patients understand that medical treatments will be ineffective or only try to prolong life. And when they decide to share such thoughts with the care providers, prognosis statements and discussions for palliative care could be initiated at an appropriate time.

"If I was aware that there would be only a small chance for a person to survive the cancer, I would tell the doctor to let him/her go instead of trying to cut something out of him/her. Aggressive treatment would only create unnecessary pain and likely be ineffective." (Female, 66, breast cancer).

Another informant thought similarly; she added that there was no value in putting patients who are at the end of life on a life-sustaining machine.

"I mean if I am aware that it is very likely that I am going to die in a short period of time and the doctor will keep resuscitating me for nothing, or on the other hand, there are some conditions for which the doctor would possibly put me on a long-term machine, I would choose neither of them." (Female, 73, advanced ovarian and colon cancer).

Experience suffering from medical treatments

Most informants had heard of or had indirect experience of invasive medical procedures, and some of the patients had had direct experience of such procedures. These

experiences prompted engagement in ACP by being unwilling to let themselves or their loved ones experience the same thing again.

"I told my doctor, if the disease is severe and untreatable, or whatever, to not do anything to me. The time when I was intubated made me aware of how much I hate my life being under that condition. Even though I was moved to the post-surgery ward (after the surgery), the tube was still with me keeping my mouth open. I was aware that I was sick, but I was so thirsty, and drinking was prohibited. I was in real pain having a tube in my mouth." (Female, 73, ovarian and colon cancer).

Some caregivers could understand how it would be to have a tube in the mouth. One informant also expressed similar thoughts.

"Some patients ... they are exhausted; they want to sleep. If a treatment causes suffering, they would prefer not to receive it because they have suffered enough. To get intubated is real suffering. It would be all dried up, the throat. I can remember the moment my mom struggled to say "water", then I cried." (Female, 65, caregiver – wife).

Not wishing to burden the family

While discussing care plans, a patient may express his/her wishes not to be a totally care-dependent such that it would greatly cause a great burden for the family. Some patients could imagine how life-sustaining treatments could burden their own body and its consequences for their children. These thoughts were found in both patients who were recently retired and the oldest-old.

"Everyone will arrive at that point. I think I would like to pass painlessly, which is to be managed in any way to be pain-free. If I am about to pass, I and my kids agreed that we would choose not to undergo any burdensome treatments like surgery... The kids were worried about me being paralyzed and bed bound. They said they could handle it if it happens... I said I preferred not to burden my kids, let them live their lives. It cannot be stopped when I have to go." (Female, 66, breast cancer).

Another patient shared his awareness towards creating a chronic burden to the family as a result of putting a patient on a long-term life sustaining machine, and commented on his perceived benefits of a living will together with a family-related dilemma.

"If it (the use of a life sustaining machine) is not too long, like 45 days, I think it is acceptable ... But, it is difficult to tell (if other people would see a living will as beneficial) because people have different beliefs. Some relatives are attached to the patients. They might insist on sustaining the patient's life to be as long as possible. But for me, I reaffirm what I said." (Male, 64, advanced lung cancer).

Having a close caretaker

Having a family member with a close relationship with the patient could help the patient identify a surrogate decision maker for healthcare.

"No discomfort here, I confirm that. I can write (her daughter's) name as my surrogate decision maker. It is exactly her because she is the one closest to me and knows a lot about my health." (Female, 66, breast cancer).

Trusting doctor-patient relationships

Many informants expressed the opinion that trust in their physician would help them feel comfortable with what was suggested by the physician, including an invitation to take part in ACP. One of them compared trust in their physician and adhering to their advice with her adherence to religious principles.

"Allah gives us the capability to think and consider things using our brain... We have always adhered to religious principles, but when it comes to diseases and their treatment, we trust our physician as our number one resource. (Female, 54, caregiver – daughter)

One caregiver shared that good communication experiences could make them feel more relaxed for further discussions.

"When we were with the doctor, I had several questions. After the doctor addressed them and explained them to us clearly, we felt more hopeful. At first, we had, let's say, 10% of hope." (Female, 47, caregiver – daughter).

On the other hand, a family could be greatly discouraged by traumatizing messages from the physician, and thus further ACP discussions could be difficult.

"The first time she saw a doctor at the provincial hospital, the doctor shouted out, "Your cancer is gigantic!" She went back home, and she became drained.

She did not cook or do housework as usual. I could see that she was clearly discouraged." (Female, 34, caregiver – daughter).

Discussion

This qualitative study explored how elderly patients with cancer and their caregiving family members think about ACP. Our study included both patients and the caregiving family members of those patients who had various types of cancer, including metastatic cancer. The study families had various socioeconomic features, and they commonly had more than one generation in the family. The caregivers who agreed to participate in the interviews were all females. Three concepts of thought towards ACP engagement were identified as behavioral modifiers. The families' behaviors regarding the ACP concept were generally formulated through the lens of the combination of perceived benefits and barriers to ACP engagement, and the cues they experienced through their life or cancer treatment course. We found that the barriers and cues to ACP engagement had a range of opinions, to some extent depending on whether the interviewee was a patient or caregiver similarly to the concepts identified in previous studies investigating the engagement of ACP in elderly [29, 38].

ACP as an advantageous opportunity

Some informants indicated their beliefs that ACP could enable cancer patients to receive their preferred treatment through authorizing their surrogate to follow their preferences. This perceived benefit was consistent with what has been reported by elderly patients in general and in older individuals with chronic diseases [39–41]. Earlier research also showed that ACP helped increase the sense of control for end-of-life care for many terminal patients [42, 43]. Additionally, ACP was seen as an opportunity to examine one's own preferences and share what one values with the family and care professionals. This conformed with another study in South Korea [44], which found that the ability to exercise his/her own will towards medical care was the major reason (38.9%) to proceed with ACP.

Barriers to ACP engagement

The acceptance of ACP could be impeded by several factors involving any of the patients, family and/or care professionals [3]. According to prior systematic reviews [12, 29], care professionals need to tackle several patient-related barriers, including lack of knowledge and understanding of their diseases and ACP, influences from their beliefs, and perceptions towards medical care and of the role of ACP. It has been over a decade since living wills have been officially accepted in Thai law, and various forms of this document have been developed

and distributed by different groups to help patients who might wish to follow this path [17], for example, the Bao Jai (means relieving) book and Thai standard forms for ACP. However, most of our informants were not aware that these types of documents existed. This possibly complicated undisclosed end-of-life wishes in Thailand since older people tend to have their own preferred end-of-life care [19].

ACP has been perceived by some people as a form of communication delivering unfavorable information, potentially causing stress or demotivation among patients, families, and even healthcare practitioners [3, 45–47]. The current study found that concerns in delivering bad news could be another important barrier to ACP engagement. Some families might be concerned about distress and discouragements if their loved ones participated in ACP and that they could lose their willpower and could not be able to tolerate the cancer treatment. These underlying thoughts appeared to motivate them to avoid starting values discussions and talking about end-of-life care with their elderly relative or even concurring with the healthcare provider to withhold unfavorable news and limit the patient's involvement in the discourse [17]. Complicating matters further, older cancer patients might also be considerate of their family and therefore reluctant to express wishes that they think could worry their family. This type of cultural sensitivity has been hypothesized in an earlier study in Asian families [12]. Amidst this intertwined unexpressed preferences in a family, clinicians can play significant roles in delivering honest information and mediating the family dynamics. Previous study found that 87% of general cancer patients [48] and 95% of metastatic cancer patients [30, 49] preferred to receive information about their cancer from their attending physician.

Cues for ACP initiation

Although there are no standard guidelines concerning when ACP should be initiated, in earlier studies specialists have recommended that the person who is willing to initiate an ACP conversation should observe if there are patient-centered cues, for instance, when the patient initiates the conversation, after the patient is diagnosed with a new life-limiting disease, or when there is a change in the patient's circumstances [3, 50]. In the current study, we identified cues in which interpersonal relationships were intertwined. The cues cover signals in which the patient's perceptions were directed toward his/her own experience or concerns, for instance, having multiple comorbidities or becoming aware of an unfavorable prognosis, and interpersonal qualities such as trusting relationship with their physician. There could be an opportunity for care providers who can assess if such cues are present, even if not, establishing trust with

cancer patients and their families allowed the provider to initiate ACP discussions.

Study limitations and further studies

Our qualitative descriptions were derived from non-hematological cancer patients and their family caregivers in the south of Thailand who required radiotherapy, and thus the findings of this study might have limited generalizability to older cancer patients in other settings. Also, we had a relatively low response rate. The high refusal rate to participate might have reflected the unfamiliarity with ACP of most Thai families or perhaps be partly attributable to our strict protocol, which required all informants to participate in our consultation room. In addition, only female caregiving family members agreed to participate in our interviews, and thus the data of the caregivers' thoughts could be biased towards gender-related experiences. However, in order to clarify this potential bias, we consulted two debriefers to obtain their more experienced views concerning palliative care and oncology to confirm whether the saturation of the qualitative information was sufficient to draw at least tentative conclusions regarding a better understanding of the patients' attitudes towards ACP [35]. Future studies should include other cancer types and have a better balance of male-female caregivers to acquire more in-depth perceptions from male-related family members.

Conclusions and implications

Although ACP perceived as an advantageous opportunity for many of our participants, there were also concerns about it raising uncomfortable questions. During general consultations, care professionals might first observe if there are any cues indicating the patients are ready for ACP, then introduce the ACP benefits through personalized instances, emphasizing that ACP would help the patients to receive their preferred treatment via their trusted doctors or surrogate decision makers. Such timely initiation and personalizing the advantages could make ACP more acceptable [51]. Nevertheless, several barriers such as a perceived low utility of ACP or family efforts to maintain an optimistic atmosphere should not be overlooked [2, 3, 52]. These intertwining patient-family-provider relationships on the contemplation of ACP engagement should always be considered when a successful ACP for Thai older cancer patients is desired.

Abbreviations

| | |
|------|------------------------------------|
| ACP | Advance care planning |
| AD | Advance directives |
| ECOG | Eastern Cooperative Oncology Group |

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12904-024-01536-x>.

Supplementary Material 1

Supplementary Material 2

Acknowledgements

We express our appreciation for the invaluable contribution of our informants and pilot participants. Our gratitude also goes out to Associate Professor Temsak Peunggrassami and Mrs. Prajuab Nuurai for their support and constructive advice, and to the Department of Radiology and the dedicated staff at the Oncology Radiotherapy Clinic, Songklanagarind Hospital, for their support throughout this study. Special recognition is due to Mr. David Leslie Patterson from the International Affairs Office, Faculty of Medicine, Prince of Songkla University, for his assistance in editing the English language of this manuscript. We would also like to acknowledge the financial support provided by the Faculty of Medicine, Prince of Songkla University, which allowed the successful execution of this research.

Author contributions

SS and SA conceptualized the study. SS, SA, RK, PV were responsible for the study design. SS conducted the in-depth interviews. SS and PL analyzed the data. PL and RK debriefed and discussed the qualitative findings. SS wrote the first draft of the manuscript. All authors have read and approved the manuscript as submitted for publication.

Funding

This study was funded by the Faculty of Medicine, Prince of Songkla University. The funder did not participate in the design of the study design, data collection, analysis and interpretation, or manuscript preparation.

Data availability

The transcripts analyzed in this study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

This study was performed in accordance with the Declaration of Helsinki. The ethical approval was provided by the Human Research Ethics Committee, Faculty of Medicine, Prince of Songkla University (project number REC 65-417-9-1). Written informed consent was obtained from each participant before the start of the interviews.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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Received: 3 October 2023 / Accepted: 30 July 2024

Published online: 21 August 2024

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