นิพนธ์ต้นฉบับ Original Article

ทัศนคติต่อการเขียนแสดงเจตนารมณ์ของตนเองในวาระสุดท้ายของชีวิต

ชนิกานต์ วงศ์ประเสริฐสุข ธัญญรัตน์ ประมวลวงษ์ธีร

ภาควิชาเวชศาสตร์ครอบครัว ศูนย์การแพทย์ปัญญานั้นทภิกขุ ชลประทาน มหาวิทยาลัยศรีนครินทรวิโรฒ

บทคัดย่อ

การดูแลผู้ป่วยระยะสุดท้าย เป็นการเพิ่มคุณภาพชีวิตให้กับผู้ป่วยและครอบครัวที่มีภาวะโรคคุกคาม ต่อชีวิต ซึ่งมีการเผยแพร่แนวทางดูแลรักษาอย่างแพร่หลาย ผู้ป่วยมีสิทธิวางแผนการดูแลในวาระสุดท้าย และการเสียชีวิตของตนเองได้ โดยการเขียนหนังสือแสดงเจตนารมณ์และสื่อสารให้ครอบครัวรวมทั้งบคลากร ทางการแพทย์ได้รับทราบ จากประสบการณ์การทำงานของผู้วิจัยพบว่า ผู้ป่วยส่วนใหญ่เห็นข้อดีของการเขียน หนังสือแสดงเจตนารมณ์ในวาระสุดท้ายไว้ล่วงหน้า แต่ไม่ได้เขียนเป็นลายลักษณ์อักษร งานวิจัยเชิงคุณภาพนี้ ศึกษาทัศนคติและอุปสรรคต่อการเขียนแสดงเจตนารมณ์ของตนเองในวาระสุดท้ายของชีวิต โดยการสัมภาษณ์ เชิงลึกกลุ่มตัวอย่างจำนวน 30 คนแล้วนำมาวิเคราะห์ข้อมูล พบว่าปัจจัยที่มีผลต่อการวางแผนในวาระสุดท้าย คือปัจจัยด้านครอบครัว สังคม และความเชื่อด้านศาสนาของแต่ละคน ร่วมกับประสบการณ์ที่เคยพบเห็น ผ้ป่วยในวาระสดท้ายไม่ว่าจะเป็นด้านบวกหรือลบ มาเป็นความต้องการในวาระสดท้ายของตนเอง โดยมีประเด็น ที่วางแผน ได้แก่ การจัดการทรัพย์สิน การดูแลรักษารวมถึงการช่วยฟื้นคืนชีพ สถานที่และบรรยากาศในช่วง วาระสุดท้ายของชีวิต การฝากดูแลคนในครอบครัว และการจัดการหลังการเสียชีวิต ซึ่งผู้ให้สัมภาษณ์แต่ละคน ให้ความสำคัญต่างกัน โดยผู้ให้สัมภาษณ์เกือบทั้งหมดยังไม่เขียนเจตนารมณ์ในวาระสุดท้ายของตนเองเป็น ลายลักษณ์อักษรด้วยเหตุผล คือ อุปสรรคการสื่อสารในครอบครัว เป็นภาพลักษณ์ที่ไม่ดีสำหรับสังคมไทย ยังไม่ ้ถึงเวลาที่ควรจะเขียน หรือไม่ทราบวิธีการเขียนเอกสาร ผู้ให้สัมภาษณ์ส่วนใหญ่มีความเห็นว่าเวลาที่เหมาะสม คือในช่วงอายุประมาณ 60-70 ปี หรือเริ่มเจ็บป่วยด้วยโรคที่ร้ายแรง ซึ่งการรับทราบทัศนคติในการเขียนแสดง เจตนารมณ์ในวาระสุดท้ายของชีวิตนี้ บุคลากรทางการแพทย์สามารถนำมาประยุกต์ใช้ตามบริบทแต่ละพื้นที่ใน การวางแนวทางดูแลรักษาผู้ป่วยและครอบครัวแบบประคับประคองได้ รวมถึงป้องกันแก้ไขอุปสรรคที่อาจทำให้ ไม่ได้ตอบสนองตามความต้องการของผู้ป่วยในช่วงวาระสุดท้าย

คำสำคัญ: หนังสือแสดงเจตนารมณ์ วาระสุดท้าย การดูแลแบบประคับประคอง พินัยกรรมชีวิต

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Attitudes toward writing self-advance directives

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Abstract

Palliative care, which is widely applied in many hospitals around the world, can help improve the quality of life for patients and their families, facing the problems associated with a life-threatening illness. The palliative patients can design their end-of-life care and prepare for their ultimate death by writing an advance directive and communications to their family and medical staff. From the researcher's experience, most of patients hardly write their advance directives. Thus, this qualitative research studied about attitudes toward advance directives, the barriers for writing, and responding patients' desires by in-depth 30 sample interview and data analysis. The factors that affect an individual's end-of-life plan are family issues, the social and religious beliefs combined with their experience of end-of-life patient care, whether positive or negative, also influenced the views on their own advance directive plan. Typically, an advance directive plan includes property management instructions, the treatment plan and resuscitation wishes, the preferred place and atmosphere during the last moments of life, future planning for family members, funeral and after death management. Each interviewee gave different information depending on their concern about their life. Even through some interviewees planned their last day through realizing the advantages of writing an advance directive and recognizing the disadvantage that might happen if they did not tell family members about their wishes for their final days, almost all of them had not previously documented any thoughts on the issues. Their reasons for their prior inactivity on the subject, including difficulty communication within the family, it was bad image for Thai society, not appropriated time for writing, or not know how to start writing. Upon, accepting the notion that it is wise to write an advance plan, the interviewees felt that the optimal time for writing the document was between 60 and 70 years of age or when they first become seriously ill. The information from this research can be applied to the field of palliative care in each workplace for physicians and medical staff to understand patients' attitudes toward their desired treatment at the end-of-life and help them to write advance directives comfortably to ensure they receive an appropriate treatment as their wishes by resolve the barriers and help their families to prepare for grief and loss.

Keywords: advance directives, end-of-life, palliative care, living will

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Introduction

Palliative care or end-of-life care is an important topic in many parts of the medical care industry and is widespread in many hospitals around the world. The World Health Organization (WHO) defines¹ palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, including physical, psychosocial, and spiritual". In Thailand, palliative care has increasingly been developed in recent years and the public generally know, from many sources, that patients and families have the rights to know and decide their own treatment for end-of-life care. The Thai National Health Act 2007², section 12, states, "A person shall have the right to make a living will in writing to refuse medical treatment that is merely provided to prolong his/her terminal stage of life or to make a living will to refuse treatment to cease the severe suffering from illness. If an act was done by the medical health professional in compliance with the living will, it shall not be held an offense and shall not be liable to any responsibility whatever".

An advance directive or a "living will" as it is more commonly called is a document that allows written communication of a patient's preferences to the medical professional for treatment in the final stage

of their lives in view of a request to respect their rights to design their own death by the medical professionals not prolonging their death or increasing their suffering by resuscitating them against their prior wishes.

From the researcher's experience in palliative care working, it is often the case that most physicians communicate a prognosis of a fatal disease to relatives rather than directly to the patient, and it is then the relatives who usually decide about the treatment instead of the patient. This is similar to a study carried out in Thailand³, where it has been found that relatives who know the diagnosis of a disease often conceal (also known as a "conspiracy of silence") the information from the actual patient, leading to the patients not having the opportunity to make their own decisions about their end-of-life care. Indeed⁴, most patients should know the truth about their illness and do not want to suffer excessively from a disease or indirectly through its treatment. In addition, the researcher has found that some patients actually have their own plan, but it is usually not formally documented. although they tend to agree⁵ in nature with the advance directives⁶. The reasons⁷ for patients not to have an advance directive include "I never thought about this before", "My family already know my wishes", and "I am too busy with my work and family". Social, cultural, and racial differences also affect people's attitudes toward writing an advance directive, 8 with a tendency for them to be more commonly written in western than in eastern cultures.

The present research is aimed at exploring the Thai people's attitudes toward writing an advance directive. Here, the term attitude⁹, in a psychological sense, means understanding the feelings of a person toward something that results from an experience or environment that causes that person to react or act on it in a certain way, either positively or negatively. An attitude measurement is a subjective measure of the person inclination to express a feeling. Observing that person's behavior or speech, and interpreting those feelings is a measurement to find a relationship with their attitudes. This study was carried out with healthcare workers and other people as part of the general public at Panyananthapikkhu Chonprathan Medical Center, which is in an urban location in Nonthaburi, Thailand, in order to compare and link the factors that influence a person's decision to write their own advance directive.

Objectives

- 1. To study the attitude of patients toward writing self-advance directives at Panyananthapikkhu Chonprathan Medical Center, Srinakharinwirot University, Nonthaburi province, Thailand.
- 2. To study the barriers of writing self-advance directive.
- 3. To study the barriers in responding to patients' advance directive.

Materials and Methods

The study was approved by the ethical review committee for research in human subjects, Panyananthaphikkhu Chonprathan Medical Center Srinakharinwirot University, number EC 013/58. After informed consent. the qualitative study was performed using an in-depth interview with tape recording, by asking question and listening to interviewees' responses based on a questionnaire. Interviewers offered the opportunity to express their feelings and expectations about end-of-life plans, especially their attitudes toward writing an advance directive. The study population comprised Thai nationality, 20-80 years old, who were fully conscious and could give information in an interview at Panyananthapikkhu Chonprathan Medical Center, comprising patients and relatives who came to hospital or whom received the home visit service, as well as medical staff in the hospital. A samples size of 30 was involved in the formal data collection. The researchers transcribed and analyzed the data by draw out patterns from concepts, categorized, and identified the topics as objectives of the study, and finally explained the results and discussed. All processes were over after a period of eight months.

Results

From the in-depth 30 sample interviews, which involved interviewees with different socio-economic backgrounds, there

were 10 males and 20 females. The samples could be divided in to the following age groups: six samples of 20-40 years of age, twenty samples of 41-60 years of age and, four samples of 61–80 years of age. Most of the interviewees were graduates with at least a Bachelor's degree and an average monthly income of THB 10,001-30,000. Almost all were Buddhists, although the sample included two Christians and two Muslims. Eleven interviewees were physicians, nurses, nurse assistants, health educators, and a volunteer rescuer. Fifteen of the sample interviewees had already known about advance directives and one had even already written their own. The data from the in-depth interviews were analyzed and the topics were divided as follows.

Experience with end-of-life patients and advance directives

Almost all the interviewees had experience with end-of-life patients, including:

A. Experience of seeing or caring for relatives who have a lifethreatening illness or end-of-life event in the family

These interviewees experienced seeing end-of life patients and doctor's care in resuscitating, such as by tracheal intubation or chest compression, patients suffering from either an acute or chronic illness. Interviewee number 14 discussed

the difference in patient care experience "For the case of prolonged bed-ridden patients, their relatives would talk easily about not providing intubation or no surgical operation. But in acute illness patients, it's hard time for family members and usually they cannot accept until the end (resuscitation)". Some interviewees had good experience in caring for patients at home and had bad experiences about resuscitation using medical treatments; on the contrary some had an opinion that dying at home left a bad impression with other family members. Also, some interviewees had good experiences related to a death occurring peacefully in hospital without resuscitation.

B. Experience from work

Healthcare workers, such as physicians, nurse, and volunteer rescuers, often see end-of-life patients and death as part of their work. But when they lose a close relative, it naturally has more effect on their feelings. Interviewee number 17 said "I am used to seeing many patients' deaths, but when I saw her... Oh... this is my mother, she was going to die".

C. Experience from the public media

This covers experience gained through television programs, radio, or newspaper reports on the death of a famous person, who people can recognize and who may know something about their care from the media reports about their end of life and death. Interviewee number 1 said "An example is Por (a famous actor); they tried to resist and prolong his death, but finally he passed away".

In addition to the experience of seeing terminally ill and last-hour patients, interviewees also tended to know about their plans and demanded for their end-oflife care, which they told to relatives when they were still healthy. Some interviewees were aware there might be problems if the documents were not written before, such as conflicts in the family for accepting the decisions about resuscitation treatment. An interviewee number 7 said "What I could not deal with that situation.. I wanted to help, but my mom didn't want the tube inserted (intubation), but at that time my brother wouldn't respond to anything (cry while speaking)".

Interviewees who were medical officers mentioned a "no resuscitation document" that a physician or nurse would give to a patient or relative to sign as evidence of the patient's wishes near the end of their

life. The physicians usually ask the relatives, rather than the patient directly, about the resuscitation plan. Nowadays, more people understand about living wills from public media, as confirmed by interviewee number 23 who searched for information by herself and had written her own advance directive. "I know life is uncertain. I hand-wrote my advance directive and felt more comfortable afterwards... I had already done the things I knew I should do".

Almost all the interviewees agreed with writing advance directives. Interviewee number 14 gave an opinion "Advance directives show civilization. Patients can leave peacefully, having dignity and autonomy. On the other hand, trying to prolong death is uncivilized and selfish. Health workers have to do resuscitation for the patients to protect themselves. If you have a document to protect them, this can pass as proof of the patient's desires in a civilized society".

Factors that influence decisionmaking at the end-of-life time

Attitudes toward end-of-life plans and the decision to write an advance directive document depend on many factors.

A. Experience from seeing an endof-life patient

Interviewees applied their end-of-life experiences with close family members or through working to have their own mindset and thought about their own life and care they would desire in the last moment of their life. They could see the benefit of advance directives and knew the need to address the problem about resuscitating a patient who would then need prolonged care, possibly while in severe threatening-illness and in a dependency condition.

B. Concepts of community and family beliefs

Social value in communities is an important factor affecting people's attitudes to end-of-life plans and dying. For example, the dying-at-home concept is common in some communities, as mentioned by some interviewees, who told about rural beliefs and lifestyle, where everyone helps each other in the community. In addition, interviewees from the same family tend to have a similar attitude.

C. Influence from religious beliefs or after-death concepts

Some interviewees have strong religious beliefs and outline them in their end-of-life plan. Buddhist beliefs include aspects about the preparation for death, collecting merit for life after death, and the next life. A good death in their thoughts is still to remain conscious until the last

breath and to stay with their loved family members to the very last moment.

Islamic religion has beliefs about collecting merit too, but they are different in practice and their goal is to go to Heaven. Interviewee number 6 said "I study the Qur'an seriously and practice five things including Allah is the only God, Ramadan Fasting, pray 5 times a day, make Zakat donation, and go to the Haj ceremony. If all have been done, the merit will be accumulated and I can go to Heaven after death". Muslims believe that God sets out everything in life. They cannot escape death and distress is just a test from God, and also there is life after death. The attitude about a good death in Islam is to die peacefully in doing God's purpose and having done all the practices required as part of their belief.

In Protestantism Christianity, Protestants believe that their spirit moves apart from their body after death and stays with God in Heaven. "I will donate my body because the ceremony is useless for the dead and the rest, it only increase a burden on my relatives. My spirit will live in heaven with God", i: said interviewee number 7.

Important issues about end-of-life planning and dying

The end-of-life plan of each interviewee varied according to the person's own characteristics, social background, life values, and concerns about their property or family. These issues could be grouped as follows.

A. Property issues

Proper property planning and management consists of informing relatives about their own property and how to distribute this to close family members or others as identified in the will.

B. End-of-life care and resuscitation issues

Interviewees plan for their own treatment depending on their understanding and experience about supportive or prolongedlife treatment, such as intubation, cardiac massage, nasogastric tube feeding, and morphine infusion for pain control. Some have specific conditions for treatment, according to interviewee number 14, "If I cannot take care of myself, please let me go. Human dignity means one should be able to live independently". The current Thai society is moving toward more single families, so caring for people who are chronically ill or who have dependencies in the family is becoming harder to find a caregiver from among family

members and there is unusually an increased cost burden for such care.

C. Place and atmosphere for the last moment of life

Interviewees described the place and atmosphere that they wished for, i: interviewee number 9 "In my last moment of life, I want to be in a peaceful place near my children and family. We are holding hands together and see their faces. It can be anywhere, home or hospital". Some had an opinion about it being more convenient for relatives if they died in hospital.

D. Family concerns

Some interviewees show their concern for family members by telling plans to the people they trusted most. Including, their principles for a good life and teachings for the family.

E. Management after death

Plans for after death, such as the day of the funeral, atmosphere, and religious ceremony, were talked about, with some interviewees wanting to help their families to make it easier for them to make the funeral arrangements. While some agreed with body or organ donation, some disagreed because they believed in life after death and rebirth.

Barriers to writing an advance directive

Most of the interviewees found advantages and benefits for writing an advance directive, including respecting people's dignity and relieving family conflict. Some had already planned their own end-of-life time and even told their relatives, but hardly any had actually written out a formal document, for a variety of reasons.

A. Communication problems with family members

A communication barrier can exist caused by family members feeling uncomfortable to listening about a relative's advance directive plan or feeling it is too ominous to talk about death. One interviewee suggested public relations should be utilized to acknowledge palliative information and advance directives. A family with end-of-life experience together had more chance to be open to communication about life and death.

B. I never think about it, it's not time to think of such things or I simply cannot imagine it just now

Some interviewees had never thought about their own advance directives before. Some thought it was too far ahead to plan them now or they could not know the future situation, so they didn't want to decide them. Comments from several interviewees that when the advance directives should be written, for sample, interviewee number 30 said "I am still healthy so I do not want to start to write [my advance plan], but if I know I have a severe disease, I travel to a dangerous country or I am more than 60, I will write it because I know the end is near".

Other comments are that they felt stressed and worried when they think about their endof-life time or they don't have enough time to think about the complete detail.

C. It gives a bad image, like cursing

End-of-life communication is different for many people in Thai society. It was commonly felt that advance directives should be written at an appropriate age and under life-threatening health conditions. Interviewee number 14 gave an opinion, "If you write your advance directives as you are still healthy and not old, others will think you are having concealed serious-illness in your body". One interviewee said that writing an advance directive was just like cursing himself.

D. Not knowing how to start writing

Some interviewees would like to write an advance directive but did not know how to start or never heard of advance directives before. Experience from one interviewee indicated that some health professional did not encourage her to write the advance directives.

Barriers to responding to patients' advance directive

Although some patients had written their own living will, they might not be responded in their time of need because of some barriers or problems.

A. Patient symptoms could not be managed at home

Even though a patient and family member may plan for staying at home in the last moment of life, the patient may have symptoms that cannot be relieved and managed at home. So the caregivers did not want to see the patient suffer, or the patients themselves may request to go to hospital. Some relatives had concerns about potential difficulties in managing patients if they die at home.

B. Family's attitudes, values, and beliefs

The family usually has a strong opinion that caring for

patients to help them live as long as possible is the best. Interviewee number 14 said "In the last moment of life, relatives think they are the guardians, and if they did not do all they could as society expects, then they would be condemned. The Thai society does not respect a person's own rights and dignity".

C. Family conflicts

Physicians have to decide whether to resuscitate patients in cases where the family members do not all agree together or in line with relatives' need sometimes more than the patient's themselves. "In front of the relatives, one hundred percent of physicians will perform resuscitation even though the patients might not want it, but the relatives want and expect it. Technically, in law, we win, but it wastes time, makes us to feel bad, and become subject of from social damnation. Just performing CPR for an hour, even though we know it is useless", said interviewee number 14.

Discussion

Advance directives in Thai society are not widely used, even though people know more about palliative care nowadays. This is similar to in Western countries¹⁰, most cancer

patients and healthy people agree with advance directives but only 10 to 20 percent of them have written one, which is typically associated with the deteriorating health. In some areas¹¹, healthcare professional have little understand advance directives and feel pressure or discomfort¹² when they suggest to patients writing the document or talking about this issue in their limited time, and more than half of them thought the patients' relatives would not agree with 13. Physicians¹⁴ are typically not taught about communication with palliative patients, so they usually discuss the issues with the relatives rather than with the patients. Barriers in communication in family about advance directives can result in relatives having not prepared themselves for grief and loss, then they may decide on actions different to the patient's needs or wishes. In Eastern family-centered cultures¹⁵, patients authorize the family to make a decision, which is often the case in Thailand.

Communication about advance directives may begin by patient opening a conversation and the physician giving information for their advance care planning, even though they may not have a serious illness. On the other hands, healthcare professional teams may talk with patients who have passed through a severe threatening illness and want to plan for the future concerning treatment goals and a management plan for the last moment of their life¹⁶. The important purpose is communicating the patients' desires to

healthcare teams and their family, so they can follow the patients' own decision about resuscitation. A study in United States¹⁷ about factors that influence nurses' and physicians' decision making during resuscitation, reported that physicians focused on the patients primarily over their families. It was different to this study that physicians have a tendency to do as the family desire in crisis situation, partly to relieve stress and potential conflicts, which can have a psychological impact on their work.

The suggestion is they should have a management plan or guideline in workplace for healthcare professional, or assign palliative care teams. Each medical department¹⁸ can see advantages and disadvantages. Family physicians can meet patients early on, develop a good relationship with them, and better understand the context in providing continuous care so that the patients can talk to the physician with trust and ease, but there are some limitations on communicating information among primary, secondary, and tertiary care. Oncologists can plan treatment and discuss with patients about disease progression, staging, prognosis, and choice of treatment, but may have less time to talk. So the palliative care team; physicians, nurses, or social workers should work together and share information with patients and their families¹⁹.

Palliative care team establishments should suit for each specific hospital service system. Public health service can give advice and comprehensive consultation for patients and their families in a holistic continuous care process. The team should detect and solve problems to completely write advance directive, such as family's belief, bad experience and fear about end-of-life time, and encourage them to have good attitude about advance care planning²⁰. And the health care professional should prepare patients and family for taking care of their be loved ones to leave peacefully. Also it

is important to acknowledge the impact on healthcare workers the issues around palliative care and advance directive for reducing physicians' anxiety when they meet potential conflicts within family members. Other strategy is publicizing the important of human's dignity, right and benefits of planning their end-of-life care and have positive attitude to advance directives.

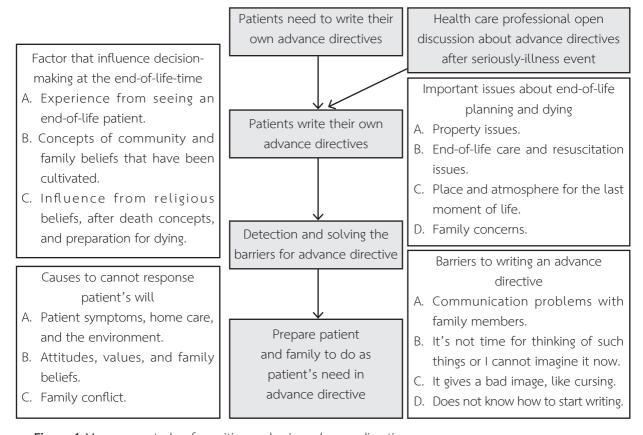


Figure 1 Management plan for writing and using advance directives

Conclusion

Palliative care is an approach treatment that improves the quality life of patients and their family members facing problems associated with life-threatening illness by preparing their ultimate death following the patients' will. An advance directive is an important communication to their family and medical staff. The factors that most affect the end-of-life plan are

family issues, social and religious beliefs including individual experience about illness and dying. The topics in an advance directive plan include property management, the place or atmosphere during the end-of-life hour, the treatment plan and preferred resuscitation, including funeral and after death management. All interviewees saw advantages and agreed with the advance directives but almost all did not write them. Their reasons included the directive presented a bad image for Thai society; it was not appropriate time to write, or the patients did not know how to start writing. The palliative care team can support patients write an advance directive and communicate end-of-life issues which lead to comfortable care corresponding to the patient's will and supporting their families in the last moment of patient's life.

Recommendation

Sample interviewees were conducted at Panyananthapikkhu Chonprathan Medical Center in an urban community, which may be different to other areas in terms of lifestyle, social backgrounds, and beliefs. The results of this study should be applied carefully for appropriate use.

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