

Living Will Awareness and Collective Trust between Physicians, Cancer Patients and Caregivers: A Qualitative Study

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Abstract

The purpose of this study was to explore the awareness and attitudes of living wills among cancer patients in early stages and their family caregivers.

Methods

Study Design

The author conducted semi-structured interviews with nine patients and five family caregivers at the Gynecology Clinic in Phramongkutklao Hospital between January 2014 and March 2014. Purposive sampling method was used to select various ages, clinical staging and diagnosis for the study. After approaching the participants, the interviewer introduced himself then asked the participants about the purpose of their visit to assess if they were aware of the diagnosis. After explaining the objective of the study, written informed consent was obtained and the participants then had an individual interview. The guidelines for the interview were derived from a living will document sample 1 designed by **The National Health Commission Office (NHCO) of Thailand (Additional file 1) [23]**. Family caregivers were addressed by either themselves or the patients. Data were gathered until saturation was reached.

Interviews

All of the interviews were video recorded for nonverbal language interpretation. Conversations were fully transcribed along with field notes and an audit trail immediately after each session. After demographic data collection, participants were asked if they ever heard of a living will then were given the document to read. The interviewer answered any questions and gave further explanation to the participants until no more questions arose. The session continued after the participants had finished reading the document. Three aspects were explored: awareness of and attitudes towards living wills, comprehension of medical terminology in the document and decision-making. The interview took 30 to 50 minutes each session, depending on the participant.

Data Analysis

Open codes were created and analysed using investigator triangulation method. The codes were discussed, modified, and merged by the authors and final revised codes were developed afterward. Emerging concepts were extracted and analysed using a thematic analysis approach. Themes were based on the model (Figure

Table 1: Participant Characteristics; a One participant was diagnosed with both cervical and breast cancer.

Regarding the final hour of their lives, nine of the participants requested the Do Not Resuscitate (DNR) option while the other five wanted a proxy (Table 2).

Decision	DNR	Proxy	
		Doctor	Relative
Total			

their money and property after their death, whereas three of them thought it was a life insurance. This misunderstanding might partially have been caused by the Thai word, "Pinaikam Chi-vit/" (the life insurance/will), which was a misleading translation.

"Living will... Is it about life insurance?"

After reading the document, 13 of them had positive attitudes toward the document.

"It's good. From when I saw my gravely ill mother, there would be some tubes and...well....she was...so delirious that she would pull all of those tubes all the time, feeding tube, IV fluids, and stuff. It was so miserable...so I don't want the same thing happening to me."

Another participant felt emotionally negative regarding the document but added that it helped her to reflect about her illness. This could be seen as a positive attitude toward the document as well.

"It makes me feel kinda..sad..depressing...But it also got me to think about myself. What would I do if I were...in that [terminal] state?"

When asked about medical terminologies, medical procedures and decision-making 12 of the participants related to their past experiences rather than from the document they just read.

[Definition of Nasogastric (NG) feeding] "I saw it. You have to put it [liquid food] through the...nose."

[Indirect experience of Intubation] "The guy who got better after he was intubated told me that it was a very painful experience because they had to shove the tube in you. It hurts so much, he said."

[Negative direct experience of intubation] "It was so painful..suffocating...like you can't breathe at all. I heard someone calling me but I can't [breath] It was [suffering]....so I loathe it and don't want it again."

Five of the participants, who did not have any prior knowledge and experience about medical terminology and medical procedures, failed to understand most parts of the document.

[When asked about cardiopulmonary resuscitation (CPR)] "I can't answer that...I don't have much experience about it [CPR], you know? So, I don't [know]..... and the document that I read earlier? I don't even pay much attention to it (chuckle)."

Nine had direct experiences with death and terminal patients and were aware of procedures they had witnessed before, such as NG feeding or CPR and used these experiences as references.

[When asked about definition of NG feeding] "Yeah [used to do it herself]...a tube. You feed them through here [tube]. See how they make a hole here?then I push the liquid food through there"

However, due to the document's complexity and multitude of issues covered, some participants still did not fully understand the document even after a full explanation from the interviewer.

[When probed to explain about one of the medical terminologies] "I know about some words in there! (Sound upset) But you have to explain it too! I just get some part of it, not the whole thing!"

Participants' decisions were based on mutual trust of their doctor and family members, reflecting Thai collectivism culture

A homogenous finding regarding decision-making of the participants was the concept of trust. Doctors in Thailand are still

highly regarded. All of the participants trusted their doctors explicitly, leaving most of the decisions to them and would follow their advice.

"I think I would leave the decision to my primary doctor if I should go on [treatment] with number one, two, or three. My husband also has a great credential about him. Something like,prolonging life, we won't know these kinds of stuff better than a doctor. If my doctor says that it can be cured then it can, if he says that it could not be cured (chuckle) then, well, it can't be cured, no?"

"Have to do everything according to my doctor. I follow everything he says"

If the patients did not receive a clear explanation about their illness from their doctors, they often sought other sources, people who they trusted or even from the internet so that they could rely on the information they wanted.

[After she was diagnosed with cancer without a clear treatment plan]"I browsed through the internet and stuff. My friends and relatives also said that if I went through surgery, there is a very high chance of being cured. 100%, they said"

When making comments about their own illness or decision-making during the final moment, almost all (7) of the patients took their family members into account.

[Reason for making a living will]"Another thing is that I always want to be independent. Don't want to be a burden to other people [her family]"

From another perspective, nearly all (4) of the caregivers transferred their thoughts regarding the illness and made decisions on the patient's behalf too.

[When asked about the patient's decision making]"I think...if it eventually comes to this (point at the living will).. about who would make the decisionsI...I...I will do it. Well, because, because. she [his wife] would have trusted me? Because since the beginning of her treatment, I am the one who brought her here, doing things to make her better so...the rest is my duty, my obligation, to make decisions"

As for the Advance Care Plan (ACP), the answers were divided in two groups. The first group (five patients and four caregivers) had thought about ACP or already had made a verbal plan with their relatives.

[When asked about ACP]"Yeah.... Sometimes I just kept thinking...what if I were very ill?If it were that miserable then I want to...go [die]. No need for further suffering, no need to pump [CPR], no nothing. If I were that bad then I don't want anything. Living like that is just being a burden to those who are left behind"

The second group (four patients and one caregiver), all of whom were patients and caregivers that did not have a clear understanding of their illness, did not think about ACP at all.

"Nope (shaking head). Not at all...I don't want to think about it... don't wanna. Because it's too stressful,depressing...Don't wanna think about it at all"

Patients' and caregivers' perceptions of illness and autonomy need to be assessed

Surprisingly, some of the participants (5) did not fully understand about their own illness or those they had been taking care of. This lack of understanding was partly due to the improper truth-telling process from the physicians or the lack thereof.

[When asked about her diagnosis and treatment plan] "It was not clear at all. They did chemo just twice. didn't tell me that there would be both chemo and radiation. They just told me after they did all of these I know nothing (sound upset). Just twice [chemo]....then it came back [cancer] and all they did was just the chemo twice."

[When asked about her diagnosis] "When I knew that I had cancer....At first, I didn't know (smile sadly)....don't know at all. My doctor didn't tell me. After the operation, there was this one doctor

truly understand about their disease, future treatment plan, thus leading to initiating ACP and AD with a clear understanding afterward.

In conclusion, all of the participants had not heard of a living will before and thus it was impossible to ascertain one of the primary objectives of the study, i.e., living will awareness in cancer patients and their caregivers. However, since all of the participants had positive attitudes toward the document, assessing this in a larger scale is noteworthy. These findings reflect an urgent need for strategies to promote living will awareness. Public relations, help from the media and education to raise awareness among both healthcare providers and the general populations on a larger scale are also still needed [24].

Recommendations

Living will awareness in Thailand needs further assessment.

Because this was the first study to explore living will awareness and attitudes in Thailand, further assessment is still needed. A study in a larger population will help us grasp a better understanding of the national situation and lead to proper interventions afterward.

Contents of living will document.

The document needs to be simplified so that readers could have a

References

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