

Advance Care Planning: Attitudes of Catholic Nuns

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INTRODUCTION

Advance care planning (ACP)

Advance care planning (ACP) is a process whereby individuals discuss, state and document their values and wishes regarding medical care with their caregivers, in the event that they are incapacitated from making decisions on their own.

Aim

This semi-qualitative study seeks to better understand Catholic nuns' perspectives towards ACP with the aim of helping them with their ACP in the future. The hypothesis was that Catholic nuns may have different barriers, perceptions and needs of ACP in view of their religious belief.

METHODS

A talk on ACP was given to 23 Canossian Catholic nuns at St. Joseph's Home, Singapore. Each participant was made to answer 7 questions on a scale to evaluate the quantitative aspect to these questions. A focus group was held and a combination of open questions, as well as clinical scenarios, were discussed with the respondents in order to understand what is meaningful and valuable to them in ACP. The data was analyzed via open, axial and selective coding in order to arrive at several overarching themes.

Table 1. Baseline characteristics of participants

Age	Range 27-77 yrs; Mean 56 yrs.
Area of Vocation	Health Care Related 48% Non -Health Care Related 35% Unknown 17%
Pre-existing medical problems	69.3% Yes 34.7% No
Previously heard of ACP	56.5% Yes 44.5% No
Has an existing ACP	4.3% Yes 95.7% No

RESULTS

6 themes pertaining to what ACP meant to the nuns (Table 2) and 5 themes on the process of conducting ACP (Table 4) are shown.

The nuns considered ACP to be important in helping them speak for themselves so as to avoid burden on their natural family and blame on their religious family. They also saw it as a way to explore the meaning of life.

Doing ACP as an continual process was important to them. They perceived their ability to understand medical terms during ACP as essential. They believed faith affects their ACP choice. While there were some concern about the extent to which they can individually decide on their ACP choices, most of the nuns felt that the church would be supportive of whatever decisions they made.

The questionnaire showed that patients generally believed that ACP is useful and not similar to euthanasia. The participants were divided on whether doctors would give up on them more easily if they had an ACP (Table 3)

Table 2. Themes Usefulness and Fears about ACP

Theme	Transcript
Being able to speak for oneself	"Be able to consciously speak, to determine my wish" "Help the doctor know what to do" "Only myself will know whether further medical treatment is actually good for me or not"
Quality of life	"It's about the quality of living and the quality of dying"
Respecting the choice	ACP means "quality living and gracious dying" "Respecting the dignity of the person"
Fears about ACP	"When I am in ICU gasping for my breath, of course I want to live, maybe my ACP 'tak pakai' (invalid)" "Are you afraid I bankrupt your accounts" "Are you helping the government save money"
Not burdening others	Maintain harmony and prevent conflict among members of the family To reduce guilt and blame among the family
Ensuring Natural Family do not blame religious family	"If this plan is documented, then the decision made is not being blamed by people who does not understand the situation" Talking about a sister who refused dialysis: "I called her own family, not the religious family because she had sisters, so to make sure that we are not blamed for this decision."
Exploring the meaning of life	"This one is like a tool for me into reflection of life" "Start with what is the meaning of life and you find meaning in this sure end"

Table 3. Graded response questions about ACP

ACP useful to myself.	Range 3-5, mean 4.6
ACP useful to doctors.	Range 3-5, mean 4.3
ACP useful to family members.	Range 3-5, mean 4.4
ACP is similar to euthanasia.	Range 1-5, mean 1.7
Doctors will give up on me more easily if I have an ACP.	Range 1-5, mean 2.7
I fear dying.	Range 1-5, mean 2.0
If I were dying, quality of life is important to me.	Range 1-5, mean 4.3
If I were dying, prolonging life is important to me.	Range 1-5, mean 1.5

* Score range: 1 strongly disagree – 5 strongly agree

Table 4. Themes on preference of the manner for ACP to be conducted

Theme	Transcript
It is a process that progresses and changes	Some decisions can be made "on the spur of the moment" "So I think it is a process." Even "for family members it is also a process" "They may say wah you do this kind of thing to your parents." "At different stage(s) of our lives, our reason for living may change. Maybe for example, I am the only sibling left to look after my parents. So at that stage, of course I want to live a bit longer. So at different stages, it is a different kind of commitment."
Setting and facilitator	"It must not be a threat, not in a frightening setting." "I think with the facilitator, it would be more helpful if he is of the same faith." The "maturity of a person" and "experience" of the person is important.
Religious Aspect	"I think the religious belief is important, once you know that life belongs to God, right, you switch off the machine, sometimes you don't even go, you continue." "There are some doubts regarding the belonging of a religious body, how far can I actually decide (for myself)." "The religious family will not determine very much because this is my choice, my autonomous choice. It's my theology and my image of god if anything that will color my choices." "We also have our rights. and I'm saying this is a modern world lah, that I think the church also respects our desires."
Medical terms need clarification	"The point of clarification today is because extraordinary has become ordinary." "If I were in this country where things were not so advanced, things could be quite different. Nature will takes its course much faster than any other thing." "Like for example, some of my friends and family members; for them it's still old mentality. It's euthanasia." "Because sometimes in the layman terms and in the medical terms, how do you know what is extreme and what is like you know, too much, what is extraordinary and what is ordinary." "Because we were just doing some courses on dementia and the last stage is when a person is just like a vegetable. So what... is that also the same as terminal sickness?"

DISCUSSION & CONCLUSION

ACP is important to the nuns, and is viewed as a process rather than as an event. They seem to view it as an existential exercise more than a mere medical documentation. They do not seem to fear dying, and quality of life is generally more important to them than prolonging life. The nuns were open to discussing end of life issues and felt strongly about letting their family know about the ACP plans (to reduce burden). This is contrary to a previous study conducted in palliative care patients in Singapore which showed that there was a cultural taboo concerning end of life discussion and that patients were less open to discussing their decision with family members. (Ng R, et al. BMJ Supportive & Palliative Care 2013;3:343-348) This could be attributed to their faith, but could also be due to the fact that the nuns were a healthy population compared to the palliative care patients.

We learnt from the nuns that ACP can be a exploratory exercise for our patients. When conducting ACP for people with religious inclination, having maturity of thought and similar faith is important.

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