



WARD RESEARCH  
I N C O R P O R A T E D

# Healthcare Provider and Lay Person Attitudes and Perceptions of Advance Care Planning: A Focus Group Report

**Prepared for:**



**KŌKUA MAU**  
"Continuous Care"

Hawai'i Hospice and Palliative Care Organization

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# Objective and Methodology

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- **Objective:** To conduct a qualitative assessment of the attitudes toward advance care planning among lay people and healthcare providers, with an eye toward crafting messages that will motivate more advance care planning and conversations.
- **Methodology**
  - Two (2) 90-minute focus groups conducted June 13, 2017, among 15 Oahu lay people, segmented by age,
    - Group 1: 65-79 year olds
    - Group 2: 50-64 year olds
  - One (1) 90-minute focus group among 9 Oahu nurses and social workers, conducted June 15, 2017
  - Three (3) 30-minute one-on-one interviews with Neighbor Island nurses and social workers
  - Four (4) 30-minute one-on-one interviews with physicians, statewide
  - Lay people participants were recruited from the Ward Research Participant Referral Network. A good mix of demographic characteristics, including ethnicity, gender, and area of residence, was recruited.
  - Healthcare provider participants were recruited through a list of physicians, nurses, and social workers provided by Kokua Mau. All of the participants were involved in advance care planning in some form. Participants were emailed a letter from Kōkua Mau, telling them about the study and asking for their participation, and an invitation to participate from Ward Research.
  - All focus groups were held in the Ward Research focus group facility in downtown Honolulu and moderated by Rebecca S. Ward, President of Ward Research.
  - Interviews were conducted via telephone by Rebecca S. Ward and Margarita Ayala, Senior Analyst at Ward Research.

# Summary of Findings

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- **Normalize the serious illness and end of life care topic among lay people and normalize the conversation between primary care physicians and patients. Talk about it early and often--- in schools, workplaces, community workshops, forums, and other public spaces.**
- **Understanding of serious illness and end of life care --- as well as documents such as advance healthcare directives, healthcare powers of attorney, and POLST --- was found to be low. More education about these topics is needed.**
- **More training, reimbursements, and incentives may encourage physicians to initiate the serious illness and end of life care conversations with their patients but, until then, nurses and social workers are the best sources of information and community outreach by these healthcare providers should be encouraged.**
- **The system of care needs to be more consistent, as there are often breaks in the chain when it comes to end of life care.**
- **In order to be effective in encouraging conversations and planning, messages must communicate urgency, must relate to people on a personal level, and communicate that not having a plan will cause stress for loved ones.**

# Attitudes Toward Planning for Serious Illness and End of Life Care

- Planning for serious illness and end of life care is seen as something that can be dealt with later and, after it has been dealt with, not to be revisited.
- **There is a lack of understanding of serious illness and end of life care.**
  - When talking about serious illness and end of life care, comments from participants often turned to burial preferences and/or estate distribution.
  - When made to think about serious illness and end of life care, most of the participants tended to think of short-term care or the time shortly before death when all that is left to do is “to pull the plug.”

***“It’s in the back of my mind, but I’ve never really given it a lot of thought, I guess, because all 3 of us have been really fortunate as far as health is concerned. The closest thing I can think of is my mother-in-law is in a nursing home right now. She has dementia. That’s the only thing that would trigger thoughts about that. Otherwise I’m on the daily grind just trying to keep my head above water.” 50-64 year old***

***“I really don’t think about long term care because I keep myself fit. So, I’m thinking I won’t need it. If I have a back problem, I do certain exercises for back pain.” 65-79 year old***

# Advance Healthcare Directives and Healthcare Powers of Attorney

- **Understanding of advance healthcare directives and healthcare powers of attorney found to be low.**
  - Many of the lay people in the focus groups said they have advance healthcare directives but, based on their comments, the documents they referred to may not actually be advance healthcare directives.
  - Few have shared copies of their advance healthcare directives with their healthcare providers, instead keeping the document at home or with their attorneys; some have not even shared copies of the document with their family members.

*“I have a directive. It’s at home. My wife knows about it and she’ll know what to do with it when the time comes.” 50-64 year old*

*“My husband told me to write down what I want and give it to my son, who is probably going to do whatever he wants anyway.” 50-64 year old*

- POLST
  - According to healthcare providers, one of the most common questions asked by patients is the difference between an advance healthcare directive and a POLST.
  - Patients reportedly are often confused by DNR orders and sometimes change their minds after additional explanation.

# Barriers and Motivators to Planning for Serious Illness and End of Life care

- **The topic of serious illness and end of life care needs to be normalized, since the primary barrier to having the conversation is that talking about death make people uncomfortable.**
  - A few lay people said that they would like to have conversations with family members, but that their family members are “in denial” and refuse to accept death as a possibility.
- **The primary motivator to talking about serious illness and end of life care is experiencing first or second-hand the consequences of a loved one not having an end of life care plan.**
  - Some of the lay people said that they completed an advance healthcare directive because they do not want their loved ones to have to go through the difficulty of determining what exactly they would want.
- The serious illness or death of a loved one is another motivator for serious illness and end of life care conversation.

***“I think having a terminal illness makes you think about it. With my two parents, me and my sisters were forced into it. Both of them went into an operation and when they came out they were dying. They had a stroke during the operation. They were brain dead, but they were on machines. They had wills, but no type of directive, so my sisters and I were arguing whether or not they should stay on the machines or pull the plug. That made me think that I didn’t want my kids to go through that at all. It was terrible.” 50-64 year old***

# Conversations with Primary Care Physicians

- **Serious illness and end of life care as a topic of conversation between patients and primary care physicians also needs to be normalized.**
  - Some lay people said that they feel uncomfortable if their physician brought up serious illness and end of life care; they would start thinking that something is seriously wrong.
  - Similarly, some physicians felt that talking about end of life care with their patients might signal a “loss of hope” in their patients.

***“The doctor doesn’t handle that part of your life. They can help you with what is solvable. They can make that decision as far as what they think. But, as far as a directive or a decision to make after whatever happens to you, I don’t think that’s their place. I mean, you could ask. They’re probably pretty wise and seen a lot of stuff, so it might be good advice, but I don’t think that’s their place unless you have a good relationship with them.” 50-64 year old***

***“In certain cases, especially among cancer patients where positive thinking is really important, some doctors don’t want to have the conversation because it might signal to their patients that they are losing hope. And you don’t want that because if they feel that you are losing hope, then it makes it more difficult for them to hold on to their hope.” Healthcare Provider***

- Physicians are also perceived by some lay people as busy and not having time to talk about the topic.

# Normalizing the Topic

- To normalize the topic, talk about serious illness and end of life care early and often---in schools, through community workshops and forums, at the doctor's office, and even at work---according to participants.

*"The more often you talk about it, the more normal it is going to be. A lot of information travels via word-of-mouth. If one person goes to a workshop about advance directives, they'll tell their friends and then their friends will become more interested. The first step is really just to talk about it; get it out there." Healthcare Provider*

*"Community forums, community workshops, go in front of grocery stores and talk about it. You need to reach out to the community and if you are out there often enough, it becomes normal." Healthcare Provider*

*"I'd like to see more movement in the employer groups. Looking at healthy environments with people, most of them have had the experience with a parent or sibling, so they can normalize it by going through the discussion and starting the documents. Then they can take it home and talk to their parents or talk to their siblings about it. If we reached out before they're in the healthcare system, we'd be moving into the right direction." Healthcare Provider*



# The System of Care

- Age and health status or change in health status are the most common prompts for healthcare providers having end of life care conversations with their patients.
- **The system of care needs to be more consistent. As it is now, according to a healthcare provider, “The system of care doesn’t lend itself to any kind of continuity.”**
  - Patients move through the system without the proper end of life care documents or not understanding their end of life care documents
  - Breaks in the chain occur because of presumptions made by different providers at different areas of care, caused by lack of communication, disorganization, or lack of time.

***“When you go into the in-patient arena where the physicians are saying they need to go to hospice, there’s very brief interaction between the physician, the social worker, and the hospice people, and there’s no trust, there’s no relationship. So, they are going out the door without documents. The physician in the hospital is saying hospice will take care of it and the hospice is asking why they haven’t had these conversations.” Healthcare Provider***

***“I think that many times we have conversations with a patient with advanced cancer talking about this, trying to get them around to this and every time they act shocked like they never heard of it before. Then the hospitalist calls up and asks ‘What have you been doing?’ And I’m saying, ‘Have you read my notes? Look back at 2012. I started talking about this.’” Healthcare Provider***

# Encouraging Primary Care Physicians to Have End of Life Care Conversations with Patients

- **More training, incentives, and reimbursements may encourage more physicians to initiate serious illness and end of life care conversations with their patients.**
  - Healthcare providers in the focus group and interviews said there needs to be more training and education so that primary care physicians can feel more comfortable initiating the conversation with their patients and learn how to use the available tools.
  - Reimbursements (that are supposedly in place but seemingly not effective yet) or other incentives for the actual time spent talking to patients may also encourage physicians to initiate the conversation.

*“Physician education and the priority of why this is an important conversation, giving them the tools, videos, skilled people coming to the clinics to provide education and get the message out that we need to start this early.” Healthcare Provider*

*“Healthcare providers who are going out and learning about the tools are people who are interested in learning how to do it better. Other people are too busy to go and have patients they’ve got to see.” Healthcare Provider*

- **Until then, nurses and social workers are the best sources of information about advance care or end of life care planning. Community outreach by these providers should be further encouraged.**

# Message Testing

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- In order to be effective, messages must:
  - Communicate urgency;
  - Relate to people on a personal level; and
  - Communicate that not having a plan will cause stress for loved ones.

***“I think if you wanted to do something like this, you’d have a situation where you are in a hospital and you’d have your family there. They’re either crying, yelling, screaming at each other trying to figure out what the hell to do. That would be the motivation right there.” 50-64 year old***

***“If they don’t want to do it (to plan) for themselves, then they should plan for their family members. A lot of people assume that their kids would know what they want, but arguments happen and you don’t want that.” Healthcare Provider***

***“I think that you have to mention the effects that it has on family. It’s already going to be stressful and having to guess what you want is going to make it even more stressful.” Healthcare Provider***

# Message Testing

- Most effective out of 7 messages tested:
  - End of life decisions should not be made at the end of life.
  - If the unexpected happens, who will speak for you?

	NUMBER INDICATING THAT MESSAGE IS TOP THREE MOST EFFECTIVE		
	50-64 year old lay people	65-79 year old lay people	Healthcare providers
Talk about it. Write it down. Share it with others.	3	3	6
Planning ahead prepares you and those you love for the “what ifs” in life.	0	6	0
Give yourself and your loved ones peace of mind by completing an advance healthcare directive.	8	1	0
If the unexpected happens, who will speak for you?	0	7	7
End of life decisions should not be made at the end of life.	5	5	5
There are lots of decisions to be made in today’s medical world.	0	0	0
In order to honor your wishes, your doctors need to know them first.	8	1	0

- Three videos tested (Advance Care Plans, SPEAK UP, What’s your excuse?) were not found to be very effective.

# Appendices