Learning Objectives

- Describe individual's receptivity and reactions to telephonic advance care planning
- Compare telephonic ACP with in-person conversations
- Evaluate the feasibility of offering telephonic ACP as an alternative to in-person conversations
Background and Objective

• An Advance Care Plan (ACP) includes the decisions and preferences individuals share about the healthcare they would want to receive in the event that they are unable to speak for themselves.
• This is based on individuals’ personal priorities and value systems.
• An ACP requires one to choose an advocate to make those decisions (i.e. health care agent) and to discuss the kinds of life-sustaining treatments one would want in the event it were appropriate.
Background and Objective

- Physicians and medical professionals are expected to complete ACPs with their patients.
- However, many do not have the time or resources to do this. In addition, many do not feel equipped to assist their patients with this task.
- Many older adults do not have an ACP.
- For those who do have an ACP, those plans are not always accessible to the providers who may need them.

Background and Objective

- UnitedHealth Group (UHG) and AARP are interested in developing a telephonic ACP program that will remove the barriers that prevent people from articulating their wishes.
- Thus the purpose of this project was to test the feasibility of telephonic ACP discussions.
- A second objective was to obtain knowledge that could be used for a future awareness/education/intervention campaign that effectively promotes advance care planning conversations.
Methods

• 10 participants were recruited to participate in an in-person telephonic ACP discussion in the research laboratory and a debrief session afterwards.
• Participants were stratified by age, race, and employment status.
• All interviews were audio and video recorded.

Methods

• Various ACP models were used to develop this study.
  The flow of the ACP facilitation was based on the evidence-based models reviewed:
  1. Discussion of ACP knowledge and whether the participant had a plan.
  2. Describing what living well meant to them.
  3. Naming a primary and secondary health advocate.
  4. Describing religious or spiritual influences that may impact decisions.
  5. Explaining the kind of the care they would want if there was a sudden illness or injury.
• Debrief session afterwards:
  1. Described how the session made them feel
  2. Discussed the use of the telephonic component
  3. Provided feedback on the ACP facilitator
  4. Considered sources from which they would feel comfortable getting information about this ACP resource
Key Insights: Defining Advance Care Planning

• Most participants were unclear what an ACP was and first defined it as:
  • Funeral planning
  • Medical plan coverage
  • Long-term care
  • Preparation as one ages

• Most participants did not have an existing ACP.
  • One participant thought he already had one but was unsure where it might be.
  • Another participant had already spoken to his wife about it and was clear that the plan included “his wishes if he was incapacitated.”

Implication: Lack of clarity of an ACP may be likely a reason many older adults do not have a plan.

Key Insights: Personal Experiences

• Participants discussed personal experiences with family or friends who had become ill or injured:
  • One participant had lost three of her sons and her husband. Each incident had happened quickly. As a result she felt she “had no example of long-term care” and “did not want to be a burden on her family.”
  • Another participant had a son who died in a car accident. She was “relieved he had passed so he was not a vegetable. He was 30 years old.” She was also grateful that he had already told her the music he wanted played at his funeral.
  • A participant described how she had cared for her mom and dad in their final days and was frustrated that the medical staff had made decisions for them. She said, “I do not want strangers to make decisions for me like mom and dad had.”
  • Another participant discussed how he watched his mother have a hard time at the end of her life, and that he had already had cancer himself. From these experiences, he recognized the importance planning for the future.

Implication: The more experiences that the participant had the more clarity they had regarding what they might want in the future.
Key Insights: Living Well

- Participants were asked: What would a good day look like? What does living well mean to you?
  - Many participants struggled to put this question in context. Some participants even responded by asking for clarification.
  - Responses were varied and included:
    - Spending the day with family
    - Travel
    - Nice dinner
    - Prayer/faith
    - Not having stress
    - Being able to care for oneself
    - Not being in pain
    - Having coffee
    - Spending time with good people

Implication: The notion that articulating what constitutes a good day can be used as guideposts for decision makers did not prove true. It was too broad and confusing without context. Alternative approaches may include repositioning to understand what constitutes a comforting or health environment.

Key Insights: Living Well

- Participants described their ideas and expectations about living well with the following reflections:
  - “Every day is a good day.”
  - “Ideal would be if the whole family could be together.”
  - “Good food, clean, groomed, well cared for, my hair dyed.”
  - “Being healthy…not in pain…have a cup of coffee…man around town.”
Key Insights: Choosing a Health Care Advocate

Who you want to be your healthcare decision maker (healthcare advocate)?

• All participants were able to name a health advocate and a secondary health advocate.
• Those who were married often chose their spouses. However, one married participant considered his wife and himself a unit and referred to his choice of health advocate as a shared decision.
• Adult children were a frequent choice as well (for both primary and secondary).

Key Insights: Choosing a Health Care Advocate

• Primarily participants were looking for health advocates who could remain calm and make good decisions. They could be compassionate but not overly emotional.
• Participants wanted to make sure that their health advocate understood their values and belief system.
• Some health advocates were chosen because they had experiences with medical issues or the medical system.
• A few participants struggled about not offending one family member over the other.

Implication: Prompting people to think about the qualities of an advocate can be a differentiator. The first person that comes to mind may not always be the best fit.
Key Insights: Choosing a Health Care Advocate

- Participants described their thoughts on health care advocates as follows:
  - “My wife...she has dealt with medical issues in her family and she keeps her cool and knows how to ask questions.”
  - “I saw what happened with my husband and my sons... my son can handle this.”
  - “Someone compassionate to let go, someone open to natural alternatives.”
  - “Similar religious beliefs, someone who shares our morals, someone is on the same page in lifestyle... they recognize the lifestyle we have been living.”
  - “I want them to make a decision on what is best for everyone in the family. Do what is medically necessary and makes sense for everyone in the family.”

Key Insights: Religious or Spiritual Influences (Culture and Comforts)

What cultural, religious, spiritual, or personal beliefs you may have that impact your decisions?

- Many participants were religious but did not feel this would impact a decision regarding end of life decisions. One participant did feel his Catholic teachings would guide him till the end.
  - “I believe in right to life and natural end of life – if I’m being kept alive by artificial means at what point is it ok to pull the plug so to speak – that’s something I don’t dwell on or haven’t given too much thought...It would be important to follow your faiths teachings.”
- Many participants described that their religious or cultural beliefs in the context of the care they would like to receive, discussing the importance of having clergy visit them and having people pray for them.
  - “I’m Jewish and if I had to go to hospice I’d want a Jewish hospice but I’m not religious...I would want a Jewish burial.”
  - “I am Christian so that would be part of the equation...clergy visit and prayers would be important.”

Implication: It is important for advocates to understand spiritual beliefs for end of life that may otherwise be assumed or unexpressed.
What healthcare you would like to receive if you have a sudden illness or injury?

• The discussion related to a sudden illness or injury revolved around how much of a chance they would have to recover. For example, during her discussion, one woman said “the science might change and I don’t want to screw up and make the wrong decision.”
• There was also discussion among some participants regarding alternative treatments and mistrust of the medical community. “Coconut oil can clear the brain. Try that before they give me tons of drugs.”

Key Insights: Sudden Illness or Injury

Many participants first responded to the question of with the concept of not wanting to be on life support and endorsing “pulling the plug.” However, when presented with any sort of uncertainty to what end of life might mean, they were clear that if there was hope they might want to reconsider.

• “Let nature takes its course…but mobility is something to consider.”
• “If there was a chance I would become myself then I would want them to try but if not, then no.”
• “Some limitations are okay, like paralysis or being blind but no vegetable state.”
• “At some point they will have to let go. How does 30 days sound?”
• “Little chance? I want a little while and if little chance doesn’t happen then I can die.”
• “If I do have a chance…I will fight for it.”
• “If there is a chance, then take all measures.”

Implication: Older adults may need clarification on end of life decisions as they are not clear cut. A differentiated solution will help provide clarity when there is little or no hope.
Key Insights: Environment in Case of Sudden Illness or Injury

Wishes related to the atmosphere they would want in the room in case of a sudden illness or injury-related event included having family and friends around them, having music, and as one participant noted, “a healing environment.”

- “Music is important for the soul…it has the ability to put life back in you.”
- “I don’t want a whole lot of people, quiet and peaceful, music, no crying.”
- “I would want alternative medicine to be considered.”
- “I want it quiet and peaceful in a healing environment turn on some music – don’t cry and tell me you love me you should have told me that before.”

Detailed Findings: Feedback on Telephonic ACP

- All participants reported feeling pleased overall with the telephonic option, with the main outcome the ability to articulate the conversations they need to have with their health care advocates.
- Three participants felt more comfortable over the phone.
- The oldest of participants (76+) still felt more comfortable in-person but were clear that the telephone was feasible as well.
- Overall, participants reported these conversations to elicit feelings of confidence, reassurance, and calmness.
- Only two participants reported feeling overwhelmed from this conversation, but still felt the conversation was worth having
Detailed Findings: Feedback on Telephonic ACP

Regarding the Phone:

• “It may have been a little better for me. I might have been uncomfortable in person…I might have felt he was expecting me to answer a certain way…it worked for me.”
• “I felt that I related to him more over the phone than I would have in person.”
• “Face to face you’re there and you can see the expressions on their face but it was fine over the phone…and it got me thinking about it. The phone would be fine.”

Reassurance:

• “I am reassured because I will put things in writing and people will treat me the way they want to treat themselves.”
• “I was able to express myself including my spiritual part and I was not rejected.”
• “I feel reassured because I like expressing it.”

Detailed Findings: Feedback on Telephonic ACP

• A key component of the telephonic ACP process was the facilitator.
• Participants connected with the facilitator through this process and provided very positive feedback as a result.
• Overall, they felt he was incredibly empathetic and sensitive to the topic, non-judgmental and easy to talk too even when they discussed their own personal beliefs, a good listener (demonstrating this by summarizing what they had said), articulate, informative, and personable.

“John was pleasant and sensitive and he put a lot of thought into how to present himself.”

“He is a good talker, he doesn’t pressure…brought up some ideas that you don’t think about.”

“I was able to express myself and give it to you from my heart and you accepted it…Most of the time the spiritual part is pushed to the side and you didn’t do that and I thank you for that.”

Implication: Facilitators will need to be trained to be patient, empathetic, knowledgeable, and non-judgmental.
On the importance of having an ACP discussion with a health care advocate:

- “There are ways to protect my life and my way of life and the way I want to continue living. I need to communicate as much as I need to my doctor, priest…my decisions that are going to be made are going to be final. So they are uncomfortable but you have to face reality.”

- “Saying the words was scary…advance directives and not really knowing what it is and what was going to happen but after he explained it I was really comfortable…having this conversation put a whole different light on it for me.”

On thinking about the conversation to have with a health care advocate:

- “I don’t want to screw up and make the wrong decision. A higher power (someone knowledgeable in healthcare) can make the decision…you really don’t know.”

Detailed Findings: Feedback on Telephonic ACP

Participants reported they would welcome this service offered from a physician, clergy, insurance company, or AARP.

- “Perhaps during open enrollment.”
- “I would like to do this with my pastor.”
- “AARP would be a great place to go.”

They felt that ACP discussions should be held earlier in life and when an individual is healthier, or before it becomes “too late.”

- “You shouldn’t have to be sick for your doctor to bring it up…they should recommend it for everyone.”
Summary

1. Participants overwhelmingly felt assured and confident as a result of these discussions.
2. The main objective of the study was validated, participants were very open to having ACP discussions over the phone.
3. Participants spent a long time discussing who they wanted as their health care advocate and how they came to that decision.
4. Furthermore, participants described in detail the surrounding comforting or healing environment they would want if they were incapacitated.
5. Characteristics that contributed to the success of the telephonic ACP were the empathy the facilitator demonstrated and his non-judgmental discussion with them.

Next Steps: Considerations for a Future Product

• Project team should:
  • Develop tools for the individual to navigate conversations for family members not chosen as the health care advocate.
  • Include a health care advocate attribution component to help individuals think through what would best suit their needs.
  • Consider blended or non-traditional family structures to be inclusive of all participants' situations.
  • Scripting needs to be refined and retested to better estimate the duration of these discussions.
  • Incorporate the kind of environment that individuals will want as part of the ACP product.
  • Explore approaches of defining what “having a chance for survival” means.
  • Consider online tools that may be effective in educating participants on the use of an ACP.
Next Steps: Future Opportunities to Consider

• Future research should include a larger sample size, the use of a survey, and the perspective of the health care advocate.
• A follow-up with the participants to determine if this intervention was effective and its levels of impact would be an integral part of future evaluations.
• This research does provide valuable information on the opportunities that a telephonic ACP can provide to older adults.

Thank You!
Any Questions?