

A Multi-Methodological Examination of Perceptions Surrounding Advance Care Planning (ACP)

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A Multi-Methodological Examination of Perceptions Surrounding Advance Care Planning (ACP)

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Background

According to the National Institute on Aging (NIA), advance care planning (ACP) involves learning about the decisions that might need to be made regarding medical treatment near the end of life and considering these ahead of time.¹ ACP “informs and empowers patients to have a say about their current and future treatment”, enabling patients to receive care in line with their goals of care and values.² ACP allows for improvement in patient and family experience at the end of life, as well as provision of patient choice.³

According to national data, approximately 56% of individuals surveyed have not communicated their end-of-life wishes with anyone else.⁴ A paltry 23% of people have actually put their wishes into writing; only 7% are estimated to have had end-of-life discussions with their doctor.⁴ Despite these statistics, over 80% of individuals surveyed felt it was important to have these discussions with their physicians. This data is mirrored locally; the LVHN DCH found that the majority of people surveyed understand or have heard about an AD, but only 47% of these individuals have completed one.⁵

Problem Statement & Goals

There is a discrepancy between knowledge of ACP and the actual completion and discussion of ACP between patients and clinicians.

GOALS:

- Assess the perceptions surrounding ACP and related topics (e.g., advance directives, end of life care) among participants: patients, families, clinicians, and the researcher
- Elucidate challenges to having conversations around ACP in the healthcare system

Methods

- QI project through the LVHN Department of Community Health
- 3-PRONGED APPROACH**
 - Community ACP– pre and post quantitative surveys
 - LVHN Staff ACP– one-time quantitative surveys
 - Multi-site experiences in 3 contexts:
 - Professional:** medical student/clinician (Internal Medicine, Palliative Medicine, C/L Psychiatry)
 - Community:** researcher, facilitator
 - Personal:** patient, family member
- Qualitative data analysis
 - Initial coding
 - Thematic analysis

Results

COMMUNITY ACP

Table 1. Community ACP Events FY16-17⁶

# People Reached	370
# of Events	8
Types of Events	Hello Conversation Game, Info Table, Video/Discussion
Gender	72% female 28% male
Education	79% finished more education after high school 21% high school or less
Age	43% under 65 57% 65+
Understand/heard of AD	87%
Completed AD	48%

LVHN STAFF ACP

Table 2. LVHN Staff ACP Events⁷

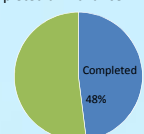
# People Reached	343
Gender (n=343)	67.1% female 26.2% male 0.3% other
Education (n=343)	34.4% some college 21.3% Bachelor's degree 14.9% HS diploma 10.5% graduate degree 5.0% some HS
Age (n=312)	66.6% under 65 33.4% 65+
Understand/heard of AD (n=331)	82.5%
I am comfortable talking with my family about EoL wishes (n=309)	93.9% yes 6.1% no
I am comfortable talking with my physician about EoL wishes (n=309)	90.9% yes 9.1% no
Completed AD (n=332)	26.2% yes 73.8% no
If yes: have you shared your AD with your family (n=30)	96.7% yes 3.3% no
If yes: have you shared your AD with your physician? (n=30)	50% yes 50% no

COMMUNITY ACP

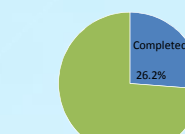
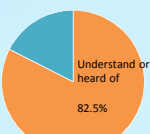
Advance Directive Knowledge



Completed an Advance Directive



LVHN Staff ACP



MULTI-SITE EXPERIENCES

Table 3. Multi-site experiences

Major categories by participant group	
All	Emotional response to ACP Communication
Patients	Emotional response to clinical care Patient choice/autonomy Patient experience Comfort/familiarity Identity
Family Members	Emotional response to patient care Family relationships/caregiver support Family decision-making Comfort/familiarity
Clinicians	Clinical behavior Clinical decision-making Clinician emotion

Discussion

This multi-methodological analysis points to potential difficulties and misconceptions around discussion of ACP. The quantitative data also echo prior findings that there is a gap between knowledge of ACP and completion of an AD.

Two primary categories that recurred within each layer of qualitative data analysis are 1. emotional response to ACP, and 2. communication. All encompassed by the analysis—patients, families, clinicians, and the researcher—experienced strong and wide-ranging emotions when engaging with ACP-related topics. Secondly, each participant group was found to have experiences surrounding the communication of ACP-related issues, including barriers to communication and miscommunication. Sub-themes reveal issues including: seeing ACP as inapplicable to own life, reluctance to discuss EoL issues and ACP, as well as family as essential to provide support and assist with decision-making.

This QI project entailed leadership and all components of emotional intelligence throughout the process. Both researchers had to engage those around them in emotionally fraught topics, and have strong leadership for the organization of various events.

Conclusions & Implications

These findings indicate that there are communication gaps and strong emotional responses to ACP and End of Life issues in general, which should be more thoroughly studied to elucidate how progress can be made to move ACP discussions forward.

Suggestions for future research:

- Use Grounded Theory to develop theoretical explanations to:
 - Understand reasons underlying misconceptions about ACP in our community and medical system
 - Make improvements on the reasons elucidated
- Assess and address gaps in medical education in relation to ACP understanding and discussion

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