Advance Care Planning (ACP): Role of Occupational Therapy Practitioners

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REACH
Research on Ethics, Aging and Community Health

Introduction

- Early discussions and/or documentation regarding preferences for future medical planning and late-life care, known as **advance care planning (ACP)**, are critical for many patient populations, yet significant barriers to ACP have been identified[3]:

Role ambiguity and uncertainty (who is responsible for ACP?)	Institutional barriers (time, training, insurance reimbursement)	Clinicians questioning the value of ACP	Avoidance of ACP

- **Decision aids** are digital tools that increase patients' knowledge of their condition, leading to more informed decisions regarding their medical care[4].
- Based on the **DART clinical trial (Decision Aid for Renal Therapy)**, a decision aid tailored for chronic kidney disease (CKD) patients to engage in dialysis modality decision-making (ClinicalTrials.gov NCT03522740)[5], **DART-ACP (Decision Aid for Renal Therapy – Advance Care Planning)** was developed.
- Wolters Kluwer, an information services company, developed DART-ACP using Emmi, a web-based program that synthesizes complex medical information for patients and their families.
- This qualitative study aimed to inform changes to the DART-ACP decision aid using perspectives from patients and clinicians to assist in increasing ACP completion among patient populations.
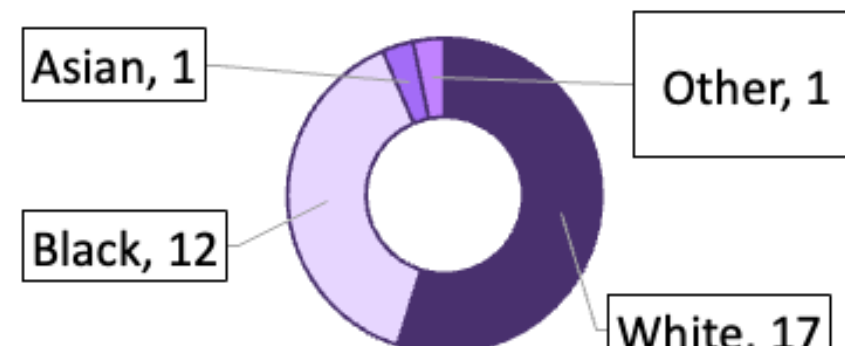- Through analyzing these clinician and patient perspectives, new questions arose regarding occupational therapy practitioners' scope of practice within the process of ACP when working with their patients.
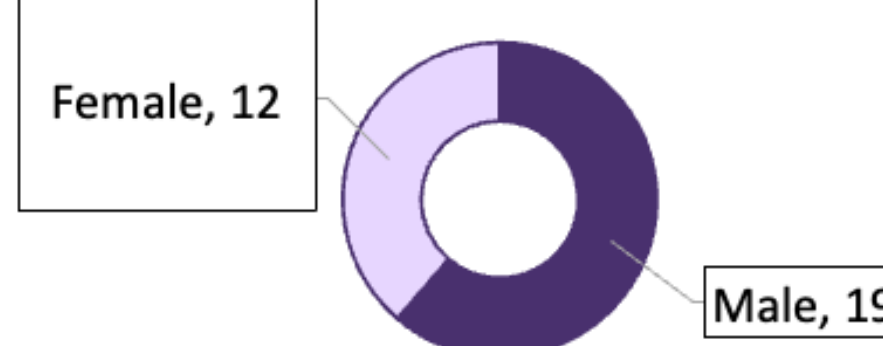
Participants

Patients, n=31

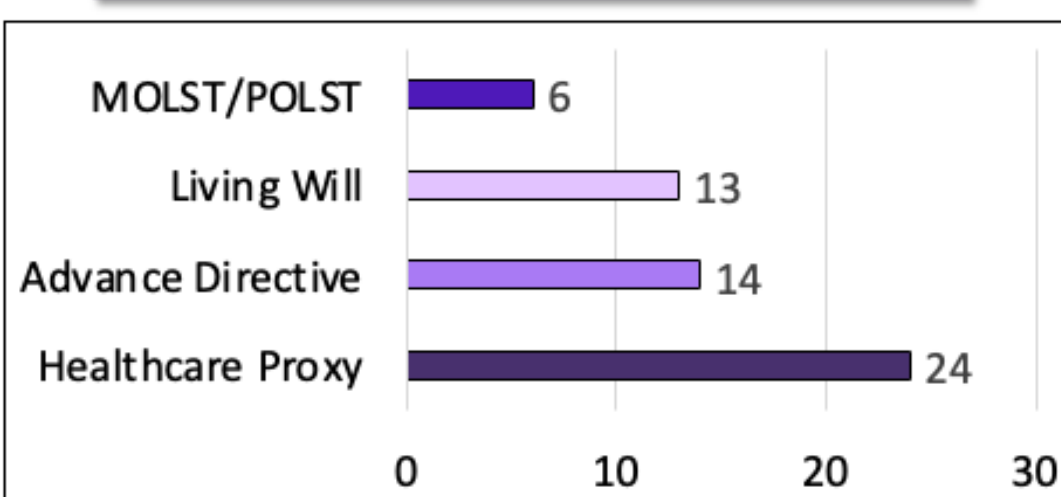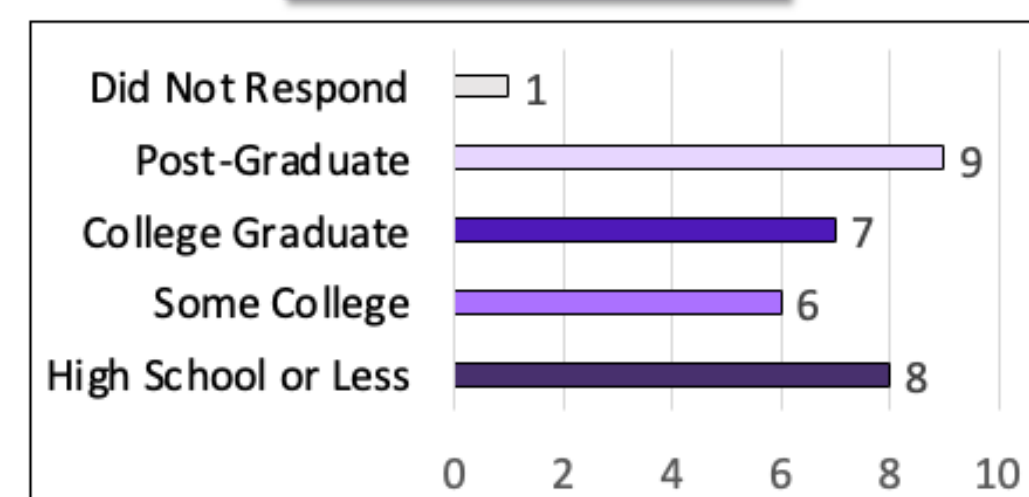| 50+ years old	CKD Stage 4 or 5	English-speaking

Race and Ethnicity
- Asian, 1
- Other, 1
- Black, 12
- White, 17

Gender
- Female, 12
- Male, 19

Completed ACP Documentation
- MOLST/POLST: 6
- Living Will: 13
- Advance Directive: 14
- Healthcare Proxy: 24

Education Level
- Did Not Respond: 1
- Post-Graduate: 9
- College Graduate: 7
- Some College: 6
- High School or Less: 8

Clinicians, n=29

Region
- Mid-Atlantic: 1
- West: 6
- South: 10
- Northeast: 12

Race
- Did Not Respond: 5
- Other: 1
- Black: 1
- Asian: 5
- White: 17
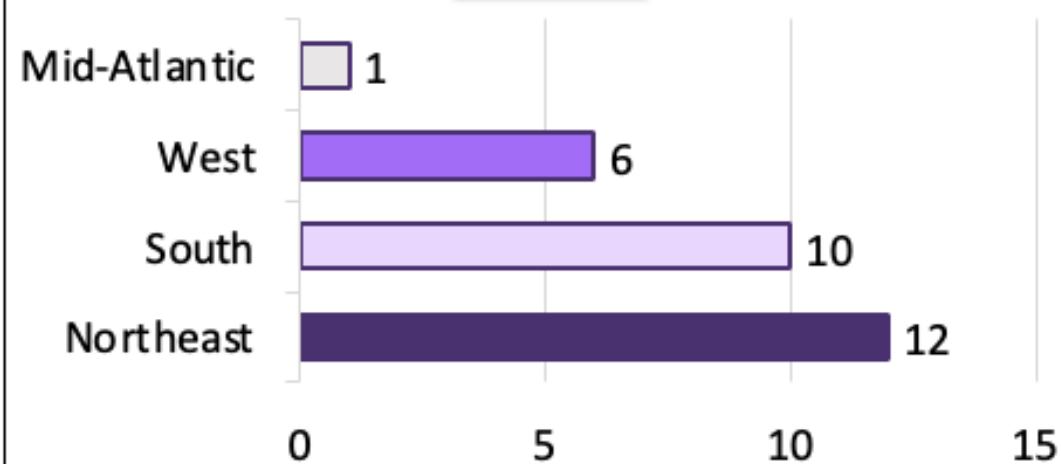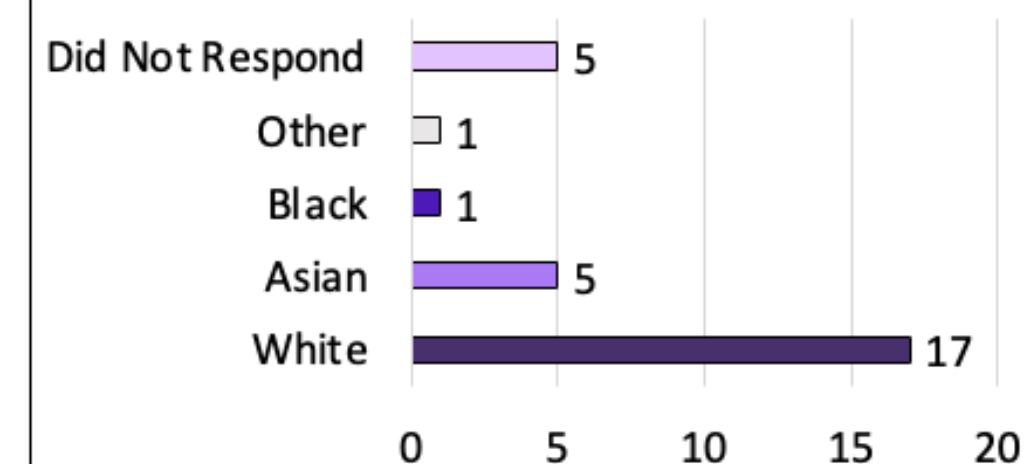
All Nephrologists	38% Female

Methods

Development of DART-ACP Modules → Human-Centered Design

Discovery Phase	Design Phase	Pre-Testing Phase
• Medical writer at Emmi was guided through search of relevant literature, including studies and systematic reviews to inform module content	• Patient focus groups provided feedback for videos • Program was made available to hospitals and clinicians for two weeks for general review and comment	• Viewing of DART-ACP was followed by a semi-structured interview with patients and clinicians and took place from March 2022-March 2023

Thematic Analysis

Interviews were transcribed verbatim → Preliminary codebooks (clinicians and patients) were developed by research team → Codebook was refined and interviews were cross-coded and recoded to ensure agreement → Codes were organized into themes and subthemes

Results and Themes

"It's something that everybody could understand…that video's not disrespecting anybody…[the modules] enlightened my perspective…I think folks can benefit from it." (Patient)

Openness to Web-Based Education

Most patients stated the modules were clear and easy to use. A majority of ACP-avoidant patients found the videos to be acceptable. Several clinician and patient participants expressed concerns about accessibility due to technological barriers for older patients.

"It was very thorough, it was informative, and I think it was presented in a format for most patients to understand." (Clinician)

"I think it's a very good overview of what ACP is and how and when that is indicated and who needs to get involved. It's great resource." (Clinician)

Capacity of DART-ACP to Engage Patients

Multiple participants mentioned the videos had motivated them to start the ACP process and impacted their perspective on how much say they would have at the end of life. Several clinicians advised utilizing tailoring to increase patient engagement.

"I just realized better do it today instead of procrastinate." (Patient)

"If you gave me just a blank sheet, you would never get an answer. Yeah, like, do you want this? Do you believe in that, and if so, what do you want? Stuff like that…" (Patient)

Difficulty Conveying Granularity of EOL Decisions

Communicating prognosis was cited as a challenge by clinicians due to patient anxiety. Clinicians advised that patients tend to struggle with ACP due to hypothetical situations. Participants recommended including examples of ACP documentation to familiarize viewers with the process.

"Maybe show them the MOLST form, and ask them what we want them to actually decide on…" (Clinician)

"I'm glad that you guys included a palliative care part of it because it's sometimes wrongly associated with the hospice or end-of-life care." (Clinician)

Desire for More Info on Palliative Care

Clinicians praised the inclusion of palliative care videos and the explanation of the differences between palliative care and hospice care. Several patients stated the modules were the first time they had been exposed to information on palliative care.

"Yeah, I thought that was very informative…That was the most enlightening part…I've heard of [palliative care]. I didn't understand what it was." (Patient)

Discussion

- Overall, clinicians and patients generally viewed the decision aid favorably in areas of content, format, and accessibility.
- Clinicians stressed that patients may be making ACP decisions or conveying preferences without adequate knowledge of the impact of life-saving procedures on their quality of life.
- By emphasizing real-world examples and lived experiences within our next iteration of the modules, we can better assist CKD patients in the full understanding and completion of ACP.
- When and where patients should view the modules remains up to discussion when considering time restraints in the clinic.
  - Can patients readily get follow-up questions answered at home?
- Patients questioned how to obtain referrals to palliative care, pointing to barriers to referrals between nephrologists and palliative care physicians.
  - Previous gaps that have been identified include[6]:

Low opportunity for interaction between providers	Lack of knowledge of role	Patient and family resistance	Education and training

- The emergence of the geriatric nephrology subfield to address specific needs in the older CKD patient population can bridge the gap between CKD patients and palliative care[7, 8].
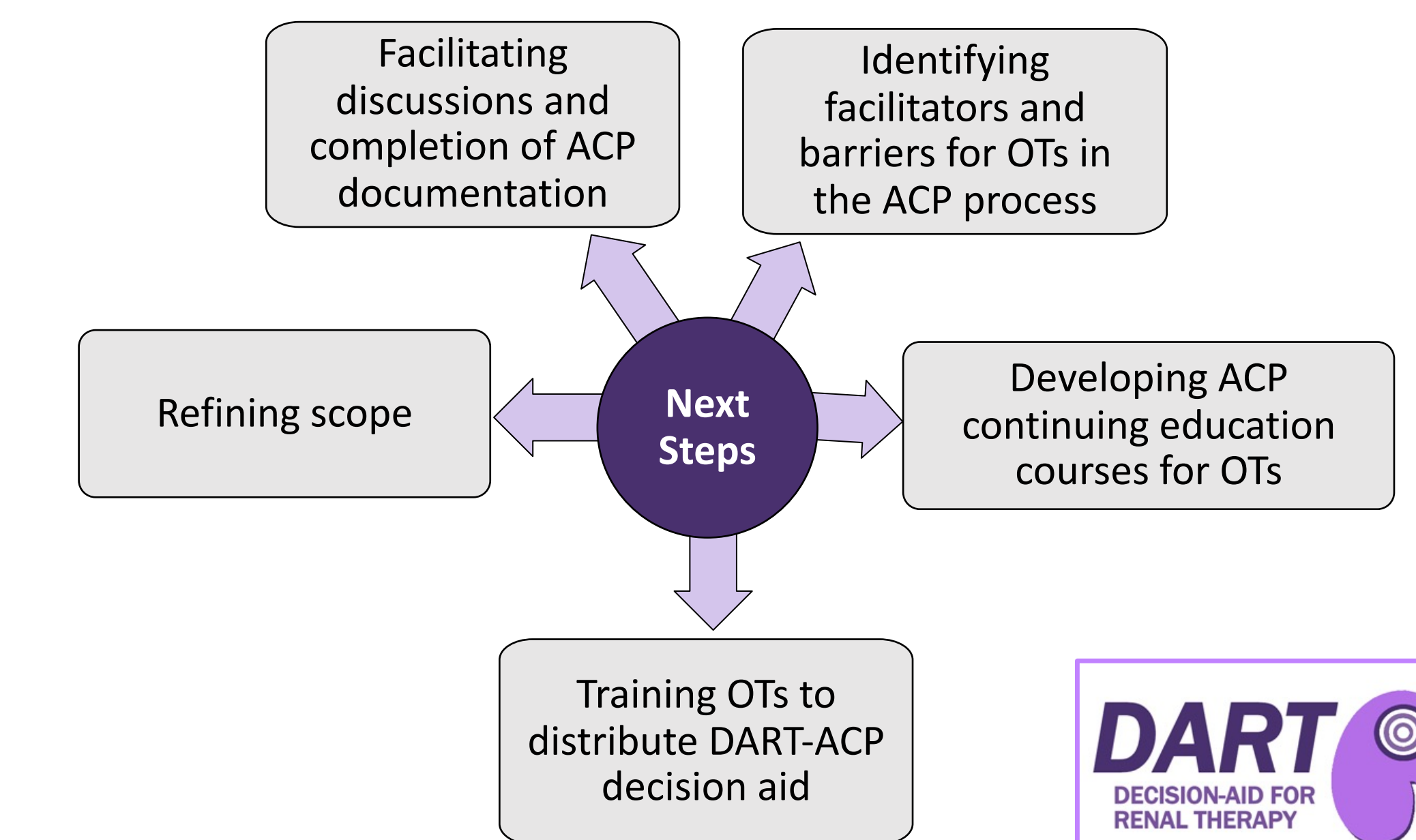
What is Our Role?

- Occupational therapy practitioners' current established role in palliative and end-of-life care[9]:

Evaluation and assessment	Occupational performance	Energy conservation	Caregiver education

Although we have a more established role in palliative and hospice care, **there are currently unidentified gaps in facilitating earlier advance care planning discussions with patients for occupational therapy practitioners, not limited to**[10]:

Knowledge and awareness of ACP	Lack of training	Lack of defined scope

Next Steps:
- Facilitating discussions and completion of ACP documentation
- Identifying facilitators and barriers for OTs in the ACP process
- Refining scope
- Developing ACP continuing education courses for OTs
- Training OTs to distribute DART-ACP decision aid

DART
DECISION-AID FOR RENAL THERAPY

References
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