Challenges in Advance Care Planning in Primary Care: A Systematic Review

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CONFLICT OF INTEREST

• The authors certify they have no affiliations with any organization with any financial interest or non-financial interest in the subject matter discussed in this presentation.
ABSTRACT SUMMARY

• The greatest obstacle to Advance Care Planning (ACP) is initiating the difficult conversation about death and planning for the end that is culturally sensitive and patient-centered.

• Poor end-of-life communication skills, lack of relationship building skills, and time constraints were the highest rated barriers to ACP.

• Improving outcomes will be discussed.
Challenges in Advance Care Planning (ACP) in Primary Care: A Systematic Review

**Background**
The Advance Care Planning (ACP) Report presented to Congress in 2008 identified the greatest obstacle to ACP is initiating the difficult conversation about death and making a plan for the end. Discussing ACP earlier in the trajectory of a terminal illness facilitates an opportunity for patients to make informed decisions. (http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.pdf)

**AIM**
Barriers & Facilitators to EoL Conversations in Adults with a Life Limiting Illness

**Study Design**

- Systematic Literature Review
- Narrative Synthesis

**Emergent Domains**
- Communication
- Psychosocial
- Systems
- Education
- Biomedical

**Results**
- Database Searches: n=1850 Citations
- Titles/Abstracts Screened: n=1005
- Full Texts Reviewed: n=66
- Studies Included in SR: n=31

**Implications for Primary Care**
- Improve Prognostication
- System Changes
- Integrating ACP in Model of Care
BACKGROUND

• There are 49.2 million people over the age of 65 with an increase to 82.3 million expected in 2040.¹

• Sixty percent of the US population has at least one chronic disease; 42% have multiple chronic conditions.²

• In the early 1900s, people died early from accidents, infections, or lethal conditions.³

• Modern medical technology has increased life expectancy, yielding a protracted pathway of chronic illness. Americans live longer with chronic conditions and disabilities affecting their quality of life and timing of death. ⁴⁻⁸
BACKGROUND

• When asked, generally Americans voice a desire to die at home and to have control over their care. Preferences for end-of-life (EoL) care and patient autonomy can be preserved with Advanced Care Planning (ACP).

• Past reports have targeted physicians’ EoL communication during hospitalizations.

• ACP by health care providers (HCP) working in a primary care setting is limited. This systematic review incorporated ACP by physician and non-physician HCPs in outpatient venues.
The greatest obstacle to ACP was initiating the difficult conversation to talk about death and making a plan for the end.¹⁰
Purpose and Aim

Barriers & Facilitators for Patient & Health Care Provider (HCPs) to initiate ACP discussions among adults with a life limiting illness in an outpatient setting
Challenges in ACP
Study Design & Methods

Study Design

Systematic Review

Narrative Synthesis
METHODS

• A systematic review and narrative synthesis were undertaken to determine ACP state of the science from 1996 through 2018.

• Databases were searched were Medline, PubMed, CINAHL, PsycINFO, and Web of Science.
  - In addition, handsearching of key journals, Internet searching, and citation searching were performed.
Search Strategy

Databases: Medline, PubMed, CINAHL, PsycINFO, Web of Science; electronic journal searches

Terms: communicat*, end-of-life, terminal*, palliative, hospice, dying, death, advanced care planning, terminal care, barrier*, facilitat*, nurse*, practition*, primary healthcare, physician*

13 Quantitative

n=1850
Citations

845 Duplicates removed

n=1005
Titles/Abstracts screened for eligibility

939 Non-eligible studies with exclusion criteria

n=66
Total number of full-text studies reviewed

35 Studies reclassified with exclusion criteria

n=31
Studies considered for inclusion in evidence tables

1 Article excluded

14 Qualitative

3 Mixed

13 Quantitative

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14 Qualitative
Challenges in ACP

Results

- 31 studies met inclusion criteria
- 132 Barriers & Facilitators identified
- 5 Domains emerged during analysis
Challenges in ACP

Results

Five Domains

Communication

Psychosocial

Systems

Education

Biomedical
Challenges in ACP
Results

Frequency of Barrier & Facilitator Domains

<table>
<thead>
<tr>
<th>Domains</th>
<th>Number of Barriers &amp; Facilitators</th>
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<tbody>
<tr>
<td>Communication</td>
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Challenges in ACP

Results

Barrier & Facilitator Domains

Wenrich et al\textsuperscript{17} conducted focus groups of patients, family members, health care workers and expert EoL physicians. Six components of EoL communication were highlighted.

1) Using honesty and candor when discussing condition and prognosis\textsuperscript{17}
2) Willingness to talk about death and dying\textsuperscript{17}
3) Delivering bad news in a sensitive manner\textsuperscript{17}
4) Active listening\textsuperscript{17}
5) Encouraging engagement and questions\textsuperscript{17}
6) Assessing patient cues and knowing the correct time to talk about dying\textsuperscript{17}
Challenges in ACP
Results

Psychosocial

1) Troublesome relationship with patient and family members $^{18,19}$
2) Avoidance of the dying patient $^{17}$
3) Anxiety & emotional burden $^{20}$
4) Cultural differences $^{22}$
Challenges in ACP

Results

Barrier & Facilitator Domains

Systems

1) Lack of time$^{18-29}$
2) Lack of clinician role clarity$^{22,26}$
3) Need for staff training$^{22}$
4) Resource linkage$^{21}$
5) Care coordination$^{26}$
6) Institutional support$^{22}$
7) Physician support$^{22}$
Challenges in ACP
Results

Barrier & Facilitator Domains

Education

1) Lack of prognostication skills $^{18,24,25}$

2) Delay EoL talks due to overestimating the patient’s life expectancy$^{18}$

3) Need for public and patient education on ACP$^{22,26,27}$
Challenges in ACP Results

Barrier & Facilitator Domains

1) Single terminal diagnosis versus multiple comorbidities

2) Patients who have not been sick

3) HCPs perceptions that patients with longer life expectancy are not ready to discuss ACP

4) Facilitators include declining health and older age patients

5) Patients with cancer are typically more accepting of their diagnosis and prognosis
Challenges in ACP
Implications for Practice

• Providing early identification of a patient’s end-of-life concerns, goals, and wishes are stepping stones toward a path for improved quality of life for dying patients and their families.

• What are the implications for primary care APRN practice?
Challenges in ACP
Implications for Practice

How can Health Care Providers Support Patients?

- Prognostic Disease Trajectory
- Full Disclosure of Treatment Options
- Support Patients in Resetting Goals to Prevent Futile Medical Interventions
Challenges in ACP
Implications for Practice

- Need to develop specific EoL communication skills
- Improve prognostication skills
- Avoid medical jargon
- Balance hope and honesty
- Build relationships with patients and family members
- Collaborate with health care team members
- Need to start the EoL conversation
- Be open, honest, but dose the truth
Challenges in ACP Practice Implication

First
ACP needs to be an open, honest, integrated, ongoing process to identify the person’s EoL goals and ensure his or her wishes are fulfilled.

Second
Trustworthy HCP-patient relationship with effective communication is essential to the ACP process.

Third
Clinicians require additional training and knowledge specific to EoL care.

Fourth
Public needs to be educated on EoL issues to facilitate engagement in the ACP process to make informed decisions.
• Is ACP communication part of our nursing education at the BSN, MSN, & Doctoral levels?
• What teaching/learning strategies work best?
• Does having ACP initiated in Primary Care improve patient/family members quality of life/dying?
• Does templated ACP patient education improve initiation of ACP documentation?
• Do social media sites facilitate patient-centered care?
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REFERENCES


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