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

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Purpose:

The Administration on Aging estimates 49.2 million people in the United States are over the age of 65. This number is expected to be 82.3 million in 2040. Sixty percent of the US population has at least one chronic disease, and 42% have multiple chronic conditions (Rand, 2017). Modern medical technology has increased life expectancy, and along with that—a protracted pathway of chronic illness. Americans live longer with chronic conditions and disabilities affecting their quality of life and timing of death. 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). The greatest obstacle to ACP is initiating the difficult conversation about death and planning for the end that is culturally sensitive and patient-centered. The ACP process should be engaging, individualized, and a continuum of honest communication to identify EoL goals. Past reports have targeted physicians' EoL communication during hospitalizations. While having ACP prior to hospitalization is optimal, there is limited data on ACP by health care providers (HCP) working in a primary care setting. This systematic review incorporated ACP by physician and non-physician HCPs in outpatient venues. Our aim was to identify, categorize, and analyze the barriers and facilitators to ACP in adults with a life-limiting illness in an outpatient setting.

Methods:

A systematic review and narrative synthesis were undertaken to determine ACP state of the science from 1996 through 2018. The following databases were searched for relevant peer-reviewed nursing and medical studies: Medline, PubMed, CINAHL, PsycINFO, and Web of Science. Our search term strategy included: communicat*, end-of-life, terminal*, palliative, hospice, dying, death advanced care planning, advance directives/psychology* terminal care/psychology*, barrier*, communication barrier, facilitat*, behavior, helping nurse*, practitio*, primary healthcare, physician*. In addition, handsearching of key journals, Internet searching, and citation searching were performed.

Results:

A total of 1,850 citations were retrieved. Applying inclusion/exclusion criteria resulted in 31 studies for analysis. The Critical Appraisal Skills Programme was used to appraise and summarize the quality and relevance of the included studies. The pertinent data from each study was amalgamated to form the summary evidence table. Studies were organized as qualitative, quantitative, or combined methods. Extracted information includes (1) study/location/year, (2) aim or purpose, (3) design, (4) method, (5) sample, (6) setting, and (7) key findings—barriers and facilitators. Most studies were from the United States, but also included Canada, Netherlands, Australia, Belgium and Scotland. Patients and HCPs made up the largest samples. The patients most frequent life-threatening conditions were chronic obstructive pulmonary disease and cancer. Five domains emerged during data analysis: communication, psychosocial issues, health care systems, educational needs, and biomedical concerns. Inadequate end-of-life communication skills, lack of relationship building skills, and time constraints were the highest rated HCP barriers to implementing advance care planning.

Conclusion:

Patients want HCPs to initiate ACP conversations. HCPs are obliged to improve prognostication, communication, and relationship-building skills so that patients can receive timely decision-making information earlier in the trajectory of their terminal illness. Discussing advance life plans during primary care visits facilitates an opportunity for patients to render informed decisions, attain improved symptom control, and provide opportunities for closure. Findings have implications for nursing practice, education and research. (540 words)

Title:

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Keywords:

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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.

Content Outline:

- Background
 - Population Demographics
 - Standards & Guidelines
- Purpose and Aim
 - Barriers & Facilitators to End of Life Conversations
 - Review, Categorize, Analyze
 - Study Design & Methods
 - Systematic Literature Review
 - Narrative Synthesis
 - Results
 - State of the Science
 - Emergent Domains

- Communication
- Psychosocial
- Systems
- Education
- Biomedical
- Implications for Practice
 - Primary Care Advanced Practice Nurses
 - Nursing Education

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Author Summary: Dr. Willson is a Sigma Theta Tau, International Virginia Henderson Fellow. She has taught graduate level nursing for 32 years. A focus of her research agenda has been standardized testing, concept-based curriculum in nursing education, self-management, and access to care for multicultural populations.

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Author Summary: Dr. Gondran is an experienced Family Nurse Practitioner working in the primary care arena with patients across the lifespan. Addressing end of life issues and advanced care planning is an integral part of her clinical practice. Sue Ellen is passionate about patients receiving timely decision-making information earlier in the trajectory of terminal illness to facilitate improved quality of life and opportunities for closure.