Factors in Comfort and Preparedness with Advance Care Planning in Pediatric Clinicians; A Review

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Abstract

Background: Many clinicians and staff members working with pediatric patients over their career will treat seriously or terminally ill children and likely face the death of a patient. However, there is a wide variation of experience, comfort, and preparedness around providing advance care planning (ACP) or end-of-life (EOL) care, and little knowledge of which factors play a role across pediatric medical settings.

Objective: To examine which factors affect self-reported pediatric clinician and staff comfort and preparedness on ACP and EOL care.

Methods: A systematic literature review was performed from EMBASE, CINAHL, MEDLINE, and PsychINFO published between January 2000 to November 2022 and last searched on November 18, 2022. “Advance care planning”, “advance directives”, and “code status” search terms were used and studies surveying pediatric clinicians and staff about pediatric patients were included. We excluded studies on adult populations (>21 years), literature reviews, collections of abstracts, and those performed outside the United States or not in English. Any measure or self-reported data around knowledge or comfort made a study eligible, we collected reference data regarding the author, year, objective, number of participants, subject characteristics, sample design, intervention (if applicable), comfort items surveyed, factors of comfort/preparedness, and study conclusion.

Results: 1,127 studies were retrieved, with twenty-three meeting all inclusion criteria. Nine were interventional, and fourteen were solely focus groups, interviews, or surveys. All studies discussed various aspects of comfort or preparedness around ACP, EOL care, or pediatric palliative care (PPC), including discussing ACP or goals of care, caring for patients at EOL, discussing or documenting code status, or support or debriefing after a patient's death. Twenty studies noted that the presence of educational interventions would have a positive impact on comfort or preparedness in various aspects of ACP or EOL care, with ten noting a benefit to didactic experiences, two to simulated or role-playing educational sessions, and three commenting on both didactic and simulated or role-playing sessions. Other factors found in more than one study include lack of debriefings or grief support after the loss of a patient, lack of a PPC team or difficulty consulting PPC, time limitations, lack of personal experiences in ACP or EOL care, or different comfort levels by hospital role.

Discussion: Limitations of this review include the foundation in subjective data increases the risk of sampling bias and potential lack of generalizability based on low response rates and studies occurring at one or a small number of institutions or programs within an institution. Incorporation of formal ACP and EOL care instruction into training for anyone providing medical care to pediatric populations is critical. By increasing the comfort and preparedness of clinicians and staff, we can improve the quality of care provided to these patients and their families. Interventions can include didactics, case discussions, or standardized patient sessions, and further research is required to determine the most effective intervention and frequency of education or training provided, as well as how long these interventions have an impact.