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

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Introduction

- Pediatric clinicians and staff will treat seriously or terminally ill children over the course of their career, likely facing the death of a patient.
- Majority of research on advance care planning (ACP) and end-of-life (EOL) care has focused on adult populations which cannot be extrapolated to pediatrics due to fundamental differences including medical decision-making largely performed by someone other than the patient and Do-Not-(Attempt) Resuscitation (DNAR) orders are not standard of care.
- Wide variation in experience, comfort, and preparedness providing EOL care and ACP.
- While some research has been done on the clinician perspectives and implementation of various interventions, policies, and/or programs covering ACP or EOL care, there is no centralized understanding of comfort and preparedness factors.

Objective

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

Methods

- Systematic literature review querying EMBASE, SINAHL, MEDLINE, and PsychINFO.
- Inclusion criteria included publications between January 2000 to November 2022, English language studies taking place within the United States, and "views study" on participant perspectives.
- Exclusion criteria includes studies including or focused on adult populations (considered over 21 years old based on American Academy of Pediatrics guidelines²) and systematic literature reviews.
- References were imported using EndNote and screened.
- Any measure or self-reported data around knowledge, preparedness, or comfort made a study eligible, whether it was before, after, or not compared to an intervention, with no limits on the point of time or length of intervention.

Results

- 1,127 studies were retrieved and 23 met all inclusion criteria.
- Nine studies were interventional, with eight interventions on trainees and one on staff.
- Fourteen studies were solely focus groups, interviews, or surveys: four on trainee populations and ten on staff members.
- 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 present in more than one study include lack of debriefings or grief support after the loss of a patient, lack of a pediatric palliative care (PPC) team or difficulty consulting PPC, time limitations, lack of personal experiences in ACP or EOL care, or different comfort levels by hospital role.

Identification of studies via databases and registers Records removed before Records identified from: Duplicate records removed Databases (n = 4)EMBASE (n = 478) (n = 284)Records marked as ineligible CINAHL (n = 187)MEDLINE (n = 408) based on date (n = 73)PsychINFO (n = 54)Records removed for other reasons (n = 0)Records excluded for occurring Records screened outside the United States (n = 251) (n = 770)Records excluded for including adult populations (n = 210) Reports sought for retrieval Reports not retrieved (n = 309)(n = 2)Reports excluded: Reports assessed for eligibility Chart reviews or (n = 307)retrospective studies (n = 71)Case reports or collections of abstracts (n = 51) Literature reviews (n = 13) Informational or guidance articles (n = 12) Non-clinician or staff perspectives (n = 137) Included Studies included in review (n = 23)

Figure 1. PRISMA 2020 flow diagram

Summary and Conclusion

- This study suggests that while numerous factors influence comfort and preparedness, the most significant influence on clinicians and staff is the presence of formal educational opportunities or training.
- This study is limited by the fact that the responses are overwhelmingly subjective, most are single institution or single program studies, the study was performed by only one reviewer, and was limited to only US studies.
- By making changes to improve comfort and preparedness with ACP and EOL care, willingness to have these conversations will increase along with the understanding of when and how to do so, resulting in an overall benefit to patient care.
- Determining appropriate interventions, policies, or programs to address house staff needs may work to increase the quality of care provided to patients and families.

Future Directions

- Institutions should assess their current resources including educational opportunities, PPC access, and support after the loss of a patient.
- Further research is required to determine the most effective intervention, appropriate frequency provided, and how long these interventions have an impact.
- Implementation of educational interventions for pediatric clinicians and staff should be first line, with a focus on addressing biases, medical resources and knowledge, and communication training.
- Further examination of factors that do not lend themselves naturally to an intervention such as staff schedules or subspecialty choices.

References

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