

Development of a Tool To Assess
Knowledge , Attitudes and Experience
of Pediatric Health Care Professionals
have with Advance Care Planning :
Pilot Study

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Problem

- Advance directives and advance care planning not well understood
- Most literature focuses on adults, surrogates or health care professionals understanding of or use of them
- No conceptual model has been used to help describe or define this process of advance care planning in pediatrics
- In pediatrics the literature has focused on adolescents in oncology or parents with children in oncology and their attitudes towards the use of advance directives
- Children facing life threatening illness go beyond just oncology diagnosis and are often facing advancing chronic disease and frailty that have treatment goals that are continually changing
- What little pediatric literature that exists states that parents want to engage in the process but need to feel engaged and listened to and health care professionals (HCP) for many reasons including: lack of knowledge; attitudes about death and dying and lack of experience in death and dying are hesitant to engage in these conversations
- As pediatric health care professionals do we understand what they need or what we need to engage with them?

Objective

- To modify an existing tool(KAESAD) measuring nurses and knowledge of, attitudes towards and experience with advance care planning and validate the tool among pediatric health care professionals caring for children facing life threatening illness

Conceptual Model

Shared Decision Making

- Partnership
- Explicit dialogue
- Informed patient
- Informed health care professional
- Shared decision making
- Completeness

Design

- A descriptive study will be used to establish the psychometric properties of an adapted survey for pediatric health care professionals. In this study, the following will occur:
 - Step One: through item generation establish face validity and feasibility of an adapted version of the KEASAD and
 - Step Two: reduce items to establish content validity, using a group facilitation process known as the Delphi.
- The Delphi involves an iterative multistage process designed to transform opinion into group consensus through item reduction.

Setting and Sample

Step One : Item Generation

For item generation a purposive focus group made of 'experts' will be chosen to review the KEASAD. Permission has been obtained from the creator of the KAESAD to adapt the measure. Eligibility criteria for this phase includes :being an individuals whose professional experience is in the area of clinical pediatrics and/or palliative care and knowledgeable about advance care planning/advance directives.

Step Two: Item Reduction

- The reduction phase, will be conducted as a Delphi process.
- This involves another purposive group whose eligibility criteria include; being a noted expert in pediatric palliative care within Canada and practicing within hospital, community or hospice settings. They are representative of a variety of healthcare professionals with the majority being nurses and physicians.
- This is an easily obtainable sample as these individuals are well known within the practice of general pediatrics, as well as palliative care I will obtain the names from a known membership list of the national group of the Canadian Network of Pediatric Palliative Care.

Method

Step One : Item Generation

- A purposive group of health care professionals and academics will be given a summary of the research study and an original copy of the KAESAD, and an executive summary of the conceptual model prior to the meeting.
- They will be asked to attend one 3 hour session to review the KAESAD, the conceptual model and recommend any initial changes in format, structure and type of questions.
- All proceedings will be based on the data collected the original tool, the items in the KEASAD(115 items) will be revised for the next step.
- **Finally**, this group will also be asked (via email) to evaluate the final adapted version to assess how long it will take to complete the questionnaire to aid in the information given to participants in item reduction phase.

Data Management and Analyses

Step One: Item Generation

- Changes to the items of the KAESAD will be made to reflect the evaluation by the small group of experts.
- This will help to establish face validity of the adapted tool. Reliability and validity of the actual KAESAD were established through a pilot test/retest and an expert panel prior to the main survey in the United States using nurses caring for adult oncology patients (Jezewski, 2003).

Step Two: Item Reduction

- The modified tool will be sent via email to a group of health care professionals. These key contacts will also be asked to approach other health care professionals who they think might be interested in being part of the consensus building and they consider have experience with and an understanding of the pediatric palliative population.
- The Delphi process is a research method for eliciting consensus opinions from experts using an iterative process known as rounds. The number of rounds used varies although 2-3 is usually sufficient. The Delphi is considered complete when there is a convergence of opinion or when a point of diminishing return is reached.
- The first round will take the items Step 1 and ask the professionals to rate the items on a scale of 1-10 based on relevance and usefulness. Relevance and usefulness help to define the content validity of the items generated for an adapted survey. Any questions receiving a rating of 6 or above on relevance and usefulness will be retained for the second round.
- The second round will include an analysis questions from round one, In Round 2 any questions receiving a rating of 7 or above on usefulness and relevance will be retained. Another round will be added if convergence has not been obtained in this round.
- To maintain the rigor of this method a response rate of 70% for each round is suggested This rigor will be supported by reminder e-mails that will be sent within one week of the initial e-mail and every two days until the end date of each round



Anticipated Outcomes

- The goal of this process is to develop a tool that is both valid and reliable in the assessment of attitudes, knowledge and experience with advance care planning for pediatric health care professionals.
- This study will contribute important information necessary to determine educational supports, tools and models needed by pediatric health care professionals to feel they are equipped to fully engage with families in advance care planning about their child's end of life care