



Sample Scientific Paper Abstract Submission

Prioritizing Outcomes for Advance Care Planning Research: Consensus from a Multidisciplinary, International Delphi Panel (TH307A)

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Objectives

- Describe an Organizing Framework developed by a large, multi-disciplinary Delphi panel regarding patient-centered ACP outcomes.
- Present patient-centered ACP outcomes ranked in order of importance by a large, multi-disciplinary Delphi panel.

Original Research Background: Without a shared understanding of standardized quality metrics that define successful advance care planning (ACP), it is difficult to compare interventions across systems and populations.

Research Objectives: To use a large, multi-disciplinary, Delphi panel of ACP experts to create an Organizing Framework, and identify and rank patient-centered ACP outcomes.

Methods: We first conducted literature reviews and solicited input from 5 international ACP conferences to collate ACP outcomes into an Organizing Framework. Next, we conducted 3 Delphi panel rounds with a 52-member panel of researchers, clinicians, legal experts, and policy makers. Panelists were asked to prioritize patient-centered outcomes, comment on the Organizing Framework, and rank outcomes on a 7-point “not-at-all” to “extremely important” scale. We used content analysis of panelists' comments to iteratively update the Framework and outcomes and present data back for Delphi panel review. We also calculated the mean rankings (\pm SD).

Results: Panelists were from USA, Canada, Netherlands, and Australia; 63% were women, and 71% were researchers. Outcome domains identified for the Organizing Framework included: moderators (i.e., demographics), process/mediators (i.e., attitudes), actions (i.e., discussions/documentation tasks), quality of care (i.e., satisfaction with care/communication), and healthcare (i.e., utilization). After 3 rounds, 138 ACP outcomes were identified. The top 5 outcomes included (1)care consistent with goals, mean 6.70 (\pm SD 0.31); (2)surrogate designation, 6.68 (0.44); (3)surrogate documentation, 6.48 (0.39); (4)discussions with surrogates, 6.44 (0.33); and (5)identifying values and goals 6.40 (0.62). Documentation of an advance directive was ranked 14th, 5.98 (0.59). The panel was unsure how to best measure care consistent with goals.

Conclusion: A large, international Delphi panel came to consensus about an Organizing Framework and important outcomes to define successful ACP.

Implications for research, policy or practice: This work will allow researchers, healthcare organizations, and policy makers to standardize outcomes that can be compared across sites. More research is needed to standardize the care consistent with goals measure.



Sample Scientific Poster Submission

Accuracy of Adult Children in Predicting Older Parent Quality of Life Valuations (S782)

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Objectives

- Understand the range of within- and across-family knowledge adult children have about parent QOL valuations.
- Articulate variation in child-parent concordance across different states of poor health.

Original Research Background: Adult children often collaborate with older parents on parent care decisions, and some are called upon to make decisions for their parents. To do either successfully, adult children need awareness of their parent's care preferences and values. However, families rarely have conversations about these issues and instead assume that values are known.

Research Objectives: The goals of this project were to establish 1) the degree to which adult children know how their older parent would evaluate quality of life (QOL) in different health circumstances, 2) variability in children's knowledge, both across and within families, and 3) the direction of any mis-estimation children make relative.

Methods: Adult children predicted their older parent's responses to a series of questions regarding factors that might influence their quality of life (QOL) should they ever become seriously ill.

Results: Forty families were recruited (40 parents, 70 children); 83% of the parents were mothers, and 59% of the children were daughters. Across all families, children were only modestly knowledgeable about parent QOL valuations (Spearman's $\rho = .31, p = .01$). The range of accuracy was large across the entire sample of families and within families. Some adult children within families were very knowledgeable about parent values, whereas other children

within the same family were no better than chance at estimating how their parent defined a good or bad QOL. Similarly, some families, as a unit, were more consistent in their knowledge than others. As a group, children tended to underestimate how negatively their parents felt about some compromised health circumstances.

Conclusion: Adult children have only modest awareness of how their older parent would judge quality of life in different compromised health states.

Implications for research, policy or practice: Evidence-based interventions are needed to improve family knowledge, and, perhaps more usefully, competence at having effective conversations about care preferences and values.