

5.1 Finding the "Right" Outcomes of ACP (themed session)

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Identification, Implementation and Evaluation of Indicators to Monitor Successful Uptake of Advance Care Planning in Alberta

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Background: In 2014, a province-wide policy for advance care planning (ACP) and Goals of Care Designation (GCD) was implemented in Alberta, Canada; nevertheless, few quality indicators have been rigorously developed or evaluated for measuring the uptake of ACP/GCD.

Methods: In phase I, we performed a systematic literature review and environmental scan to identify potential ACP/GCD indicators. A Delphi consensus-based approach, consisting of 3 rounds of face-to-face meetings and/or online surveys, was used to develop a short list of indicators. In phase II, the panelists met face-to-face to operationalize and implement the indicators. In phase III, two validated questionnaires and semi-structured interviews of 60 individuals (stratified by manager/practitioner and physician/nurse) are being used to evaluate the usability and acceptability of the implemented indicators on a dashboard interface.

Results: A total of 132 potential indicators were identified in phase I. The indicators were reduced and refined to 18 after 3 Delphi rounds. Phase II resulted in 9 valid and feasible indicators in a measurable format (i.e. numerator, denominator, data source defined). The Phase III protocol is under ethical review and potential participants' recruitment is underway.

Conclusions: Of 132 quality indicators for ACP/GCD, 9 are feasible, valid, usable and acceptable for monitoring performance in the rollout of ACP/GCD. This set of indicators shows promise for describing and evaluating ACP/GCD uptake throughout a complex, multi-sector healthcare system.

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The challenge of finding the 'right' outcome to measure the effects of ACP - Part I

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Background: Advance care planning (ACP) is increasingly implemented in oncology and beyond, but a definition of ACP and recommendations concerning its use are lacking. This hinders the development of ACP programmes and the evaluation of ACP's effectiveness.

Methods: We used a formal Delphi consensus process to help develop a definition of ACP and provide recommendations for its application in healthcare, policy and research.

Results: Of the 109 experts (82 from Europe, 16 from North America, and 11 from Australia) who rated the ACP definitions and its 41 recommendations, agreement for each definition or recommendation was between 68-100%. ACP was defined as the ability to enable individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate. Recommendations included the adaptation of ACP based on the readiness of the individual; targeting ACP content as the individual's health condition worsens; and, using trained non-physician facilitators to support the ACP process. A list of outcome measures is also presented to enable the pooling and comparison of results of ACP studies.

Conclusion: This large international Delphi panel was able to come to a consensus on an ACP definition and recommendations. This represents an important first step in providing clarity with a view to further policy and research in this field. We believe that our recommendations can provide guidance for clinical practice, ACP policy, and research.

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The challenge of finding the 'right' outcome to measure the effects of ACP - Part II

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Background: Standardized outcomes that define successful advance care planning (ACP) are lacking. The objective of this study was to create an Organizing Framework of ACP outcome constructs and rate the importance of these outcomes.

Methods: This study convened a Delphi panel consisting of 52 multidisciplinary, international ACP experts including clinicians, researchers, and policy leaders from four countries. We conducted literature reviews and solicited attendee input from five international ACP conferences to identify initial ACP outcome constructs. In five Delphi

rounds, we asked panelists to rate patient-centered outcomes on a seven-point “not-at-all” to “extremely important” scale. We calculated means and analyzed panelists’ input to finalize an Organizing Framework and outcome rankings.

Results: Organizing Framework outcome domains included process (e.g., attitudes), actions (e.g., discussions), quality of care (e.g., satisfaction), and health care (e.g., utilization). The top five outcomes included 1) care consistent with goals, mean 6.71 (\pm SD 0.04); 2) surrogate designation, 6.55 (0.45); 3) surrogate documentation, 6.50 (0.11); 4) discussions with surrogates, 6.40 (0.19); and 5) documents and recorded wishes are accessible when needed 6.27 (0.11). Advance directive documentation was ranked 10th, 6.01 (0.21). Panelists raised caution about whether “care consistent with goals” can be reliably measured.

Conclusion: A large, multidisciplinary Delphi panel developed an Organizing Framework and rated the importance of ACP outcome constructs. Top rated outcomes should be used to evaluate the success of ACP initiatives. More research is needed to create reliable and valid measurement tools for the highest rated outcomes, particularly “care consistent with goals”.

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The challenge of finding the 'right' outcome to measure the effects of ACP: Part III

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Background: A key outcome of successful advance care planning is consistency between patient goals of care and the care provided. However, assessing consistency is methodologically challenging due to conceptual and logistical barriers as well as practice limitations.

Methods: The team reviewed the literature and identified key methodological barriers to measuring care consistency with patient preferences and goals of care. Strategies to overcome these barriers are proposed.

Results: Key methodological barriers include: 1) the specificity and relevance of documentation about preferences and goals of care; 2) the availability of documentation about preferences and goals of care; 3) the stability of documented preferences and goals of care; 4) the timing of treatments provided and identifying decisions not to treat (“non- events”); and 5) calculating rates of consistency. Strategies to address these methodological barriers include using tools to document specific preferences, incorporation into electronic health records, period reassessment of preferences, prospective data collection, and using percent agreement to report consistency.

Discussion: There are clear challenges to assessing care consistency with preferences and goals of care. The ability to assess and report on this important outcome of successful advance care planning requires focused efforts to improve practice.

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The challenge of finding the 'right' outcome to measure the effects of ACP - Part IV

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Background: There is little agreement about which outcomes are the most important outcomes to use in ACP trials. Previous studies have taken the first important steps to address this challenge by developing a consensus definition of ACP, a list of outcome measures for ACP studies and an organizing framework regarding outcomes that would define successful ACP in research. The extensive work they undertook included consulting multidisciplinary, international experts in Delphi panels. However, these expert panelist mainly consisted by healthcare professionals, lawyers, and researchers. Patients and family caregivers might rate the importance of outcomes for ACP differently. However, little is known about the most important and desired outcomes of ACP from patients’ and family caregivers’ perspective.

Methods/Design: In this presentation, we will present the results of 1) a scoping review of the literature to identify desired outcomes of ACP from patients’ and families’ perspective, and 2) expert panels and/or interviews with patients, family caregivers, patient representatives, etc. to define in ranking in the outcomes according to their importance to achieve when engaging in the process ACP.

Conclusion: The results of this study will provide an overview and ranking of outcomes that are considered as (most) important when engaging in ACP from patients’ and family caregivers’ perspectives. These results will add to the knowledge base regarding outcomes to measure successful ACP and might help researchers who are considering to perform evaluation studies of ACP interventions to reflect upon appropriate outcomes that are relevant to patients and family caregivers.