

3.4 Components of ACP

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Complex interventions guiding Advance Care Planning conversations: A Systematic Review

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Background: Conversation guides support professionals to conduct ACP-conversations, yet insight in essential components is limited. This systematic review aims to evaluate the content, rationale and empirical evidence on the effect of ACP interventions based on conversation guides.

Methods: Medline, Embase, PsychINFO and CINAHL were searched from January 1, 1998 to February 23, 2018 to identify peer-reviewed articles describing or evaluating scripted ACP-conversation guides. A thematic analysis of the guides was performed. Data on intervention characteristics, underlying rationale and empirical evidence was extracted.

Results: Eighty-two articles reporting on thirty-four unique interventions met the inclusion criteria. Analysis of the conversation guides revealed a framework for ACP-conversations consisting of four phases: preparation, initiation, exploration and action. Exploration of patient's perspectives on illness, living well, end-of-life (EOL) issues and decision making formed the core part of the guides. Their design was often expert-based, without an underlying theoretical background. Empirical evidence on the effect of the interventions was based on heterogeneous outcome measures. Dyad congruence and preference documentation rates increased among intervention subjects in most studies. The studies showed varying effects on knowledge of ACP, decisional conflict, quality of communication and preferences-concordant care. Qualitative research showed that participants appreciate the importance and benefits of ACP-conversations, yet perceive them as difficult and emotional.

Conclusion: ACP-conversation guides address a diversity of themes regarding illness, EOL and decision making, with a focus on the exploration of patient's perspectives and preferences. Evidence on translation of explorative information into specific treatment preferences and consequences for care as provided is limited.

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Evaluation and further development of a Dutch question prompt list on palliative care from the perspective of patients and family.

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Background: Patients and family often do not know what to expect of an advance care planning (ACP) consultation. Question prompt lists (QPL) help them to gain insight into and express their wishes and questions. We developed the 'Leiden Guide for Palliative care' (LGP), combining an adapted Edmonton Symptom Assessment Scale and a translated QPL on palliative care¹, to hand out before the ACP consultation with palliative care specialists. The goals of this study were to evaluate personal experiences of patients and family with the LGP, and to further develop the LGP.

Methods: In this qualitative study semi-structured interviews with six patients and seven family members were conducted. Manual coding and thematic analysis were done by two researchers.

Results: Three main themes for optimal use of the LGP were identified: 1. Prerequisites: early in disease trajectory; adequate introduction by the healthcare professional (HCP); positive first impression. 2. Benefits: provides complete overview of ACP topics and relevant questions; facilitates end of life discussions, also between family members. 3. Practical use: preferably the LGP is reviewed with family 1-2 days before the consultation. With detailed suggestions on content and format we constructed an improved LGP.

Conclusion: Patients and family consider the LGP as helpful and useful in preparation and during ACP consultations with palliative care specialists, provided that the prerequisites are met. The usefulness of the LGP in ACP discussions with generalist HCPs and in different settings is subject of further study.

Reference: 1 Clayton J et al Br J Cancer 2003

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Development and Certification of Quality Patient Decision Aids

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Background: Individuals with serious illness face complex healthcare decisions which have important and lasting consequences. Person-centered care can be achieved when personal values, goals, and beliefs are aligned with the actual care provided.

Person-centered decision-making requires a) clear, accurate and unbiased information about **all** options, including risks versus benefits; b) clinician investment and expertise in engaging and communicating with patients; and c) the effective integration of personal values, goals, and beliefs into choices. Person-centered decision aids (PDAs) are tools designed to help patients and providers in the process of shared decision-making. Research shows, high quality PDAs lead to increased knowledge, more accurate risk perception, reduced indecision about care, and improved patient engagement.

Methods: Based on criteria developed by the International Patient Decision Aids Standards Collaboration (IPDAS), *Healthier Washington Initiative*, Washington State, USA, developed and implemented a process of certifying PDAs to assure they are effective, accurate, unbiased tools to use in the shared decision-making process. Implementation of quality PDAs can be standardized using the fundamentals described in the National Quality Forum's (NQF) National

Quality Partners(NQP) Playbook—Shared Decision-Making in HealthCare.

Results: This presentation will review certification criteria for developing high-quality PDAs. A four-phased approach will be discussed that describes the process of developing and certifying three serious illness decision aids and their integration within Respecting Choices® person-centered decision-making programs.

Conclusion: Development and certification of quality PDAs in healthcare organizations using a standard approach to the decision-making process can support a culture of person-centered care.

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Sustainable implementation of Advance Care Planning in Asia: An Interpretive-Systemic Framework for National Development

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Background: To examine the underpinnings of Asia's first national Advance Care Planning (ACP) programme, and to identify the dynamics, mechanisms and systemic factors that influence the implementation of ACP in Singapore.

Methods: A qualitative interpretive-systemic focus group study with 4 professional stakeholder groups who played critical roles in the ACP programme. Study included 63 physicians, nurses, medical social worker and allied health workers from 7 public hospitals and specialist center that incorporated ACP into clinical practice.

Results: Framework analysis revealed 19 themes, organized into 5 categories including: (1) Life and Death Culture (social perception of death, biomedical model, health system hierarchy, health seeking behaviors), (2) ACP Coordination (institutional leadership, programme receptiveness, interdisciplinary trust, preparatory training), (3) ACP Administration (practice diversity, work flow, operation clarity), (4) ACP Outcomes (care preferences, medical-social dissonance, performance measures, intrinsic values), and (5) Sustainability Shift (public life and death education, holistic end-of-life care training, governance and service alignment, empowered citizenry). These further formed an interpretive-systemic framework of sustainable ACP, reflecting the social, cultural, political, operational and spiritual contexts that support national ACP development.

Conclusion: This research provides insights on developmental and implementation challenges of Asia's first national ACP programme. ACP should be supported by public health strategy for enhancing individual, professional, and institutional readiness for end-of-life conversation before programme commencement. It emphasizes the importance of health policy, organizational structure, social discourse, and shared meaning in planning and delivery of ACP to aid care decision making among Asian patients and their families facing terminal illness and mortality.

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Estimating and communicating prognosis in palliative care: a cross-sectional survey among physicians in the Southwest region of the Netherlands

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Background: Advance care planning is important for patients with an advanced illness and a limited life expectancy. We explored experiences from physicians from different settings with estimating and communicating patients' poor prognosis.

Methods: A survey study was performed in 2017 in the Southwest region of the Netherlands among a random sample of physicians working in primary care, hospitals and nursing homes (n=2212).

Results: 547 physicians participated: 259 general practitioners (GP's), 205 hospital physicians (HP's) en 83 nursing home physicians (NHP's). In total, 61.1% stated that they can adequately estimate if a patient will die within a year; 66.7% stated that they can adequately estimate a life expectancy of less than three months and 76.1% a life expectancy of less than a week. When a patient is estimated to have a prognosis of less than one year, 75.0% of all physicians indicate that they always/often discuss their wishes for treatment and care. For patients with an estimated prognosis of less than three months, 85.9% of HP's discuss patients' wishes, compared to 96.1% of GP's and 91.6% of NHP's. After hospital admission of patients with a limited life expectancy, 29.0% of GP's and 16.9% of NHP's indicate that they always/often receive adequate information from HP's about patients' wishes.

Conclusion: The majority of physicians indicate that they can adequately estimate a patient's limited life expectancy and that they tend to discuss patients' wishes if they have a poor prognosis. Information transfer concerning patients' wishes for treatment and care can be improved.

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Examining patient-reported barriers to talking about Advance Care Planning (ACP) with Family Physicians: a Multi-Site Survey

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Background: Advance care planning (ACP) can improve satisfaction with end-of-life care among patients and families and reduce unwanted treatments. Primary care is an ideal setting in which to facilitate ACP. This study

analyzed the reasons why patients find it difficult to discuss ACP with their family physicians.

Methods A self-completed, validated questionnaire about four ACP engagement behaviours and barriers was administered to patients aged 50 and older in 20 family practices in Canada. The questionnaire included an open-ended question about what makes it difficult to talk about ACP with the family physician. Four authors analysed the open-ended comments using thematic content analysis.

Results: 810 patients (mean age=66, 55.6% female) participated. Of the 53% (n=428) of patients who had talked to someone about end-of-life medical treatments, only 18% (n=75) had talked with their family physician. Patients identified the following barriers to ACP conversations: 1) They feel too young, healthy and well; 2) They abdicate responsibility to their physician; 3) They worry about a negative impact of ACP on the physician relationship; 4) Inadequate time during appointments; 5) They feel ACP is emotionally difficult to discuss with their physician.

Conclusions: Our findings suggest that patients need help preparing for ACP conversations, both to change the perception that ACP conversations only occur at the end-of-life and to normalize these discussions between patients and physicians. There is an opportunity for family physicians, who have longstanding relationships and frequent visits with patients, to have ACP conversations.