

Annotated Bibliography

Advance Care Planning: *Starting the Conversation*



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Ahluwalia SC, Levin JR, Lorenz KA, Gordon HS. (2012). Missed opportunities for advance care planning communication during outpatient clinic visits. *J Gen Intern Med.* 27(4):445-51

BACKGROUND: Early provider-patient communication about future care is critical for patients with heart failure (HF); however, advance care planning (ACP) discussions are often avoided or occur too late to usefully inform care over the course of the disease.

OBJECTIVE: To identify opportunities for physicians to engage in ACP discussions and to characterize physicians' responses to these opportunities.

DESIGN: Qualitative study of audio-recorded outpatient clinic visits.

PARTICIPANTS: Fifty-two patients \geq 65 years recently hospitalized for HF with one or more post-discharge follow-up outpatient visits, and their physicians (n = 44), at two Veterans Affairs Medical Centers.

APPROACH: Using content analysis methods, we analyzed and coded transcripts of outpatient follow-up visits for 1) patient statements pertaining to their future health or their future physical, psychosocial and spiritual/existential care needs, and 2) subsequent physician responses to patient statements, using an iterative consensus-based coding process.

RESULTS: In 13 of 71 consultations, patients expressed concerns, questions, and thoughts regarding their future care that gave providers opportunities to engage in an ACP discussion. The majority of these opportunities (84%) were missed by physicians. Instead, physicians responded by terminating the conversation, hedging their responses, denying the patient's expressed emotion, or inadequately acknowledging the sentiment underlying the patient's statement.

CONCLUSIONS: Physicians often missed the opportunity to engage in ACP despite openers patients provided that could have prompted such discussions. Communication training efforts should focus on helping physicians identify patient openers and providing a toolbox to encourage appropriate physician responses; in order to successfully leverage opportunities to engage in ACP discussions.

Azoulay E, Chaize M, & Kentish-Barnes N. (2014). Involvement of ICU families in decisions: fine-tuning the partnership. *Annals of Intensive Care*, 4:37

Families of patients are not simple visitors to the ICU. They have just been separated from a loved one, often someone they live with, either abruptly or, in nearly half the cases, because a chronic condition has suddenly worsened. They must cope with a serious illness of a loved one, while having to adapt to the unfamiliar and intimidating ICU environment. In many cases, the outcome of the critical illness is uncertain, a situation that causes considerable distress to the relatives. As shown by our research group and others, families exhibit symptoms of anxiety (70%) and depression (35%) in the first few days after admission, as well as symptoms of stress (33%) and difficulty understanding the information delivered by the healthcare staff (50%). Furthermore, relatives of patients who die in the ICU are at risk for psychiatric syndromes such as generalized anxiety, panic attacks, depression, and posttraumatic stress syndrome. In this setting of psychological distress, families are asked to consider sharing in healthcare decisions about their loved one in the ICU. This article aims to foster the debate about the shared decision-making process. We have three objectives: to transcend the overly simplistic position that opposes paternalism and autonomy, to build a view founded only on an evaluation of actual practice and experience in the field, and to keep the focus squarely on the patient. Families want information and communication time from the staff. Nurses and physicians need to understand that families can share in decisions only if the entire ICU staff actively promotes family involvement and, of course, if the family wants to participate in all or part of the decision-making process.

Barnato, AE, O'Malley JA, Skinner JS, Birkmeyer JD. (2019) Use of Advance Care Planning Billing Codes for Hospitalized Older Adults at High Risk of Dying: A National Observational Study. *J. Hosp. Med.* 4;229-231. doi:10.12788/jhm.3150

We analyzed advance care planning (ACP) billing for adults aged 65 years or above and who were managed by a large national physician practice that employs acute care providers in hospital medicine, emergency medicine and critical care between January 1, 2017 and March 31, 2017. Prompting hospitalists to answer the validated “surprise question” (SQ; “Would you be surprised if the patient died in the next year?”) for inpatient admissions served to prime hospitalists and triggered an icon next to the patient’s name. Among 113,621 hospital-based encounters, only 6,146 (5.4%) involved a billed ACP conversation: 8.3% among SQ-prompted who answered “no” and 4.1% SQ-prompted who answered “yes” (for non-SQ prompted cases, the fraction was 3.5%; $P < .0001$). ACP conversations were associated with a comfort-focused care trajectory. Low ACP rates among even those with high hospitalist-predicted mortality risk underscore the need for quality improvement interventions to increase hospital-based ACP.

Billings JA, Bernacki R. (2014). Strategic targeting of advance care planning interventions: the Goldilocks phenomenon. *JAMA Intern Med.* 174(4):620.

Strategically selecting patients for discussions and documentation about limiting life-sustaining treatments-choosing the right time along the end-of-life trajectory for such an intervention and identifying patients at high risk of facing end-of-life decisions-can have a profound impact on the value of advance care planning (ACP) efforts. Timing is important because the completion of an advance directive (AD) too far from or too close to the time of death can lead to end-of-life decisions that do not optimally reflect the patient’s values, goals, and preferences: a poorly chosen target patient population that is unlikely to need an AD in the near future may lead to patients making unrealistic, hypothetical choices, while assessing preferences in the emergency department or hospital in the face of a calamity is notoriously inadequate. Because much of the currently studied ACP efforts have led to a disappointingly small proportion of patients eventually benefitting from an AD, careful targeting of the intervention should also improve the efficacy of such projects. A key to optimal timing and strategic selection of target patients for an ACP program is prognostication, and we briefly highlight prognostication tools and studies that may point us toward high-value AD interventions.

Blomberg BA, Quintana C, Hua J, Hargis-Fuller L, Laux J, Drickamer MA. (2020). Enhancing Advance Care Planning Communication: An Interactive Workshop With Role-Play for Students and Primary Care Clinicians. *MedEdPORTAL.* 18;16:10973.

INTRODUCTION: Increased clinician training on advance care planning (ACP) is needed. Common barriers to ACP include perceived lack of confidence, skills, and knowledge necessary to engage in these discussions. Furthermore, many clinicians feel inadequately trained in prognostication. Evidence exists that multimodality curricula are effective in teaching ACP and can be simultaneously targeted to trainees and practicing clinicians with success.

METHODS: We developed a 3-hour workshop incorporating lecture, patient-oriented decision aids, prognostication tools, small-group discussion, and case-based role-play to communicate a values-based approach to ACP. Cases included discussion of care goals for a patient with severe chronic obstructive pulmonary disease and one with mild cognitive impairment. The workshop was delivered to fourth-year medical students, then adapted in two primary care clinics. In the clinics, we added an interprofessional case applying ACP to management of dental pain in advanced dementia. We evaluated the workshops using pre-post surveys.

RESULTS: Thirty-four medical students and 14 primary care providers participated. Self-reported knowledge and comfort regarding ACP significantly improved; attitudes toward ACP were strongly positive both before and after. The workshop was well received. On a 7-point Likert scale (1 = *unacceptable*, 7 = *outstanding*), the median overall rating was 6 (*excellent*).

DISCUSSION: We developed an ACP workshop applicable to students and primary clinicians and saw improvements in self-reported knowledge and comfort regarding ACP. Long-term effects were not studied. Participants found the role-play especially valuable. Modifications for primary care clinics focused on duration rather than content. Future directions include expanding the workshop's content.

Candrian, C, Hertz, SL, Matlock D, Flanagan L, Tate C, Kutner JS, Lum HD (2020). Development of a Community Advance Care Planning Guides Program and the RELATE Model of Communication, *Am J Hosp Palliat Care*, 37(1):5-11.

OBJECTIVE: Quality communication is an important aspect of advance care planning (ACP). This study evaluates a certification program that trains lay people in communication skills to support community-based ACP conversations.

METHODS: The program was developed with an emphasis on communication skills training. The testing of the program included ACP Guides and conversation partners, who were hospice volunteers, to assess the use of communication skills in ACP conversations. The evaluation used direct observations of conversations between trained ACP Guides and conversation partners as well as semi-structured interviews with those trained to become ACP Guides and those participating in the conversation.

RESULTS: Twenty-two ACP Guides participated in the testing phase with a retention rate of 100% completing all 4 sessions. The RELATE model of communication emerged during program development and testing. Evaluation of 15 ACP Guides having ACP conversations found that trained ACP Guides could use the RELATE model of communication to support ACP conversations.

CONCLUSION: A community-academic partnership developed an ACP Community Guides Program that trained individuals to have community-based ACP conversations. Next steps include additional testing of the program and RELATE in small numbers, especially among minority populations, to evaluate acceptability and usability of this approach.

PRACTICE IMPLICATIONS: Laypersons with concrete communication skills can facilitate effective peer-to-peer ACP conversations.

Chiu C, Feuz MA, McMahan RD, Miao Y, Sudore RL. (2016). "Doctor, Make My Decisions": Decision Control Preferences, Advance Care Planning, and Satisfaction With Communication Among Diverse Older Adults. *J Pain Symptom Manage*. 51(1):33-40.

CONTEXT: Culturally diverse older adults may prefer varying control over medical decisions. Decision control preferences (DCPs) may profoundly affect advance care planning (ACP) and communication.

OBJECTIVES: To determine the DCPs of diverse, older adults and whether DCPs are associated with participant characteristics, ACP, and communication satisfaction.

METHODS: A total of 146 participants were recruited from clinics and senior centers in San Francisco. We assessed DCPs using the control preferences scale: doctor makes all decisions (low), shares with doctor (medium), makes own decisions (high). We assessed associations between DCPs and demographics; prior advance directives; ability to make in-the-moment goals of care decisions; self-efficacy, readiness, and prior asked questions; and satisfaction with patient-doctor communication (on a five-point Likert scale), using Chi-square and Kruskal-Wallis analysis of variance.

RESULTS: Mean age was 71 ± 10 years, 53% were non-white, 47% completed an advance directive, and 70% made goals of care decisions. Of the sample, 18% had low DCPs, 33% medium, and 49% high. Older age was the only characteristic associated with DCPs (low: 75 ± 11 years, medium: 69 ± 10 years, high: 70 ± 9 years, $P = 0.003$). DCPs were not associated with ACP, in-the-moment decisions, or communication satisfaction. Readiness was the only question-asking behavior associated (low: 3.8 ± 1.2 , medium: 4.1 ± 1.2 , high: 4.3 ± 1.2 , $P = 0.05$).

CONCLUSION: Nearly one-fifth of diverse, older adults want doctors to make their medical decisions. Older age and lower readiness to ask questions were the only demographic variables significantly associated with low DCPs. Yet, older adults with low DCPs still engaged in ACP, asked questions, and reported communication satisfaction. Clinicians can encourage ACP and questions for all patients, but should assess DCPs to provide the desired amount of decision support.

Ganz FD (2019). Improving Family Intensive Care Unit Experiences at the End of Life: Barriers and Facilitators. *Crit Care Nurse*, 39(3):52-58.

Experiencing the end of life of a family member in the intensive care unit is clearly difficult. An important role of critical care nurses is to help family members through this challenging period. This article highlights a few clinically significant barriers and facilitators related to improving family experiences at the patient's end of life that have received less attention in the literature thus far. Facilitators include specific aspects of communication, the nurse's role as the coordinator of care, bereavement care, promoting a "good death," and caring for health care providers. Barriers include medical uncertainty and differences in values and culture.

Jack B et al. (2020). Exploring the impact on frontline staff of training in advance care planning. *Nursing Times* [online]; 116: 11, 27-31.

Timely advance care planning discussions and subsequent documentation are essential for optimal care. Studies have reported a lack of confidence and preparedness among frontline staff, resulting in potential delays. A study aimed to assess the impact of a one-day course on staff's perceptions of advance care planning in a range of settings. A survey was distributed following the course and the data analysed through descriptive statistics and thematic content analysis: 94% of staff felt their knowledge of advance care planning had increased and 95% felt more confident about undertaking it. Four themes were identified in qualitative responses awareness of advance care planning, confident communication, recording and documenting, and being an advance care planning advocate. This model of delivery has reached a large number of frontline staff across multiple settings and the findings have shown the value of this course and its potential impact on clinical practice.

Mehter HM, McCannon JB, Clark JA, Wiener RS. (2018). Physician Approaches to Conflict with Families Surrounding End-of-Life Decision-making in the Intensive Care Unit. A Qualitative Study. *Ann Am Thorac Soc*.15(2):241-249.

RATIONALE: Families of critically ill patients are often asked to make difficult decisions to pursue, withhold, or withdraw aggressive care or resuscitative measures, exercising "substituted judgment" from the imagined standpoint of the patient. Conflict may arise between intensive care unit (ICU) physicians and family members regarding the optimal course of care.

OBJECTIVES: To characterize how ICU physicians approach and manage conflict with surrogates regarding end-of-life decision-making.

METHODS: Semi-structured interviews were conducted with 18 critical care physicians from four academically affiliated hospitals. Interview transcripts were analyzed using methods of grounded theory.

RESULTS: Physicians described strategies for engaging families to resolve conflict about end-of-life decision-making and tending to families' emotional health. Physicians commonly began by gauging family receptiveness to recommendations from the healthcare team. When faced with resistance to recommendations for less aggressive care, approaches ranged from deference to family wishes to various persuasive strategies designed to change families' minds, and some of those strategies may be counterproductive or harmful. The likelihood of deferring to family in the event of conflict was associated with the perceived sincerity of the family's "substituted judgment" and the ability to control patient pain and suffering. Physicians reported concern for

the family's emotional needs and made efforts to alleviate the burden on families by assuming decision-making responsibility and expressing nonabandonment and commitment to the patient. Physicians were attentive to repairing damage to their relationship with the family in the aftermath of conflict. Finally, physicians described their own emotional responses to conflict, ranging from frustration and anxiety to satisfaction with successful resolution of conflict.

CONCLUSIONS: Critical care physicians described a complex and multilayered approach to physician-family conflict. The reported strategies offer insight into pragmatic approaches to achieving resolution of conflict while attending to both family and physician emotional impact, and they also highlight some potentially unhelpful or harmful behaviors that should be avoided. Further research is needed to evaluate how these strategies are perceived by families and other ICU clinicians and how they affect patient, family, and clinician outcomes.

Moore CD, Reynolds AM. (2013). Clinical update: communication issues and advance care planning. *Semin Oncol Nurs.* 29(4):e1-e12

OBJECTIVES: To provide a clinical update on practical strategies to enhance the quality of communication in the palliative and end-of-life medical care settings.

DATA SOURCES: Published articles, textbooks, reports, and clinical experience.

CONCLUSION: The components of effective and compassionate care throughout the advanced illness trajectory require thoughtful and strategic communication with patients, families, and members of the health care team. Unfortunately, few health care professionals are formally trained in communication skills.

IMPLICATIONS FOR NURSING PRACTICE: Nurses who possess self-awareness and are skilled in effective communication practices are integral to the provision of high-quality palliative care for patients and families coping with advanced malignancies.

Peck V, Valiani S, Tanuseputro P, Mulpuru S, Kyeremanteng K, Fitzgibbon E, Forster A, Kobewka D. (2018). Advance care planning after hospital discharge: qualitative analysis of facilitators and barriers from patient interviews. *BMC Palliat Care.* 17(1):127.

BACKGROUND: Patients who engage in Advance Care Planning (ACP) are more likely to get care consistent with their values. We sought to determine the barriers and facilitators to ACP engagement after discharge from hospital.

METHODS: Prior to discharge from hospital eligible patients received a standardized conversation about prognosis and ACP. Each patient was given an ACP workbook and asked to complete it over the following four weeks. We included frail elderly patients with a high risk of death admitted to general internal medicine wards at a tertiary care academic teaching hospital. Four weeks after discharge we conducted semi-structured interviews with patients. Interviews were transcribed, coded and analysed with thematic analysis. Themes were categorized according to the theoretical domains framework.

RESULTS: We performed 17 interviews. All Theoretical Domain Framework components except for Social/Professional Identity and Behavioral Regulation were identified in our data. Poor knowledge about ACP and physician communication skills were barriers partially addressed by our intervention. Some patients found it difficult to discuss ACP during an acute illness. For others acute illness made ACP discussions more relevant. Uncertainty about future health motivated some participants to engage in ACP while others found that ACP discussions prevented them from living in the moment and stripped them of hope that better days were ahead.

CONCLUSIONS: For some patients acute illness resulting in admission to hospital can be an opportunity to engage in ACP conversations but for others ACP discussions are antithetical to the goals of hospital care.

Sinha S, Gruber RN, Cottingham AH, Nation B, Lane KA, Bo N, Torke A. (2019). Advance Care Planning in A Preoperative Clinic: A Retrospective Chart Review. *J Gen Intern Med*;34(4):523-525.

Patients seen in preoperative testing clinics are at an increased risk of surgical complications and most are incapacitated for during anesthesia. Advance directives (ADs) are important to guide care in the event of emergencies when patients are unable to speak for themselves. The goal of this study was to determine the frequency with which ADs are completed for patients seen in preoperative clinics prior to elective surgery and identify demographic and clinical characteristics associated with having ADs available in the electronic medical record (EMR). Our findings suggest that there is a significant opportunity for improvement in ACP in this clinical setting. Future research should focus on processes to make ACP more available to high-risk patient populations.

Toguri JT, Grant-Nunn L, Urquhart R. (2020). Views of advanced cancer patients, families, and oncologists on initiating and engaging in advance care planning: a qualitative study. *BMC Palliat Care*. 19(1):150.

BACKGROUND: Advance care planning (ACP) is a process by which patients reflect upon their goals, values and beliefs to allow them to make decisions about their future medical treatment that align with their goals and values, improving patient-centered care. Despite this, ACP is underutilized and is reported as one of the most difficult processes of oncology. We sought to: 1) explore patients' and families' understanding, experience and reflections on ACP, as well as what they need from their physicians during the process; 2) explore physicians' views of ACP, including their experiences with initiating ACP and views on ACP training.

METHODS: This was a qualitative descriptive study in Nova Scotia, Canada with oncologists, advanced cancer out-patients and their family members. Semi-structured interviews with advanced cancer out-patients and their family members (n = 4 patients, 4 family members) and oncologists (n = 10) were conducted; each participant was recruited separately. Data were analyzed using constant comparative analysis, which entailed coding, categorizing, and identifying themes recurrent across the datasets.

RESULTS: Themes were identified from the patient / family and oncologist groups, four and five respectively. Themes from patients / families included: 1) positive attitudes towards ACP; 2) healthcare professionals (HCPs) lack an understanding of patients' and families' informational needs during the ACP process; 3) limited access to services and supports; and 4) poor communication between HCPs. Themes from oncologists included: 1) initiation of ACP discussions; 2) navigating patient-family dynamics; 3) limited formal training in ACP; 4) ACP requires a team approach; and 5) lack of coordinated systems hinders ACP.

CONCLUSIONS: Stakeholders believe ACP for advanced cancer patients is important. Patients and families desire earlier and more in-depth discussion of ACP, additional services and supports, and improved communication between their HCPs. In the absence of formal training or guidance, oncologists have used clinical acumen to initiate ACP and a collaborative healthcare team approach.

Volandes A (2015). *The Conversation: A Revolutionary Plan for End-of-Life Care*. Bloomsbury USA; 1st edition (January 13, 2015)

There is an unspoken dark side of American medicine--keeping patients alive at any price. Two thirds of Americans die in healthcare institutions, tethered to machines and tubes at bankrupting costs, even though research shows that most prefer to die at home in comfort, surrounded by loved ones. Through the stories of seven patients and seven very different end-of-life experiences, the author demonstrates that what people with a serious illness, who are approaching the end of their lives, need most is not new technologies but one simple thing: The Conversation. He argues for a radical re-envisioning of the patient-doctor relationship and

offers ways for patients and their families to talk about this difficult issue to ensure that patients will be at the center and in charge of their medical care.

Website Resources:

CDC Advance Care Planning – Selected Resources for the Public

<https://www.cdc.gov/aging/pdf/acp-resources-public.pdf>

AMA How to talk to patient about advance directives <https://www.ama-assn.org/delivering-care/patient-support-advocacy/advance-directives-how-talk-patients-about-them>

National Healthcare Decisions Day – Advance Care Planning Resources

<http://www.nhdd.org/public-resources#where-can-i-get-an-advance-directive>

AARP Listing by state to find free advance directive forms and instructions

<https://www.aarp.org/caregiving/financial-legal/free-printable-advance-directives/>

<https://getpalliativecare.org/>