

EFFICACY OF NURSE-LED ADVANCE CARE PLANNING IN PATIENTS WITH
CHRONIC DISEASES: A SYSTEMATIC REVIEW

by

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Abstract

Advance care planning (ACP) allows patients to discuss and negotiate their preferences for the future including clinical management at the end of life. Over the past few decades, despite multiple large-scale educational and legal efforts to promote engagement in advance care planning and completion of advance directives, over 60 percent of Americans have not completed advance directives (AD). Vulnerable populations such as elderly individuals and patients with chronic diseases are in particular need of ACP. Even though AD completion rates have increased, there is more work to be done. Barriers to advance care planning cited by studies include unwillingness by patients to engage in ACP and overestimation of prognosis (Hole and Salem, 2016). Physician-related barriers include limited time and poor ACP documentation (Bergenholtz et al. 2019). To address the gaps in ACP, research has examined the impact of non-physician members of the health care team on ACP engagement. The purpose of this systematic review was to evaluate the effectiveness of nurse-led advance care planning and engagement in EOL discussions on advance directive participation rates among adult patients with chronic diseases. Four final studies were included in this systematic review utilizing PRISMA guidelines and CASP tool for to ensure study integrity. Results of this review demonstrate the benefits of nurse involvement in ACP. The ACP process is multi-factorial with many aspects in which nurses can have impact. Implications of this study include the importance for APRNs to identify where nurses can be involved in the ACP process to improve AD completion rates and documentation. APRNs can be at the forefront in improving education and training in ACP and can become more involve in policies that support improved ACP.

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Efficacy of Nurse-led Advance Care Planning among Patients with Chronic Diseases: A Systematic Review

Background/Statement of the Problem

The Centers for Disease Control and Prevention (CDC) recognizes the public health opportunity to educate Americans, and especially older adults, about advance care planning (ACP) and to improve their quality of care at the end of life. Planning for the end of life is increasingly being viewed as a public health issue, given its potential to prevent unnecessary suffering and to support an individual's decisions and preferences related to the end of life (CDC, 2018). There have been multiple large-scale educational and legal efforts to promote the completion of advance directives over the past few decades, for example, Medicare's decision to reimburse physicians for advance care planning counseling, effective since January 1, 2016, (CDC, 2020). Despite the previously mentioned initiatives to improve advance care planning there is still a deficiency in completing ACP.

A systematic review done by Yadav et al. (2017) illustrates where the insufficiencies are in terms of ACP. The authors conducted a systematic review that examined 150 articles published on advance directive completion at the patient level within the US between January 1, 2011, and December 31, 2016. The findings suggest that the prevalence of advance directives among patients has almost doubled from 21 percent to 38 percent. While this increase is significant, the study results suggest that most Americans remain without a completed advance directive even after thirty years of legislative and research initiatives. The study also showed that while vulnerable populations (people in nursing homes or hospice, older adults, those with dementia and

other neurologic diseases, and other chronic diseases) do appear to have comparatively high advance directive completion rates, approximately half of the members of these populations are still without any such directive. Another finding of the review is a lack of evidence supporting advance directive completion among other vulnerable patient populations (Yadav et al., 2017).

Barriers to addressing advanced care planning have been studied thoroughly. The Institute of Medicine's *Dying in America* (Institute of Medicine, 2015) highlighted that the reluctance to engage in advance care planning sometimes originates in patients' sense that the initiative to do so should come from clinicians, hence the importance of providers bringing up ACP with their patients who may be fearful of discussing the topic with family or be waiting for someone else to initiate discussion. Also, people often do not realize they have a terminal disease, what that disease is, or that they are dying. Patients with chronic diseases may have unrealistically optimistic expectations of their prognosis. A systematic review by Hole and Salem (2016) noted that among patients with heart failure, the median self-estimated life expectancy was 40% longer than predicted by a validated model. Outpatients receiving hemodialysis were more optimistic about prognosis than their nephrologists and overestimated their chances of surviving 5 years. Patients with heart failure and COPD were approximately three times more likely to die in the next year than they predicted. Hence the need for health care providers to take the lead to begin the ACP conversation with patients.

The dependence of patients on someone else within their healthcare team to initiate conversations to facilitate ACP has been met with some difficulty from clinicians. Clinicians have cited barriers to appropriately discussing ACP with patients, such as

limited time and inappropriate documentation of ACP as described in an article by Bergenholtz et al. (2019). The qualitative study was done in Denmark to identify barriers to addressing end-of-life (EOL) discussions. A multidisciplinary approach to conversations and appropriate ACP can possibly address these issues. Nurses can actively engage in these activities with patients, as they are more accessible and usually encounter these patients more frequently than providers in any care setting.

A systematic review by Blackwood et al. (2019) has shown that nurses are receptive to being educated on end-of-life conversations and ACP. Nurses greatly appreciate the need for appropriate ACP and have reported an increase in knowledge and confidence after receiving training. Nurses have become more instrumental in recommending to providers the need to initiate end-of-life and ACP conversations.

Researchers have also suggested that non-providers can appropriately be trained to engage in EOL discussions and advanced care planning. Arnett et al. (2016) did a state-wide online survey of interprofessional health care team members to understand current system supports for ACP, including clinical routines, workflow processes, and policies relating to ACP in Colorado clinical settings. They found that two-thirds of respondents agreed that members of the interprofessional team other than physicians can provide advance care planning, with appropriate training. However, there is a lack of evidence that nurses can successfully engage in end-of-life discussions and advance care planning and can effectively help to promote an increase in advance care planning. Therefore, the purpose of this systematic review is to answer the question: does nurse-led advance care planning and engagement in end-of-life discussions improve advance directive completion rate among adult patients with chronic diseases?

Literature Review

Historical Perspectives on Advance Care Planning

Challenges to end-of-life treatment options have long been the focus of debate among providers, policymakers, and the public. In past times, decisions on end-of-life care were based on professional authority under the assumption that physicians acted in the patients' best interest. With advancements in medical technology, came the need to investigate the ethical appropriateness of life-sustaining treatments. Individuals and families, in the context of the consumer rights movement, pursued to reduce the use of life-sustaining treatments under certain circumstances where life prolongation was deemed to be ethically unjustifiable. The first attempt to refine end-of-life care was with the living will introduced by the California Natural Death Act of 1976. Living wills are personal statements indicating that the declarant does not wish to have life-sustaining treatment if he or she is in a terminal condition with no hope of recovery (CDC, 2018).

Well-publicized legal cases in the 1970s and 1980s focused the public's attention on withdrawing life-sustaining treatments from individuals who had lost decision-making capacity. Two cases involving young women, Karen Ann Quinlan and Nancy Cruzan, challenged the laws regarding end-of-life decisions. These and other cases, as well as legislation at the state level, gave rise to a legal model of advance care planning that focused on legal or procedural protections of vulnerable individuals (U.S. Department of Health and Human Services, 2008).

Despite the increase in states with laws supporting living wills in the 1980s, there was still a need to place limitations on life-sustaining medical procedures to better protect individuals' rights and wishes. The Patient Self-Determination Act was enacted by

Congress in 1990 to encourage competent adults to complete advance directives. The Act required all health care facilities receiving Medicare or Medicaid reimbursement to ask patients whether they have advance directives, to provide information about advance directives, and to incorporate advance directives into the medical record (Health and Human Services, 2008).

The Impact of ACP on patients

A panel of multidisciplinary, international ACP experts consisting of 52 clinicians, researchers, and policy leaders from four countries and a patient/surrogate advisory committee sought to develop a consensus definition for ACP for adults to better guide clinical, research, and policy initiatives. The definition agreed upon was, “ACP is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences for future medical care”. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals, and preferences (Sudore et al., 2017).

The evidence that ACP positively impacts the quality of end-of-life care in a way that is aligned with the definition above-mentioned is substantial. ACP has been associated with the mitigation of aggressiveness of medical care at the end-of-life. Brinkman-Stopplenberg et al. (2014) systematically reviewed 113 studies, most of which originated from the United States (81%) and were performed in hospitals (49%) or nursing homes (32%). Do-not-resuscitate orders (39%) and written advance directives (34%) were most often studied. ACP was often found to decrease life-sustaining treatment, increase the use of hospice and palliative care, and prevent hospitalization. The review also found that more complex ACP interventions (e.g., those that included other

components in addition to completing ADs) were found to have greater benefits compared with usual care. These included increased compliance with patients' end-of-life wishes, a decrease in subsequent hospitalization, a decrease in in-hospital deaths and intensive care unit deaths, and an increase in in-home deaths.

Nursing home residents are typically older and frail, and thus vulnerable to becoming victims of traumatic heroic efforts to prolong life. One study showed the deleterious effects of hospitalization on nursing home residents with pneumonia. A retrospective cohort study by Griffith et al. (2020) looked at Medicare enrollees aged greater than 65 years old who were hospitalized in a nursing home in the United States from 2013 and 2014 with pneumonia. The authors found that among the members of the cohort, 79,558 (37.1%) died during or within 60 days of hospitalization and 113,228 (52.8%) had severe disability following admission, for a total of 192,736 (89.9%) with the primary composite outcome. Among patients without severe disability prior to hospitalization (<4 activities of daily living (ADL) limitations, n = 46,702), 66.3% (n = 30,982) experienced the primary outcome of severe disability or death. Most patients with no prehospitalization ADL limitations (52.5%) experienced the composite outcome, as did most patients with all levels of prehospitalization functional limitations. Among patients with severe disability prior to hospitalization, 96.4% (n = 161,754) experienced the primary outcome and 39.3% (n = 66,014) of these patients died during or within 60 days of hospitalization. The study looked at nursing home residents who were treated in the hospital for pneumonia, nursing home residents who were treated in their facilities were not included in this study. Therefore, a comparison of survival benefits cannot be made in this study, however, this study highlights the need for advance care planning.

Chronic Diseases

The burden of chronic diseases on health and health care has garnered awareness as government agencies such as the CDC publish statistics showing the impact on mortality in the U.S. The CDC cites those chronic conditions are responsible for most of the deaths in the country, with heart disease and stroke accounting for one-third of the deaths alone (CDC, 2021). Chronic diseases are defined broadly as conditions that last one year or more and require ongoing medical attention or limit activities of daily living or both. The CDC list of conditions that fall into that group are heart disease, cancer, chronic lung disease, stroke, chronic kidney disease, Alzheimer's disease, and diabetes. In terms of economic costs, 90 % of the nation's 3.8 trillion in health care expenditures are for people with chronic physical and mental health conditions (CDC, 2021). This number should correlate with a significant number of people living with a chronic disease which is true as the CDC states that 6 out of 10 adults in the US have a chronic disease and 4 in 10 adults have 2 or more. Hence, on a national level, the burden is substantial, and from the CDC's definition of chronic disease alone, there is an intuitive understanding that on a personal level the disease(s) is/are quite burdensome.

The Institute of Medicine (IOM) report, *Living well with chronic illness: A call for public health action*, (2012), highlights the consequences of chronic illness and depicts a myriad of factors that include physical, mental, and social consequences that affect patients and their family members, friends, and caregivers. The report indicated that illnesses tend to cluster among older adults, with 43% having 3 or more illnesses and 23% having more than 5, thereby increasing the degree of disability and the dependence on healthcare. Maresova et al. (2019) published a systematic review to identify and

summarize conditions leading to ADL dependency in relation to chronic disease, with a detailed examination of the 21 articles included. The systematic review confirmed that chronic disease is the main cause of disability, going on to state that chronic diseases contribute more to the prevalence of severe disability, with impairment of basic activities of daily living. Elderly patients with a diagnosis of arthritis, stroke, or diabetes could be monitored more effectively by considering the impact of these conditions on abilities (Maresova et al., 2019). Disabilities due to the burden of chronic diseases may have a negative impact on quality of life.

Patients may live for years with multiple illnesses, rather than dying suddenly, patients with chronic disease often experience a gradual decline in health punctuated by exacerbations of disease. There is no cure for chronic diseases and over time conditions worsen and compensatory mechanisms begin to weaken leading to intensification of burden and serious illness. Patients with chronic diseases will ultimately find themselves in the realm of serious illness in the final stage of their lives, a stage that is full of complexities and uncertainties. A systematic review by May et al. (2016) was done to summarize and synthesize published qualitative studies to characterize factors that shape patient and caregiver experiences of chronic heart failure, chronic obstructive pulmonary disease (COPD), and chronic kidney disease. The authors identify that as patients with chronic disease approach the final stages they are further burdened by factors leading to pathophysiological deterioration which limits their ability to participate independently in self-management and healthcare processes.

Consequently, individuals experience new dependencies on health services and new demands on informal networks that provide care and social support. All these factors

must be balanced against the wider demands of everyday life (May et al., 2016). The systematic review looked at 53 qualitative and mixed methods studies that included patient populations diagnosed with chronic heart failure, chronic kidney disease, or chronic obstructive pulmonary disease, and formal or informal caregivers and health professionals in healthcare settings. The authors identified the significant burdens of the patient population and their caregivers, the burden of symptoms that are inevitable and lead to lethal acute episodes of disease. Also, the burden of treatment includes moral responsibilities, affective and cognitive demands, increased workload, and economic consequences of participation in self-management and formal healthcare (May et al., 2016).

May et al., 2016 found that there were key factors that further limit patients, caregivers, and health care services to adapt to the ever-changing situations surrounding disease progression. One factor is a patient deficit rooted in poor understanding and non-adherence to treatment regimens and expressed through a lack of motivation to participate. Second, there is a professional deficit rooted in poor communication and coordination and expressed in a reluctance to engage in end-of-life planning. These are significant burdens that further limit the capacity of patients to make sense of their illness and its effects and according to the authors of the study, these domains can be good targets for new interventions that respond to the combined disadvantages that they may face.

The inherent limitation of qualitative reviews was discussed by the authors and their efforts to mitigate this limitation. They cited the difficulty identifying sets of ideas about individual patient experiences and behaviors from different reviews that might

explain variations in assumptions and perspectives (May et al., 2016). The authors utilized an analytic approach to synthesize sets of attributions to help detect underlying conventional assumptions. Despite this limitation, the study presented valuable insights into the interactions of factors that further increase uncertainties and complexities in the management of patients with advanced chronic diseases and their caregivers against the backdrop of the health care system.

Conversations with Patients with Chronic Diseases

As discussed in the previously mentioned study, patients with chronic diseases often find it difficult to make sense of their illness and its effects. Mishel's theory of uncertainty in illness was at first introduced as a middle-range theory to explain how uncertainty affects the psychological adjustment to the cancer experience and was later expanded to include chronic illness. Mishel argues that disease complexity, poor information provision, and the unpredictability or ambiguity of events interfere with a patient's ability to confer meaning, thereby increasing uncertainty (Mishel, 1988). Using this theory as a conceptual framework, Etkind et al. (2016), authored a secondary analysis of in-depth qualitative interview data from studies that included patients with a range of advanced illnesses. The interviews were from six studies of patients with heart failure, COPD, motor neuron disease, renal disease, liver disease, metastatic cancer, and patients in intensive care.

One major theme identified in the study was the role of communication in line with Mishel's observation that lack of information was one key contributor to uncertainty. One recommendation of the authors of this study was that further research is warranted into evidenced-based typology to structure discussions with patients so that

information and support are tailored to patients' priorities. By providing patients with appropriate levels of information, involving them in decision-making according to their level of engagement, and discussing present and/or future care according to the individual's temporal focus, clinicians may be able to better individualize the care of patients with an uncertain prognosis (Etkind et al., 2016).

Improving communication between clinician and patient has been a long-standing goal that involves many challenges and complexities. Discussing goals of care with chronic disease-affected patients offers the opportunity for individuals to identify their life and care goals and for clinicians and patients to jointly promote goal attainment.

Provider Perceptions on Goals of Care Conversations and ACP

Early conversations between clinicians and patients about goals of care may improve a patient's quality of life and prevent non-beneficial care near the end-of-life, but these conversations are limited in frequency and scope (IOM, 2015). These conversations are challenging especially in the United States where there are many cultural and religious beliefs. A mixed methods study by Periyakoil et al. (2015), was designed to empirically identify barriers faced by doctors conducting effective EOL conversations with diverse patient groups and to determine if the doctor's age, gender, ethnicity, and medical subspecialty influenced the barriers reported. The study consisted of multi-specialty doctors who care for seriously ill patients in two large teaching hospitals in California (Stanford Hospital and Clinics and the VA Palo Alto). Of the 1234 eligible participants, 1040 participated (84.3% response rate). The participating doctors were given a questionnaire that asked questions: Have you encountered any barriers to conducting effective EOL conversations with seriously ill patients and families? If yes, to

what extent conducting effectual EOL conversations with patients and families who belong to a different cultural/ethnic background was challenging. Please list the top three barriers (if any) that you have faced in conducting effective EOL conversations including those with patients and families who belong to an ethnic/racial group different from your own (Periyakoil et al., 2015).

Results of the study showed over 99% of doctors reported barriers and 85.7%, found it very difficult to conduct end-of-life conversations with all patients and especially so with patients whose ethnicity differed from their own. Asian-American doctors reported the most difficulty conducting end-of-life conversations with their patients at 91.3%, followed by African Americans (85.3%), Caucasians (83.5%) and Hispanic Americans (79.3%). The biggest doctor-reported barriers to effective EOL conversations are (1) language and medical interpretation issues, (2) patient/family religious-spiritual beliefs about death and dying, (3) doctors' ignorance of patients' cultural beliefs, values, and practices, (4) patient/family's cultural differences in truth handling and decision making, (5) patients' limited health literacy and (6) patients' mistrust of doctors, and the health care system. This study highlights the many different patient factors that need to be considered when approaching patients with end-of-life/goals of care conversations. There is an urgent need to train doctors to conduct culturally competent end-of-life conversations early in the trajectory of any chronic and serious illness to promote goal-accordant care.

Another study examined the challenges experienced by different levels of providers, such as medical doctors, physician assistants, and nurse practitioners. In a study conducted at Massachusetts General Hospital, Ganguli et al. (2016) utilized a

survey to assess the level of clinician engagement in end-of-life conversations, comfort level with making recommendations for resuscitation, and use and perception of the Massachusetts medical orders for life-sustaining treatment (MOLST) form. Forty-four percent of physicians and 33.0% of advance practitioners [AP] (nurse practitioners and assistant physicians) reported they discussed goals of care with all patients with serious illness. Fifty-one percent of physicians and 32.1% of APs reported that they offered prognostic information “all of the time” to patients/families who wanted to hear it. Physicians and APs were more likely to feel comfortable recommending resuscitation if they felt resuscitation would be helpful to the patient (55.7% of physicians and 35.1% of APs strongly agreed) than recommending against it if they felt it would not be (41.0% of physicians and 25.3% of APs strongly agreed). Forty-five percent of physicians and 55.1% of APs reported that they were aware of the MOLST form, 22.9% of physicians and 24.7% of APs reported that they or their team filled out such a form at least once in the previous 12 months. The most frequently reported barriers to using the form among physicians and APs included deeming MOLST as not applicable to their patients (55.3% and 50.0% respectively), lack of awareness (25.4% and 25.9%), lack of time (13.0% and 6.0%), and patient/family unwillingness to discuss the topic (12.6% and 16.7%). APs also reported that it was challenging for them to raise the issue (Ganguli et al., 2016).

A common theme in these studies is the need for more provider training in end-of-life/goals of care conversations and more time and space to meet the unique challenges that each patient and provider experiences. A study by Curtis et al. (2018) demonstrated the benefits of addressing patient-and provider-specific hurdles. The authors conducted a cluster-randomized trial of providers (n = 132) recruited from two large health systems in

the Pacific northwest and adult patients within those two health systems who had two or more visits with a clinician in the last 18 months and had one or more life-limiting chronic illness (n = 537). Clinicians were randomized to the bilateral, pre-conversation, communication-priming intervention (n = 65) or usual care (n = 67), with 249 patients assigned to the intervention and 288 to usual care. The intervention consisted of a survey designed to identify individual preferences, barriers, and facilitators for communication about end-of-life care completed by patients in the intervention arm. The completed surveys were then sent to clinicians by email or fax one or two working days prior to the patient's target clinic visit. The objective of this intervention was to prime clinicians and patients for a brief discussion of goals of care during a routine clinic visit. The results of this study demonstrated that the intervention was associated with increased occurrence and quality of goals of care discussions at the clinic visit. Occurrence of such discussions was more likely in the intervention group among all patients (74%, n = 137 vs 31%, n = 66; $P < .001$) and among the subset of patients who did not explicitly report that they wanted to avoid such a discussion (78%, n = 112 vs 28%, n = 44; $P < .001$). Participating clinicians' electronic health record documentation of goals of care discussion was also higher for the intervention group among all patients (62%, n = 140 vs 17%, n = 45; $P < .001$), with similar findings for patients who did not explicitly report a desire to avoid discussion (63%, n = 114 vs 17%, n = 34; $P < .001$). Quality ratings of goals of care discussions at the target visit were higher in the intervention group than in the control group (Curtis et al., 2018).

As successful as this study was in encouraging patient-specific goals of care conversations, there were important limitations in the selection bias of patients and

providers who were accessible and willing to participate. To gain the benefits of this intervention institutions would need to incorporate a multidisciplinary team that will ensure patients will have equal access to surveys. One key lesson that can be drawn from this study is the importance of getting to know a patient's preferences and beliefs and a stepwise approach to goals of care conversations.

Nurses' Role in Goals of Care Conversations and ACP

It can be inferred from the previously discussed studies that providers often are unprepared for (or uncomfortable) having difficult, ongoing conversations with patients about their care preferences and healthcare goals. Nurses hold a special relationship with patients as they spend more time with and know patients on a more personal level. An Australian study by Fan & Rhee (2015) looked at nurses' confidence and motivational levels initiating goals of care discussion and ACP via a cross-sectional online survey. Nurses were recruited through nursing organizations and local Medicare offices. One-hundred, forty-seven, mostly female registered nurse participants completed surveys, with a median of 50 and 60 years of age. The authors found that nurses were generally positive toward their involvement in ACP and believed it would be beneficial for the community. Their confidence in facilitating ACP increased as their familiarity with patients increased. They exhibited a high level of interest in taking part in training and education in ACP. Barriers to their involvement in ACP included the lack of a good documentation system and limited patient-education resources.

Ora et al. (2019) conducted an integrative review that focused on articles published between 2008 and 2018 that studied nurse-led models and outcomes related to palliative care in chronic obstructive pulmonary disease. The integrative review looked at

four randomized controlled trials and two qualitative studies that described nurse-led models that introduced palliative care practices to patients with chronic obstructive pulmonary disease. The authors found that ACP was found to be the most common focus for nurse-led interventions in chronic obstructive pulmonary disease, and results demonstrated an improvement in end-of-life discussions and completion of advance care directives.

Lally et al. (2020) utilized a quality improvement framework to increase the number of serious illness conversations occurring in an accountable care organization using a script delivered telephonically by nurse care managers. The script was a modified version of the Serious Illness Conversation Guide. The landmark Serious Illness Conversation Guide serves as a framework for physicians, nurses, social workers, chaplains, allied health professionals, and other clinicians to explore topics that are critical to gaining a full understanding of and honoring what is most important to patients. The guide has been used in many health care institutions across the country. It was first developed by Bernacki et al, 2015 at the Dana Farber Institute. Questions from the script related to individual goals of care were embedded in the EMR system and nurse care managers were prompted to ask these questions every three months to monitor the progression of the goals of care conversations. During the first month of this project, 33% of the study population had documented conversations utilizing the guide. By the final month, that rate had increased to 86% (Lally et al., 2020). The study supports evidence that nurses can be valuable members of the multidisciplinary team providing patients with timely and meaningful goals of care discussions and ACP.

Patients with chronic disease trajectories are similar. There are no cures and chronic diseases often lead to serious illnesses which can become burdensome for patients and caregivers. End-of-life care can be better managed, by establishing the priority of the patient's right to autonomy and the values most important to an individual. There are many barriers to appropriate goals of care discussions and facilitating patients' right to autonomy. Incorporating nurses in the advance care planning process by taking advantage of the nurse-patient relationship, can aid in lowering the barriers to appropriate advance care planning. The purpose of this systematic review was to evaluate the effectiveness of nurse-led advance care planning and engagement in EOL discussions on advance directive participation rates among adult patients with chronic diseases.

Theoretical Framework

An Advance Directive Decision-Making Model adapted from Imogene King's Theory of Goal Attainment was used to guide the systematic review. King's theory deals with a nurse-client relationship in which each person brings their own perceptions of self, role, and personal levels of growth and development. The nurse and client communicate, first in interaction and then in transaction, to gain mutually set goals. The assumptions are: (1) Perceptions of the nurse and client influence the interaction process; (2) goals, needs, and values of the nurse and client influence the interaction process; (3) individuals have a right to knowledge about themselves; (4) individuals have a right to participate in decisions that influenced their lives, health, and community services; (5) individuals have a right to accept or reject care; and (6) goals of health professionals and goals of recipients of health care may not be congruent (King, 1981).

King's (1981) theory of goal attainment is composed of an intermingling of a three systems concept, the interrelationship of the personal (individual), interpersonal (group), and social (society) systems. The personal system contains the individual components of perception, self, body image, growth and development, space, and time. The interpersonal system is composed of interaction, communication, transaction, role, and coping. The social system as containing the components of organization, authority, power, status, and decision making. This system incorporates all four domains of nursing, the person/client, environment, health, and nursing. It incorporates 10 components extracted from the personal and the interpersonal systems: perception, growth and development, self, space, time, interaction, communication, transaction, role, and coping.

Goodwin et al. (2002) adapted the theory to develop the advance directive decision-making (ADDM) model, Figure 1). Perception is holistic, more than a sum of its parts, with both the registered nurse/Nurse Practitioner (RN/NP) and the client autonomous with rights of self-determination. Both must first determine to enter the interaction: The RN/NP must perceive when education is appropriate and sufficient; the client must determine what decision (if any) to make, when to make the decision, and to whom to make it known. The interpersonal system contributes two concepts to the process, interaction, and role. Interaction is two-way communication with nonverbal cues considered and confidentiality maintained. This interaction is accomplished by the complicated process of communication and is not only the exchange of information but also the processing of this information (King, 1981). Both the nurse and the client bring individual perceptions as they interact verbally and nonverbally. The initial goals of the RN/NP are to determine the client's level of advance directive knowledge, to add any essential information, and potentially to advocate for the informed choices the client has selected, when the need arises. The client will then make the decision to either act or inaction, either action will support the right to self-determination.

Roles are assumed by both the RN/NP and the client. The nurse assumes the role of facilitator—not an enforcer or an evaluator. The client is in the role of mutual partner for goal attainment—not in a sick role. This client role is one of active participation. The social system contributes three additional concepts: power, status, and decision-making. Power is recognized as client-controlled and directed—utilizing the knowledge, skill, and expertise of the RN/NP to support the client. Status is recognized as the ability and authority to make decisions. The RN/ NP is stratified as competent, assistive, and

knowledgeable. Decision-making is a process in which the client selects one action from alternatives. Decision-making is also active from the RN/NP's vantage as deciding if education is appropriate [time], effective [cognitive], and sufficient [adequate] (Goodwin et al., 2002).

The model (Goodwin et al., 2002) gives a good outline for what to expect in an advance care planning discussion between nurse and patient. Successful advance care planning facilitated by the nurse is wholly dependent on the training received by the nurse. Appropriate advance care planning training for the nurse should reflect these elements. Within this systematic review, the studies selected will be critiqued for the appropriateness of training, which would be guided by this model.

Figure 1

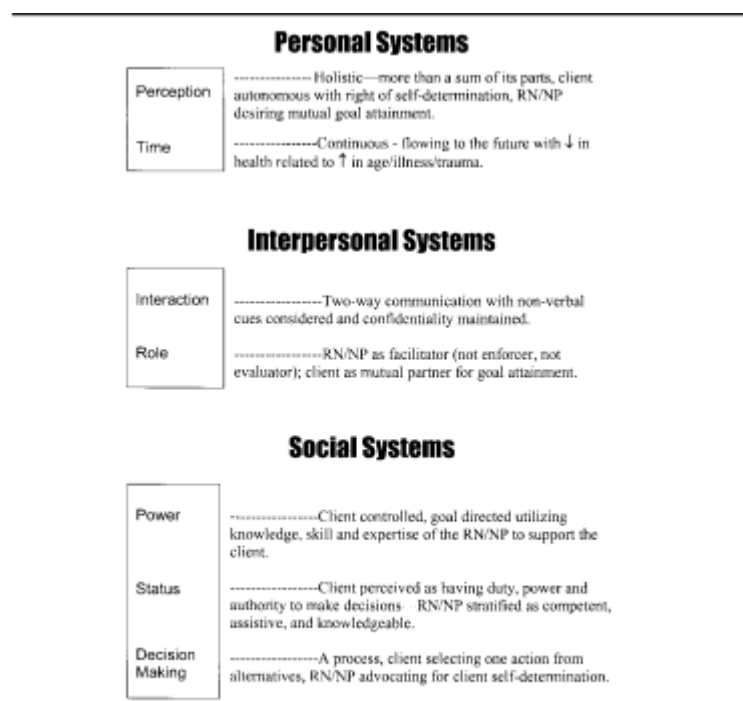


Figure 4. Seven Components of the Advance Directive Decision-Making Model
NOTE: RN = registered nurse; NP = nurse practitioner.

Method

Purpose

The purpose of this systematic review was to evaluate the effectiveness of nurse-led advance care planning and engagement in EOL discussions on advance directive participation rates among adult patients with chronic diseases. The research question guiding this review was: Does nurse-led advance care planning and engagement in end-of-life discussions improve the advance directive completion rate among adult patients with chronic diseases?

Inclusion and Exclusion Criteria

The inclusion criteria included randomized controlled trials assessing the effect of nurse-led advance care planning initiatives on advance care planning completion rate, adult patients with chronic diseases managed in hospital and outpatient care settings, and articles written in English within the last 10 years. Nurses providing the intervention must be formally trained in advance care planning. The exclusion criteria included patients with average life expectancy, studies greater than ten years old, and articles not in English

Search Strategy

Databases used for the systematic review were PubMed, CINAHL and Google Scholar with full text. An initial search term “advance care planning”, was conducted in each database. The search was then narrowed further with the terms: “Nurse-led” and “chronic disease”. The search was limited to randomized control trials from January 2012

to June 2022. Articles were then individually reviewed to determine if the criteria had been met for inclusion in this systematic review.

Data Collection and Appraisal

The Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) statement was used as a guide to search and analyze articles used in this systematic review (Appendix A). The PRISMA guidelines were used to assess the strengths and weaknesses of each article in the review. The PRISMA statement consists of an evidence-based checklist of 27 items that are considered crucial for accurately reporting and evaluating a research study (Daley, 2016). The checklist was divided into categories found in basic research including title, abstract, introduction, methods, data collection processes, results, and discussion, bias reporting, limitations, with an additional section providing information regarding funding. Once the articles met these criteria, the articles were then further investigated for eligibility and omitted if unable to meet previously established inclusion and exclusion criteria using the PRISMA Flow Diagram (Appendix B).

To evaluate the findings in a systematic way and utilize findings to make clinical practice decisions, the Critical Appraisal Skills Programme (CASP) checklist was used (Appendix C). The CASP tool was utilized to critically appraise the randomized control trials to determine the credibility of the studies that were used in this systematic review (CASP, 2020). All 11 questions regarding fairness, equality, and randomization of participants; measured outcomes; generalizability of results, and risk-benefit analysis of trials were documented for each study to reach a comprehensive conclusion regarding the scientific integrity of the research (Appendix D).

Articles were reviewed methodically, and relevant information from each individual study were recorded in two data collection tables created by this author. Data collection tables were created and tailored to meet the focus of this systematic review. Appendices E1-E4 gathered basic demographic information and outline patient and setting characteristics. Appendices F1-F4 outlined the characteristics of advance care planning interventions provided to the intervention group and the impact of the interventions.

Data Synthesis and Analysis

Data was synthesized to document any correlation between intervention and rate of completion of advance directives. Secondary outcomes such as impact of the intervention on patients and nurses in the form of patient/nurse satisfaction and perhaps escalation of end-of-life discussions with providers was examined. The data were analyzed independently for each individual study, while assessing the strengths and weaknesses to identify the validity of the results presented in each study. A cross-study analysis (see Appendix H) was performed to compare results and strengths and weaknesses across studies to answer the proposed problem statement.

Results

The PRISMA flowchart and the exclusion/inclusion criteria were used to select articles for this systematic review (see Appendix A). The initial search yielded 201 results with seven duplicates eliminated. A total of 194 articles titles and abstracts were reviewed to determine if they met inclusion, a total of four studies were selected. The full texts of those four articles were read and reread for eligibility, all four were included in this systematic review. Study characteristics and pertinent information were extracted and organized into the data collection tables (see Appendices E and F). The studies were critically appraised using the CASP checklist (see Appendix G). A Summary of each study is presented as follows in chronological order.

A randomized controlled trial study by Sinclair et al. (2017) (see Appendices E1 and F1) sought to address whether a systematic nurse-led, facilitated ACP intervention is effective in increasing ACP readiness and uptake among patients with advanced respiratory disease. Additionally, the authors aimed to identify patient factors associated with ACP readiness at baseline and to identify patient and contextual factors with ACP uptake. The study was implemented in a metropolitan and rural setting in Western Australia. The metropolitan setting was a respiratory department at a tertiary hospital. The rural setting situated approximately 400km away was comprised of general practice clinics, residential aged care facilities, and the local community hospital in a town of approximately 30,000 people. Eligibility for the study included patients who were diagnosed with a chronic, severe respiratory disease (lung cancer, mesothelioma, malignant pleural effusion, COPD, or interstitial lung disease). Disease states of these patients had to fulfill one or more of the general or disease-specific criteria predicting

“high-risk” of death. Patients eligible for this study needed to be receiving treatment in one of the study settings and were 18 years and older.

In this study (Sinclair et al., 2017) during recruitment, potential participants were informed that they may be invited to discuss the medical care they would want if they were unable to make or communicate their wishes on end-of-life care and life-sustaining treatments. Those who consented to the study and expressed a strong preference to receive or avoid the facilitated ACP intervention were assigned to their preferred intervention or usual care (control) arm respectively. Some were ambivalent about the intervention. There was a total of 149 participants, of which 61 patients who strongly preferred ACP were assigned to the intervention group, of the 67 patients who were ambivalent, 45 were randomly assigned to the intervention group, totaling 106 patients in the intervention group. The usual care group consisted of 21 patients who strongly preferred no ACP intervention and 22 of those who were ambivalent that were randomly assigned.

The intervention consisted of nurse-led support to the participant, their family, and their doctor to facilitate engagement in ACP. A nurse facilitator was employed in each setting to coordinate recruitment, deliver the intervention, and collect surveys. There were two nurses involved, both were senior nurses with vast experience in communication with chronically ill patients. The nurses and the broader research team participated in a full-day workshop delivered by an external consultant using evidence-based resources adapted with permission from Respecting Patient Choices. Participants who received the intervention were offered meetings with the nurse facilitator to discuss their illness and prognosis, reflect on goals and values for medical care, talk about these

with loved ones and doctors, appoint a substitute decision-maker (SDM) and /or formally document future treatment preferences in an advance directive (AD). Follow-up meetings with the nurse facilitator were scheduled opportunistically, or by patient request.

The primary outcome, ACP uptake was measured by participants' completion of a validated survey that assessed the stage of readiness to engage in relevant aspects of ACP. Surveys were completed at baseline, 3- and 6-months post-consent. Documentation included completion of a written AD, documentation of an SDM, and discussion about life-sustaining treatments with loved ones and providers. Formal ACP uptake was defined as self-reported completion of written AD. For participants who died or were lost for follow-up prior to 6-month survey, the self-report data were supplemented by a medical notes audit. Informal ACP uptake was defined as self-reported completion of at least one discussion about life-sustaining treatments with doctors on 6-month follow up, or documentation of ACP conversations found at notes audit. Secondary outcomes were measured by administered EuroQol 5 Dimensions, a 5-level survey to assess health-related quality of life (HRQOL). Satisfaction with healthcare was assessed using the Patient Satisfaction Index (PSI), a validated 23-item instrument, social support was assessed by the seven-item ENRICH tool, which scored instrumental and social aspects of support.

Results from this study demonstrated that there was an increased likelihood of having ACP uptake at 6-month follow-up (relative risk (RR) 3.65, 95% CI 1.70 to 7.85) among those assigned to receive the intervention (54/106, 50.9%), compared with those assigned to usual care (6/43, 14.0%). There was also increased ACP uptake at 6-month

follow-up (RR 2.58, 95% CI 1.55 to 4.31) among those with a strong preference for the intervention (42/61, 68.9%) compared with those allocated randomly to receive the intervention (12/45, 26.7%). Among those assigned to ACP intervention, those with a strong preference (Pref-ACP) had an OR of 6.1 (95% CI 2.6 to 14.3) of ACP uptake, compared with those allocated randomly (Rand-ACP). There was no difference between those allocated randomly to ACP and those assigned to usual care (OR 1.6, 95% CI 0.5 to 5.8). Informal ACP uptake was significantly higher at 6-month follow-up (76/106, 71.7%) compared with baseline (33/ 106, 31.1%, $p < 0.001$) for those assigned to the intervention, while those assigned to usual care did not show a significant difference in uptake over time (12/43, 27.9% vs 20/43, 46.5%, NS). Among participants assigned to receive the ACP intervention (Pref-ACP or Rand-ACP) with baseline and 3-month follow-up data available (N=82), completion of ACP discussions about life-sustaining treatments with loved ones increased from baseline to 3-month follow-up (62% vs 77%, $p < 0.001$). Among participants assigned to usual care (Pref-CON or Rand-CON) with baseline and 3-month follow-up data available (N=26), ACP discussions with loved ones showed a trend towards increase over time (50% vs 73%, $p = 0.06$). The rate of self-reported AD completion at 6-month follow-up was higher in the Pref-ACP group (21/32, 66%) compared with the Rand-ACP group (7/33, 21%; RR 3.09, 95% CI 1.53 to 6.25, $p < 0.001$) (Sinclair et al., 2017).

While utilizing the CASP checklist (see Appendix G1) to critically appraise this study by Sinclair et al. (2017), it was noted that the research question was clearly focused and there was some element of randomization. Randomization was partially done as the intervention and control groups were comprised of participants who had a strong

preference for or against the intervention and participants who were deemed to be ambivalent. Participants who were considered ambivalent were then randomized into intervention and control groups. Sample size was lower than needed to determine clinically relevant differences precisely. A target sample size of $n = 150$ in each study setting was based on a power calculation of 0.80, assuming a log-normal distribution, and a 75% ratio of geometric mean levels of ACP uptake between the usual care and intervention arms. However, the number of participants from both settings in this study was 149. It was impossible to blind participants to their intervention allocation due to the nature of the ACP intervention. A preference design component introduced a self-selection bias which should be accounted for when findings were interpreted, which was done. There was similar representation from rural and metropolitan settings across intervention and control groups. This is significant to note because in the rural setting, the nurse facilitator was able to visit participants in a range of settings; this resulted in a tendency for multiple ACP discussions, often of shorter duration.

A cluster-randomized controlled trial by Houben et al. (2019) (see Appendices E2 and F2) assessed whether a single, structured, 1.5 hours, nurse-led ACP-session can improve the quality of end-of-life care communication between physicians and patients with COPD. The study's secondary aim was to study the prevalence of ACP discussions with physicians 6 months after ACP; changes in symptoms of anxiety and depression of patients and loved ones and quality of death and dying. This study took place at one academic and three general hospitals in the Netherlands from June 2013 to October 2015. The population consisted of a convenience sample of patients with advanced COPD (Global initiative for chronic Obstructive Lung Disease stage III, IV or quadrant D with a

modified Medical Research Council (mMRC) dyspnea grade ≥ 2) who were recently discharged after hospital admission for an acute COPD exacerbation. Exclusion criteria included the inability to complete questionnaires because of cognitive impairment or unable to speak and/or understand Dutch. A total of 165 patients and 196 loved ones were randomized to intervention and control groups. Participating patients received the intervention or usual care depending on the randomization of their chest physician (n=29).

Participants in the intervention arm received an ACP session in their home environment in the presence of their loved ones within 4 weeks after discharge. The session was 1.5 hours long provided by eight respiratory nurse specialists who received a 2-day training, which consisted of the theoretical background of the importance of ACP and practicing end-of-life care communication skills. The primary outcome measure was quality of end-of-life care communication 6-months after baseline, which was assessed using the end-of-life subscale of the QOC (quality of communication) questionnaire. Secondary outcome measures were the prevalence of ACP discussions with physicians 6-months after ACP; changes in symptoms of anxiety and depression of patients and loved ones and quality of death and dying. To measure prevalence of ACP-discussions, patients were asked at baseline and after 6-months whether they discussed end-of-life care preferences with a healthcare professional and if so, with which healthcare professional they discussed their preferences. Symptoms of anxiety and depression were measured at baseline and 6months in patients and loved ones using the Hospital Anxiety and Depression Scale (HADS). Quality of death and dying was assessed using the Quality of Death and Dying (QODD) questionnaire.

Results from the Houben et al. (2019) study were that QOC end-of-life care communication score significantly improved in the ACP-intervention group (2.37 points; 95% CI 1.76 to 2.98; $p < 0.001$) but did not change in the control group (0.32 points; 95% CI -0.15 to 0.80 ; $p = 0.18$). Multilevel linear regression analysis showed that the mean difference in QOC end-of-life care communication score was significantly higher in the ACP-intervention group compared to the control group, when clustering for physician (28 clusters) and adjusting for age and previous ACP-discussions. Six months after randomization, 38 out of 73 patients in the ACP-intervention group (52.1%) reported an ACP-discussion with another healthcare professional other than the intervention nurse against 19 out of 64 patients in the control group (29.7%) ($p = 0.003$).

The impact of the intervention on anxiety and depression symptoms was as follows: Symptoms of anxiety improved significantly within the ACP-intervention group (-1.1 points; 95% CI -1.99 to -0.23 ; $p = 0.01$) but did not significantly change in the control group (-0.4 points; 95% CI -1.38 to 0.66 ; $p = 0.48$). Symptoms of depression did not change ($p = 0.60$ and $p = 0.23$ for intervention and control group, respectively). Linear regression analysis showed no significant difference in symptoms of anxiety and depression between patients in both groups at 6-month follow-up, when adjusting for age and symptoms of anxiety or depression at baseline, respectively. Symptoms of anxiety improved significantly within the loved ones in the ACP-intervention group (intervention group: -0.9 points; 95% CI -1.7 to -0.2 ; $p = 0.02$) but did not change in the control group (-0.0 points; 95% CI -0.9 to 0.9 ; $p=0.98$). Furthermore, symptoms of depression did not change within both groups ($p = 0.60$ and $p = 0.72$ for intervention and control group, respectively). Linear regression analysis showed that loved ones in the intervention group

had significantly fewer symptoms of anxiety in comparison with loved ones in the control group at 6-month follow-up, when adjusting for symptoms of anxiety at baseline and gender (Houben et al., 2019).

Critical analysis of the Houben et al. (2019) study using the CASP checklist (see Appendix G2) revealed the study's sample size was not large enough to detect any difference between the intervention group versus the control group. A sample size calculation with a level of significance of 5% and a power of 90% implied that 135 patients per group were needed. However, at the 6-months follow-up there were 73 patients in the intervention group and 64 patients in the control group and the number of loved ones in the intervention and control groups were 80 and 69 respectively. The groups were dissimilar at baseline with the ACP-intervention group patients being younger than the control group participants and had discussed ACP less frequently prior to the study.

A pilot randomized controlled trial by Kizawa et al. (2020), see Appendix E3 and F3) aimed to examine the effects of a brief nurse intervention with versus without visual materials on outcomes related to advance care planning interventions including goal of care preference, CPR preference, and health care proxy in elderly Japanese patients with chronic disease. This study was designed to compare outcomes between groups, but the authors also looked at before and after comparisons within the groups to examine the feasibility of this type of nurse intervention and whether this intervention improved outcomes.

Inclusion criteria for the patients were age 65 years or older, receiving regular medical treatment by general practice or hospital physicians for at least one chronic

illness, including cardiovascular disease, malignant disease, pulmonary disease, or renal disease, and capable of understanding and speaking Japanese. A total of 220 patients were enrolled and were randomly assigned to a control group (brief nurse intervention using verbal descriptions, n = 103) and an intervention group (brief nurse intervention using visual materials, n = 117). The study was implemented in a Japanese primary care outpatient setting from January 2018 to February 2018.

In the Kizawa et al. (2020) study, the intervention was provided in a private room in a public conference facility. The participants received a 30-minute (both groups) face-to-face, one-to-one intervention from the nurses. In a brief introduction section, the interviewer explained why advance care planning was valuable, then the concepts of the three types of goal of care (life-prolonging care, limited medical care, and comfort care). Details of a designated health care proxy and life-sustaining treatment such as CPR (what was carried out and efficacy) were also explained. After all interactions were completed, the research nurses asked the participants again to clarify their goal-of-care preference, CPR preference, and whether they designated a health care proxy. In the control group, all information was given verbally. In the intervention group, a PowerPoint presentation provided visual information to supplement verbal information. The PowerPoint slides incorporated pictures of specific clinical situations, that is, a patient receiving CPR and intubation. There were six nurses providing the intervention, they were all oncology nurses with five or more years of clinical experience, one of them was a certified oncology nurse. Each nurse had received four-hour interactive education, including actual interaction with a participant before the study from one of the authors.

Results from the Kizawa et al. (2020) study revealed that there was no significant group difference in the post intervention goal-of-care preference between the groups. Adjustment for age obtained the same results: $p = 0.330$ (current condition), $p = 0.884$ (terminal condition), and $p = 0.703$ (bedridden condition). At the baseline, $p < 0.001$). A statistically significant difference was not observed in any of the remaining outcomes, that is, the number of participants who designated a health proxy, knowledge of CPR, and readiness for advance care planning. Before and after comparisons indicated a significant increase in these outcomes in both intervention and control groups. The number of participants who designated a health proxy increased from 29% to 65% in the intervention group and from 22% to 52% in the control group, respectively ($p < 0.001$ each).

Upon critical appraisal of the Kizawa et al. (2020) study utilizing the CASP checklist (Appendix G3) it was noted that the sample size used in this study was adequate. A sample size of 100 per group was needed to detect a difference between groups with a power of 80%, intervention and control groups had $n = 117$ and $n = 103$ respectively. The research question was somewhat clearly focused which is common in pilot studies, a portion of the hypothesis was addressed by the collection of information pre- and post- intervention that was not subject to randomization. Both groups were similar at the start of the trial, however, it was noted that the participants in both groups were largely made up of men with college-level education (80%) which may impact generalizability.

A randomized controlled trial by Gabbard et al. (2021) (see Appendices E4 and F4) sought to determine whether an ACP pathway, combining nurse navigators

embedded within a Medicare Accountable Care Organization (ACO) with a health care professional-facing electronic health record (EHR) discussion and documentation, improved ACP documentation within the EHR for vulnerable older adults within the outpatient primary setting. Eligibility for this study was that patients had to be 65-years or older, affiliated with an ACO, and had seen their primary care professional within the past 12 months. They were additionally required to have evidence of multimorbidity (Weighted Charlson Comorbidity Index ≥ 3), and an indication of either cognitive or physical impairment, and/or frailty. Cognitive and physical impairments were defined based on diagnosis codes derived from previous encounters and questions from the Medicare annual wellness visit. Frailty was based on an EHR-derived measure (electronic frailty index, eFI) based on the theory of deficit accumulation, with eFI greater than 0.21 taken to indicate frailty.

In the Gabbard et al., (2021) study, patients were excluded if they had moderate to severe hearing loss, were non-English speaking, and if no phone number was available. Moderate to severe dementia based on the Short Portable Mental Status Questionnaire (SPMSQ), patients on hospice, in a long-term care facility, or who transferred care to a different primary care provider were also excluded from the study.

Patients were randomly assigned to intervention and control (usual care) groups using the Zelen design. With the Zelen design, all participants are randomized prior to informed consent, and then only patients randomized to the intervention are approached for consent, subsequently enrolled, and received the intervention. Patients who declined the intervention still factored into overall estimates of effectiveness under an intent-to-treat paradigm, here facilitated by passive outcome follow-up via the EHR performed

under an approved waiver of informed consent. Nurse navigators were trained in ACP using Respecting Choices, participated in a 1-hour training session to review the protocol and the telephone version of ACPWise, and observed a short roleplay example of a telephone pre-visit ACP discussion. ACPwise an integrated EHR ACP interface created specifically for this study, allowed primary care professionals to document ACP in a standardized manner using structured data elements within the EHR, while also allowing for free-text comments and responses (Gabbard et al., 2021).

The nurse navigator completed a brief pre-visit, telephone-based ACP planning discussion with the patient to help prime and engage them in the ACP process. This consisted of the nurse navigator discussing why ACP is important, and then reviewing a script covering health-related goals, things that bring meaning to the patient's life, preferred location of death, health-related concerns, and naming a surrogate discussion maker. The nurse navigator rated the patient's level of engagement over the telephone as either pre-contemplative, contemplative, or action phase. They then scheduled the patient for an in person dyad visit with their surrogate decision maker or loved one and primary care professional in conjunction with their upcoming annual wellness visit. If the patient had recently completed their annual wellness visit, they were scheduled for an independent ACP visit. Nurse navigators used the telephone version of ACPWise to document these discussions and forwarded their note to the patient's primary care professional. After completion of the ACP telephone visit, patients were mailed an ACP packet which contained additional information about ACP and a copy of the North Carolina Advance Directive (Gabbard et al., 2021).

After a patient completed their pre-visit ACP telephone visit with the nurse navigator, they were scheduled to complete a dyad ACP visit with their primary care professional and once completed, their primary care professional used the ACPWise documentation program to document and bill for their discussion. Additional topics incorporated into ACPWise that were not covered by the nurse navigators included disease understanding, prognosis, unacceptable states at the end of life related to their goals (e.g., not being able to live without being hooked up to machines), reviewing and/or completing an advance directive, and whether to use or avoid 5 treatments: resuscitation, mechanical intubation, artificial feeding, intravenous fluids, and antibiotics. Patients were given the option if desired to opt-out of the telephone pre-visit and only complete an in-person dyad visit or to complete only the telephone pre-visit. After the visit, patients were asked to complete a survey to assess the quality of communication and engagement, and primary care professionals were asked to complete a satisfaction survey about their experience. Patients who were randomized to usual care (control arm) received usual care and were not approached.

A total of 765 participants were randomized between November 2018 and April 2019 in the Gabbard et al., (2021) study. A total of 6 patients died prior to randomization, leaving a final population of 759 participants. A total of 146 (49.6%) out of the 294 eligible participants randomized to the nurse navigator group consented to participate and 139 completed the intervention. Results showed that the primary outcome of documented ACP within the EHR occurred in 160 patients randomized to the nurse navigator group (42.2%) as compared with 14 (3.7%) in the usual care group ($P < .001$). There were large increases for naming a surrogate decision-maker; having an advanced directive, living

will, or power of attorney; and completing a MOLST form (all $P < .001$). Use of billing codes for ACP visits occurred in 96 (25.3%) of 379 patients randomized to the nurse navigator group, as compared with 5 (1.3%) of 380 patients in the usual care group ($P < .001$).

Upon critical appraisal of the Gabbard et al. (2021) study utilizing the CASP checklist (see Appendix G4), the study had a clear research question, and participants were randomized using the Zelen design to intervention and control groups. Participants in the control group were not approached and hence did not receive informed consent. The authors estimated that a total sample size of 765 participants was needed to detect a difference between groups with greater than 80% power. The study screened 759 participants, with 379 randomized to the intervention group and ultimately 139 participants received intervention. Data from the initial 379 randomized participants were used for primary analysis, questioning the integrity of the results.

Cross Study Analysis

A cross-study analysis of the research articles included in this study was conducted (see Appendix H). Components such as training given to the nurses providing interventions, type of ACP intervention, impact on ACP, and limitations of each study were observed. All four studies incorporated participants with chronic diseases. Two studies examined ACP interventions in patients with respiratory diseases exclusively. Houben et al. (2019) studied the impact of intervention on patients with COPD, and the study by Sinclair et al., (2017) focused on patients with varying types of respiratory diseases such as COPD, interstitial fibrosis, and malignancies. The other two studies, Kizawa et al., (2020) and Gabbard et al., (202) looked at ACP interventions in

participants with differing chronic diseases. The mean ages in these studies were between 65-80 and disease severity was assessed by using disease-specific scales, that is, spirometry in COPD and interstitial fibrosis. Disease severity was also guided by the number of recurrent admissions within a 12-year period. For studies that included varying types of chronic diseases, disease severity was rated by using the Charlson comorbidity index. The Charlson comorbidity index score predicts risk of death within 1 year of hospitalization (NCI, 2021).

ACP interventions across all groups involved discussion of participants' illnesses and prognosis, goals and values for future medical care. The delivery of interventions was unique to each study. Participants were provided interventions either at home or via phone call, or in an outpatient clinic. Kizawa et al., (2020) conducted a study to observe differences in delivery modalities of an ACP intervention. The authors compared the effect of ACP intervention via verbal format only vs. verbal format with visual aids. They found no differences between the modalities, however, a significant impact on both interventions and designation of health care proxy was observed.

The nurses executing the intervention in all studies were experienced nurses who have worked with chronically ill patients. In two studies, Sinclair et al., (2017) and Gabbard et al., (2021), training was adapted from an outside source, "Respecting Choices". According to CAPC.org (Center to Advance Palliative Care), "Respecting Choices" is an internationally recognized evidence-based model of advance care planning that creates a health care culture of person-centered care, honoring an individual's goals and values for current and future health care. A systematic review of the published evidence for "Respecting Choices" by MacKenzie et al., 2018, found that there was a low

level of evidence that “Respecting Choices” and derivative models increase incidence and prevalence of Advance Directive and Physician Orders for Life-Sustaining Treatment (POLST) completion. The authors also found that there was a high level of evidence that “Respecting Choices” and derivative models increase patient-surrogate congruence in Caucasian populations. In studies by Houben et al., (2019) and Kizawa et al., (2020), nurses’ training involved elements of ACP and practicing of communication skills.

All four studies’ primary aims were to evaluate nurses’ ability to improve rates of ACP discussion and ACP uptake. The primary outcomes were measured by either survey to assess ACP readiness or documentation of SDM, and presence of formal and informal ACP documentation. Secondary outcomes measured associating aspects of ACP discussions such as factors associated with readiness for ACP discussion as noted in a study by Sinclair et al., (2017). Impact of symptoms of anxiety and depression were secondary outcomes examined in the study by Houben et al., (2019). The study by Kizawa et al., (2020) examined CPR knowledge and preference as secondary measures. Billing codes were examined in the Gabbard et al., (2021) study as secondary outcomes. Primary and secondary outcomes presented in each study are noted in data collection tables (see Appendices F1-F4).

Summary and Conclusions

Planning for the end-of-life is increasingly viewed as a public health issue, given its potential to prevent unnecessary suffering and to support an individual's decisions and preferences related to the end-of-life (CDC, 2018). Advance care planning is increasingly recognized as valuable to patients' overall care in that it is a crucial action to ensure receipt of goal-accordant medical care. Despite decades of large-scale educational and legal efforts to promote an increase in rates of ACP discussion and completion of Advance Directives, there are still deficiencies in the completion of ACP. A systematic review by Yadav et al., 2017 suggested that while vulnerable populations (people in nursing homes or hospice, older adults, those with dementia and other neurologic diseases, and other chronic diseases) do appear to have comparatively high advance directive completion rates, approximately half of the members of these populations are still without any such directive.

These vulnerable patients often do not realize the importance of ACP. Studies have shown that patients, at times are not aware that they have a terminal disease, what the disease is, or any understanding of prognosis. Patients with chronic diseases may have unrealistically optimistic expectations of their prognosis. A systematic review by Hole and Salem (2016) noted that among patients with heart failure, median self-estimated life expectancy was 40% longer than predicted by a validated model. Outpatients receiving hemodialysis were more optimistic about prognosis than their nephrologists and overestimated their chances of surviving 5 years. Patients with heart failure and COPD were approximately three times more likely to die in the next year than

they predicted. Therefore, there is a need for health care providers to take the lead to begin the ACP conversation with patients.

Even though health care providers are aware of their responsibilities in providing opportunities to engage in ACP discussions with their patients, they are often met with numerous challenges in implementing these discussions. Study by Bergenholtz et al. (2019) noted that clinician-cited barriers to appropriately discussing ACP with patients included limited time and inappropriate documentation of ACP. Nurses are uniquely positioned in a patient's encounter with the healthcare system, the nurse-patient relationship in most settings is usually characterized by interactions that are often frequent and with long periods of engagements in where a nurse gets to know the patient holistically. This relationship can be used advantageously to increase engagement in ACP. Several studies, discussed earlier in this paper, have shown that nurses have had positive impact on aspects of palliative care.

The purpose of this systematic review was to evaluate the effectiveness of nurse-led advance care planning and engagement in EOL discussions on advance directive participation rates among adult patients with chronic diseases.

The theoretical framework used to guide this systematic review builds on the nurse-patient relationship to promote engagement of ACP and end-of-life discussions. An Advance Directive Decision-Making Model adapted from Imogene King's Theory of Goal Attainment describes the nurse in the role of facilitator—not an enforcer or an evaluator. The client is cast in the role of a mutual partner for goal attainment—not in a sick role. This client role is one of active participation. The social system contributes three additional concepts: power, status, and decision-making. Power is recognized as

client controlled and directed— utilizing the knowledge, skill, and expertise of the RN/NP to support the client. This systematic review hypothesized that with appropriate training, nurses can be a valuable facilitator of advance care planning.

Databases used to conduct a comprehensive search on the topic were CINAHL, Pubmed and Google Scholar. The search strategy ultimately yielded four randomized control trials to be used in this systematic review. Relevant data were identified and organized using two data collection tables produced by this author (Appendices D1-4 and E1-4). Each study was analyzed for robustness using the Critical Appraisal Skills Programme (CASP) Randomized Control Trial Checklist (Appendix G). Cross analysis of the studies was conducted utilizing the chart in Appendix H.

There were positive effects noted in all four studies on varying aspects of ACP, limitations, and results are presented in the cross-study analysis. The study by Sinclair et al., (2017) found that there was an increased likelihood of having ACP uptake at 6-month follow-up among those assigned to receive the intervention, compared with those assigned to usual care. But no significant differences in documentation of AD between intervention group and usual care group. The authors also found that preference for the intervention correlated with positive results. They noted an increase in ACP uptake at 6-month follow-up (RR 2.58, 95% CI 1.55 to 4.31) among those with a strong preference for the intervention (42/61, 68.9%) compared with those allocated randomly to receive the intervention (12/45, 26.7%). The rate of self-reported AD completion at 6-month follow-up was higher in the Pref-ACP group (21/32, 66%) compared with the Rand-ACP group (7/33, 21%; RR 3.09, 95% CI 1.53 to 6.25, $p < 0.001$). With pre-intervention vs. post-intervention comparisons, the authors found that informal ACP uptake was

significantly higher at 6-month follow-up (76/106, 71.7%) compared with baseline (33/106, 31.1%, $p < 0.001$) for those assigned to the intervention, while those assigned to usual care did not show a significant difference in uptake over time (12/43, 27.9% vs 20/43, 46.5%, NS).

The findings suggested that higher rates of formal (self-reported completion of a written AD and nomination of SDM) and informal (self-reported completion of at least one discussion about life-sustaining treatments with doctors at 6-month follow-up, or documentation of ACP conversations found in notes) ACP uptake were particularly higher among those with a strong preference for the intervention, and those who engaged in multiple sessions with the nurse facilitator. Examination of secondary outcomes measures found that factors that increase ACP uptake were having undertaken two or more nurse-facilitated ACP discussions. Also, higher rates of ACP discussions with doctors occurred among participants who had a family/caregiver involved in at least one of the facilitated ACP discussions.

One of the challenges encountered by this study was recruitment difficulties that led to a small sample size which can affect generalizability. The study was also limited by using the same nurses who facilitated the ACP intervention to collect follow-up survey responses and to undertake medical notes audits; this may be a source of bias. Another limitation noted was that follow-up data was difficult to attain over time due to the attrition rate (associated mostly with patients dying), the authors sought to address this where possible by supplementing self-report measures with information obtained from follow-up medical notes audits. The intervention was delivered in both home and

hospital environments, however, the sample size was too small for the authors to stratify the data to assess the impact of both settings on ACP discussions.

In the study by Houben et al., (2019), the nurse-led ACP intervention was provided as an augmentation to improve physician-patient quality of end-of-life care communication in patients with COPD. The authors found that QOC end-of-life care communication score significantly improved in the ACP-intervention group (2.37 points; 95% CI 1.76 to 2.98; $p < 0.001$; 95% CI -0.15 to 0.80; $p = 0.18$). Multilevel linear regression analysis showed that the mean difference in QOC end-of-life care communication score was significantly higher in the ACP-intervention group compared to the control group, when clustering for physician (28 clusters) and adjusting for age and previous ACP-discussion. The authors of this study hypothesized that the nurse-led intervention would overcome important barriers such as the physician-reported barrier of lack of time. It was also felt that the nurse-led intervention was done at an opportune time to initiate ACP discussion, after being discharged from a hospitalization. Even though this study by Houben et al., (2019) had positive results suggesting that the nurse-led intervention improved physician-patient end-of-life communication, there were limitations in this study that need to be considered. As seen in most palliative care studies, there were challenges to recruitment of participants leading to a sample size that was too small based on sample size calculation. The study was implemented as a home-based intervention for which the nurses travelled to the patient's home to deliver the ACP-session. This could be a potential barrier for dissemination and implementation, since in clinical practice, it may not be feasible and too expensive to deliver the ACP-session in the home environment. The study only assessed communication about end-of-

life care and the prevalence of ACP-discussions from the patient's perspective, which may raise the risk of recall bias.

The findings of the Kizawa et al., (2020) study suggested that there was no significant difference between the groups in primary outcome measures (documentation of goals of care preference). However, the authors found that the brief nurse intervention increased documentation of a patient-designated health care proxy and improved the knowledge of CPR and patient readiness from baseline in both groups. These results imply that the brief nurse intervention utilizing visual aids or without had positive impacts on aspects of the ACP process. Simple interventions using verbal descriptions by nurses may be effective to aid patients in formally designating a health care proxy. The limitations of this study were that the patient sample was from an online commercial database and may be biased, for example, highly educated males. Also, the intervention materials were not made through a fully rigorous development process.

The study by Gabbard et al., (2020) examined the impact of the nurse navigator-led ACP pathway combined with a health care professional-facing EHR ACP interface on improving ACP documentation. The authors found that the primary outcome of documented ACP within the EHR occurred in 160 patients randomized to the nurse navigator group (42.2%) as compared with 14 (3.7%) in the usual care group ($P < .001$). The results are questionable considering that elsewhere in the paper it was reported that 139 participants received the intervention. Also mentioned, was that 37% of completed ACP forms were done in the initial ACP-discussion visit and the remainder 63% were scanned into the EHR at a later time. With these noted inconsistencies, one may wonder how much of the ACP documentation was an effect of the nurse-led intervention. Other

limitations of this study were that generalizability may be limited because participants were recruited from a single health system, all were within an ACO population, patients who were non-English speaking or residing within a long-term care facility were excluded, and the majority of randomized patients were White.

Limitations of this systematic review: only four RCT's were selected due to the low number of studies available on this topic, studies used in this systematic review were all underpowered based on sample size calculation -a common trend in palliative care research due to recruitment challenges. Generalizability was also impacted by the studies' settings. There were a variety of settings across all studies where the interventions were delivered. The Sinclair et al., (2017) study held ACP discussions in home and outpatient settings. The intervention in the Houben et al, (2019) study was home-based. Gabbard et al., (2021) delivered the intervention via telephone and in-person visit in clinic. In the (Kizawa) et al., (2020) study the intervention was implemented in a public space. Another limitation noted across all four studies, was that the groups were all mostly homogenous. In three studies, Houben et al, (2019) Sinclair et al, (2017), and Gabbard et al., (2021) included mostly white participants, and the Kizawa et al., (2020), population studied was solely Japanese. Cultural and spiritual considerations are important aspects of ACP discussions. This systematic review hypothesized that nurses can provide effective ACP intervention to patients with chronic diseases given that they receive appropriate training. In all studies training was provided to the nurses, however, training differed across studies with only two studies utilizing a standardized educational program.

Despite these limitations, this systematic review provides sufficient evidence that nurse-led engagements in ACP and end-of-life discussion can be effective in improving AD completion rates. ACP is a complex process with various end-points to examine, the findings in this systematic review lead to recommendations for further research on the effects of nurse-led ACP interventions on various aspects of ACP.

Recommendations and Implications for Advanced Nursing Practice

The roles of advanced practice nurses (APNs) are rapidly evolving, with APNs becoming an integral part in almost every arena of healthcare. The reach of APNs is expanding, and more APNs are at the center of interdisciplinary teams caring for patients with chronic diseases. It is imperative that APNs become skilled at providing timely and sensitive ACP discussions to patients with chronic diseases. Intervening with appropriate ACP discussions with the goal of supporting patients with chronic disease in the completion of advance directives is very valuable to ensure that these patients receive goal-concordant medical care. Documentation of ACP discussions and the patients' wishes in the EHR is a crucial step in ensuring that patients receive goal-concordant care. APNs can incorporate proper documentation of ACP discussions and AD in their practice and promote such practice amongst health care team members. APNs can engage other members of the interdisciplinary team namely nurses to assist in providing this valuable intervention to patients with chronic diseases. APNs can identify the special relationship between registered nurses and patients and their families as an opportunity for the promotion of ACP discussions.

This systematic review demonstrated the value of registered nurses' evolving roles in advance care planning especially in patients with chronic diseases by providing varying proposing capacities in which nurses could assist the healthcare team in providing patients with appropriate ACP discussions to increase AD completion rates. ACP discussions consist of complex processes that are multifactorial that require multiple encounters with the health care team to execute. This systematic review looked at the varying aspects of ACP discussions in which registered nurses can provide support.

The Advanced Directive Decision-Making Model (ADDM) by Goodwin et al., (2002) was the theoretical framework used to guide this systematic review. The model describes the nurse-client relationship and the benefits that it holds as the nurse can be a supportive agent in patient decision making. The model also delineates the importance of the nurse becoming an expert to vehicle the supportive role, noting the importance of appropriate training. When utilizing registered nurses to provide ACP interventions, the APN must ensure that they undergo appropriate training especially from a well-researched source. APNs can also promote more research in this area to better identify how nurses can be a valuable participant in ACP discussions by utilizing the advantageous nurse-client relationship.

APNs can support policies and legal initiatives to support registered nurses' engagement in ACP for the goal of increasing AD completion rates. Legal initiatives can assist in ensuring that appropriate reimbursements can be made for the valuable work done by registered nurses in improving ACP. APNs can be at the forefront of change by promoting the art of nursing to be used at a higher level to meet the needs of the patients.

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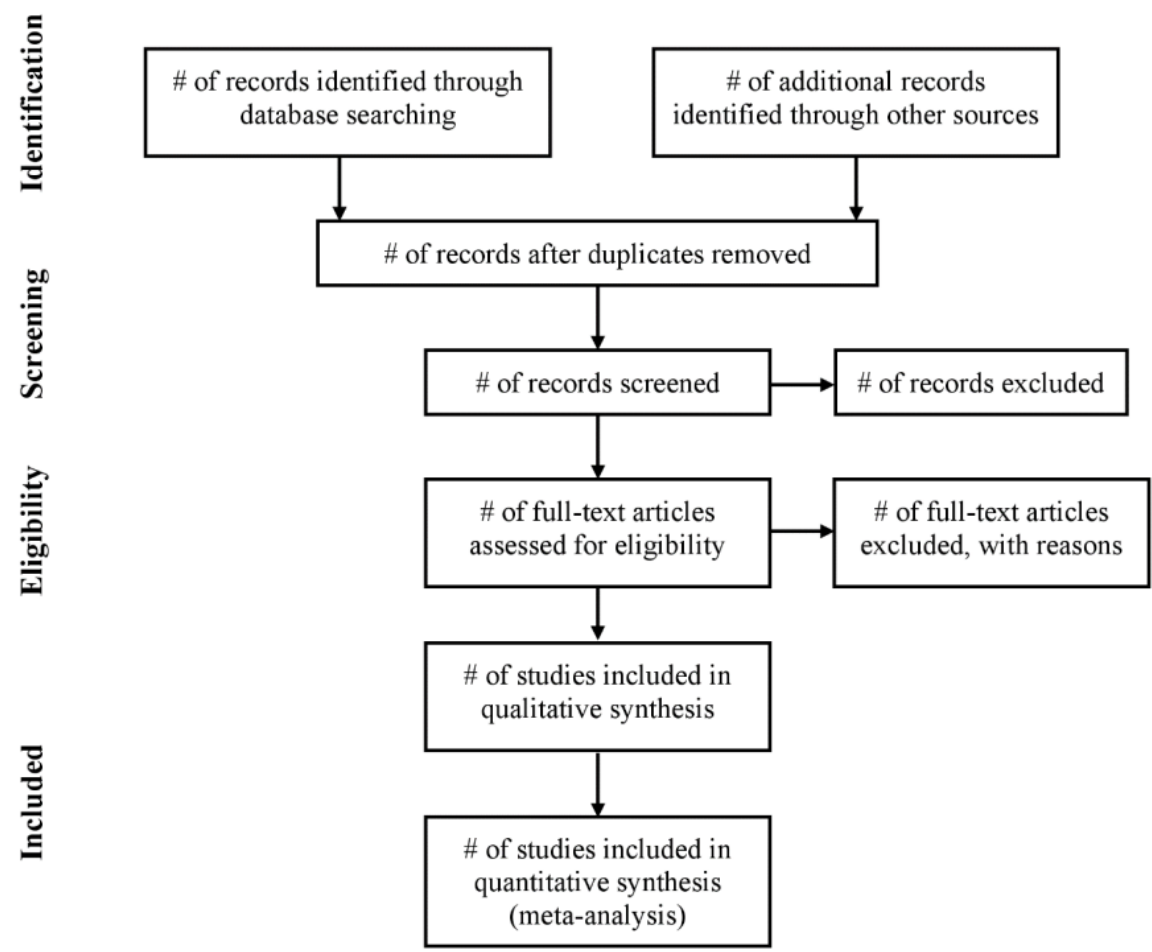
Appendix A

Section/Topic	#	Checklist Item	Reported on Page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome-level assessment (see Item 12).	
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group and (b) effect estimates and confidence intervals, ideally with a forest plot.	
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., health care providers, users, and policy makers).	
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review level (e.g., incomplete retrieval of identified research, reporting bias).	
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	

doi:10.1371/journal.pmed.1000097.t001

Check List for Preferred Reporting Items for Systematic Reviews and Meta-Analyses (Moher et al., 2009)

Appendix B

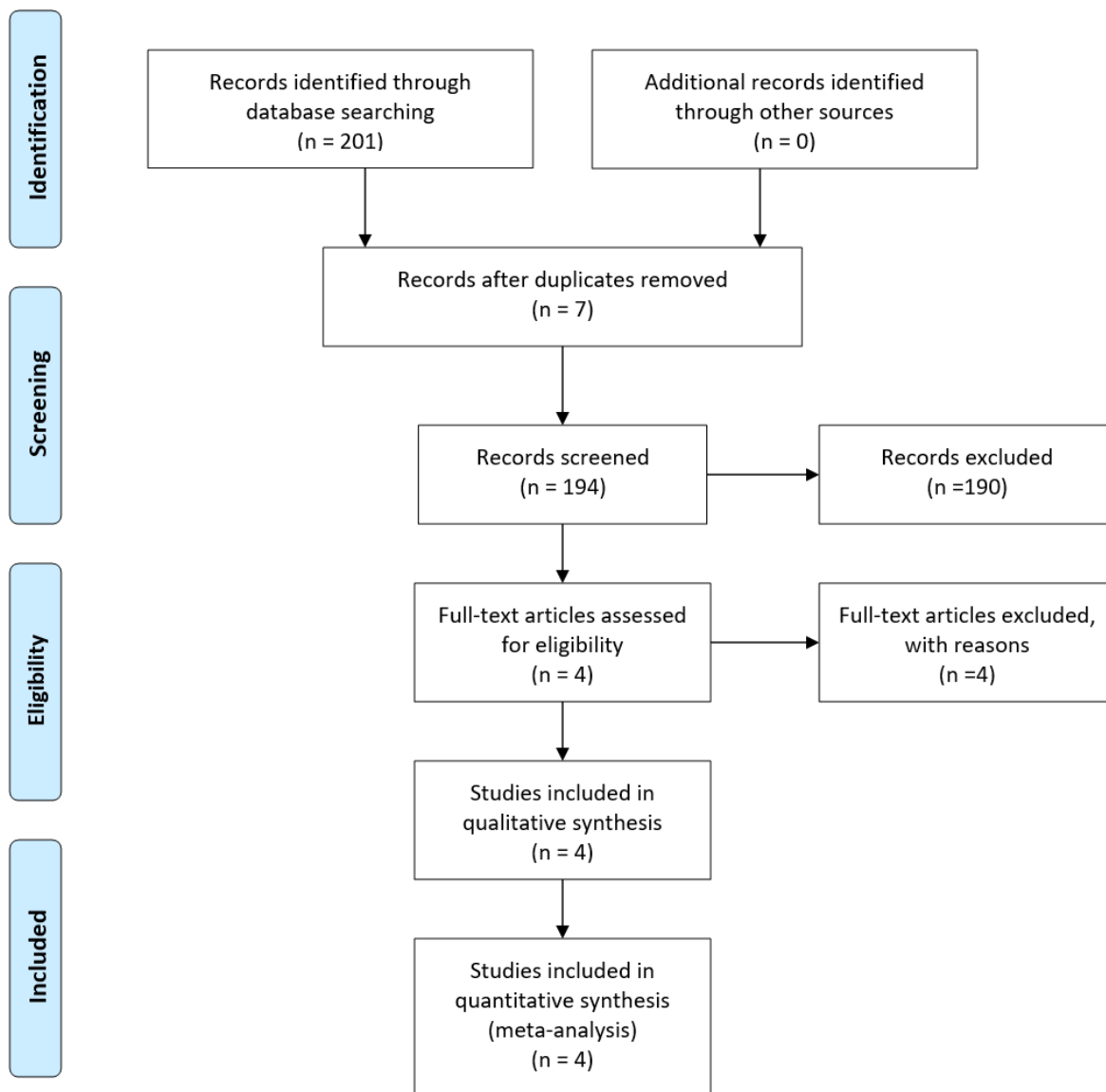


Flow diagram for preferred reporting items for systematic reviews and meta-analyses (Moher et al., 2009)

Appendix C

Critical Appraisal Skills Programme				
1	Did the study address a clearly focused research question?	Yes	Can't Tell	No
2	Was the assignment of participants to interventions randomized?	Yes	Can't Tell	No
3	Were all the patients who entered the trial properly accounted for at its conclusion?	Yes	Can't Tell	No
4	<ul style="list-style-type: none"> • Were the participants 'blind' to intervention they were given? • Were the investigators 'blind' to the intervention they were giving to participants? • Were the people assessing/analyzing outcome/s 'blinded'? 	Yes	Can't Tell	No
5	Were the groups similar at the start of the trial?	Yes	Can't Tell	No
6	Aside from the experimental intervention, were the groups treated equally?	Yes	Can't Tell	No
7	Were the effects of intervention reported comprehensively?	Yes	Can't Tell	No
8	Was the precision of the estimate of the intervention or treatment effect reported?	Yes	Can't Tell	No
9	Do the benefits of the experimental intervention outweigh the harms and costs?	Yes	Can't Tell	No
10	Can the results be applied to your local population/in your context?	Yes	Can't Tell	No
11	Would the experimental intervention provide greater value to the people in your care than any of the existing interventions?	Yes	Can't Tell	No

Appendix D



Flow diagram for preferred reporting items for systematic reviews and meta-analyses (Moher et al., 2009)

Appendix E

E1: Data Collection Tool 1

Sinclair, C., Auret, K. A., Evans, S. F., Williamson, F., Dormer, S., Wilkinson, A., Greeve, K., Koay, A., Price, D., & Brims, F. (2017). Advance care planning uptake among patients with severe lung disease: A randomized patient preference trial of a nurse-led, facilitated advance care planning intervention. <i>BMJ Open</i> , 7(2). https://doi.org/10.1136/bmjopen-2016-013415				
Purpose	Design	Inclusion/Exclusion Criteria	Setting	Sample
The primary research question addressed in this study is whether a systematic nurse-led, facilitated ACP intervention is effective in increasing ACP readiness and uptake among patients with advanced respiratory disease.	The study was a multi-centre open-label randomized controlled trial of nurse-led facilitated ACP with a preference arm enabled participants with strong preferences (to receive or avoid the intervention) to be assigned to their preferred group	Eligible patients for this study were diagnosed with a severe, chronic respiratory disease (lung cancer, mesothelioma, malignant pleural effusion, COPD, or interstitial lung disease). Had fulfilled one or more of the general or disease-specific criteria predicting “high risk” of death, based on the Gold Standards Framework were receiving treatment in one of the study settings. Patients were excluded if they lacked capacity to consent, did not speak English, were on an “end-of-life” pathway or expected to die in the next 48hrs	The study was implemented in a metropolitan and a rural setting in Western Australia. The metropolitan setting was a tertiary hospital respiratory department. The rural setting consisted of general practice clinics, residential aged care facilities and the local regional hospital in a town of ~30,000 people.	Over a 15-month period, 215 were confirmed eligible and invited to participate. Of those participants, 150 consented, with one withdrawing before assignment. One hundred – six were randomly allocated to the study arm and 43 assigned to usual care. The sample was mostly male (63%), with a moderate-low educational status. COPD was the most common respiratory disease (64%). Thirty-six percent of participants were deceased, at 12-month follow up

E2: Data Collection Tool 1

Houben, C. H., Spruit, M. A., Luyten, H., Pennings, H.-J., van den Boogaart, V. E., Creemers, J. P., Wesseling, G., Wouters, E. F., & Janssen, D. J. (2019). Cluster-randomized trial of a nurse-led advance care planning session in patients with COPD and their loved ones. <i>Thorax</i> , 74(4), 328–336. https://doi.org/10.1136/thoraxjnl-2018-211943				
Purpose	Design	Inclusion/Exclusion Criteria	Setting	Sample
To assess whether a single structured, 1.5 hours, nurse-led ACP session can improve quality of end-of-life care communication between physicians and patients with COPD	Cluster randomized control trial	Patients with advanced COPD Global Initiative for Chronic Obstructive Lung Disease stage III, IV, or quadrant D with a modified Medical Research Council (mMRC) dyspnea grade >2). Have been discharged after a hospital admission for an acute COPD exacerbation. Exclusion criteria were inability to complete questionnaires because of cognitive impairment and inability to speak/understand Dutch	Patients were recruited from one academic and three general hospitals in Netherlands between July 2013 and October 2015.	Total of 165 participants. Total 89 patients were randomized to the ACP intervention group and 76 to the control group. Each participant was asked to identify one to four loved ones for participation in the study. Total 109 loved ones of patients randomized to the intervention group and 87 loved ones of patients randomized to the control group

E3: Data Collection Tool 1

Kizawa, Y., Okada, H., Kawahara, T., & Morita, T. (2020). Effects of brief nurse advance care planning intervention with visual materials on goal-of-care preference of Japanese elderly patients with chronic disease: A pilot randomized-controlled trial. <i>Journal of Palliative Medicine</i> , 23(8), 1076–1083. https://doi.org/10.1089/jpm.2019.0512				
Purpose	Design	Inclusion/Exclusion Criteria	Setting	Sample
To examine the effects of brief nurse intervention with visual materials on the goal of care preference, cardiopulmonary resuscitation preference, and designation of a health care proxy	Pilot Randomized-controlled trial	Inclusion criteria: age 65 years and older, receiving medical treatment for at least one chronic illness, capable of speaking and understanding Japanese.	Primary care outpatient setting	Total of 220 patients were enrolled (117 participants in the intervention group and 103 in the control group).

E4: Data Collection Tool 1

<p>Gabbard, J., Pajewski, N. M., Callahan, K. E., Dharod, A., Foley, K. L., Ferris, K., Moses, A., Willard, J., & Williamson, J. D. (2021). Effectiveness of a nurse-led multidisciplinary intervention vs usual care on advance care planning for Vulnerable older adults in an accountable care organization. <i>JAMA Internal Medicine</i>, 181(3), 361. https://doi.org/10.1001/jamainternmed.2020.5950</p>				
Purpose	Design	Inclusion/Exclusion Criteria	Setting	Sample
<p>To determine whether a nurse navigator-led ACP pathway combined with a health care professional-facing EHR interface improves the occurrence of ACP discussions and their documentation within the EHR</p>	<p>A randomized effectiveness trial using the Zelen design, in which patients are randomized prior to informed consent, with only those randomized to the intervention subsequently approached to provide informed consent.</p>	<p>Patients were eligible for this study if they were 65 years and older, if they were affiliated with an ACO and if they have seen a PCP within the past 12 months. Have evidence of multimorbidity (Weighted Charlson Comorbidity Index>3) and an indication of either cognitive or physical impairment, an/or frailty. Patients were excluded if they had moderate to severe hearing loss, non-English speaking or if they had moderate to severe dementia. Patients on hospice, in a long-term facility or who transferred care to a different PCP were also excluded.</p>	<p>Eligible patients were identified from 8 primary care practices in the Piedmont area of North Carolina across 5 different counties</p>	<p>A total of 146 (49.6%) out of 294 eligible participants were randomized to the nurse navigator group and 139 completed the intervention. The mean patient age was 77.7 years, with 18.7% participants being 85 years and older. Of all the randomized participants, 59.9% were female, 17.1% were Black or African American. Patients had a median of 14 outpatient encounters and 71.4% within the 2 years prior to randomization</p>

Appendix F

F1: Data Collection Tool 2

Sinclair, C., Auret, K. A., Evans, S. F., Williamson, F., Dormer, S., Wilkinson, A., Greeve, K., Koay, A., Price, D., & Brims, F. (2017). Advance care planning uptake among patients with severe lung disease: A randomized patient preference trial of a nurse-led, facilitated advance care planning intervention. <i>BMJ Open</i> , 7(2). https://doi.org/10.1136/bmjopen-2016-013415			
Intervention	Description of Training Received	Primary Outcome	Secondary Outcome
Participants assigned to the intervention were offered an appointment with the nurse facilitator to discuss their illness and prognosis, reflect on goals and values for future medical care, talk about these with loved ones and doctors, appoint a substitute medical decision-maker (SDM), and/or formally document future preferences in an advanced directive (AD). Follow up meetings with the nurse facilitator were scheduled opportunistically, or by participant request	Senior nurses with extensive experience in communication with severely ill patients participated in a full day workshop delivered by an external consultant using evidence-based resources adapted with permission from <i>Respecting Patient Choices</i> .	ACP uptake was measured by: (1) validated survey tool done at baseline, 3-month, and at 6-month post-consent to assess stage of readiness to engage in aspects of ACP such as: completion of a written AD, documentation of an SDM, discussion of life-sustaining treatments with doctors. (2) at 12 months after consent participants' medical notes were audited from the time of consent to assess the presence of formal or informal documentation of patient preferences regarding future medical care.	(1) identify patient factors associated with ACP readiness at baseline, and (2) identify patient and contextual factors associated with ACP uptake among those who were assigned to receive the facilitated ACP intervention.

F2: Data Collection Tool 2

<p>Houben, C. H., Spruit, M. A., Luyten, H., Pennings, H.-J., van den Boogaart, V. E., Creemers, J. P., Wesseling, G., Wouters, E. F., & Janssen, D. J. (2019). Cluster-randomised trial of a nurse-led advance care planning session in patients with COPD and their loved ones. <i>Thorax</i>, 74(4), 328–336. https://doi.org/10.1136/thoraxjnl-2018-211943</p>			
Intervention	Description of Training Received	Primary Outcome	Secondary Outcome
<p>Nurses provided and ACP-session in the patient's home environment in the presence of the patient and loved one(s) with in 4 weeks of discharge. After the ACP session, nurses completed a feedback form with the patient, which summarized patients' preferences for end-of-life care and end-of-life care communication</p>	<p>Eight Respiratory nurse specialists received a 2-day training, which consisted of theoretical background on the importance of ACP, practicing end-of life communication skills and the structured ACP-session during the study</p>	<p>The primary outcome measure was quality of end-of-life care communication 6 months after baseline, which was assessed using the end-of-life subscale QOC questionnaire</p>	<p>Secondary outcome measures were the prevalence of ACP discussions with physicians after 6 months; changes in symptoms of anxiety and depression of patients and loved ones and quality of death and dying.</p>

F3: Data Collection Tool 2

Kizawa, Y., Okada, H., Kawahara, T., & Morita, T. (2020). Effects of brief nurse advance care planning intervention with visual materials on goal-of-care preference of Japanese elderly patients with chronic disease: A pilot randomized-controlled trial. <i>Journal of Palliative Medicine</i> , 23(8), 1076–1083. https://doi.org/10.1089/jpm.2019.0512			
Intervention	Description of Training Received	Primary Outcome	Secondary Outcome
Participants in both groups received a 30-minute face-to-face intervention from the nurses. In the control group all the information was given verbally. The intervention group, visual information was added to the verbal description using a Power point presentation	All nurses had five or more years clinical experience in oncology. Each nurse received four-hour interactive education, including actual interaction with a participant before the study.	The primary outcome was documentation of the goal of care preference.	Secondary outcomes were documentation of CPR preference, documentation of designated health care proxy, knowledge of CPR and readiness for advance care planning.

F4: Data Collection Tool 2

<p>Gabbard, J., Pajewski, N. M., Callahan, K. E., Dharod, A., Foley, K. L., Ferris, K., Moses, A., Willard, J., & Williamson, J. D. (2021). Effectiveness of a nurse-led multidisciplinary intervention vs usual care on advance care planning for Vulnerable older adults in an accountable care organization. <i>JAMA Internal Medicine</i>, 181(3), 361. https://doi.org/10.1001/jamainternmed.2020.5950</p>			
Intervention	Description of Training Received	Primary Outcome	Secondary Outcome
<p>The nurse navigator completes a brief pre-visit, telephone-based ACP planning discussion. The nurse navigator then rated patient's level of engagement as either pre-contemplative, contemplative, or action phase. They then scheduled the patient for an in-person dyad visit with their surrogate decision maker or loved one and PCP in conjunction with their upcoming annual wellness visit. After completion of the ACP telephone visit, patients were mailed an ACP packet and a copy of the North Carolina Advance Directive.</p>	<p>Nurse navigators were trained in ACP using <i>Respecting Choices</i>, participated in 1-hour training session to review the protocol and the telephone version of ACP-wise and observed a short role play example of a telephone pre-visit ACP discussion</p>	<p>The primary outcome was new documentation of ACP discussions within the EHR. Identified through and initial manual review of the EHR by 2 independent reviewers blinded to the randomized assignment.</p>	<p>They included use of billing codes, documentation of a designated surrogate decision maker, and completion and upload of new ACP legal forms (i.e. advance directives, living wills, or power of attorney) within the HER.</p>

Appendix G1

Sinclair, C., Auret, K. A., Evans, S. F., Williamson, F., Dormer, S., Wilkinson, A., Greeve, K., Koay, A., Price, D., & Brims, F. (2017). Advance care planning uptake among patients with severe lung disease: A randomised patient preference trial of a nurse-led, facilitated advance care planning intervention. <i>BMJ Open</i> , 7(2). https://doi.org/10.1136/bmjopen-2016-013415				
1	Did the study address a clearly focused research question?	Yes	Can't Tell	No
2	Was the assignment of participants to interventions randomized? Partially, both the intervention and control group was subdivided into participants' preference and participants who were randomized.	Yes	Can't Tell	No
3	Were all the patients who entered the trial properly accounted for at its conclusion? Number of participants who were lost to follow up or deceased were reported	Yes	Can't Tell	No
4	<ul style="list-style-type: none"> • Were the participants 'blind' to intervention they were given? • Were the investigators 'blind' to the intervention they were giving to participants? • Were the people assessing/analysing outcome/s 'blinded'? 	Yes Yes Yes	Can't Tell Can't Tell Can't Tell	No No No
5	Were the groups similar at the start of the trial? They were similar in terms of demographics especially illness severity, but not similar in size.	Yes	Can't Tell	No
6	Aside from the experimental intervention, were the groups treated equally?	Yes	Can't Tell	No
7	Were the effects of intervention reported comprehensively?	Yes	Can't Tell	No
8	Was the precision of the estimate of the intervention or treatment effect reported? confidence intervals were reported	Yes	Can't Tell	No
9	Do the benefits of the experimental intervention outweigh the harms and costs?	Yes	Can't Tell	No
10	Can the results be applied to your local population/in your context?	Yes	Can't Tell	No
11	Would the experimental intervention provide greater value to the people in your care than any of the existing interventions?	Yes	Can't Tell	No

Appendix G2

Houben, C. H., Spruit, M. A., Luyten, H., Pennings, H.-J., van den Boogaart, V. E., Creemers, J. P., Wesseling, G., Wouters, E. F., & Janssen, D. J. (2019). Cluster-randomized trial of a nurse-led advance care planning session in patients with COPD and their loved ones. <i>Thorax</i> , 74(4), 328–336. https://doi.org/10.1136/thoraxjnl-2018-211943				
1	Did the study address a clearly focused research question?	Yes	Can't Tell	No
2	Was the assignment of participants to interventions randomized?	Yes	Can't Tell	No
3	Were all the patients who entered the trial properly accounted for at its conclusion?	Yes	Can't Tell	No
4	<ul style="list-style-type: none"> • Were the participants 'blind' to intervention they were given? • Were the investigators 'blind' to the intervention they were giving to participants? • Were the people assessing/analyzing outcome/s 'blinded'? 	Yes Yes Yes	Can't Tell Can't Tell Can't Tell	No No No
5	Were the groups similar at the start of the trial? At baseline, patients in the ACP intervention group were younger than control group and had discussed ACP less frequently.	Yes	Can't Tell	No
6	Aside from the experimental intervention, were the groups treated equally?	Yes	Can't Tell	No
7	Were the effects of intervention reported comprehensively?	Yes	Can't Tell	No
8	Was the precision of the estimate of the intervention or treatment effect reported?	Yes	Can't Tell	No
9	Do the benefits of the experimental intervention outweigh the harms and costs?	Yes	Can't Tell	No
10	Can the results be applied to your local population/in your context?	Yes	Can't Tell	No
11	Would the experimental intervention provide greater value to the people in your care than any of the existing interventions?	Yes	Can't Tell	No

Appendix G3

Kizawa, Y., Okada, H., Kawahara, T., & Morita, T. (2020). Effects of brief nurse advance care planning intervention with visual materials on goal-of-care preference of Japanese elderly patients with chronic disease: A pilot randomized-controlled trial. <i>Journal of Palliative Medicine</i> , 23(8), 1076–1083. https://doi.org/10.1089/jpm.2019.0512				
1	Did the study address a clearly focused research question?	Yes	Can't Tell	No
2	Was the assignment of participants to interventions randomized?	Yes	Can't Tell	No
3	Were all the patients who entered the trial properly accounted for at its conclusion?	Yes	Can't Tell	No
4	<ul style="list-style-type: none"> • Were the participants 'blind' to intervention they were given? • Were the investigators 'blind' to the intervention they were giving to participants? • Were the people assessing/analyzing outcome/s 'blinded'? 	Yes	Can't Tell	No
		Yes	Can't Tell	No
		Yes	Can't Tell	No
5	Were the groups similar at the start of the trial?	Yes	Can't Tell	No
6	Aside from the experimental intervention, were the groups treated equally?	Yes	Can't Tell	No
7	Were the effects of intervention reported comprehensively?	Yes	Can't Tell	No
8	Was the precision of the estimate of the intervention or treatment effect reported?	Yes	Can't Tell	No
9	Do the benefits of the experimental intervention outweigh the harms and costs?	Yes	Can't Tell	No
10	Can the results be applied to your local population/in your context? There are cultural differences that may impact the application of result findings to the local population	Yes	Can't Tell	No
11	Would the experimental intervention provide greater value to the people in your care than any of the existing interventions?	Yes	Can't Tell	No

Appendix G4

Gabbard, J., Pajewski, N. M., Callahan, K. E., Dharod, A., Foley, K. L., Ferris, K., Moses, A., Willard, J., & Williamson, J. D. (2021). Effectiveness of a nurse-led multidisciplinary intervention vs usual care on advance care planning for Vulnerable older adults in an accountable care organization. <i>JAMA Internal Medicine</i> , 181(3), 361. https://doi.org/10.1001/jamainternmed.2020.5950				
1	Did the study address a clearly focused research question?	Yes	Can't Tell	No
2	Was the assignment of participants to interventions randomized?	Yes	Can't Tell	No
3	Were all the patients who entered the trial properly accounted for at its conclusion? However, it appears that data from patients who did not receive nurse navigator ACP intervention was used for primary analysis.	Yes	Can't Tell	No
4	<ul style="list-style-type: none"> • Were the participants 'blind' to intervention they were given? • Were the investigators 'blind' to the intervention they were giving to participants? • Were the people assessing/analyzing outcome/s 'blinded'? 	Yes Yes Yes	Can't Tell Can't Tell Can't Tell	No No No
5	Were the groups similar at the start of the trial?	Yes	Can't Tell	No
6	Aside from the experimental intervention, were the groups treated equally?	Yes	Can't Tell	No
7	Were the effects of intervention reported comprehensively?	Yes	Can't Tell	No
8	Was the precision of the estimate of the intervention or treatment effect reported?	Yes	Can't Tell	No
9	Do the benefits of the experimental intervention outweigh the harms and costs?	Yes	Can't Tell	No
10	Can the results be applied to your local population/in your context?	Yes	Can't Tell	No
11	Would the experimental intervention provide greater value to the people in your care than any of the existing interventions?	Yes	Can't Tell	No

Appendix H

Author, Year	Intervention	Nurses' Training	Impact on ACP	Limitations
Sinclair et al., 2017	Initial appointment with the nurse facilitator to discuss their illness and prognosis, reflect on goals and values for future medical care, talk about these with loved ones and doctors, appoint a substitute medical decision-maker (SDM), and/or formally document future preferences in an advanced directive (AD). Follow up meetings with the nurse facilitator were scheduled opportunistically, or	Two senior nurses with extensive experience in communication with severely ill patients participated in a full day workshop delivered by an external consultant using evidence-based resources adapted with permission from <i>Respecting Patient Choices</i>	Increased likelihood of having ACP uptake at 6-month follow-up (relative risk (RR) 3.65, 95% CI 1.70 to 7.85) among those assigned to receive the intervention (54/106, 50.9%), compared with those assigned to usual care (6/43, 14.0%). Increased ACP uptake at 6-month follow-up (RR 2.58, 95% CI 1.55 to 4.31) among those with a strong preference for the intervention (42/61, 68.9%) compared with those allocated randomly to receive the intervention (12/45, 26.7%)	Assignment to study arm was unblinded. The preference design introduced a self-selection bias, which complicates interpretation of the data. Study sample was smaller than anticipated and data were collapsed across the two recruitment sites, preventing comparisons across site. The same nurses who facilitated the ACP intervention also collected follow-up survey responses and undertook medical notes audits; this may be a source of bias

Author, Year	Intervention	Nurses' Training	Impact on ACP	Limitations
Houben et al., 2019	Nurses provided and ACP-session in the patient's home environment in the presence of the patient and loved one(s) with in 4 weeks of discharge. After the ACP session, nurses completed a feedback form with the patient, which summarized patients' preferences for end-of-life care and end-of-life care communication	Eight Respiratory nurse specialists received a 2-day training, which consisted of theoretical background on the importance of ACP, practicing end-of life communication skills and the structured ACP-session during the study	QOC end-of-life care communication score significantly improved in the ACP-intervention group (2.37 points; 95% CI 1.76 to 2.98; 95% CI -0.15 to 0.80; p=0.18). Multilevel linear regression analysis showed that the mean difference in QOC end-of-life care communication score was significantly higher in the ACP-intervention group compared to the control group, when clustering for	<p>Sample size was too small based on the sample size calculation.</p> <p>Sample size calculation did not account for clustering</p> <p>The long-term impact of the intervention on patient-physician end-of-life care communication was not studied.</p> <p>The current study was based on a home-based intervention for which the nurses travelled to the patient's home to deliver the ACP-session, which limits generalizability.</p>

Author, Year	Intervention	Nurses' Training	Impact on ACP	Limitations
Kizawa et al., 2020	Participants in control and intervention groups received a 30-minute face-to-face intervention from the nurses. In the control group all the information was given verbally. The intervention group, visual information was added to the verbal description using a Power point presentation	All nurses had five or more years clinical experience in oncology. Each nurse received four-hour interactive education, including actual interaction with a participant before the study.	There was no significant group difference in the post-intervention goal-of-care preference between the groups. Adjustment for age obtained the same results: $p = 0.330$ (current condition), $p = 0.884$ (terminal condition), and $p = 0.703$ (bedridden condition). Regarding CPR preference, the group difference did not reach statistical significance (+12% vs. 0%, $p = 0.063$ in a terminal condition; +14% vs. 3.9% in a bedridden condition, $p = 0.057$). In the intervention group, there was a significant increase in the number of patients who did not want CPR (55% to 67% in a	The patient sample was from an online commercial database and may be biased, for example, highly educated males. The intervention materials were not made through a fully rigorous development process. Measurement outcomes, especially goal-of-care preference, were used after modification without a formal validation process

Author, Year	Intervention	Nurses' Training	Impact on ACP	Limitations
(cont'd)			<p>terminal condition, $p = 0.003$; 67% to 80% in a bedridden condition, $p < 0.001$).</p> <p>The number of participants who designated a health proxy increased from 29% to 65% in the intervention group and from 22% to 52% in the control group, respectively ($p < 0.001$ each)</p>	
Gabbard et al., 2021	<p>The nurse navigator completes a brief pre-visit, telephone-based ACP planning discussion. The nurse navigator then rated patient's level of engagement as either pre-contemplative, contemplative, or action phase. They then scheduled the patient for an in-person dyad visit with their surrogate</p>	<p>Nurse navigators were trained in ACP using <i>Respecting Choices</i>, participated in 1-hour training session to review the protocol and the telephone version of ACP-wise and observed a short role play example of a telephone pre-visit ACP discussion</p>	<p>Documented ACP within the EHR occurred in 160 patients randomized to the nurse navigator group (42.2%) as compared with 14 (3.7%) in the usual care group ($P < .001$).</p> <p>Use of billing codes for ACP visits occurred in 96 (25.3%) of 379 patients randomized to the nurse</p>	<p>Participants were recruited from a single health system, all were within an ACO population, patients who were non-English speaking or residing within a long-term care facility were excluded, and the majority of randomized patients were White.</p> <p>Given the pragmatic design,</p>

Author, Year	Intervention	Nurses' Training	Impact on ACP	Limitations
(cont'd)	decision maker or loved one and PCP in conjunction with their upcoming annual wellness visit. After completion of the ACP telephone visit, patients were mailed an ACP packet and a copy of the North Carolina Advance Directive.		navigator group, as compared with 5 (1.3%) of 380 patients in the usual care group ($P < .001$).	the depth of survey information collected from patients was limited, due to no contact with patients randomized to usual care.