

Advance Care Planning in Advanced Heart Failure

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Abstract

Background. Nearly one in five patients recently admitted to the hospital for heart failure will die within 30 days of discharge. Despite this poor prognosis, most do not recall discussing end of life preferences with a health care provider. Advance care planning helps to ensure that patients receive care that aligns with their goals and wishes, and helps engage them in shared decision making with providers in an ongoing and iterative process. The American College of Cardiology 2017 ACC Pathway for Optimization of Heart Failure Treatment recommends the use of patient decision aids followed by personalized advance care planning conversations.

Local Problem. Patients with advanced heart failure who are referred to the outpatient heart failure clinic are generally not candidates for advanced interventions such as transplant or ventricular assist devices and are at high risk for hospital readmission. The purpose of this project was to align clinic practice with current recommendations by increasing the number of ACP conversations conducted by nurse practitioners through implementation of a patient video decision aid as a catalyst for conversation.

Interventions. During a follow-up outpatient visit to the clinic after hospitalization, patients were shown a 6-minute video introducing them to ACP. The video describes levels of medical care they may choose if they become sick including life prolonging care, limited medical care, and comfort care. The video was shown by clinic staff, which included a community health worker, a nurse coordinator and an infusion nurse. Follow-up conversations were conducted by clinic nurse practitioners and documented in the electronic health record using standardized documentation. Data collection occurred over 10 weeks and data were compared to a comparable period in the preceding year.

Results. Nearly one third (n=62, 30%) of eligible patients were shown the ACP video and nearly two thirds (n=40, 65%) of those who saw the video had a follow up ACP conversation with a nurse practitioner. This was a 20-fold increase from two documented ACP conversations in a comparable period in the preceding year. A chi-square test was used to test associations of the occurrence of ACP conversations at baseline and after the instructional video was added to visits. Using a nominal scale, patients seen after the video was added were significantly more likely to have an ACP conversation initiated by the provider ($\chi^2 = 19.66$, $df = 1$, $p < .001$). There was no difference between the baseline and implementation groups in whether patients had an advance directive in the medical record ($\chi^2 = .14$, $df = 1$, $p < .05$).

Conclusion. Use of a video decision aid was an effective way to increase the number of ACP conversations with patients who have advanced heart failure. The sustainability of this practice change hinges on access to appropriate patient video decision aids. The use of Medicare ACP billing codes may offset the cost of video access.

Advance Care Planning in Advanced Heart Failure

Advance care planning (ACP) is a process for people to prepare for a time when they are not able to express their own wishes for medical care. The ACP process incorporates clarification of patients' values, or what matters most to them, and specifying treatment options that align with their values. The process also involves designation of a surrogate decision maker to make decisions on their behalf in the event they are not able to do so. At either end of the continuum of decision making are 1) prioritizing life goals or beliefs that align with prolonging life with active treatment or 2) prioritizing comfort and quality of life over treatments that may or may not be life-prolonging (Butler, Ratner, McCreedy, Shippee, & Kane, 2014). At any point on the continuum, patients must be able to understand their prognosis and weigh the potential costs and benefits of possible treatment and care options if they are to make informed decisions that align with their values.

A patient's level of health literacy may affect their ability to accurately assess the pros and cons of treatment options and understand the implications of treatment choices. Low health literacy correlates with higher use of aggressive interventions and is an independent risk factor for poor health outcomes (Vollandes & Paasche-Orlow, 2007; Vollandes, et al, 2008). A systematic review of health literacy and heart failure by Cajita, Cajita, and Han (2016) found that an average of 39% of patients with heart failure have low health literacy.

Chronic heart failure (HF) is a terminal disease process with significant effects on quality of life. The American Heart Association (AHA) forecasts that by 2030 more than eight million adults in the United States will be living with HF and total medical costs associated with HF are expected to rise to \$69.7 billion (Heidenreich, et al., 2013). Approximately one-half of patients

with HF die within five years of their diagnosis and up to 18% of patients recently admitted to the hospital for HF die within 30 days of discharge (Marchetti, et al, 2016; Wedel, et al, 2009).

Despite these statistics, individual prognostication is difficult because patients with HF have an unpredictable course with exacerbations, relatively stable periods of recovery, and decline that can be gradual or precipitous in between (Goodlin, 2009). In addition, providers and patients can be uncomfortable discussing limited prognosis and plans for end-of-life (You, et al., 2017). The American College of Cardiology (ACC) Foundation and American Heart Association (ACCF/AHA) National Guideline for the Management of Heart Failure (Yancy, et al., 2013) recommends that clinicians discuss ACP and resuscitation choices with patients starting early in disease progression. However, one study found that 83% of patients who were hospitalized with advanced heart failure did not recall discussing end of life preferences with their doctor (Young, Redfield, Strand & Dunlay, 2017). Uncertainty about timing of conversations and barriers on the part of both clinicians and patients contribute to this gap between recommendations and practice (You, et al, 2017; Ahluwalia, Levin, Lorenz & Gordon, 2011).

Patient decision aids support decision making by helping patients clarify goals, values, and preferences, and by providing education about treatment options and the associated burdens and benefits (Stacey, et al., 2017). They can be paper, electronic, or video based. Use of patient decision aids can foster greater patient involvement and confidence in decision making, and greater alignment of treatment choices with patient goals and values. They can be an important aid to address low health literacy. Patients demonstrate improved knowledge and more accurate risk perception when decision aids are used either before or as part of conversation with providers (Stacey, et al., 2017). The 2017 ACC Pathway for Optimization of HF Treatment

(Yancy, et al., 2018) recommends the use of patient decision aids to help patients understand treatment options prior to personalized conversations with their health care providers.

The purpose of this DNP project was to increase the number of ACP conversations conducted by nurse practitioners (NPs) in an outpatient advanced heart failure clinic by implementing a patient video decision aid to clarify levels of medical care available at end-of-life.

Goals of the Project

The goals of this project were for non-clinician clinic staff to read a narrative script and show an ACP decision-support video to more than 50% of patients on their second or subsequent clinic visit after hospital discharge. This set the stage for the primary goal, which was to increase the number of advance care planning conversations with NPs to greater than 50% of patients who saw the video during the ten-week implementation period. A systematic review that included 795,909 people in 150 studies found that approximately one third of United States adults had completed an advance directive (Yadav et al., 2017). ACP conversations were not tracked. The project goals were based on these findings and the experience of a local community hospital outpatient heart failure clinic that implemented an ACP video decision aid and achieved a 50% rate over three years (J. Patton, personal communication, February 5, 2018).

A potential secondary effect of increasing the number of ACP conversations was an increase in the number of documented advance directives among patients who were engaged in ACP conversation. All ACP conversations do not inevitably lead to completion of advance directives, however without the conversations, advance directives are unlikely to happen.

Theoretical Framework

This project used the Promoting Action on Research Implementation in Health Services (PARiHS) model as both a framework for organization and a guide to implementation (Rycroft-Malone, 2010). The three key elements of the framework as proposed by Kitson, Harvey and McCormack (1998) are evidence, context, and facilitation. Evidence describes the quality of available evidence, its robustness and accessibility. Context refers to the culture and leadership of the site, the resources available and the types of evaluation used such as clinical, performance, economic, and experience. Facilitation incorporates skills and attributes necessary for the structures and processes of the practice change. This process includes learning and teaching approaches, sustained partnership, and critical reflection. The PARiHS model also encompasses ideas of role clarity, teamwork and effective organizational structures.

The project organization phase was guided by the first two elements, evidence and context. The strength and quality of the evidence was evaluated in the context of the identified practice problem. Evidence-based solutions to the problem were then evaluated for practicality given the resources, opinion leaders, decision making style and relationships between managers and workers at the site.

The implementation phase was guided by the facilitator but shaped by and adapted to context, such as stakeholders' roles and organizational structure. Kitson, Harvey and McCormack (1998) were careful to distinguish between the facilitator of a project and the local opinion leaders. The facilitator may be a person from outside the organization who initiates the project and guides its implementation but does not assume responsibility for long term, day to day practice change. Local opinion leaders are the formal or informal power brokers within the organization whose buy-in is important to the project's sustainability. Through emphasizing

context and facilitation, the goal of the PARIHS framework is explicitly to create sustainable change (Rycroft-Malone, 2010).

Theoretical Framework in Context

A review of evidence was conducted to determine existing solutions to the problem of inadequate ACP in the advanced HF population. An ACP video decision aid was identified as an intervention that addresses the root problem of health literacy by offering plain language descriptions and visual images of levels of medical care that is available to patients who are approaching end-of-life. These levels of medical care include comfort care focused on quality of life, limited medical care providing selected interventions, or all therapies including cardiopulmonary resuscitation and mechanical ventilation. The evidence supporting video decision aids was moderately strong, with stronger evidence in situations where the video intervention was part of an organizational culture and practice change (El-Jawahri, et al, 2016; Sadeghi, et al, 2016; Volandes, et al, 2013).

The context of the outpatient HF clinic was evaluated through conversations with stakeholders for the likelihood of successful practice and culture change. Clinic NPs, the nurse manager, and nurse coordinator, were receptive to improving ACP discussions and the lead NP, who was an opinion leader, was particularly supportive. Barriers to provision of quality ACP in the outpatient HF clinic include gaps in education and skills on the part of clinic staff and providers, as well as patient barriers. One NP provider reported “not knowing what to say” or when to initiate ACP discussions.

The role of the DNP project leader was to act as facilitator. The facilitator assessed the needs of clinic staff, the existing workflow and methods to incorporate process change while facilitating work flow. The facilitator also assessed knowledge, skills and training needed to

operationalize the video intervention and subsequent ACP conversations. Effective facilitation fostered stakeholders' investment in the practice change and thereby increased the likelihood of sustainable change by growing site champions to take ownership of the new practice.

The steps of implementation and uptake of the new practice were appraised throughout and were regarded as successful when NPs initiated ACP discussions with at least half the patients who saw the video by their final visit to the clinic.

Literature Review

This literature review will describe the evidence for the use of VDAs in ACP conversations with patients. The review will start by examining patient decision aids in general for their effect on patient knowledge, clarification of values, risk perception, and patient participation in decision making. Next, the use of decision-support videos in seriously ill patient populations will be explored to examine the effect on patient knowledge, comfort with video format, and patient preferences about disease prolonging treatments versus comfort care following the intervention. For evidence level and quality ratings for each article, see review table in appendix A.

Before proceeding, it is important to note that a number of the studies included in this review use the following terms which require clarification: "comfort care" to indicate aggressive symptom management representing a valuation of quality of life over length; "life-prolonging treatment," which may include intubation, and CPR, and may or may not prolong life and/or suffering; and "limited treatment" or "limited medical care" to indicate an in between choice that may include most medical management up to, but not including, intubation and CPR.

A 2017 Cochrane systematic review and meta-analysis of patient decision aids for patients who were considering health treatments or screenings included 105 studies involving

31,043 participants published from 1806 through April 2015 (Stacey, et al.). Reviewers found high quality evidence to support an increase in patients' knowledge, decreased indecision about personal values, as well as decreased decisional conflict related to feeling uninformed. Moderate quality evidence supports increased accuracy of risk perception, and a reduced number of people who were passive in the decision-making process. Lower quality evidence supports improved congruency between patient values and care choices. This meta-analysis indicates that a variety of decision aids are effective at increasing patients' knowledge of treatment options and outcomes, clarifying what matters most to them, and improving confidence in their ability to make choices. It further indicates that after using decision aids, patients are better able to accurately assess the risks of treatment against the benefits, able to take a more active role in the decision-making process, and feel equally or more satisfied with their decisions. Furthermore, the studies did not report adverse events with the use of decision aids (Stacey, et al., 2017).

In an earlier systematic review and meta-analysis of video decision aids to assist with ACP specifically, Jain and colleagues (2015) reviewed 10 randomized controlled trials with 2220 patients. The reviewers found moderate quality evidence that video decision aids for ACP increased patient knowledge of ACP. Additional evidence suggests that video decision aids increase the likelihood patients will forego cardiopulmonary resuscitation. One article included in this analysis focuses specifically on video decision aids in advanced cancer because the need to prioritize treatment based on care goals is similar in advanced cancer and HF (although disease progression in HF is less linear). Volandes et al. (2013) used a video decision support tool for cardiopulmonary resuscitation (CPR) decision-making in advanced cancer. Participants in the intervention arm were read a script and then shown a 3-minute video that uses realistic images showing three types of care: intubation and CPR, medical management without

intubation or CPR, and comfort care. The control arm was read the same script describing the three levels of care without the video. Patients who saw the video had higher knowledge scores. They were also more likely to forego CPR both immediately following the intervention and in a six week follow up phone call. Video decision aids are a new development with the advent of internet access for distribution and portable devices for viewing. While there are fewer studies of decision aids that use video, the evidence for them is consistent with the evidence for decision aids in general. Improving patient knowledge enables patients to make more educated assessments of the risks and benefits of treatment, and to take a more active role in decision making (Vollandes & Paasche-Orlow, 2007; Vollandes, et al, 2008).

A recent randomized controlled trial conducted by El-Jawahri and colleagues (2016) examined a similar video decision aid to facilitate ACP for patients with advanced HF. This trial included 246 patients, 64 years or older with an estimated likelihood of death greater than 50% within two years and used both a narrative script and brief video intervention. As in Vollandes' study (2013), both the script and a 6-minute video describe three categories of care (life-prolonging care, limited care, and comfort care) and CPR/intubation. The video also included an ACP checklist. Researchers found that although intervention and control groups were similar at baseline, the intervention subjects were more likely to forego CPR and intubation and had higher mean knowledge scores. The intervention subjects were also more likely to choose comfort care (aggressive symptom management) or limited medical care and less likely to choose potentially life-prolonging treatments that added to their symptom burden. The researchers concluded that patients who watched the video in addition to listening to the narrative description had a better understanding of their options and were more likely to prefer medical care that focused on quality of life and comfort. Importantly, participants who watched the video were also more

likely to have follow up goals-of-care conversations with their providers at one month (40% vs. 6%; $P<0.001$) and at three months (61% vs. 15%; $P<0.001$) after the intervention. These findings underscore the value of a video decision aid as a catalyst for conversation with providers.

Sadeghi, Walling, Romano, Ahluwalia and Ong (2016) conducted a smaller feasibility study that explored the use of a non-clinician health educator to deliver an ACP intervention similar to the preceding studies. Sadeghi and colleagues (2016) used a brief video shown by a hospital-based health educator to initiate ACP conversations. There were 37 participants, 70% of whom said they were more likely to talk with their provider about end-of-life preferences following the intervention. Furthermore, 92% of the participants rated the video component as helpful. The number of patients with a signed POLST form in the medical record increased from 27% to 43% in the six-month follow up chart review. This study's recruitment process may be a source of selection bias with 40% of eligible patients declining to participate. However, study authors concluded that not only is the use of non-clinician health educators feasible but also that using a video decision aid may facilitate ACP discussions.

Finally, the American College of Cardiology followed its 2013 guidelines with a 2017 expert consensus decision pathway for heart failure treatment that includes, as one of ten "pivotal issues," how to integrate palliative care and transition to hospice care (Januzzi, et al., 2018). The expert panel recommends soliciting goals of care throughout the disease process by using patient decision aids, followed by personalized and ongoing conversations. These conversations should occur at least annually and include anticipation of treatment decisions and advance care directives that identify surrogate decision makers. Unfortunately, the Advanced Care Training module for patients from the Heart Failure Society of America (<http://www.hfsa.org/module-9/>) that the panel recommends requires a moderate level of patient health literacy.

The evidence supports the use of video decision aids to increase the number of ACP conversations conducted by NPs in an outpatient advanced HF clinic. Video decision aids address low health literacy associated with poor health outcomes by using visual aids and plain language narration to improve patient knowledge of the process and content of ACP. Patients who have been shown a video decision aid for ACP are primed for follow-up conversations, and subsequent initiation of those conversations may be easier for both the patient and the provider. In the outpatient HF clinic, where the majority of a NPs time with patients is spent in symptom and disease management, finding the time and creating the opening for such necessary conversations can be a daunting task. Following the lead of Sadeghi, et al., (2016), this quality improvement project was designed to optimize the roles of clinic staff by having non-clinician community health workers perform the initial intervention of reading a brief script and showing a brief video about ACP, thus facilitating clinic NPs in conducting follow-up ACP conversations.

Implementation Plan

Project Description

The goal of this quality improvement project was to increase the number of advance care planning (ACP) conversations held by nurse practitioners (NPs) with patients who have advanced heart failure in an outpatient heart failure clinic associated with a large, urban, academic medical center. ACP incorporates clarification of patient values and goals, designation of a surrogate decision maker, and resuscitation preferences. A validated six-minute video decision aid developed by *ACP Decisions* was shown to patients at a follow-up clinic visit as a catalyst for ACP conversations with clinic NPs by the patients' final clinic visit. The community health worker, nurse coordinator, or infusion nurse introduced the video decision aid using their own words then showed the video on a monitor in the patient's private exam room. See appendix B for the narrative script used initially by clinic staff to introduce the video as they developed

their own language. Patients were included on their second or subsequent visit if they were 18 years or older, understood English, and had no cognitive impairment. They could decline to watch the video or to have follow-up ACP conversations. All three clinic NPs participated in ACP conversations.

Procedures and Timeline

This quality improvement project was implemented over 14 weeks. During week one and two, two 60-minute training sessions (see Appendix C) were held, the first to educate facilitators on the background of the project: the scope of the problem, the guideline recommendations for ACP, and how video decision aids facilitate ACP by addressing health literacy. This training included review of the narrative introduction script and viewing the video decision aid.

Facilitators were encouraged to share their personal experience of advance care planning and end-of-life decision making, as well as questions or concerns about initiating the video. Nurse practitioners were trained in specific skills for conducting ACP conversations using a structured Serious Illness Conversation Guide from Ariadne Labs (2017) (see Appendix D).

During weeks 3-4 there was a run-in period of implementation without data collection to refine the implementation process. Patients were read the narrative script and shown the video decision aid on their second or subsequent visit to the clinic. NPs invited the patients to participate in follow-up ACP conversations either on the same visit they saw the video or a subsequent one. The project leader was on site weekly for the morning huddle to review patients scheduled for that day, and as needed to observe the practice change, evaluate the process, and facilitate implementation. Data collection was conducted during weeks 5-14 of the implementation.

Data Collection and Analysis

The care team used the clinic patient report sheet during the morning huddle to track the use of the video decision aid and follow-up ACP conversations. Patient report sheets were maintained and kept by the nurse coordinator. Demographic, video, ACP conversation, and advance directive data, was collected through Epic reports which were generated bi-weekly from the electronic medical record. Data from the implementation period was compared with baseline data from patient charts using the Epic report function for a comparable 10-week period in the previous year to compare the number of documented ACP conversations that were held and to determine if there was a secondary effect of increased documentation of advance directives during implementation. Basic demographic data was compiled using audit tools without patient identifiers (See appendix F). Data analysis was conducted following completion of data collection.

Submission to Institutional Review Board

No protected health information was collected. Electronic data was stored on a private computer that was not networked. Hard copies of data were kept in a locked file drawer in a locked office. A project description was submitted to the University of Maryland at Baltimore Institutional Review Board for determination of Non-Human Subjects Research.

Sustainability

Based on the PARIHS framework, this project used methods to improve the likelihood of sustainability (Kitson, Harvey & McCormack, 1998). Early involvement of clinic staff included: clinic nurse manager and lead NP were engaged in initial planning phases, and the nurse coordinator and community health worker were solicited for ideas about integrating the practice change into existing processes, and necessary changes to process. The lead NP understood the gap between guideline recommendations for ACP and current practice and expressed a desire to

address this (C.Wade, personal communication, January 2018). Additionally, based on published evidence and the experience of a nearby community hospital, the use of a video decision aid was jointly identified with the lead NP as a strategy to increase the number of ACP conversations. The number of ACP conversations was trackable so that providers received regular feedback. As providers changed their practice and became more comfortable with ACP conversations, the culture of the clinic changed, which reinforced the practice change. NP clinicians and staff facilitators voiced disappointment at having to stop using the video (due to lack of funding) after the designated implementation period. Starting in 2016, Medicare designated two Current Procedural Terminology (CPT) codes that can be used to bill for ACP as frequently as every day if there is a reason, such as a change in patient medical status, or a conversation about or documentation of wishes for end of life care. The reimbursement rate is \$86 for the first 30 minutes in a provider's office (CPT billing code 99497), and up to \$75 for an additional 30 minutes of consultation (CPT billing code 99498) (Zeitoun, 2015). Use of these codes may incentivize providers and practices to conduct appropriate routine and iterative end of life planning conversations and may offset or even exceed the expense of video access.

Results

As represented in Table 1, the majority of the patients (N=197) who were eligible to be shown the ACP video were male (n=124, 63%), and black (n=162, 82%). Less than two percent (n=4) of patients were Hispanic, Native American, Asian or other heritage. Ages were normally distributed with three quarters of patients in the 46-75 year-old range (n=151, 76%), and only ten percent older than 75 (n=20). The mean age was 60 (SD=13).

The percent of patients with advance directives on file during the implementation period (September 24 – November 30, 2018) was compared to a group of 108 patients from the prior year (September 18 – November 24, 2017). As represented in Table 2, the baseline group was

slightly older with a mean age of 61.5 (SD 12.8) and 15% were older than 75 (n=16). There were slightly fewer but still a majority of black or African American patients (n=83, 77%), and the gender distribution was more balanced but still skewed toward males (n=61, 57%).

Nearly one third (n=62, 30%) of eligible patients were shown the ACP video. Video viewings were tracked by day and by the week using the ACP Decisions website reporting function and by the use of a designated phrase in the electronic medical record (See figures 1 & 2). As shown in Table 3, of patients who saw the video, nearly two thirds (n=40, 65%) had a follow up conversation with a nurse practitioner to discuss advance directives, surrogate decision making, and levels of medical care they would want if their health deteriorated and they were not able to make decisions. A chi-square test of independence was used to analyze the associations between 2017 baseline data and the 2018 implementation period. A chi-square test was used to test associations of the occurrence of ACP conversations at baseline and after the ACP video was added to patient visits. Using a nominal scale, patients seen after the video was added were significantly more likely to have an ACP conversation documented by the provider ($\chi^2 = 19.66$, $df = 1$, $p = <.001$).

Nurse practitioners did not track the number of patients who declined to discuss ACP or the reasons they declined, but each felt they had three or fewer patients who declined (See table 3 and figure 1). NPs reported that the balance of patients who did not have a follow up ACP conversation had visits that were limited by time (inadequate staffing, patient over scheduling, or high patient acuity with the need for extensive symptom management) or they were not documented in the electronic medical record using the capturable Smart Phrase.

Twenty eight percent of the implementation group and 26% of the baseline group had advance directives in the medical record. A chi-square test of independence was used to analyze

associations and there was no difference between the baseline and implementation groups, $\chi^2 = .14$, $df = 1$, $p = .71$ (See table 5).

Three changes were made in the process of implementation. During week three the CHW, nurse coordinator, and infusion nurse, who initiated the majority of video viewings, revealed that they were no longer using the script but had adapted it to their individual style and were introducing the video in their own words. They expressed greater satisfaction and confidence using this approach, stating that the script was cumbersome and felt too formal in the context of their relationships with patients.

Fluctuations in the number of videos shown in the first five weeks (See Figure 1) prompted a process review with the nurse manager of the clinic. This review led to a change in the daily huddle process during week five to clarify accountability by assigning a specific person to be responsible for showing the video to an eligible patient on the schedule that day, as opposed to just noting that a patient was eligible. Lastly, a Smart Phrase was created in week six to document when a patient declined to watch the video. This Smart Phrase was used for the last half of the implementation period, during which there were three patients who declined to view the video, less than 10% of those who were invited to watch it.

Changes to the huddle process increased the number of patients who were shown the video from 26 in the first five-week period to 36 in the second five-week period (Figure 1), however NP follow-up conversations decreased in the second half of project implementation (16 versus 24).

Clinic staff had not identified the need for advance care planning but rapidly adopted this quality improvement project. Their buy-in was essential to the success of the project and the degree of buy-in was an unexpected facilitator of the implementation of the video decision tool.

The NPs and patients benefited from the normalization of ACP conversations, as set up by the staff showing the video who used phrases such as, “We show this video to all our patients because we all need to think about what kind of care we want and who would speak for us if we are not able” (B. Porter, personal communication, October 15, 2018). Patients additionally benefited from the video decision aid because it addressed the barrier of low health literacy and allowed more inward reflective time while it was being shown. The primary failure of the project was the expense of the video for long term use. Temporary permission for use was granted for the duration of the project but the search for an equivalent video without the cost has been unsatisfactory. Open access videos have a number of problems: many are too long, have too many details, do not show appropriate images to help patients understand treatment options, do not use racially diverse actors, and narrate too rapidly, or not in plain language. The cost of purchasing access to the suite of ACP Decisions videos will require organizational buy-in. NP schedules were also a barrier to increasing the number of ACP conversations because due to illness, holidays and vacations there were a number of days when only one of the three NPs was available, and their schedule was too full for additional conversations.

Discussion

Patients who were shown a brief ACP video decision aid were more likely to engage in follow-up ACP conversations with an NP provider. There were 40 documented ACP conversations in the ten-week implementation period compared to two in the baseline period. The video decision aid was shown to nearly one-third (30%) of eligible patients and two-thirds (65%) of those who saw the video had a follow-up conversation (Goals were 50% and 50%, respectively). Literature suggests that clinicians perceive patient and family factors as the most important barriers to end of life planning in the hospital setting (You, et al, 2017). The

experience of clinic staff during this project was that most patients and families were willing and sometimes even grateful to discuss their wishes for end of life care. It is almost certainly more difficult for acutely ill hospitalized patients and their families to contemplate their wishes for end of life care, but it may also be that providers surveyed underestimated their own biases as barriers to conversation. The experience in this clinic reinforces recommendations for routine, iterative outpatient ACP conversations with HF patients to meet the ACC standard of care (Yancy et al., 2013; Yancy et al., 2018). In addition to ethical and quality of care considerations, the ability to bill for time spent in ACP provides added incentive for providers to follow guideline recommendations.

Anecdotally, NPs described increased comfort with ACP conversations as a result of the training session and as they gained experience during the project. They also credited the video for providing a standardized education that prepared patients for the conversation and they reported it was easier to segue into ACP conversation knowing their patients had watched it. After watching the video, many patients were ready to express clear wishes regarding the level of medical care they wanted and seemed to be comfortable discussing it with NP providers.

The relatively low percentage of eligible patients who viewed the video seemed to be a result of clinic context, as well as individual staff and patient characteristics, rather than patients declining to watch it. For instance, staff did not attempt to show the video and/or NPs did not attempt follow-up conversation for complex patients with heavy psychosocial burdens that were already interfering with guideline-directed therapy for HF symptom management. Likewise, the video viewing and ACP conversations were impeded by staff being busy with other responsibilities, staff and patient scheduling. In summary, if patients were asked to view the video they said yes, and if they saw the video, they were willing to talk about it.

The community health worker was primarily responsible for introducing the video decision aid. She was expert at building relationships with patients and normalizing the need for ACP conversation. Her ease with patients and with ACP for the advanced heart failure population should not be underestimated in its contribution to the high level of patient acceptance of the video. Two nurses also introduced the video when she was not available, but the majority was done by the community health worker. This corroborates the findings of Sadeghi, et al. (2016) who determined it was feasible to use non-clinician health educators to perform a hospital-based ACP video intervention to facilitate the ACP process.

There were variations in the number of ACP conversations conducted from week to week that are not adequately explained by data collected. Fluctuations in the number of providers working each day may have contributed. Patient scheduling, patient acuity, and provider bias may also have been factors. NPs expressed that they anticipated some conversations were going to be too complicated for the available time.

Many studies that examine patient preferences for end-of-life medical care seem to have a bias toward comfort care as a preferred choice. This apparent bias may in fact represent the effect of increased patient knowledge and health literacy on patient preferences. As explained by Volandes and Paasche-Orlow (2007), low levels of health literacy correlate with higher use of aggressive interventions and worse health outcomes. Patients with clearer understanding of their values, disease progression, prognosis, and treatment choices through a process of ACP are less likely to choose aggressive interventions that compromise quality of life. The video decision aid used in this project was designed to address low health literacy, thereby improving patient knowledge and understanding of all of the above.

Limitations

The project design did not differentiate the effects of NP training, comfort, and skills in communication or difficult conversations, or normalization of ACP conversations which might have been achieved other ways, from the effect of using a video decision aid. However, the use of a video decision aid, along with NP training, was an effective strategy to increase the number of ACP conversations. Bias may have been introduced because there was no tracking of how many patients declined to have ACP conversations and for what reasons, so declination of ACP conversations was based on NPs' subjective recollection.

In addition, the comparison between baseline and current documented ACP conversations may be skewed by the lack of standardized documentation used during the baseline period. It is possible there were conversations in the baseline period that were not recorded, either because the standardized phrasing was not available, or there was less focus on documentation of conversations. The lack of statistical difference in the number of advance directives between the baseline and implementation groups may be a result of the short implementation period.

Finally, the cost of ongoing access to the patient decision videos was a limitation to the sustainability of the practice change. As previously discussed, it may be possible to offset the cost through appropriate billing, but this requires not just the buy-in of local clinic administration and providers, but of the greater hospital system to commit to the upfront cost.

Conclusion

Implementation of a video decision aid was an effective way to increase the number of ACP conversations in an outpatient clinic with patients who have advanced heart failure. The video decision aid was accepted by most patients and helped the clinic normalize the process ACP. Increasing and routinizing patient opportunities for ACP are recommended in both the

2013 ACC/AHA guidelines for HF and the 2017 ACC Pathway for Optimization of HF Treatment (Yancy et al., 2013; Yancy et al., 2018). The sustainability of this project depends on greater organizational buy-in and purchasing a subscription to the video suite or committing to another decision aid. This process can be incentivized by opportunities to recapture the costs by using Medicare ACP billing codes.

Although systemic, structural, provider, and patient barriers still exist, the benefits for our patients of increased knowledge and understanding of their disease process, treatment options, and engagement in decision making are compelling reasons to increase the number of conversations we are having with them.

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Table 1
ACP in Advanced Heart Failure Implementation Group

	n	%	Range	Mean (SD)
Age	197		69	59.6 (13)
<30	5	2.5		
31-45	21	10.7		
46-60	80	40.6		
61-75	71	36.0		
>75	20	10.2		
Gender				
Male	124	62.9		
Female	73	37.1		
Race				
Black	162	82.2		
White	31	15.7		
Other	4	2		
Advance Directive in chart	55	27.9		
Yes	142	72.1		
No				

Table 2
Baseline Group

	n	%	Range	Mean (SD)
Age	108		63	61.5 (12.8)
<30	1	.92		
31-45	10	9.2		
46-60	43	39.8		
61-75	38	35.2		
>75	16	14.8		
Gender				
Male	61	56.5		
Female	47	43.5		
Race				
Black	83	76.9		
White	22	20.4		
Other	1	.92		
Advance Directive in chart	28	25.9		
Yes	80	74.1		
No				

Table 3
Video Viewings and Follow-up ACP Conversations

	n	%
	197	
Video		
Yes	62	30.5
No	135	68.5
ACP Conversation		
Yes	40	20.3
No	157	79.7

Table 4
 Conversation Pre-Post Crosstabulation

	Count	Baseline	Intervention	Total
Conversation	Observed	2	40	42
	Expected	14.7	27.3	42.0
No Conversation	Observed	105	158	263
	Expected	92.3	170.7	263.0
Total	Observed	107	198	305
	Expected	107.0	198.0	305.0

Note: $\chi^2 = 19.66$, $df = 1$, $p = < .001$. No cells (0.0%) have expected count less than 5.

Table 5

Results of Chi-square Test for Advance Directives in EMR by Group

Advance Directives	Baseline	Implementation
Yes	28 (26%)	55 (28%)
No	80 (74%)	142 (72%)

Note. $\chi^2 = 0.14$, $df = 1$, $p = .71$. Numbers in parentheses indicate column percentages.

* $p < .05$

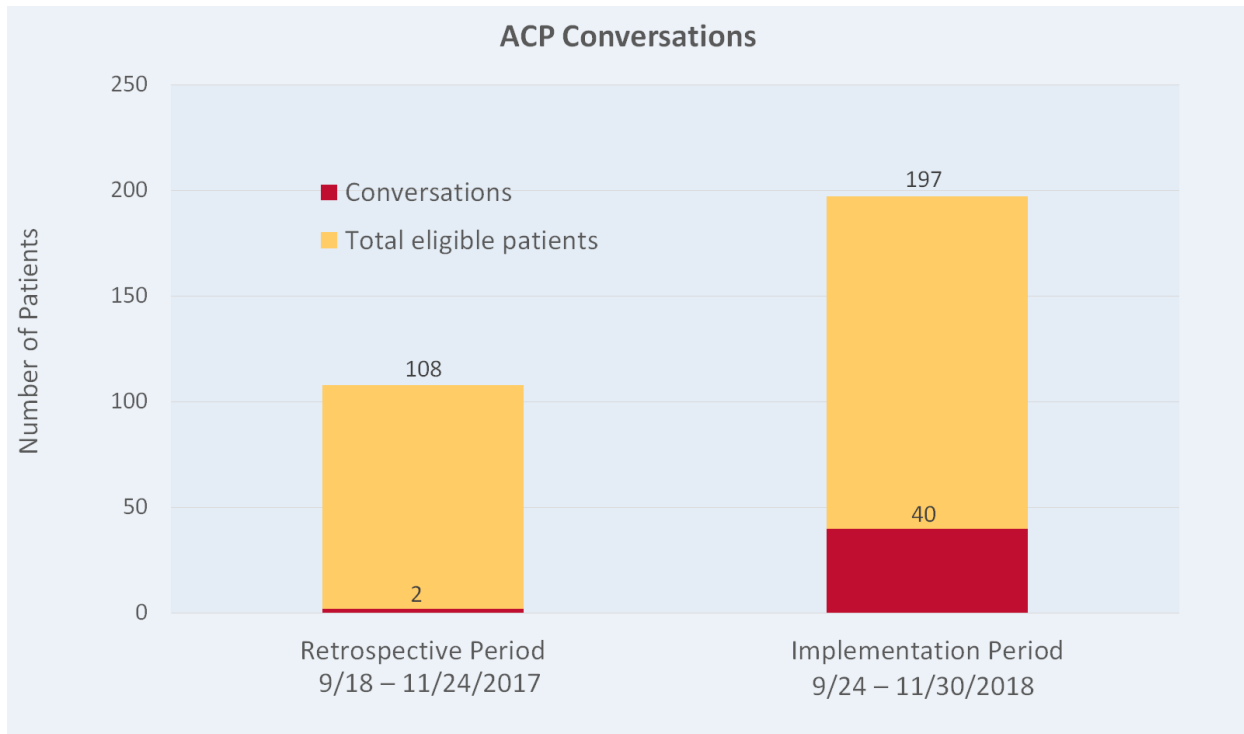


Figure 1
ACP Conversations during baseline period and implementation period

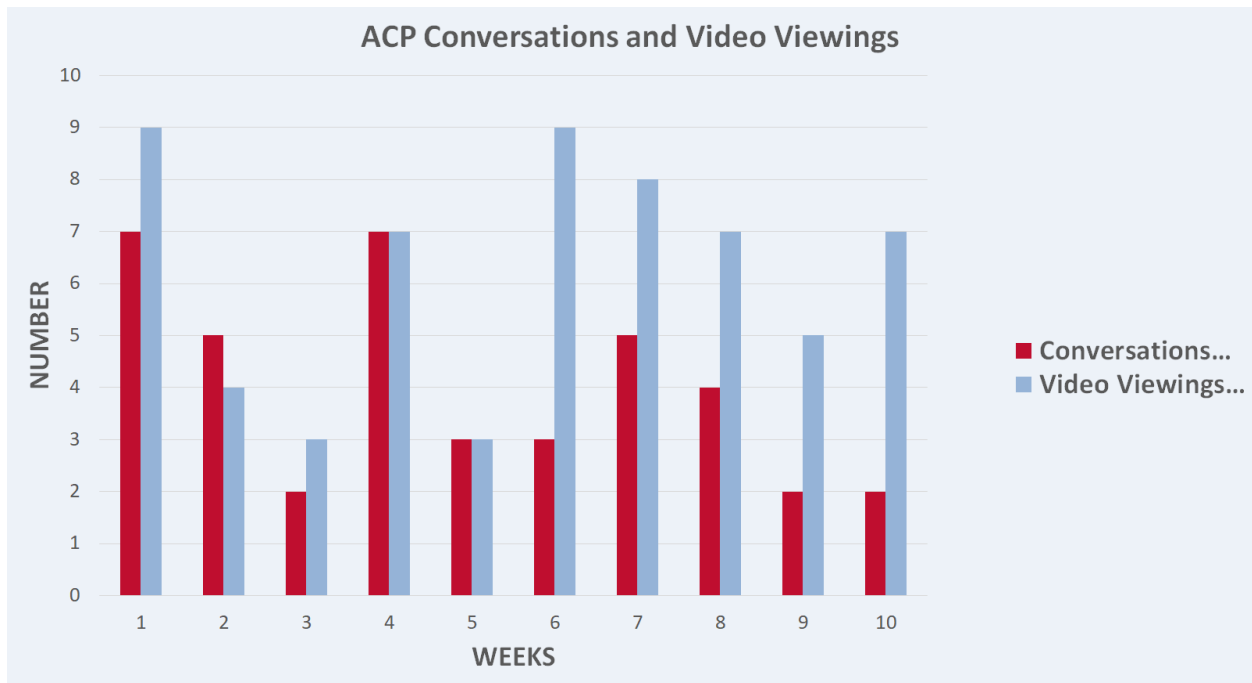


Figure 2
Video viewings and follow-up conversations during ten-week implementation period

Appendix A
Evidence Review Table

Authors (year)	Study Objectives/ Intervention	Design & Sample (<i>n</i>)	Intervention	Outcomes studied (how measured)	Results	Level/ Quality Rating*
El-Jawahri et al. (2016)	Comparison of using a goals of care video and narrative vs narrative alone for improved end-of-life care decision making	Randomized controlled trial (246) Control (123) Intervention (123)	Outpatient setting with patients with advanced cancer who received either narrative description or narrative and video of end-of-life care decisions	Preferences for end-of-life care, uncertainty, and comfort with the video 6 point pre- & post-Knowledge Assessment Questionnaire, and whether they wanted cardiopulmonary resuscitation	Intervention arm: <ul style="list-style-type: none"> • More likely to forego CPR (68% vs. 35%; $p < 0.001$) and intubation (77% vs. 48%; $P < 0.001$) • Higher mean knowledge scores (4.1 vs. 3.0; $P < 0.001$). • More likely to choose comfort care (51% vs. 30%) or limited care (25% vs. 22%) • Less likely to choose potentially life-prolonging care (22% vs. 41%) • 82% were “very comfortable” with the video 	Level II/B
Jain et al. (2015)	Review of the impact of video decision aids to assist with ACP	Systematic Review Randomized controlled trials (10) Patients (2220)	Included trials that compared a video decision aid to a non-video-based intervention to assist with choices about life sustaining treatment decisions	Knowledge related to ACP, preference for life-sustaining treatments	<ul style="list-style-type: none"> • Moderate quality evidence suggests greater ACP knowledge (standardized MD, 0.58; 95% CI 0.38 to 0.77) • Low quality evidence suggests patients were less likely to prefer CPR (pooled risk ratio, 0.50; 95% CI 0.27 to 0.95) 	I/B

Authors (year)	Study Objectives/ Intervention	Design & Sample (<i>n</i>)	Intervention	Outcomes studied (how measured)	Results	Level/ Quality Rating*
Januzzi, et al. (2018)	Expert consensus decision pathway for optimization of heart failure treatment	Expert opinion	Recommendation to use patient decision aids and personalized conversations about goals of care, advance directives and surrogate decision making	Literature review and structured conversation process conducted by an interdisciplinary panel of experts		IV/A
Sadeghi et al. (2016)	Feasibility study for use of a video decision tool	Patients (37)	In-hospital HF patients, using a non-clinician health educator and ACP video to encourage completion of advance directives	Completed POLST form or advance directives post intervention and at 6-month follow up by phone and chart review	<ul style="list-style-type: none"> • Post intervention, 49% vs. 36% of patients had a POLST or advance directive at six-month follow up ($p=0.03$) 	Level VI/B
Stacey et al. (2017)	Assess the effects of decision aids for people facing treatment or screening decisions	Systematic review Randomized controlled trials (105) Patients (31,043)	Included trials that compared use of decision aids to usual care and/or alternative interventions.	Attributes related to decision making process (e.g. decisional conflict, indecision, & passivity), to choices made (e.g. knowledge,	<ul style="list-style-type: none"> • Decision aids increased knowledge (MD 13.27/100; 95% CI 11.32 to 15.23) • Accuracy of risk perception (RR 2.10; 95% CI 1.66 to 2.66) • Congruency between values and choices (RR 	I/A

Authors (year)	Study Objectives/ Intervention	Design & Sample (<i>n</i>)	Intervention	Outcomes studied (how measured)	Results	Level/ Quality Rating*
				choice made, & risk perception)	2.06; 95% CI 1.46 to 2.91) <ul style="list-style-type: none"> • Decreased decisional conflict (<i>MD</i> -8.81/100; 95% CI -11.99 to -5.63) • Passivity (RR 0.68; 95% CI 0.55 to 0.83). • Appeared to improve patient-clinician communication. 	
Volandes et al. (2013)	Comparison of using a goals of care video and narrative vs narrative alone for improved decision making regarding resuscitation for pts with advanced cancer	Randomized controlled trial (150) Control (80) Intervention (70)	Outpatient setting with advanced cancer pts who received either narrative description of CPR and resuscitation vs the narrative plus video depiction of resuscitation in an ICU setting	Stated CPR preferences at baseline and at 6-8 weeks, Knowledge about CPR was assessed using 4 questions	Intervention arm: <ul style="list-style-type: none"> • Were less likely to want CPR (20% vs 48%; $P<0.001$). • Had higher Knowledge scores (2.6 ± 1.3 vs 3.3 ± 1.0; $p<0.001$) 	Level II/A
Yancy, et al. (2017)	Expert consensus decision pathway for optimization of heart failure treatment	Expert consensus	Recommends use of decision support tools (decision aids) followed by dynamic and personalized conversations	Multidisciplinary panel used a structured process and literature review		IV/A

Note: ACP = advance care planning; CI = confidence interval; CPR = cardiopulmonary resuscitation; HFpEF = heart failure preserved ejection fraction; HFrEF = heart failure reduced ejection fraction; MD = mean difference; POLST = physician orders for life sustaining treatment; RR = relative risk; 95% CI = 95% confidence interval; * “Examining the Support for Evidence-Based Nursing Practice,” by R. P. Newhouse, 2006, *Journal of Nursing Administration*, 36(7-8), 337-340.

Appendix B

Narrative Script

Hi, my name is _____ and I am the _____. We talk with all our patients about what kind of medical care they want. We do this so that if there is a time when you become sicker, we can take care of you in the way you want to be taken care of. This is called advance care planning. Is it okay with you to talk about this now?

There are a few steps to advance care planning. The steps of advance care planning are:

1. Learning about your health condition
2. Talking to your loved ones about what is important to you
3. Talking with your health care team about what is important to you
4. Appointing someone who will speak and make decisions for you at a time when you are not able to.

I am going to show you a video that describes advance care planning and some choices about medical care. I will first review these three choices with you. After you watch the video, you will have the opportunity to talk with your nurse practitioner to answer any questions and talk about your wishes.

The choices for medical care that I want you to think about are life-prolonging care, limited medical care, and comfort care.

With life-prolonging care, we will do everything possible to prolong your life. This would include cardiopulmonary resuscitation, or CPR, when doctors and nurses push on your chest and use electric shock to try to restart your heart if it were to stop; being placed on a breathing machine, when a tube is placed down your throat and attached to a machine to help you breathe (this is sometimes called life support); and all other medicines and procedures available in the intensive care unit, or ICU. The goal is to prolong life even if the treatment will not cure you.

The second category, limited medical care is to maintain physical and mental functions. You may be hospitalized and receive intravenous, or IV, medications like antibiotics, or a feeding tube. It does not include CPR or a breathing machine. The goal is to maintain the physical and mental functions you have.

The third category, comfort care, includes care to improve your comfort such as pain relief, food and water, and being in a place you are comfortable, such as your home. Comfort care does not include CPR or a breathing machine, or being in the ICU. It does not usually include IV medications or feeding tubes. The goal is relieving pain and maximizing your comfort.

These are the three categories you will see in the video.

Adapted from Volandes, A.E., Paasche-Orlow, M.K., Barry, M.J., Muriel R Gillick, Kenneth L Minaker, Yuchiao Chang, ...Mitchell, S.L. (2009). Video Decision Support Tool for Advance Care Planning in Dementia: Randomised Controlled Trial. *British Medical Journal*, 338. doi: <https://doi.org/10.1136/bmj.b2159>

Advance Care Planning Video

ACP Decisions video: Goals of Care for Advanced Disease (6 minutes)

Goals of Care for Advanced Heart Failure (6 minutes)

Appendix C

Lesson Plans

All Participants Training

Learning Objectives	Content Outline	Method of Instruction	Time Spent	Method of Evaluation
Describe the background of the problem and the project	<ol style="list-style-type: none"> 1. Gap between guideline recommendations for ACP and current practice 2. Role of health literacy in choices about medical care 3. Use of decision aids in ACP: patients better informed, more knowledgeable, clearer about their values, more accurate risk perception, no adverse effects on health outcomes or satisfaction. 	Direct instruction	60 minutes	Brief quiz
Define the terms advance directive, living will, health care proxy, advance care plan, & surrogate decision maker	<ol style="list-style-type: none"> 1. Examine differences and overlap between ADs and MOLST forms. 2. Differentiate between advance directives and MOLST forms 			
Describe the process of advance care planning	<ol style="list-style-type: none"> 1. Understanding 2. Reflection 3. Discussion: Goals, fears, worries, sources of strength, critical abilities, tradeoffs, family 4. Designation of surrogate decision maker 5. Designation of preferences for medical care 			
Explain ACP to people who lack understanding using the narrative script and video decision aid	<ol style="list-style-type: none"> 1. Narrative script 2. Video decision aid 3. Practice explaining 			Teach back

Nurse Practitioners ACP Conversation Training

Learning Objectives	Content Outline	Method of Instruction	Time Spent	Method of Evaluation
Recognition of and ability to address barriers to ACP conversations	<ol style="list-style-type: none"> 1. Patient barriers: anxiety, denial, desire to protect family members 2. Clinician barriers: lack of training, comfort, and time, difficulty with prognostication 3. Get comfortable with emotion 	Direct instruction	60 minutes	Teach back
Use a structured communication format for ACP conversations to help individuals make informed treatment decisions	<ol style="list-style-type: none"> 1. Serious Illness Conversation Guide (see Appendix E) 	Direct instruction Role modeling		
Develop interview skills to enhance ACP conversation	<ol style="list-style-type: none"> 1. Explore the meaning of words and phrases 2. Paraphrase/clarify 3. Verbalize empathy 4. Affirm/reaffirm the purpose of the conversation 5. Listen for themes that relate to ACP 	Direct Instruction		

Appendix D

Serious Illness Conversation Guide

Conversation Flow

1. Set up the conversation

- Introduce purpose
- Prepare for future decisions
- Ask permission

2. Assess understanding and preferences

3. Share prognosis

- Share prognosis
- Frame as a “wish...worry”, “hope...worry” statement
- Allow silence, explore emotion

4. Explore key topics

- Goals
- Fears and worries
- Sources of strength
- Critical abilities
- Tradeoffs
- Family

5. Close the conversation

- Summarize
- Make a recommendation
- Check in with patient
- Affirm commitment

6. Document your conversation

7. Communicate with key clinicians

Serious Illness Conversation Guide

Patient-tested Language

Set up	“I’d like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — is this okay? ”
Assess	“What is your understanding now of where you are with your illness?” “How much information about what is likely to be ahead with your illness would you like from me?”
Share	“I want to share with you my understanding of where things are with your illness...” <i>Uncertain:</i> “It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I’m worried that you could get sick quickly, and I think it is important to prepare for that possibility.” OR <i>Time:</i> “I wish we were not in this situation, but I am worried that time may be as short as ___ (<i>express as a range, e.g. days to weeks, weeks to months, months to a year</i>).” OR <i>Function:</i> “I hope that this is not the case, but I’m worried that this may be as strong as you will feel, and things are likely to get more difficult.”
Explore	“What are your most important goals if your health situation worsens?” “What are your biggest fears and worries about the future with your health?” “What gives you strength as you think about the future with your illness?” “What abilities are so critical to your life that you can’t imagine living without them?” “If you become sicker, how much are you willing to go through for the possibility of gaining more time?”
Close	“How much does your family know about your priorities and wishes?” “I’ve heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we ___. This will help us make sure that your treatment plans reflect what’s important to you.” “How does this plan seem to you?” “I will do everything I can to help you through this.”

