

“There’s no cure for this condition”: How physicians discuss advance care planning in heart failure.

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ABSTRACT

Objective: To evaluate the extent to which physicians engage in recommended elements of advance care planning (ACP) communication during outpatient clinic visits with heart failure (HF) patients.

Methods: We conducted a qualitative content analysis of 71 audio-recorded and transcribed outpatient visits with 52 patients ≥ 65 years recently hospitalized for HF and their physicians (n=44).

Results: We identified 25 instances of ACP-related communication over 15 of the 71 visits: In 17 instances, physicians explained the nature of HF but only once was the life-limiting potential of HF mentioned. Physicians discussed goals of care in 6 instances but elicited their patients' preferences in only 2 of those instances. Finally, physicians encouraged documentation of preferences in 2 instances.

Conclusions: Despite recommendations for early ACP with HF patients, physicians rarely engaged in fundamental elements of ACP discussions during outpatient visits. We suggest a stepwise approach to supporting the process of ACP communication in practice.

Practice Implications: Given the importance of ACP in helping patients plan for their future care, outpatient clinicians should be helped to incorporate these discussions in the routine care of their HF patients. Using a simple heuristic might help physicians engage in fundamental elements of ACP during busy outpatient visits.

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Key Words: Communication, qualitative, advance care planning, heart failure

1. Introduction

Patient-clinician communication about advance care planning (ACP) is critical to helping patients prepare and plan for their future care, by enhancing their understanding about their diagnosis, treatment, prognosis, and choices in end of life care [1]. ACP is especially important for patients with heart failure (HF), who face a highly uncertain and variable trajectory, marked by frequent exacerbations and increasingly complex treatment decision-making. HF patients report wanting to engage in ACP discussions with their physician as early as at the time of diagnosis [2], and recent guidance recommends that clinicians initiate ACP discussions in the outpatient setting, prior to and in anticipation of clinical decline, when a considered evaluation of treatment preferences is possible [3]. However, evidence that HF patients are unaware of their choices and alternatives related to future care [4-6] suggests that ACP is often underused or delayed until the end of life, or an emergent clinical need arises [5].

Providing physicians with practical guidance for conducting these often difficult and time-intensive discussions might increase the use of ACP in the outpatient setting. Although little guidance regarding the structure and process of an ACP discussion exists, various elements of ACP have been highlighted as important for physicians to engage in with their patients, including **explaining** the nature and trajectory of heart failure [2, 7-9], **eliciting** patient preferences for care [10-13], and **encouraging** patients to document their identified treatment preferences [14-17]. As part of a complete ACP discussion, these elements can help patients understand the implications of their disease, calibrate their expectations within the context of their illness, and articulate their care preferences to their providers. We previously examined if and how patients raised ACP discussions with their physicians and whether physicians responded to this opportunity [18]. In the current study we sought to evaluate the extent to which physicians

engaged in these recommended ACP elements (i.e., explaining, eliciting, and encouraging) in actual practice during outpatient clinic visits with recently hospitalized HF patients.

2. Methods

2.1 Participants and Data Collection

We obtained data from a prospective observational cohort of patients hospitalized for heart failure at two Veterans Affairs (VA) Medical Centers. Patients in this study had one or more audio-recorded outpatient post-discharge follow-up visits with a participating primary care internist or cardiologist within 6 months of their hospital discharge. From this study cohort, we selected patients age 65 years or older (N=52), because we believed ACP communication would be more likely in an older population. Of these, 19 participants had two post-discharge visits; however, we viewed each visit as a unique opportunity to raise and engage in an advance care planning discussion and thus included every transcribed visit in our analysis (n=71). An experienced transcriptionist transcribed the audio-recordings verbatim and removed all individually identifiable physician and patient information prior to analysis. We collected patient and provider demographics and provider practice characteristics through self-report. Through a chart review of echocardiography results within 12 months of admissions we recorded left ventricular ejection fraction. We also determined the number of chronic conditions per patient through chart review. We obtained physician-reported American Heart Association/American College of Cardiology (AHA/ACC) stage of heart failure with a physician questionnaire completed after the follow-up outpatient visit. This system characterizes progression of heart failure by classifying patients into 4 stages: patients at high risk for developing HF, e.g.; those with diabetes or hypertension (Stage A), patients with structural disorder but no clinical signs of

HF (Stage B), patients with current or past clinical HF (Stage C) and patients with end-stage refractory HF (Stage D) [21]. The institutional review board at both participating hospitals approved the study and patient and provider participants provided informed consent.

2.2 Analysis

We conducted a qualitative content analysis of the 71 transcripts to examine the frequency and content of care planning communication. A preliminary codebook including coding guidelines and examples was developed, guided by the three elements of ACP communication described above: a) **explaining** the nature and course of heart failure; b) **eliciting** patient preferences for care, and c) **encouraging** documentation of patient preferences. In brief, we characterized any discussion of the mechanisms, trajectory, or prognosis of heart failure as an explanation of heart failure; any discussion of patient preferences or wishes for care or any explanation of specific treatment goals (i.e.; life-prolonging or palliative) as eliciting patient preferences and goals of care; and any discussion of formal (e.g.; living will) or informal (e.g.; progress note) documentation of preferences as encouraging documentation (Table 1).

Two investigators (SCA and JRL) used this codebook to first independently code the transcripts, in order to establish consensus regarding the definition and application of individual codes. The investigators met after every 10 transcripts were coded to refine coding rules and discuss and resolve any differences in coding. We resolved coder disagreement about the presence or definition of a code through a discussion about the coding rationale with a third investigator (HSG). It was determined that consensus regarding the use of the codebook had been reached (i.e., that codes were being applied consistently) after the first 30 transcripts were completed in this manner. The remaining 31 transcripts were coded by a single investigator

(SCA), with periodic review by the entire research team to maintain trustworthiness. We calculated the frequency of ACP communication overall as well as the frequencies of each of the three elements of ACP communication. We counted each instance an element was raised during the visit; for example, if the physician explained the life-limiting nature of heart failure at the beginning of the visit, and then raised it again later in the visit, we counted that as two discrete instances of explaining the nature and course of heart failure.

3. Results

3.1 Participant Characteristics

Patient participants (n=52) had a mean age of almost 71 years, were predominantly male (98.0%), Black/African American (51.9%), and were unmarried/single (63.5%) (Table 2). Patients had mean EF of 34.4% (SD 14.5) within 12 months of study enrollment, and mean BNP of 2535 pg/ml (SD=3487) at hospital admission. Physicians reported AHA/ACC HF stage for 29 out of the 52 patients, rating 93.1% as Stage C or D. Physician participants (N=44) had a mean age of almost 38 years, were predominantly male (57.5%) and White (42.5%), and were in practice for an average of 11.4 years. The majority of physicians in our study were internists (78.1%) and practiced more than 30 hours per week (82.9%).

3.2 Frequency of ACP

We found 25 discrete instances of ACP communication over 15 of the 71 visits. There were 17 instances of **explaining** the nature and course of heart failure; 6 instances of **eliciting** patient preferences for care; and 2 instances of **encouraging** documentation of patient preferences.

In the majority of visits (11 out of 15 visits) where we identified ACP communication, physicians raised only a single element of ACP communication and in four of these 11 visits the single element was raised twice (i.e., repeated). The single ACP element in 10 of these 11 visits was explaining the nature and course of HF, and in the other one was eliciting patient preferences for care.

Less frequently, physicians raised multiple elements of ACP communication. In two out of the 15 visits where ACP communication was identified, physicians both explained the nature and course of HF as well as elicited patient preferences for care (i.e.; 2 ACP elements). In another two visits, physicians explained the nature and course of HF, elicited patient preferences for care, and encouraged documentation of identified preferences (i.e; all 3 ACP elements).

3.3 Content of ACP

When explaining the nature and course of heart failure to their patients, physicians often provided a general definition of heart failure without specifically referring to the progressive or life-limiting nature of the disease (n=10 instances).

“Congestive heart failure...the heart doesn't squeeze very well. There is a number called the ejection fraction. The ejection fraction is how much do you pump out with each beat. Normal would be about 60%...congestive heart failure we start talking about when people eject less than half or 40%. Last time we checked [yours] was about 35%. So that's low.”

“There's portions of your heart that are weak, that barely beat. So they're not beating as strong. Normally your heart would beat real strong beats if everything is normal. Some of your heart is just beating at maybe 50% of where it used to be.

In a few instances (n=6), physicians did specifically describe the progressively declining trajectory of heart failure:

“Unfortunately that's the nature of the disease that's going on. When the heart gets weak it's very difficult to get it better. The best things we generally can do, we want to keep it from getting any worse.”

“Your condition may not get a whole lot better, but sometimes it could get worse too, so you need to realize that there are some things which you may not be able to do like you were doing before.”

In only one instance did a physician refer to the terminal nature of the disease:

“The medications can control your symptoms and make you feel better and even increase the life expectancy, but there is no cure. There’s no cure for this condition”.

When eliciting patient preferences for care, physicians often (4 out of 6 instances) described specific treatment goals or expected outcomes without actively eliciting their patients’ preferences for that treatment:

“Getting to a significant dose of your beta blocker is probably the most important thing to do for you. That is the medication that will decrease the chance of dying. It will prolong life. That’s why we increased it.”

“The digoxin they started because it can make your heart beat stronger. It doesn’t really help in terms of mortality, but it helps in terms of making your symptoms of shortness of breath better and it reduces the time that you need to come in the hospital because of your heart problem.”

In all six of these instances, the physician refers to the broader care goals of life-prolongation and palliation within the context of routine HF treatments, but overlooks the opportunity to engage the patient in a deeper discussion of their preferences for these goals. In two instances, physicians did actively elicit their patient’s preferences for care; in both cases, for life-sustaining interventions.

DR: Now, do you know if, say you were having trouble breathing and they said they might need to put a tube down your throat to hook it up to the respirator, would you want to do that?

PT: Anything that keeps me alive.

DR: Okay. And the same thing, I presume, if your heart stops. Would you want them to do shocking and CPR and all that stuff?

PT: Oh, yeah, I want that. Anything that keeps me alive, it’s okay.

Physicians encouraged documentation of patient preferences by either recommending formal documentation of a surrogate decision-maker (n=1) or by recommending the completion of a living will (n=1).

“Do you have a power of attorney? Somebody to make decisions for you if you can’t make them? So it’s important that you put it on paper, and we can set you up with the social worker to get that paperwork done”.

“You need to think what you would want to be done if your heart stops or you stop breathing. I don’t know whether you’ve addressed a living will with your loved ones...but I think you should make a recording by a living will, advanced directive, that you should not go on life support.

4. Discussion and Conclusion

4.1 Discussion

In this study of recently hospitalized heart failure patients, physicians infrequently used ACP communication during clinic visits after the HF hospitalization, and those who did often raised only a single element of ACP rather than engaging in more complete discussions that addressed all three elements as recommended in the literature. These physicians frequently explained the nature and course of heart failure by providing a general definition of HF and its mechanisms, but rarely mentioned the progressive or life-limiting potential of the disease. Elicitation of patient preferences for care, or encouraging documentation of patient preferences was uncommon. Although prior ACP discussions were not reviewed as part of this study, our data suggest that clinicians underuse a recommended [3, 25, 26] method of care delivery.

Physicians often delay communication about goals of care until emergent clinical situations [27]. Reported barriers to engaging in ACP with HF patients include a lack of time during the clinic visit for the conversation [28], not knowing what aspects of ACP to discuss, and a lack of skill and comfort with having the discussion [4]. Despite attention to the importance of ACP communication in cancer [29-43], less attention has been paid to either the outpatient setting or patients with serious non-cancer conditions [44]. Future research and quality improvement efforts should focus on identifying and leveraging opportunities for facilitating ACP communication and our study suggests that those efforts have to address the basic process as well as skill involved in effective ACP communication. .

Prior research has shown that the use of mnemonics to help clinicians remember what to say when communicating with their patients about bad news can improve clinician confidence

and skill with the task [29, 46, 47] In a similar manner, offering physicians practical guidance for conducting ACP conversations might increase such communication in the outpatient setting. We suggest that combining multiple elements of ACP communication into an ordered communication schema might provide physicians with a structured roadmap for conducting comprehensive ACP discussions. These elements (i.e., explaining the trajectory of illness, eliciting preferences, and encouraging documentation) were underused in the current study. The use of an easily taught heuristic to reflect this schema (e.g.; “The 3 E’s”) might serve to remind busy outpatient physicians, as well as non-physician providers, of the recommended components of ACP communication. Existing communication training for providers caring for cancer patients have employed a similar approach to improve communication [38]. Communication is a teachable skill, and offering clinicians a practical guide to the content of the ACP discussion might increase the use of such communication.

In addition to supporting the content of an ACP discussion, the proposed 3 E’s approach might also be used to facilitate repeated discussions over time about ACP. Because this approach involves discrete but related steps that build upon each other, physicians can use this model to discuss ACP over multiple visits, based on the patient’s preferences for communication and readiness to engage in ACP [48, 49]. Guidelines for the care of HF patients recommend having multiple care planning discussions over the course of the illness, to review and reconfirm patient preferences and decisions, particularly at key milestones [3]. Although we lacked data to examine ACP communication longitudinally, future research might examine the utility of this approach to supporting engagement in ACP over time, particularly in the outpatient setting.

Difficulty in identifying the “right” patient for an ACP discussion might also contribute to the underuse of ACP communication, particularly in the outpatient setting, where HF patients may be well compensated. Overcoming this difficulty would need to be integrated into an approach to increasing ACP communication. A sentinel event such as a hospitalization may help to contextualize a discussion about future care, serving as a prompt for clinicians and providing a useful entrée into an ACP discussion. In addition, certain elements of ACP might be relevant to all HF patients (e.g.; identification of a healthcare proxy) and indeed, to any patient with a serious progressive illness. While previous efforts to increase ACP communication have focused on patients who are near the end of life or whose illness trajectory is clearly terminal, future efforts should be aimed at helping providers initiate these conversations earlier in the course of the illness trajectory.

Our findings should be interpreted in the context of several limitations. First, we examined a cross-section of clinic visits and are unable to determine if ACP discussions had occurred previously. Second, documentation of advance directives was not collected as part of the larger cohort study and was therefore not available for the current analysis. It is possible that physicians did not raise ACP communication with patients with whom they had already had the discussion or with patients who already had documentation of preferences in their medical record. However, recent guidance regarding decision making in heart failure [3] supports frequent and iterative patient-clinician conversations about ACP. Moreover, given evidence that patient preferences for care change over time and with health events such as hospitalizations [51, 52], prior ACP communication or documentation should not preclude future conversations but could instead be used to stimulate further exploration of care preferences. Third, we analyzed transcribed audiorecordings of outpatient clinic visits, and were unable to evaluate non-verbal

communication behaviors. It is possible that both physicians and patients may have presented non-verbal cues that would provide additional explanation of the low levels of ACP that we found. Fourth, some of the quoted statements from physicians to patients appear to highlight an inaccurate depiction of HF or its treatment (e.g., "when the heart gets weak it's very difficult to get it better", or "there's portions of your heart that barely beat"). Although we did not specifically evaluate the quality and accuracy of language used by clinicians to provide information to patients, these statements highlight the possibility that physicians had difficulty conveying information regarding HF to their patients. Fifth, because our sample was largely limited to male U. S. Veterans age 65 and over and was small our findings about the frequency of ACP communication may not generalize to other patient populations. Nonetheless, our finding of none or low rates of ACP communication in a sample of severely ill HF patients highlights potential underuse of ACP and suggests that it is difficult for physicians to use recommended ACP communication.

4.2 Conclusion

Communication about ACP is particularly important for recently hospitalized patients with HF, who are at risk for increased mortality, readmission, and poor quality of life. Findings suggest that among this population, important elements of ACP communication occur infrequently if at all. We propose one possible framework for helping physicians to view the ACP discussion as the sum of three related steps – explaining the illness trajectory, eliciting patient preferences, and encouraging documentation of preferences. This 3 E's model might be used in practice for guiding and conducting the ACP discussion, and in communication training

programs aimed at improving ACP discussions among patients with variable illness trajectories.

4.3 Practice Implications

Reserving ACP discussions for the end of life or emergent clinical situations may deny patients the chance to adequately prepare for and plan their future care. Given the growing number of clinical and administrative tasks that outpatient physicians have to manage today, it is important to find ways to help them incorporate these discussions into their management of patients with HF. A simple heuristic focused on certain critical elements of ACP might be successfully employed to increase ACP discussions during outpatient clinic visits.

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I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story

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