Missed opportunities for advance care planning communication during outpatient clinic visits

Sangeeta C. Ahluwalia, PhD, MPH[*], Jennifer R. Levin, PhD[†], Karl A. Lorenz, MD, MSHS[†,‡]

Howard S. Gordon, MD[§,‖]

[*]Center for the Study of Healthcare Provider Behavior, VA Greater Los Angeles Healthcare System

[†] Veterans Administration Greater Los Angeles Healthcare System, Los Angeles, CA

[‡] Geffen School of Medicine at UCLA, Los Angeles, CA

[§]Jesse Brown Veterans Affairs Medical Center and VA Center for Management of Complex Chronic Care, Chicago, IL

[‖] Sections of General Internal Medicine and Health Promotion Research, Department of Medicine, University of Illinois at Chicago College of Medicine, Chicago, IL.

Corresponding author and Requests for Reprints: Sangeeta C. Ahluwalia, PhD, VA Greater Los Angeles Healthcare System, 11301 Wilshire Blvd. 111-G, Los Angeles, CA 90064

Tel: (310) 478-3711 Fax: (310) 268-4933 email: sangeeta.ahluwalia@va.gov

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ABSTRACT

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

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

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

Participants: 52 patients $\geq$ 65 years recently hospitalized for HF with one or more post-discharge follow-up outpatient visits, and their physicians (n=44), at two Veterans Affairs Medical Centers.

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

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

Conclusions: Physicians often missed the opportunity to engage in ACP despite openers patients provided that could have prompted such discussions. Communication training efforts should focus on helping physicians identify patient openers and providing a toolbox to encourage

appropriate physician responses; in order to successfully leverage opportunities to engage in ACP discussions.

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Key Words: Qualitative research, advance care planning, heart failure, physician-patient communication

Introduction

Patients with heart failure (HF) face a highly variable and uncertain illness trajectory, punctuated by frequent exacerbations and multiple complex treatment decision points (1-3). Research has shown that patients with HF want to understand the trajectory and prognosis of their disease as early as at the time of diagnosis, and that they prefer physicians to initiate such discussions (4,5). Unfortunately, most HF patients are uninformed of their prognosis and the life-limiting nature of HF (6-8), and are unaware of choices and alternatives in their future care (9). To help patients adequately prepare and plan for future care, early and regular patient-provider communication about prognosis and preferences for care is critical (10-12); however, few studies have evaluated what is actually said in practice.

Some consensus guidelines endorse early discussion of advance care planning (ACP) for this population (13,14). Some of the reasoning behind these recommendations is that early communication can help patients think about, plan, and prepare for their future care. Aspects of ACP discussions include an explanation of HF trajectory and prognosis (4,15-17), an exploration and elicitation of treatment preferences and goals of care (12,18-20), and a discussion of concerns that transcend but are related to the biomedical, such as psychosocial, spiritual, and quality of life issues (21,22). Provider attention to multiple areas of patients' concern may serve to facilitate more meaningful and productive discussions around future care.

Nonetheless, physicians face several barriers to timely ACP discussions, particularly in the outpatient setting. The highly unpredictable nature of HF makes it difficult for providers to identify the right time to engage in an ACP discussion, yet simultaneously underscores the importance of having such discussions as early as possible in the disease course. Other barriers include a lack of time during the clinic visit to raise complex issues other than immediate

biomedical concerns (23,24), and provider perception that patients are reluctant to think about their future health and care needs (23,25).

In order to help physicians engage more frequently in ACP discussions with their HF patients, we sought to understand whether opportunities for such communication might emerge naturally over the course of a clinic visit, providing entrée into what is usually a difficult and complex topic. Thus, the purpose of the current study was to identify and characterize potential opportunities for physicians to engage in ACP discussions and to examine physicians' responses to opportunities, during follow-up outpatient visits with patients recently hospitalized for HF.

Methods

Participants and Data Collection

Data were obtained from a prospective observational cohort study aimed at examining the association of patient-provider communication with outcomes among patients hospitalized for HF, from 2005-2009 at two Veterans Affairs (VA) Medical Centers. Patients in this study had one or more audio-recorded outpatient follow-up visits with a participating primary care internist or cardiologist within 6 months post-discharge (N=170). For the current study, we purposively sampled patients from this cohort age 65 years or older with one or more post-discharge outpatient visits (N=52). Of these, 19 participants had two post-discharge visits; however, we viewed each visit as a unique opportunity to raise and engage in an ACP discussion and thus included every transcribed visit in our analysis (n=71). Audio-recordings of the visits were transcribed verbatim by an experienced transcriptionist. All individually identifiable physician and patient information were removed from the transcripts prior to analysis. Patient and provider characteristics were determined through self-report and the number of chronic conditions per patient were determined through medical chart review. The institutional review board at both participating hospitals approved the study and patient and provider participants provided written informed consent.

Coding and Analysis

We conducted a secondary qualitative content analysis of the 71 transcripts using an iterative, consensus-based coding process to identify and characterize opportunities for ACP during clinic visits. Two investigators (SCA and JRL) independently read and coded the transcripts for patient statements pertaining to their future health or physical, psychosocial and

spiritual/existential care needs. We specifically focused on statements pertaining to the future to support the premise that such statements were openers for a discussion regarding planning for future care. We looked for both direct expressions (eg: "I am worried about who will take care of me if I get sicker") as well as indirect expressions that, according to the coding scheme, indicated an underlying concern or question about the future (e.g., "I get depressed thinking about having to go to the hospital again"). These patient-initiated openers were defined as opportunities for providers to engage in ACP. The same two investigators simultaneously independently coded the subsequent physician responses to the patient statements, to characterize whether or not physicians acted upon opportunities to engage in ACP communication.

The investigators met to discuss the coding process and to review initial codes after first 10, and then 20 transcripts had been coded. A coding scheme was drafted after 30 transcripts had been coded (Table 1). .Disagreement in coding between the two investigators occurred in five instances over the first 30 transcripts, all regarding indirect patient expressions of concern about the future. Consensus over the inclusion of three out of the five patient expressions in the analysis was reached through a careful discussion about coding rationale with a third investigator (HSG). There was no disagreement in coding over the physician responses to identified patient expressions.

The investigators then used this coding scheme to code the remaining 41 transcripts, meeting periodically to refine existing codes or add new ones where statements were identified that were not adequately described by the existing taxonomy. As with the first 30 transcripts, when disagreement arose about the presence or definition of a code, consensus was reached through a discussion with the third investigator (HSG). This iterative process continued until the team agreed that the coding scheme fully captured the nature of patient statements and physician

responses related to future care. We counted the frequency of patient-initiated statements and then compared codes within and across transcripts to identify and characterize categories of ACP opportunities based on physician responses. All coding and qualitative analysis was performed with the assistance of NVivo qualitative data analysis software (QSR International Pty Ltd. Version 2, 2002).

Results

Participant Characteristics

Patients in our study (n=52) had a mean age of almost 71 years, were predominantly male (98%), Black/African American (52%), and were unmarried/single (63.5%). (Table 2). Providers (n=44) had a mean age of almost 38 years, were White (42.5%), Providers (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 providers in our study were internists (78.1%) and practiced more than 30 hours per week (83%).

Opportunities for ACP

We identified 25 patient-initiated statements pertaining to the future that represented opportunities for ACP made by 13 patients with 13 different physicians. Of these 25 statements, 21 statements made by 10 patients were characterized as missed opportunities for ACP, and 4 statements made by 3 patients were characterized as taken opportunities. Of the 10 patients who had missed opportunities for ACP, four patients repeated their initial statement once and one patient repeated the initial statement twice during the visit encounter.

There were three key categories of patient-initiated statements (Table 3). First, patients articulated expressions of emotion, usually fear, anxiety or hopelessness, regarding the possibility of future decline or death,representing an opportunity to explore emotional and psychosocial concerns. Second, patients proactively requested information about prognosis or trajectory, representing an opportunity to discuss likely trajectory and prognosis. Third, patients expressed preferences for HF-related treatment and their future care, representing an opportunity to explore and elicit both specific treatment preferences and broader goals and values for care.

Physician Responses – Taken Opportunities

In 4 out of the 25 identified opportunities for ACP, physicians took the opportunity to first acknowledge the patient-initiated statement and provide support, and then to raise the relevant ACP topic. For example, in the following interaction, the patient expresses worry about the likely trajectory and prognosis of his heart failure and the physician responds by first acknowledging the patient's concerns and then leveraging the opportunity to provide an explanation of the proposed treatment plan and the expected trajectory based on that plan:

> **PT:** I might get a little depressed about my [heart failure] because I want it fixed. That's your procedure…fix it, you know? I'm worried for [caregiver], she's tired. We got married 8 years ago; I promised her 10. You gotta keep me going for 2 more years. [expression of emotion]
>
> **DR:** Yeah, I understand, I understand. It's always difficult and we'll do our best. [acknowledgement] We'll do everything we can. Hopefully we can get some improvement in the way you feel. I can tell you that these medicines are important medicines; they are life-saving and really do make people live longer and stay alive. [discussion of treatment plan and expected trajectory]
>
> **PT**: Okay doc.

Similarly, in the encounter below, the patient expresses worry about his heart and whether or not his condition will improve. The physician responds by acknowledging the concern and providing an explanation of the disease and its trajectory.

> **PT:** You know I'm not confident of how my heart is. What I'm saying is I can only see that in time my heart is not going to get any better. [expression of concern]
>
> **DR:** Yeah. Unfortunately that's the nature of the disease. When the heart gets weak it's very difficult to get it better. The best thing we can do is keep it from getting any worse. [explanation of disease]
>
> **PT**: Yeah but I have never had nothing wrong with my heart. And for something to become this bad, to me that's strange. [expression of concern]
>
> **DR**: I know. And a lot of times unfortunately that's the way heart disease presents. You've compensated and made up for a heart that might have been growing weak for

some time until finally you no longer have the reserve to make up for what your heart is not able to do on its own. I know it's difficult to appreciate that until you've gone through it. [explanation of disease and acknowledgement of patient concern]

In each of the 4 instances of taken opportunities, the physician responded immediately to the patient's statement such that patients did not have to repeat their initial statement.

Physician Responses – Missed Opportunities

In 21 out of the 25 identified opportunities, physicians missed the opportunity to engage in ACP. Of the 21 missed opportunities, 11 represented second or third repetitions of patient statements that were not appropriately addressed when first expressed. There were four types of physician responses to patient-initiated statements that led to missed opportunities: termination (7 out of 21 instances); denial (7 out of 21 instances); hedging (6 out of 21 instances); and inadequate acknowledgement (1 out of 21 instances) (Table 3).

Physicians terminated the opportunity to engage in ACP by changing the topic of the conversation from the patient's statement back to the clinical aspects of the visit. As the following excerpt demonstrates, termination was employed in response to patient expressions of emotion regarding the possibility of decline or death. Here, the physician missed an opportunity to provide information on prognosis or trajectory tailored to the patient's concerns:

DR: How do you think we can improve your eating?

PT: Can't.

DR: Not even if it's really important for your health?

PT: It doesn't matter; you're going to die when you die anyway. So you might as well enjoy it while you're here. [Patient expression of hopelessness around dying]

DR: Well we're going to need to do an x-ray of your chest today 'cause I got to see what's going on with this pain back here, okay? [Physician termination of discussion]

Physicians sometimes denied or contradicted the patient's statement, rather than acknowledging the patient's statement and leveraging it to provide support and engage in ACP. Denial was identified in response to both patient expressions of emotion regarding the possibility of decline or death, as well as to patients' articulation of preferences around HF-related treatment. Often, physician denial of patient preferences was illustrated in an attempt to override or counter the preference with a professional recommendation.

> **DR:** Good news. The interventionalist agreed you are a good candidate to have a staged PCI as an alternative to the bypass graft.
>
> **PT:** I don't know. I don't want to do it. [Patient articulation of preference]
>
> **DR:** I feel pretty strongly that we should do something to open up your arteries. Medical therapy is good, but it is not as good as an intervention. Does that make sense? [Physician denial of patient preference]
>
> **PT:** Yeah. I guess.
>
> **DR:** I think the sooner we get moving the better. You're not going to argue too much, huh? [Physician denial of patient preference]
>
> **PT:** I was about ready to say no. Nothing. Leave me alone. [Patient repeats preference]
>
> **DR:** Let's at least get this done. Then you can tell me to leave you alone. [Physician denial of patient preference]

In this example, the physician missed the opportunity to understand and address the patient's concern and to address the patient's goals for future care. When patients requested information regarding prognosis or trajectory, physicians responded by hedging, or avoiding a direct response to the request or question.

> **PT:** To be honest now, with a disease like heart failure, your life expectancy is very short, isn't it? [Patient request for information regarding prognosis]
>
> **DR:** Uh, yeah, because for all diseases, especially with lung or heart, when they're very advanced, there's an important organ that's failed and so it's – I cannot tell for sure, but –

[Physician hedging]

PT: So that means I can go anytime? [Patient repeats request for information]

DR: With a normal heart that doesn't have any problems, if you have an infection, you have a good reserve. So for you, if you have an infection or you have any problems, that can make you worse. I would say that – I cannot tell you numbers, but it's usually one to two years. [Physician hedging]

In this example, hedging represents a missed opportunity to directly respond to patient concerns about life expectancy and quality of life, and to provide information regarding prognosis, and support for planning for the future.

Finally, in one instance, a physician inadequately acknowledged the patient's implicitly expressed concerns and questions by responding directly to the patient statement, but failing to explore the underlying sentiment.

PT: I've been wondering; can I do some light push-ups?

DR: I'd rather you be careful because of your heart.

PT: Ok, yeah. See, I've been thinking about my health. 'Cuz us men think that we are invincible so we think we're still in our 20s so we be trying to do the same way but we better think, right? Cause age really makes a difference, won't it? [Patient indirectly expressing concern about future decline]

DR: Huh? Yeah, it will. [Physician inadequate acknowledgment]

PT: Yeah, age will make a difference

DR: Mm-hm.

Here, the physician missed the opportunity to explore the patient's broader concerns regarding the possibility of declining health and to discuss the likely trajectory associated with HF and the implications of that trajectory in the future.

Discussion

In this qualitative study of patient-provider communication, we found that some patients with HF have concerns, questions and thoughts regarding their future health and healthcare that they express during the clinic visit and that can serve as an entrée into a discussion about planning and preparing for the future. Physicians in our study often failed to leverage these opportunities to provide acknowledgement and support and to address relevant ACP topics. Instead, physicians responded to patient statements pertaining to the future by changing the subject back to the routine biomedical aspects of the visit, by denying or contradicting the patient's expressed emotion or preference, by hedging their responses to patient requests for information about prognosis, or by inadequately acknowledging the question or sentiment underlying the patient's statement. Evidence of such missed opportunities in ACP communication indicate that there may be actionable steps providers can take to increase ACP during outpatient clinic visits for patients with HF.

Prior studies have examined patient-provider communication for patient clues about emotional states or illness concerns (26-29) with the aim of identifying opportunities for physicians to provide empathy and support. Consistent with prior results,we found that patients with heart failure may not explicitly verbalize a desire to engage in sensitive conversations but instead offer implicit statements indicating their desire to do so. These statements were often emotionally laden, reflecting the patient's fears or anxieties about their future. Identifying, acknowledging, and exploring the underlying emotion in patient statements is critical to ensuring that patients' concerns are addressed appropriately. However, we also found that many patients proactively and explicitly requested information regarding prognosis and articulated preferences for care, providing evidence of their desire and willingness to engage in an ACP discussion with

their provider. Despite such explicit opportunities for providers to engage in these discussions with their patients, our study demonstrates that some physicians continue to have difficulty leveraging these opportunities.

There are several possible reasons for the high number (84%) of missed opportunities to engage in ACP in our study. Key among these is that physicians may simply be unaware of the openers patients offer. Characterizing patient-initiated statements pertaining to the future can help physicians identify patients who might be ready to discuss ACP and to guide their responses to such statements. In addition, characterizing patient statements can be useful in the development of educational materials for medical students and other health professionals. Communication is a teachable skill (30) and considerable evidence of the success of skills-based and role-playing trainings for improving communication regarding ACP and end of life care exist (31-37). In particular, one training program involving both communication skills education and role-playing was successful at improving physician identification of and responses to patients' emotional cues (38), underscoring the relevance of such approaches to helping providers respond adequately to patient openers regarding their desire to discuss their future care. Future work could adapt and then evaluate existing training programs for physicians who care for patients with HF and could draw upon the framework described herein.

The lack of time physicians have to address multiple topics during a clinic visit, which has previously been identified as a significant barrier to ACP (23,24) might also contribute to missed opportunities for ACP. Physicians may feel pressured to focus on task-related communication such as diagnosis and treatment, as evidenced by "termination", rather than to spend time on ACP communication. However, this behavior might be associated with longer visits because we found that among the 21 missed opportunities identified, 11 opportunities were

repeated patient statements that were initially unacknowledged and unaddressed by the physician. Data from prior studies (27,29,37) suggest that visits with missed opportunities for providing empathic communication may be longer than visits where physicians responded immediately and empathically to their patients' statements about their emotional experiences, primarily because patients would not have to repeat their initial concern. In our study, physician acknowledgment of the concern and provision of a basic level of information seemed to satisfy the patient - of the 4 taken opportunities we identified, all of them concluded after a brief response to the patient's statement or question. Attempting to tackle the gamut of ACP topics in a single visit is likely to consume considerable clinic time, but utilizing the opportunity afforded by patient-initiated statements to briefly address a single specific question or concern could pave the way for regular discussions that build upon themselves over time.

Even with adequate time during a clinic visit to discuss ACP, our results suggest that physicians may still be hesitant to leverage opportunities to engage in such conversations with their heart failure patients. The finding that some physicians hedged their responses to patient questions about prognosis, or denied patient expressions of emotion underscores the discomfort many providers face when discussing sensitive topics such as the possibility of decline or death (15,39). It may be particularly difficult for providers to discuss ACP with their heart failure patients for whom the trajectory of decline is highly variable and the timing and manner of death uncertain (40). While efforts have been made to increase physician comfort with ACP conversations through communication trainings (33,34,38,41-44), medical education may need to incorporate updated illness models for non-malignant chronic diseases to help foster physician awareness of the relevance of ACP for patients with heart failure (45).

Even though patient openers were offered in just 13 of 71 consultations, the finding that some patients proactively and explicitly broach topics considered to be of a difficult and sensitive nature, such as prognosis, stands in stark contrast to findings from earlier studies characterizing a "conspiracy of silence" between patients, providers and family members over these topics (46-50). Instead, some patients in our study sought information from their providers regarding their prognosis and often received an inadequate response. Providing prognostic information is notoriously difficult, particularly for diseases that have uncertain trajectories such as HF. In addition to difficulty in providing reliable estimates of life expectancy, providers are often caught between wanting to maintain hope and setting realistic expectations (51-54) However, research suggests that withholding prognostic information was not viewed by patients or caregivers as an effective way of maintaining hope (53,55) and current guideline recommendations encourage some attempt at prognostication (56) and early discussion of the terminal nature of HF (13) in order to help patients plan appropriately for their future. The finding that some patients express a readiness and desire to hear prognostic information should encourage physicians to discuss this topic with their patients.

Our findings should be interpreted in the context of several limitations. First, because this was a qualitative study, no conclusions can be drawn around the frequency of the missed opportunities that were identified in the analysis. Second, we analyzed transcribed audio-recordings 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 characterization of the opportunities for ACP. We examined a cross-section of clinic visits and are unable to determine if ACP discussions had occurred previously.Additionally, documentation of advance directives were not collected as part of the

larger cohort study and were not available. However, ACP is an ongoing process of communication and preparation, and earlier instances of such communication should be reaffirmed and do not preclude future conversations, particularly if the opportunity arises based on concerns or questions raised by patients themselves.

ACP discussions can be difficult for both patients and their physicians. However, early preparation and planning for the future helps to ensure that patients receive care that is concordant with their preferences throughout the course of their illness. Many patients wish to discuss their future care with their providers and raise opportunities to engage in ACP discussions during outpatient clinic visits by expressing thoughts, concerns or emotions regarding their future health and healthcare. Physician responses often fall short of fully acknowledging and leveraging these opportunities, which results in missed opportunities to provide information and support and to help patients adequately prepare for their future. Communication training efforts may need to focus on helping physicians identify patient openers and teaching them how to leverage the opportunity to engage in ACP discussions in ways that are complementary to the structure of the clinic visit.

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Table 1: Coding Scheme

Patient Statements (Y/N) and demonstrative quotes
1. Pertaining to the Future a. Future Health: "Will my heart ever get stronger?" b. Future Care: "My friend had a heart transplant; is that something I should consider?" c. Future Plans: "I worry about what will happen to my wife after I'm gone"
2. Statement Categories a. Worry/Concern i. Direct: "I'm scared of getting sicker" ii. Indirect: "Everyone has to die eventually" b. Question i. Direct: "How much longer do you think I have left?" ii. Indirect: "I'm not sure if this treatment is going to help me" c. Other
Physician Response Categories (Y/N)
1. Present (Adequate/complete response to patient statement) 2. Absent (No response to patient statement, and/or change of subject) 3. Partial (Incomplete or inadequate response; response to only part of patient statement) 4. Avoidant (Indirect or oblique response) 5. Denial (Negation of patient statement)

Table 2: Participant Characteristics

Characteristic	Value
Patients (n=52)	
Age, years, mean (SD)	70.8 (5.6)
Race, N (%)	
White	25 (48.1)
Black/African-American	27 (51.9)
Ethnicity, N (%)	
Non-Hispanic	48 (92.3)
Hispanic	4 (7.7)
Married/Partnered, N (%)	19 (36.5)
Education, N (%)	
Less than high school	12 (23.1)
Finished high school	11 (21.2)
Some college/trade school	20 (38.5)
College graduate	9 (17.3)
Number of chronic conditions, mean (SD)	2.4 (1.4)
Number of patients with 2 visits recorded, N (%)	19 (36.5)
Providers (n=44)	
Age, years, mean (SD)	37.7 (9.8)
Female, N (%)*	17 (42.5)
Race, N (%)*	
White	17 (42.5)
Black/African-American	7 (17.5)
Asian	16 (40.0)
Specialty, N (%)†	
Internal Medicine	32 (78.0)
Cardiology	9 (22.0)
Time in practice, years, mean (SD) †	11.4 (9.5)
Practice hours per week, N (%)†	
0-10 hours	4 (9.8)
11-20 hours	1 (2.4)
21-30 hours	2 (4.9)
31-40 hours	34 (82.9)

* N=40 physicians due to missing data

† N=41 physicians due to missing data

Table 3: Patient Statements Representing Opportunities for Advance Care Planning

Categories of Patient-Initiated Statements	N (%)	Quoted Example
Expressions of emotion regarding the possibility of future decline or death	21 (40)	I made 72 on Sunday, now I just have to make it to 73. I hope I make it." "Getting ready to die pretty soon…everybody got to die."
Requests for information regarding prognosis or trajectory	19 (36)	"About my weak heart, when will it get stronger?" "I'm just wondering how fatal do you think - ? I mean, any time?"
Articulation of preferences regarding heart failure-related treatments	12 (24)	"I didn't want to take Coumadin, y'all fought me to get the Coumadin. But I don't want it." "I don't know. I don't want to do [surgery]…I was about ready to say no. Nothing. Leave me alone.]"