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## ‘Goals of care conversations don’t fit in a box’: Hospice Staff Experiences and Perceptions of Advance Care Planning Quality Measurement

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### Abstract

**Background:** With rising concerns about quality of care in hospice, federal agencies recently began mandating quality measurement in hospice, including measures of Advance Care Planning (ACP).

**Objective:** To characterize hospice providers’ experiences with ACP quality measurement and their reflections on ways to improve it.

**Design:** Semi-structured in-depth interviews of hospice providers; Qualitative thematic analysis with an interdisciplinary team, facilitated by ATLAS.ti and Excel.

**Setting/Participants:** Fifty-one hospice staff from various clinical backgrounds and organizational roles in four geographically diverse non-profit, community-based hospices in the U.S.

**Measurements:** Participants were queried about their experiences with and barriers to ACP quality measurement processes in their organization, opinions about the impacts of federally mandated quality measures, and ideas for improvement.

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**Results:** Four key findings of the ACP quality measurement experience for hospice staff included variation, barriers, attitudes, and recommendations for improvement: 1) Variation: Within and across organizations, participants applied a variety of processes to measure ACP quality; exposure to and experiences with quality measurement varied based on organizational role. 2) Barriers: ACP quality measurement was impeded by limited resources, technological problems, and measurement challenges. 3) Attitudes: Participants' opinions of recently implemented federally mandated requirements for ACP quality measurement highlighted numerous downsides, unintended consequences, and few upsides. 4) Recommendations: improvements included personalizing ACP quality measures, elevating the importance of quality measurement, and streamlining processes.

**Conclusions:** Hospice staff take ACP quality measurement seriously, but insufficient organizational resources and regulatory bureaucracy create challenges. Efforts to enhance ACP quality measure nuance and assess outcomes are needed to improve care.

### Keywords

Hospice; quality measurement; quality improvement; advance care planning

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### Introduction

The dramatic rise in hospice use in the United States (U.S.) over the past decade has brought growing concerns over hospice care quality.<sup>1,2</sup> This concern has prompted increased federal regulation of hospice, namely through the Center for Medicare and Medicaid Services (CMS) Hospice Quality Reporting Program (HQRP), which requires hospices to report on key quality measures and instigates financial penalties for failure to comply.<sup>3-6</sup> Derived from National Quality Forum recommendations<sup>7-10</sup>, the HQRP includes two primary assessments: 1) the Hospice Item Set (HIS), a standardized set of process measures collected by hospice organizations on each patient; and 2) the Consumer Assessment of Healthcare Providers and Systems Hospice Survey (CAHPS), a post-death survey sent to bereaved caregivers of hospice recipients.<sup>11</sup> HQRP reporting requirements to CMS began in 2014 and public reporting began in 2017.

In the landmark report on Dying in America, communication and advance care planning (ACP) were identified as key components of end-of-life (EOL) care quality.<sup>12</sup> ACP – the process of helping individuals understand and share their values and preferences for future medical care<sup>13</sup> – has been associated with improved patient self-determination and quality of care at EOL.<sup>14,15</sup> The HQRP addresses ACP quality with a HIS process measure to assess EOL treatment preferences (Box 1). Specifically, the HIS assesses the proportion of hospice patients who have a discussion (or attempted discussion) of preferences for life-sustaining treatments, including cardiopulmonary resuscitation, hospitalization, and other life-sustaining treatments.<sup>11</sup>

Despite the growing importance and increasing regulation of quality in hospice, we know little about hospice staff experiences and perspectives of hospice quality measurement (QM). The few studies that examined hospice staff experiences with QM were conducted prior to the advent of the HQRP and the implementation of HIS, and did not focus specifically on ACP.<sup>16,17</sup> The recent implementation of these requirements provides a unique opportunity to

characterize frontline hospice staff initial experiences with ACP QM, which could help inform the ongoing development and refinement of hospice QM, its implementation, and successful delivery of goal-aligned care at EOL. Thus, the objectives of this four-site, qualitative study were to characterize hospice staff experiences and reflections on ACP QM, within the context of growing federal regulation and oversight of hospice quality.

## Methods

### Design:

This qualitative study uses data from interviews with multidisciplinary hospice professionals, as well as organizational documents (such as brochures or QM report dashboards) relevant to the discussion, documentation, and measurement of EOL treatment and care preferences in hospice. Data analysis involved inductive and deductive thematic analysis.<sup>18</sup> Methods have been described previously and are summarized below.<sup>19</sup> The University of California, San Francisco IRB reviewed this study and deemed it exempt.

### Setting/Subjects:

*Sites* were eligible if they were non-profit community-based hospices providing hospice services affiliated with the Palliative Care Research Cooperative (PCRC). Sites were selected to represent diverse geographic regions of the U.S. *Individuals* were eligible if they were employees of included hospices. They were selected to represent multidisciplinary team members from a variety of organizational roles (i.e. leadership, quality improvement (QI), frontline clinicians) and training backgrounds (i.e. physicians, registered nurses, social workers, chaplains, business/administration).

### Measurements/Data Collection:

The senior author (KLH) collected data between April and September 2016 during two-day site visits. All participants verbally consented. Interviews explored four main domains related to ACP QM, including QM practices, measurement barriers, perceptions of HIS implementation, and opportunities to improve QM. Details of these domains and examples of questions are included in Box 2. Questions were modified based on participant's organizational role and their familiarity level with organizational QM activities such as HIS. Interviews were recorded, redacted, and notes/transcripts were returned to participants for clarification, but no changes were made by participants.

### Data Analysis:

Two authors (KLH and LJH) independently reviewed the entire corpus of data to identify all relevant data, develop initial codes, and write analytic memos on emerging findings. LJH, KLH and SBG reviewed, discussed, and refined codes to ensure conceptual agreement. LJH applied the updated codebook to the entire dataset. ATLAS.ti Version 8 was used to organize, code, and extract the data for further review. LJH, KLH, and SBG iteratively reviewed and discussed the coded data to identify and affirm themes. Themes were further refined and grouped into broader findings via discussion and analytic memoing. For data citations in this manuscript, "S" indicates site number and "P" participant number; followed by a label of participant role and/or discipline.

## Results

Sites included 4 hospice organizations from the Northeast, Southeast, Midwest and West of the U.S., each with an average daily census of 200–700 patients/day. Of 71 individuals identified for recruitment, 51 agreed to participate (4 declined and 16 did not respond). Participants were evenly split across sites. Sixty-one percent were clinicians (45% nurses; 24% social workers; 16% physicians and other providers); 25% were executive leaders; 14% were QI managers or staff. Eighty-six percent of participants were non-Latinx white and 80% were female. Demographic characteristics of the sample are reported elsewhere.<sup>20</sup> Our analysis produced four key findings regarding ACP QM in hospice.

### **Finding 1. Variation: Participants applied a variety of formal and informal processes to measure ACP quality and comply with regulations; awareness and involvement with ACP QM varied based on organizational role (Table 1).**

Participants consistently communicated their commitment to providing high-quality care to patients and recognized the need/importance of measuring quality of care generally. They endorsed the importance of having conversations about and documenting goals of care or treatment preferences among hospice enrollees as part of ACP QM/QI activities, but also noted the difficulty of ensuring conversations and documentation occurred. Participants described a variety of organizational processes for ACP QM. These ranged from federally-mandated QM processes (namely HIS) to informal processes such as discussions at biweekly interdisciplinary team (IDT) meetings.

Formal assessment of ACP quality included methods to capture and report HIS as well as other organization-initiated QM/QI projects. Commonly described changes to organizational practices of ACP QM after HIS implementation included adding an ACP assessment to the admission process (i.e. standardized questions asked by team members in charge of admissions) and increased attention to documentation in the electronic health record (such as new HIS-oriented checklists). However, some participants thought that HIS had not changed ACP practices because they “were already doing that” (S3, P7, Clinician, RN). One site (Site 3) had recently completed a formal QI project focused on ACP beyond what was required by HIS, including obtaining and scanning ACP documents (i.e. advance directives and durable power of attorney forms).

Informal methods to assess ACP quality included quality review meetings and IDT meetings. Participants referred to meetings where challenging cases were discussed, such as when individuals were admitted to the hospital despite expressing a preference for limited life-sustaining treatments. Biweekly IDT meetings were noted as a place and time where ACP was reviewed and updates documented.

As expected, knowledge of and experiences with ACP QM processes varied with organizational role. QI administrators referred to federally-regulated and/or organization-initiated QM/QI endeavors. Unless part of a team that focused on admissions, clinicians referred more often to informal discussions such as those occurring at IDT. Some clinicians had limited awareness of the recently implemented HIS quality measures: “I have never used it [HIS]. That’s all I can tell you” (S2, P31, Clinician, SW/RN). Leaders referred generally

to formal QM activities, such as HIS data collection, but deferred to their QI administrator colleagues when asked for details.

**Finding 2. Barriers: ACP QM was impeded by limited resources, technological problems, and measurement challenges (Table 2).**

When asked about barriers to measuring ACP quality, participants described several types, including lack of financial, time, and human resources. As one QI administrator put it, “I wanted to hire a data analytic person this year, and it got axed during the budget process.” (S1, P18, QI leader). In addition to lack of financial resources, participants spoke to limitations of time and human resources in the face of high patient volumes. As one RN leader said about barriers to ACP QM, “We’ve close to 800 patients, and ... that’s a lot for the managers to keep their eyes on, but you need to, because it affects the quality of the care for that patient...” (S2, P29, Leader, RN). Several QI administrators spoke about how the HIS had replaced more in-depth QM endeavors because there were insufficient resources to continue with both. One QI administrator recalled: “We did at one point do internal audits, and a part of that auditing process was to measure whether or not advance directives were completed, and because of resources we no longer do that” (S1, P15, QI, SW).

Participants additionally talked about problems with technology and electronic health records as a barrier to ACP QM, and perceptions varied by role. Some clinicians shared their frustrations with the impact of QM on bedside charting. One said about their electronic health record: “I don’t think that it is as user friendly or intuitive as it could be. So, there may be times we’re taught about what should be contained in the HIS items to make it Medicare-compliant, but at times... it’s almost like a mismatch” (S3, P10, Clinician, SW). QI administrators and leaders pointed to difficulties extracting data for reviewing, auditing, and aggregating. For example, when asked about barriers to ACP QM, one leader responded: “Well, I guess [we don’t have] an easy way of mining that data” (S1, P17, Leader).

Finally, participants identified methodological challenges associated with measuring a nuanced concept like ACP. They were unsure how to create consensus measures that went beyond quantitative, objective measures (such as presence of an advance directive) to adequately assess the subjective and qualitative aspects of ACP. One leader said: “There’s easy things to measure, like do people have healthcare proxies? But how do you measure things like the patient’s—[if] what they think would be a good death is what happened for them? I don’t know how you would measure that” (S2, P27, Leader, MD).

**Finding 3. Attitudes: Participants’ opinions of recently implemented federally mandated requirements for ACP QM (i.e. HIS) highlighted numerous downsides, unintended consequences, and few upsides (Table 3).**

When asked about the impact of the HIS implementation, participants primarily highlighted negative or unintended consequences. Concerns included the limitations of HIS measures, its potential to reduce ACP conversation quality, and impacts on organizational resource allocation decisions.

Staff remarked on the limitations of HIS for capturing complexities and nuances of EOL care treatment preferences: “sometimes things don’t fit in a box. Goals of care conversations

don't fit in a box" (S2, P31, Clinician, SW/RN.) Across organizational roles, participants referred to the HIS as a mere check-off that failed to accurately measure quality and failed to improve patient outcomes. Instead, meeting HIS requirements was an administrative task "all about documentation" (S4, P41, Leader, RN) with little impact on patient care. For some, the HIS was not even viewed as a real QM activity: "Well, we currently don't [measure ACP quality]. The only thing that would come remotely close to that would be the Hospice Item Set [which] has questions on that about advance directives" (Site 1, P18, QI leader).

Participants were concerned that HIS requirements would lead organizations to "teach to the test" to improve reported metrics, at the expense of a holistic, patient-centered approach to addressing treatment preferences and goals of care. Participants expressed concern that pressure to complete HIS measures at admission limited clinicians' ability to adapt and modify care to individual patient needs and created anxiety for patients and families who were not emotionally ready for potentially difficult conversations about EOL treatment preferences: "I feel some frustration about kind of teaching to the test in a way where we're coached or expected to have certain wording when perhaps that patient or family isn't there, isn't there yet." (S3, P10, Clinician, SW). This was echoed by hospice leaders, who worried that additional resources required for HIS reduced capacity to focus on communication and patient-centered care. As one leader commented, "How do we not lose what has made this industry so amazing and so different from all other parts of healthcare where it's about a relationship, it's about trust, it's about communication?" (S3, P8, Leader).

In contrast to preceding concerns, some participants saw positives in HIS implementation (Table 3). They appreciated that the new requirements acted as a reminder and increased consistency of documentation early in the admission process. As one nurse said, "[Y]ou have to answer the question one way or the other, so you have to address it and it's [the HIS] kind of a reminder, you know, that this is very important. So I actually think it's very good" (S1, P26, Clinician, RN). Others, more ambivalent, remarked that it was a starting place for QM in hospice: "It's a first step. It may not be what exactly we would have said is the most important, but you know, we have to start somewhere...and then hope that modifications can be made over the next several years" (P1, S3, Leader, MD).

**Finding 4. Recommendations: Improvements should include personalizing ACP QM, elevating the importance of QM, and streamlining processes (Table 4).**

In response to questions about improving ACP QM, most participants recommended developing methods to deepen the assessment of quality of conversations and address subtleties of patient preferences, rather than relying solely on checklist processes like those in the HIS. Participants advocated for research to develop person-centered ACP quality measures that truly impacted care: "I think that's where I would advocate for more research being done...It's probably not going to be a one size fits all, but we can really start [teasing] out what actually we're doing that really impacts care." (S1, P24, leader, MD). Other participants expressed uncertainty of how to create nuanced measures, especially given time and resource constraints. One participant stated: "I don't know. I don't think there's a way to improve, to be honest with you" (S3, P6, Clinician, RN).



Participants recommended elevating the importance of ACP QM in hospice organizations through leadership modeling and increased education. Suggestions including having staff engage in “roleplay” activities (S1, P17, Leader) and having supervisors go with clinicians to patient visits to observe ACP conversations. Leaders talked about the importance of creating a culture where quality was viewed as essential. Participants also reflected that creating ACP outcome measures could improve measurement of delivery of goal-aligned care. A nurse QI administrator suggested: “It could be part of the survey that families get [referring to the Consumer Assessment of Healthcare Providers and Systems Hospice Survey]...so when the patient dies we check off whether or not the patient received care in accordance with preferences” (S2, P30, Clinician, QI-RN). Finally, participants advised that any new ACP quality measure be streamlined and not create additional burden for already overwhelmed and under-resourced staff and organizations.

## Discussion

Our results highlight the numerous complexities, challenges, and opportunities for ACP QM in hospice. Findings illustrate how hospice organizations have begun to incorporate emergent regulatory requirements, such as the HIS-mandated ACP quality measures, into their workflow. However, organizations face many barriers to ACP QM, including a lack of financial and other resources and technology problems. Our findings highlight the challenges of creating person-centered, nuanced measures of a complex concept like ACP. Participants in our study predominately viewed the HIS ACP measures as a task to check-off that failed to assess the nuances of care and led to a “teaching to the test” mentality at the expense of holistic care. Participants voiced a desire to deepen and improve ACP quality measures by moving from limited, objective, process measures such as HIS towards comprehensive, subjective, outcome-based measures that captured the essence of care provided in hospice.

Our findings echo and extend results from the limited existing literature on QM in hospice. Previous qualitative interviews and survey-based studies have highlighted similar barriers to QM in hospice. A lack of resources, including time, financial, technological and human, were identified barriers to QM in hospice.<sup>16,17,20</sup> In contrast, a lack of incentives or disincentives for QM was viewed as a major barrier in one study, where participants voiced concerns that there was no motivation to engage in QM activities without a mandate. This concern was notably absent from participants in our study, likely reflecting the impact of HQRP implementation, which withholds payment for failure to comply with QM requirements. For better or worse, financial disincentives do spur organizations to change behaviors.<sup>21</sup>

Our findings reinforce concerns regarding potential unintended consequences of increased regulation of QM in hospice. There is worry that regulatory requirements lead to a “check-box” mentality that actually decreases quality and encourages gaming of the system, while simultaneously placing additional resource burdens on hospices, particularly smaller and non-profit hospices.<sup>17,22–25</sup> Participants’ major concern in our study was that a “check-box” approach diminished their ability to engage in meaningful conversations with patients and families about what was important for them at EOL.



Furthermore, increased regulation and implementation of HIS were viewed as potentially leading to a “teaching to the test” approach solely to improve metrics. With all hospices trying to attain the highest possible scores on the HIS items, there are concerns about score validity and whether scores provide information to help differentiate between high and low-quality hospices. Recent quantitative findings from national assessment of HIS data found that average scores for completion of the HIS item for EOL treatment preferences were extremely high at 98%, with little variation in scores.<sup>24</sup> With this ceiling effect, hospice consumers and regulators have little information to determine hospice quality, raising serious questions regarding the utility and validity of the HIS measures.

Participants in our study voiced a desire to move away from task-based ACP quality measures towards deeper measures that reflect the traditional focus of hospice on patient-centered care and communication. Recent work in this area has generated a number of ideas for more comprehensive--yet resource-efficient--ACP QM that link process and structural measures to outcome measures.<sup>23,26–29</sup> For example, ACP measures could be added to the Consumer Assessment of Healthcare Providers and Systems Hospice Survey (CAHPS) survey, which currently does not include any such measures. Hospices could be required to report whether patients received goal-aligned care, e.g. dying at home if so desired, avoiding hospitalizations or, in a growing number of hospice recipients, receiving “intensive” life-sustaining treatments at end of life.<sup>30</sup> This could be facilitated through the development of claims-based measures<sup>31</sup>, which could assess whether a hospice recipient received high-intensity services, such as admission to the ICU or ventilation.<sup>31</sup> Whatever measures are created, frontline hospice clinicians and other stakeholders should have substantial involvement in their development.

However, while these suggestions may lead to incremental improvements in ACP QM, a complete overhaul of the current system may be required to meaningfully improve ACP quality. Regulatory approaches such as HIS have their origin in Industrial Organization QI, (e.g. improving the quality of factory-built Toyota cars) that often rely on surveillance and aversive control to change behavior.<sup>32</sup> While these methods may work well in a factory, they may not be optimized for the complex psychosocial and often highly fraught conversations surrounding EOL care. Policy measures that primarily leverage financial disincentives to try to measure and improve quality create a punitive culture in hospice care, placing additional stress on organizations and staff and potentially negatively interfering with a clinician’s interactions with patients and families. A creative approach to policy implementation could employ other means, such as financial incentives or training programs to develop skills for ACP communication, to motivate hospices to improve their approach to ACP and ultimately result in goal-aligned care.<sup>33</sup>

## Limitations

Although participating hospices represent a geographically diverse area and participants had a wide-range of organizational roles, the hospices were all large, non-profit organizations with ties to the PCRC, a membership-only group of individuals and organizations committed to palliative care research. Thus, hospices in this study are not representative of all hospices nationwide, which are increasingly smaller, newly-established, for-profit hospices<sup>5</sup>. As such,

hospices in this study may represent “exemplars” of ACP QM practices not emblematic of hospices with fewer resources. Furthermore, we do not have data on individual-level performance on ACP QM, which limits our ability to discern the relationship between attitudes towards ACP QM and performance. Finally, we lack information on whether individuals identified for recruitment by sites differed systematically from those not identified, nor do we know whether individuals who agreed to participate differed from those who did not.

## Conclusions

Understanding patient values for treatment at EOL and ensuring patients receive care aligned with these values is one of the most important components of hospice care. Thus, ensuring high-quality ACP in hospice is an imperative, as indicated by concerns felt deeply by hospice staff in this study. While incremental improvements to ACP QM could be implemented through changes to the current regulatory approach, a major overhaul that incorporates creative, less punitive approaches may be necessary before transformative improvement in ACP quality in hospice can occur.

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**Key message**

This article provides results of a qualitative study of hospice providers and their views and recommendations on quality measurement of advance care planning. Participants highlighted numerous barriers and problems with current ACP quality measurement practices and voiced a desire for ACP quality measures that led to meaningful impacts on patient care.

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**Table 1.**

Variation in formal and informal processes to measure Advanced Care Planning (ACP) quality and awareness based on organizational role

<p><b>Formal methods for ACP quality measurement and role of HIS</b></p>	<p><b>ACP processes and role of HIS</b>                  “So it starts at admission, and with the quality tab, the HIS tab that is required from CMS, end of life, sustaining measures, advance directives is part of that discussion, so all hospices need to be having that conversation at the beginning, so per our practice that’s where it start.” (S3, P9, Clinician, SW)                  “There are checkboxes in our computer documentation about whether or not we’ve had the discussion and when that first discussion that we had with them occurred. And that’s in the HIS section of the report and also in the body of the comprehensive assessment.”                  (S1, P19, Clinician, RN)  <b>Changes in processes from implementation of HIS</b>                  INTERVIEWER: When the HIS was implemented did you change your EHR forms to capture that data, or did you manage to figure out some way for it to be extracted from your existing EHR? PARTICIPANT: Yes. The EMR vendor actually has a program that they built-in there that extracts the data. The questions themselves were programmed in attached to the initial mission assessment, and so as the nurse goes along those questions will pop up, and they fill them out, and then the vendor has a program that extracts that. I have a staff person in medical records that then sends it on to our vendor, to [redacted] basically, and then the vendor actually gets it in so that we can look at the aggregate data” (Site 1, P18, QI Leader)  <b>ACP Performance Improvement Projects</b>                  We actually made an entire PIP-- in the quality world that’s a Performance Improvement Project-- about advance care planning last year.” (S3, P2, Leader, APN)</p>
<p><b>Informal methods for ACP quality measurement</b></p>	<p><b>Quality Review Meetings</b>                  “The only thing that I would say that we would monitor is post-event from a quality review perspective. So, we do piece those complex issues, service failures, complaints, something like that every other week in our quality meetings. Oftentimes, those things come up.” (S4, P47, leader, RN).  <b>Biweekly Interdisciplinary Team (IDT) Meetings</b>                  So I think it’s [ACP] asked about frequently, you know, when you asked at the IDT meetings, you know, what’s important, you know, what’s going on, you know, and there is a person who takes notes, you know, that documents the IDT discussion.” (Site 3, P1, Leader, MD)                  “They do monitor [ACP discussions]. It always comes up in our interdisciplinary team meetings every two weeks.” (S4, P50, Clinician, RN)</p>
<p><b>Variation in knowledge and experience with ACP quality measurement depending on organizational role</b></p>	<p>I know we talked about it [HIS] but I don’t remember what aspects are measured.” (S1, P22, Clinician, RN)                  “I don’t know if we have [ACP quality] specific measures, or maybe somebody else could speak to that better than I can.” (S4, P40, clinician, RN)  <b>Leadership deferring to Quality Improvement (QI) administration when asked about ACP quality processes</b>                  “Well, I mean I think that’s a great question, I’m trying to remember if it’s in the-- I think it is in the Hospice Item Set as one of the measures, so that would be-- although I’d have to go back and look &lt;inaudible&gt; one on a comprehensive assessment. It’s specifically one of the measures, so I imagine that that is. So and we have a quality care team, are you meeting with [redacted]?” (S1, P24, Leader, MD)</p>

**Table 2.**

**Barriers to Advance Care Planning (ACP) Quality Measurement (QM) in Hospice**

<p><b>Lack of financial, human, and other resources, especially in the face of high patient volumes</b></p>	<p>“Again, I think part of the challenge may be how do we prioritize to which initiatives we’re going to move on first. The challenge of time and resources can be real for us.” (S3, P8, Leader)                  “It’s very time-intensive, because you can’t run a report on it. You really need to read it, so I think one of the challenges and barriers is that it does take a big chunk of time, especially if you have 20-plus admissions a day. It does take a long period of time. And then when you see something that’s not there then I’m communicating it to the team leader of the primary team to say “This needs further follow-up. This is missing.” So it’s time-intensive, I would say.” (S3, P6, Clinician, RN)                  “So I feel like I don’t know how-- I always am curious, how are they adapting to this? Because I feel like they would struggle maybe without the infrastructure of training, measuring.” (S2, P36, Clinician, RN)</p>
<p><b>Problems with Electronic Health Records and other technology issues</b></p>	<p>“What are the barriers to monitoring it [ACPI] across-- probably our EHR is a critical-- ‘cause then there’s no easy way to see that kind of longitudinally across the patient population. So I would say that’s probably a key barrier.” (S1, P16, Leader)                  “The documentation is very tedious and we are actually in the-- I think actually next month, we’re-- our palliative program is piloting a new system that we hope to all go to in the fall. So we’ve been on multiple different systems and no system is probably going to be perfect. But we are hoping to find one that’s been designed more for hospice than for home health to make charting easier.” (S1, P19, Clinician, RN)</p>
<p><b>Methodological challenges with creating, person-centered, nuanced ACP quality measures</b></p>	<p>“The little things are sometimes the important things that documents don’t catch. They don’t catch them. I mean a care plan will say, “Don’t let me hair be messed up,” or “Make sure my nails are painted,” or “Let me eat Oreos all day,” but it’s not in a formal document that I could possibly imagine anybody but somebody serving on the team would know those things. So, I don’t know how that would be measured. I just don’t. I don’t know.” (S1, P2, Clinician, SW)                  “I mean I don’t know how you monitor it. But every care planning we have every two weeks we ask what’s most important to the patient and family and that’s their goal of care. And it can be to go to an event. Or can be-- but so when you talk about advance care planning in that way we do that every two weeks. I think the issue is how do you measure that? I mean unless you go into every single chart and say, oh yeah, this one’s got a goal to make it to graduation or Christmas or Easter or go to a baseball game. Or go to Coon Dog Day was one person’s.” (S1, P17, Leader)</p>



Attitudes: Numerous Downsides, Unintended Consequences, and Few Upsides of Hospice Item Set (HIS) Advance Care Planning (ACP) Measures

Table 3.

<p><b>Participant's negative perceptions of HIS</b></p>	<p><b>HIS is a check-list, task-oriented measure that fails to measure nuances of care quality:</b> "So the quality of those [HIS]-- we absolutely document that. The quality of it I have no idea. And, in fact, that may be one of the-- that may be a criticism of it. Okay, so I have to talk to about your constipation. Check. I have to talk about your anxiety. Check. And your trouble breathing. Check. And now I need to know about if you would like to go to the hospital or not? Oh, you would, okay, check. It seems very transactional to me because it's a process measure and it's all about documentation." (S4, P41, Leader, RN)</p> <p><b>"But I mean if I could be really honest and blunt about the hospice item set, I think my staff does it because they have to, I don't think it's something that they really-- we ask all those questions and talk about them during admission but I don't think we go into the depth or want that Medicare's original desire around why they put it out." (S4, P4, Clinician, RN)</b></p> <p><b>HIS pushing end-of-life treatment conversations before patients/family are ready, creating anxiety:</b> "I have seen some patients getting extremely agitated when we come back-- well, the admission team has started the conversation and the primary teams come in to continue the conversation per our practice and I've seen some family members get very angry, patients get very angry. "You asked me this yesterday. I told you I don't want to talk about it. Why are you bringing it up today?'" (S3, P9, Clinician, SW)</p> <p><b>HIS requires increased resources for staff time, education, training, and monitoring that may take away from patient care:</b> "You need data entry people; that's two people. It's one FTE, one point five for a hospice our size, just to enter the HIS data-- just to do that. So, we didn't have that expense, right? And then, all the education is time away from bedside now." (S3, P2, leader, APN)</p>
<p><b>Participant's positive perceptions of HIS</b></p>	<p><b>Increased consistency in addressing ACP in hospice:</b> It's forcing people to address things that need to be addressed, so, I see it only helping our quality, not hurting us." (S2, P29, Leader, RN)</p> <p><b>Encourages treatment preference conversations early in hospice admissions process:</b> "For the most part I think it's positive, because having all that taken care of in the beginning is easier for the patient and the family so that they can enjoy their time that they have while they're feeling good and then not to have to worry about things like that towards the end when you want to focus on being with your loved ones enjoying your life." (S3, P11, Clinician, RN)</p> <p><b>Mandated quality measures as first step to assessing hospice quality:</b> "That is the future we're going into and so the Hospice Item Set is just the beginning of many measures that we're gonna have to focus on to really challenge ourselves, "Are we what we think we are in terms of the care that we provide?" Those are the measurable outcomes. They give us some determination whether we are good or not." (S1, P16, Leader).</p>

**Table 4.**

**Recommendations for How to Improve Advance Care Planning (ACP) Quality Measurement in Hospice**

<p><b>ACP quality measures should be more nuanced and person-centered</b></p>	<p><b>Increase measurement nuance:</b> "I mean, thinking in terms of documentation, maybe it would be more helpful if there was more, you know, documentation in the record about specifically what happened during that conversation. You know, like we have the advance directives box that gives you like MOST on file, five wishes form filled out, health care proxy designated, but maybe it would be more helpful if there was more room to personalize that, or to be more specific about what took place in the conversation, when the conversation last took place, if more conversations need to happen or should happen." (S2, P35, Clinician, RN)                  "But it would be nice if there was some way to better score the actual content of the conversations and say-- and really be able to say, "I think our staff is an eight out of 10 on having these conversations. They get at what we need to, they follow up on what they need to," you know, whatever those are." (S3, P5, Q1, NP)  <b>Research to understand how to improve ACP quality measurement:</b> INTERVIEWER: If you had an unlimited budget to develop quality measures and implement them, what would you do around advance care planning, or would you not touch that topic at all? PARTICIPANT: Well, I think I would probably try and ascertain why families wouldn't do it and what was the degree of the discomfort around having advance directives, what are the barriers to doing it, and then sort of flesh out something that would help them overcome those barriers." (S1, P18, Q1, Leader)</p>
<p><b>Unsure how to improve ACP quality measurement</b></p>	<p>"INTERVIEWER: Are there ways that you would like to see either the frequency or the quality of the advance care planning discussions monitored or measured so you could look at patterns across all your patients? PARTICIPANT: So I say yes, but I have no idea how." (S4, P42, leader, MD)</p>
<p><b>Elevate importance of ACP quality measurement through education, leadership modeling, and outcome alignment</b></p>	<p><b>Staff education and monitoring around ACP conversations:</b> You know, education with staff, having roleplay. How do you have that about hard conversations? We do some of that with intentional interactions and how to have hard conversations. But I think that's probably something we could do more of. (S1, P17, Leader)                  "INTERVIEWER: Are there other things that could be done in the organization that would be helpful to you in terms of measuring or monitoring what's happening with patients? PARTICIPANT: Well, they have been having different supervisors go out with staff members to see how they're doing it...to see how they're doing, how they're presenting things, how things are actually working out there." (S3, P12, Clinician, SW)  <b>Leadership modeling importance of quality measurement:</b> So I think, you know, quality is something that's delivered at the bedside, and some hospice workers are going to always provide high quality care, but if you're really looking across the agency, it really has to start at the top, and leadership has to demonstrate the importance of quality, and insist that, you know, all our workers provide that." (S3, P1, Leader, MD)</p>
<p><b>Streamline measures and processes</b></p>	<p>"You need to make the documentation of it streamlined, so that it's not a big extra step, or I have to go spend five, ten minutes, doing something separate; more so that it kind of just melds into what I'm already doing, to document it." (S1, P25, Clinician, RN)                  "I think something that was manageable and kind of user friendly, I think there would be a good number that would be interested, let's put it that way." (S4, P46, Clinician, SW).</p>

**Box 1.**

Hospice Item Set Quality Measures

1. **Opioid Regimen (NQF #1617):** Percentage of patients treated with an opioid that are offered/prescribed a bowel regimen or documentation of why this was not needed.
2. **Pain Screening (NQF #1634):** Percentage of patient stays during which the patient was screened for pain during the initial nursing assessment (in first 2 days of admission to hospice).
3. **Pain Assessment (NQF #1637):** Percentage of patient stays during which the patient screened positive for pain and received a comprehensive assessment of pain within 1 day of the screening.
4. **Dyspnea Screening (NQF #1639):** Percentage of patient stays during which the patient was screened for dyspnea during the initial nursing assessment.
5. **Dyspnea Treatment (NQF #1638):** Percentage of patient stays during which the patient screened positive for dyspnea and received treatment within 1 day of the screening.
6. **Treatment Preferences (NQF #1641):** Percentage of patient stays with chart documentation that the hospice discussed (or attempted to discuss) preferences for life sustaining treatments (including cardiopulmonary resuscitation, or hospitalization, or other life-sustaining treatments). Must be completed no more than 7 days prior to admission or 5 days within admission.
7. **Beliefs/Values Addressed (NQF #1647):** Percentage of patient stays with documentation of a discussion of spiritual/religious concerns or documentation that the patient and/or caregiver did not want to discuss spiritual/religious concerns.
8. **Composite Process Measure-Comprehensive Assessment at Admission:** Percentage of patient stays during which the patient received all care processes captured by quality measures NQF #1617, NQF #1634, NQF #1637, NQF #1638, NQF #1639, NQF #1647, NQF #1641, as applicable.
9. **Hospice Visits when Death is Imminent (2-item measure):**  
 Measure 1: Percentage of patients receiving at least one visit from registered nurses, physicians, nurse practitioners, or physician assistants in the last 3 days of life.  
 Measure 2: Percentage of patients receiving at least two visits from medical social workers, chaplains or spiritual counselors, licensed practical nurses or hospice aides in the last 7 days of life.

NQF=National Quality Forum

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**Box 2.**

Participant Interview Domains and Example Questions

**Domain 1: Organizational practices to assess presence and quality of conversations about goals of care and treatment preferences, specifically in relation to the implementation of HIS.**

“How does your organization monitor or measure the presence or absence or quality or frequency of end-of-life discussions?”

“How do you use the HIS data, for example, to conduct QI or Performance Improvement Projects?”

**Domain 2: Barriers to ACP quality measurement**

“What are the barriers to measuring or monitoring ACP quality across the organization?”

**Domain 3: Staff perceptions of the implementation of the HIS, impacts on patient care, and unintended consequences.**

“What are your opinions of the HIS measures?”

“How has the HIS impacted patient care?”

**Domain 4: Ways to improve ACP quality measurement within their organization.**

“What could be done differently or better about how your organization measures ACP?”

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